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Original Paper

Accuracy of a Web-Based Time-Use Diary (MEDAL) in Assessing Children's Meal Intakes With Food Photography by Parents as Reference: Instrument Validation Study

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Abstract

Background: My E-Diary for Activities and Lifestyle (MEDAL) is a web-based time-use diary developed to assess the diet and movement behaviors of Asian school children.

Objective: This study aims to determine the accuracy of MEDAL in assessing the dietary intake of Malaysian school children, using photographs of the children's meals taken by their parents as an objective reference.

Methods: A convenience sample of 46 children aged 10 to 11 years recorded their daily meals in MEDAL for 4 days (2 weekdays and 2 weekend days). Their parents took photographs of the meals and snacks of their children before and after consumption during the 4-day period and sent them along with a brief description of food and drinks consumed via an instant SMS text messaging app. The accuracy of the children's reports of the food they had consumed was determined by comparing their MEDAL reports to the photographs of the food sent by their parents.

Results: Overall, the match, omission, and intrusion rates were 62% (IQR 46%-86%), 39% (IQR 16%-55%), and 20% (IQR 6%-44%), respectively. Carbohydrate-based items from the food categories "rice and porridge"; "breads, spreads, and cereals"; and "noodles, pasta, and potatoes" were reported most accurately (total match rates: 68%-76%). "Snack and dessert" items were omitted most often (omission rate: 54%). Furthermore, side dishes from "vegetables and mushrooms," "eggs and tofu," "meat and fish," and "curry" food groups were often omitted (omission rates: 42%-46%). Items from "milk, cheese, and yogurt"; "snacks and desserts"; and "drinks" food groups intruded most often (intrusion rates: 37%-46%). Compared to the items reported by the boys, those reported by the girls had higher match rates (69% vs 53%) and lesser omission rates (31% vs 49%; *P*=.03, respectively).

Conclusions: In conclusion, children aged 10 to 11 years can self-report all their meals in MEDAL, although some items are omitted or intruded. Therefore, MEDAL is a tool that can be used to assess the dietary intake of Malaysian school children.

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KEYWORDS

children; dietary intake; time-use diary; food photography; accuracy; mobile phone

Introduction

Background

Healthy dietary patterns developed during childhood and adolescence may track into adulthood [1]. Understanding children's dietary patterns is crucial when guiding them to develop healthy eating habits from an early age. However, measuring the diets of school children has always been challenging, as doing so relies on the children's cognitive abilities and abilities to recall dietary intake as well as estimate and indicate portion size [2,3]. While parents can be the primary proxy reporter, they may not be aware of what their child consumes away from home [4]. When children are aged approximately 7 to 8 years, their ability to recall without assistance slowly develops but only for food consumed in the past 24 hours [5], while their ability to remember and estimate portion size is still limited [6]. A study conducted in Malaysia showed that children aged 7 to 9 years can self-report their dietary intake for lunch accurately, without proxy assistance [7]. At the age of 8 to 12 years, children can self-report food intake as reliably as their parents [8]. However, self-reporting of food intake is tedious and time-consuming, which sometimes hamper the retrieval of dietary information from children [9]. Assessment tools that are intuitive, quick and simple to use, flexible, fun, engaging, nonintrusive, and age-appropriate can elicit the cooperation of children [9]. Therefore, to encourage and motivate children to self-report dietary assessment protocol, a novel assessment method may enhance the recruitment and completion rates while maintaining an acceptable level of data accuracy [2,10].

Children may find technology-based dietary assessment methods more attractive and appealing than paper-based methods [11]. The web-based dietary assessment method has proved to be a practical way of assessing children's dietary intake [12,13]. In Singapore, a web-based time-use diary, My E-Diary for Activities and Lifestyle (MEDAL), has been developed to assess the diet and movement behaviors of school children aged ≥10 years [14]. MEDAL includes food options that are popular with the major ethnic groups in Asia and also captures information on food portions, location of activities, and concurrent activities performed by the children [14]. As Malaysia shares a border with Singapore and the Malaysian population exhibits similar food preferences and lifestyle behaviors, it is thought that MEDAL can be used by them. Therefore, MEDAL has been customized for Malaysian school children, with the addition of typical foods and beverages, as well as various activities practiced by Malaysian school children (eg, Solat [Muslim prayer], standing prayer, sitting or kneeling prayer, tuition classes and music lessons, track-and-field activities, and exercise).

The reference method in validating self-reported dietary intake is direct observation, where the agreement rates (match, omission, and intrusion rates) among direct observation, web-based food questionnaires [15,16], and web-based food records [17] are compared. This method provides precise information on the types and amount of food intake, with acceptable accuracy and good reliability [18]. However, these validation studies, which use direct observation as a reference method, only validate a single meal, while validation studies should include all meals, as the food items consumed vary with meal types, locations of consumption, and options available. The previous study conducted in Singapore [14] demonstrated that children could use MEDAL to self-report food intake for 1 meal during school recess but did not determine the accuracy of MEDAL to self-report food intake for all meals.

In addition, direct observation was usually conducted by trained researchers who had undergone extensive training in the visual estimation of food consumption [18]. Therefore, direct observation can be labor-intensive and subject to reporting errors by the observer. In addition, direct observation may not be feasible during situations such as the COVID-19 pandemic when movement restriction or physical distancing hinders researchers from directly observing the children's food intake. However, while children were restricted from attending school, their parents were able to observe their children's food intake. To minimize the parents' burden as proxy reporters through direct observation, food photography by parents was adopted in this study as an objective measure to determine the accuracy of MEDAL in assessing the dietary intake of school children.

Objective

With this background, this study aimed to determine the accuracy of MEDAL in assessing the dietary intake of Malaysian school children, using photographs of their children's meals taken by parents as objective references.

Methods

Ethical Considerations

The protocol of this study was approved by the Universiti Kebangsaan Malaysia Research Ethics Committee (JEP-2019-307). Permission to conduct the study was obtained from the Ministry of Education, Malaysia; the relevant state education departments; and the school principals. The school children participating in the study were provided with informed consent forms to obtain permission from their parents before the commencement of the study.

Study Participants

This study was conducted in April 2021 (study 1) and October to December 2021 (study 2) during the COVID-19 pandemic. A total of 53 children were recruited using convenience sampling, with 25 (47%) children from 2 primary schools for study 1 and 28 (53%) children from 3 primary schools for study 2. The study 1 students attended school in person, while the study 2 students attended classes online at home due to the implementation of movement control orders.

Primary school children aged 10 to 11 years were recruited for this study. Students were eligible if they understood Malay, English, or Chinese and had access to a computer, laptop, or tablet with internet connectivity. In addition, their parents had to own a smartphone with an internet connection to take food photos before and after meals and send them to us via an instant SMS text messaging app (eg, WhatsApp or Telegram). Information on the participants' accessibility to electronic devices with internet access at home and their parents' accessibility to a smartphone with internet access were obtained in the consent form.

Study Procedures

MEDAL Web-Based App

MEDAL (National University of Singapore) is a self-administered, web-based time-use diary that captures the diet and activities of school children aged 10 to 12 years in the Asian context [14]. MEDAL was customized for use among Malaysian school children by translating the text into the Malay and Chinese languages and adding food and drinks that were consumed and activities that were performed typically by Malaysian school children. Children were requested to record daily activities from the time they woke up until bedtime for 4 days. They could choose from 6 broad categories of activities: "wash up/brush teeth," "eat and drink," "traveling," "nap/sleep," "sitting/praying activities," and "active activities."

When children recorded an "eat and drink" activity, they could choose the food and drink items they had consumed from 14 main food and drink groups (eg, breads, spreads, and cereals; curry or curry with coconut gravy; drinks; eggs and tofu; fast food; fruits; meat and fish; milk, cheese, and yogurt; vegetables and mushrooms; noodles, pasta, and potatoes; rice and porridge; snacks and desserts; soups; and supplements). For each food and drink item selected, the children also chose the portion size from 4 pictorial options (presented simultaneously) that best matched the amount consumed [14]. The children could use the "others" textbox if the items consumed were not listed in MEDAL and reported the amount consumed from the following 4 options: 1/2 portion, 1 portion, 1.5 portions, or 2 portions [14].

Demonstration of the Use of MEDAL

In study 1, we conducted a demonstration session in the computer laboratories of the participants' schools. We demonstrated how to log in and record diet and daily activities in MEDAL. After the demonstration, the participants recorded what they consumed and did for 2 weekdays and 2 weekend days. For the second day, the participants were allowed to use school computers during recess to record their diet and activities if they had not completed the first day's recording, after which they would continue recording at home for the remaining days.

In study 2, students could not attend school physically because of a government-imposed movement control order. Thus, face-to-face demonstration sessions for the students were not possible, and web-based demonstration sessions via Google Meet (Google LLC) were conducted instead. We demonstrated how to log in and record diet and activity entries with a prerecorded video. After the demonstration, the participants continued recording their entries at home using their own tablets, laptops, or computers.

Food Photography by Parents

Before the commencement of the study, all parents from both study periods were provided with standard guidelines on how to photograph the food their children were going to consume. To ensure compliance, reminders to take food photographs were sent to the parents' SMS text messaging app twice a day before breakfast and dinner. During the 4 days of the study period, parents were required to photograph all the food and drinks consumed by their children, before and after consumption, for all meals, that is, breakfast, lunch, dinner, and snacks.

In study 1, the parents photographed all meals consumed by the children during nonschool times, while we photographed the school recess meal for the non-Muslim participants. Most Muslim participants (16 out of 25, 64% children) could not eat and drink during school recess, as study 1 was conducted during the Ramadhan fasting period.

In study 2, the parents photographed all meals consumed by the children as the children attended classes at home. Every day, parents sent photographs of the food and drinks before and after consumption, along with a brief description of what had been consumed, to us via an instant SMS text messaging app such as WhatsApp (Meta Platforms) or Telegram (Telegram FZ LLC). Figure 1 presents photographs with a description of the food and drink consumed. Figure 2 presents examples of food photographs for breakfast, lunch, dinner, and snacks taken before and after consumption.

Figure 1. Photographs of the food taken before and after consumption, with a text description of the food consumed.

Lunch 1:12 pm

Chicken rice and cucumber 1:12 pm

1:13 pm

Figure 2. Examples of food photographs taken by parents before and after consumption of breakfast, lunch, dinner, and snacks.

Anthropometric Measurements

In study 1, we recorded children's anthropometric measurements at schools. Height was measured using a portable Seca stadiometer (Seca 213, SECA, Hamburg, Germany) and weight using a Seca weighing scale (Seca 803, SECA, Hamburg, Germany). In study 2, anthropometric measurements of children were self-reported by parents due to the movement control order. Parents were asked to submit their children's height and weight. Guidelines on how to make proper measurements were provided to the parents. School records of the participants' most recent height and weight were used if home measurements were impossible.

BMI was calculated from body mass (kg) divided by the square of height (m^2). BMI for age was calculated based on the World Health Organization growth reference for individuals aged 5 to 19 years [19]. *Z* scores for BMI for age were determined using the World Health Organization AnthroPlus (version 1.0.3) [20] software. The cutoff value for BMI for age for underweight was <−2 to −3 SD, overweight was >1 SD, and obesity was >2 SD. Values within > −2 SD and <1 SD were classified as normal weight.

Data Processing

The accuracy of the child-reported food items was determined by comparing the self-reports of meal intake in MEDAL with the objective measures of food photographs taken by parents. Parents took photographs of the food before and after consumption for each meal taken by their children in the 4 days corresponding to the days of record in MEDAL. The meals included breakfast, lunch, dinner, and snacks or desserts. The food photographs taken by the parents for each meal were matched with the self-report by the children in MEDAL. The food photographs that matched the MEDAL diet entries for a meal were used for analysis. Missing food photographs or MEDAL entries were excluded from the analysis.

Food items in MEDAL include single items (eg, drinks, snacks, or desserts); composite meals consisting of staple food items with ingredients from the various food groups (eg, fried noodles); and components of mixed meals consisting of staple food items (eg, white rice) with side dishes (eg, steamed meat) [21]. Food items were classified into 14 food groups.

The accuracy of self-reported meals was determined by comparing the self-reported food items in MEDAL to the food items depicted as consumed in the photographs sent by the parents before and after consumption and classifying them as matches, omissions, and intrusion rates [17].

An “exact match” refers to a situation in which the food item self-reported by a child in MEDAL matches, to the maximum extent, the food item depicted in the reference photo provided by the parent. An “approximate match” refers to a situation in which the food item self-reported by a child in MEDAL matches with slight variations to the food item depicted in the reference photo. For example, a parent provides a reference photo of a glass of full cream milk their child had consumed. However, the child self-reported having consumed low-fat milk in MEDAL. The 2 food items are not identical but are recognized as similar, as they belong to the milk category. An “intrusion” refers to food items that are self-reported by a child in MEDAL but are not depicted in the reference photo, while an “omission” refers to food items that are depicted in reference photos but are not self-reported by the child in MEDAL. For instance, if a child self-reported consuming noodles in MEDAL, but this consumption was not observed in the reference photo provided by parents, this would be considered an intrusion. In contrast, if the reference photo showed that the child had consumed white rice, but the child did not self-report any food or drinks, this would be classified as an omission.

The formulas for calculating the match, intrusion, and omission rates are as follows [17]:

Statistical Analysis

Descriptive statistics was used to summarize the characteristics of participants. The data were not normally distributed; therefore, the Mann-Whitney *U* test was used to test the differences in age between study 1 and study 2 participants. Pearson χ^2 test and Fisher exact test were performed to compare the characteristics of study 1 and study 2 participants. The accuracy of self-reported food items was determined and expressed as median match rate (%), intrusions rate (%), and omissions rate (%). Furthermore, the Mann-Whitney *U* test was used to determine the difference in match, intrusion, and omission rates between the boys and girls. Kruskal-Wallis test was used to compare the median match, intrusion, and omission rates among different meals; then, the Bonferroni post hoc Mann-Whitney *U* test was used to identify the significant paired groups among the different meals. The match, omission, and intrusion rates by food group were presented as percentages (%). Statistical analysis was performed using the SPSS Statistics (version 25.0; IBM Corp) [22]. A significance level of $P<.05$ (95% CI) was adopted.

Results

Overview

Flowcharts of participants from both study periods are presented in Multimedia Appendix 1. A total of 53 students were recruited for both study periods, with 25 (47%) children in study 1 and 28 (53%) children in study 2. However, after excluding children who did not complete MEDAL or whose parents did not provide any food photographs, only 46 (87%) children were included in the analysis. All food photographs for all meals sent over the 4 days that corresponded to the MEDAL diet entries were included in the analysis. Only the food photographs or MEDAL diet entries of the eating occasions that were missing were excluded from the analysis.

Overall, 65% (30/46) of the participants were girls, 30% (14/46) were overweight and obese, and 82% (38/46) completed 3 to 4 days of recording in MEDAL (P=.76, P=.60, and P=.22, respectively; Table 1). However, a significant association was found among the ethnic groups between study 1 and study 2 (P=.004). A higher proportion of Malays (ethnic majority group) was found in study 1 than in study 2. This was because study 1 participants were recruited from national-type schools, while study 2 participants were recruited from national-type and Chinese schools. The median age of children in study 2 (median 10.8, IQR 10.56-11.26 years) was significantly higher than the median age of children in study 1 (median 10.2, IQR 9.9-10.4 years; $P<.001$). The higher median age of children in study 2 was due to study 2 being conducted near the end of the year. Differences in sex, weight status, and the number of days of MEDAL completion between participants in study 1 (21/46, 46%) and study 2 (25/46, 54%) were not significant (P=.76, P=.60, and P=.22, respectively).

Table 1. Characteristics of participants in study 1 and study 2 (n=46).

Characteristics	Total (n=46)	Study 1 (n=21)	Study 2 (n=25)	*P* value
Sex, n (%)				.76[a]
Boys	16 (35)	8 (38)	8 (32)	
Girls	30 (65)	13 (62)	17 (68)	
Age (y), median (IQR)	10.53 (10.2-10.95)	10.2 (9.9-10.4)	10.8 (10.56-11.26)	<.001[b]
Ethnicity, n (%)				.004[c]
Chinese	18 (39)	3 (14)	15 (60)	
Malay	25 (54)	16 (76)	9 (36)	
Others	3 (7)	2 (10)	1 (4)	
BMI status, n (%)				.60[c]
Underweight	3 (7)	2 (10)	1 (4)	
Normal weight	29 (63)	14 (67)	15 (60)	
Overweight	8 (17)	2 (10)	6 (24)	
Obese	6 (13)	3 (14)	3 (12)	
Number of days of completion of My E-Diary for Activities and Lifestyle, n (%)				.22[c]
<1	2 (4)	0 (0)	2 (8)	
1	3 (7)	2 (10)	1 (4)	
2	3 (7)	2 (10)	1 (4)	
3	7 (15)	1 (5)	6 (24)	
4	31 (67)	16 (76)	15 (60)	

[a] *P* values were assessed by the Pearson χ^2 test (categorical).

[b] *P* values were assessed by the Mann-Whitney *U* test (nonparametric).

[c] *P* values were assessed by the Fisher exact test (categorical).

Match, Omission, and Intrusion Rates

Table 2 presents the match (%), omission (%), and intrusion (%) rates observed between the food photographs received from the parents and self-reported food and drink items by the participants in MEDAL. The match, omission, and intrusion rates were 62%, 39%, and 20%, respectively. The total match rate was further broken down into exact match rate and approximate match rate, which were 60% and 1%, respectively.

The median exact match rate (*P*=.03), total match rate (*P*=.004), and omission rate (*P*=.004) were significantly different among meal types. Of all meals, snacks showed a significantly lower total match rate (53%) than breakfast (83%) and dinner (75%; *P*=.01 and *P*=.02, respectively). Furthermore, snacks consumed were omitted more often (47%) than breakfast (18%) and dinner (25%; *P*=.01 and *P*=.02, respectively). Post hoc tests failed to indicate any significant difference among the meal types for exact match rate.

Table 2. Percentage of the match, omission, and intrusion rates observed between photographed meals and self-reported individual food and drink items in My E-Diary for Activities and Lifestyle (MEDAL).

Variables	Observed items[a], n	Reported items[b], n	Approximate match rate (%)[c], median (IQR)	Exact match rate (%)[d], median (IQR)	Total match rate (%)[e], median (IQR)	Omission rate (%)[f], median (IQR)	Intrusion rate (%)[g], median (IQR)
On the basis of each meal (n=46)	1267	1004	1.4 (0-6.4)	60.3 (40.1-79.8)	61.6 (46-86.4)	39.3 (15.8-54.8)	19.5 (5.9-44.2)
Meal types							
Breakfast (n=41)	330	301	0 (0-6.3)	76.3 (66.7-100)	82.5 (66.7-100)	17.5 (0-33.3)	0 (0-25)
Lunch (n=27)	329	215	0 (0-6.3)	64.3 (43.8-68.8)	64.3 (50-75)	35.7 (25-50)	0 (0-11.1)
Dinner (n=43)	526	445	0 (0-6.3)	75.0 (51.1-79.2)	75.0 (66.7-83.3)	25.0 (16.7-33.3)	4.2 (0-24.4)
Snack (n=21)	82	43	0 (0-0)	52.8 (25-100)	52.8 (25-100)	47.2 (0-75)	0 (0-50.0)
P value[h]	N/A[i]	N/A	.06	.03	.004	.004	.09
Sex[j]							
Boys (n=16)	440	339	4.0 (0-6.6)	49.2 (31-64.2)	53.0 (66.4-33.5)	49.1 (36.6-82.3)	29.7 (13-57.5)
Girls (n=30)	827	665	1.1 (0-6.8)	64.6 (48.6-87)	69.1 (55.9-87.2)	30.9 (13.3-44.1)	16.6 (4.4-32.5)
P value[k]	N/A	N/A	.94	.07	.03	.03	.26

[a] Number of food items depicted in photographs.

[b] Number of food items reported in MEDAL.

[c] Approximate match is defined as a similar food with a slight variation, eg, full-fat milk and low-fat milk. Approximate match = (number of food items reported in MEDAL with approximate matches/number of food items photographed by parents) × 100.

[d] Exact match is defined as a selection of the same food or drink item in both the photograph and self-report in MEDAL. Exact match rate = (number of food items reported in MEDAL with exact matches/number of food items photographed by parents) × 100.

[e] Total match rate = (number of food items reported in MEDAL with exact and approximate matches/number of food items photographed by parents) × 100.

[f] Omission is defined as a food or drink item depicted in the photograph but not reported in the self-administered MEDAL report. Omission rate = (number of food items reported in MEDAL with omissions/number of food items photographed by parents) 100 = [omissions/(omissions + matches)] × 100.

[g] Intrusion is defined as a food or drink item reported in MEDAL but not depicted in the photograph. Intrusion rate = (number of food items reported in MEDAL with intrusions/number of food items reported in MEDAL × 100 = [intrusions/(intrusions + matches)] × 100.

[h] Kruskal-Wallis test (*P*=.05) and Bonferroni post hoc Mann-Whitney *U* test indicated that “snacks” had significantly lower total match than breakfast (*P*=.01) and dinner (*P*=.02) and higher omission than breakfast (*P*=.01) and dinner (*P*=.02).

[i] N/A: not applicable.

[j] Results show the rates for all meals for all 4 days.

[k] The Mann-Whitney *U* test (*P*=.05).

Compared to boys, girls reported more total matches (69% vs 53%) and fewer omissions (31% vs 49%; *P*=.03, respectively). There was no significant difference between boys and girls in exact match, approximate match, and intrusion rates (*P*=.07, *P*=.94, and *P*=.26, respectively; Table 2).

Food Groups Reporting Accuracy

The match, omission, and intrusion rates of the food items were further analyzed by food groups (Table 3). At the food-group level, the “rice and porridge”; “breads, spreads, and cereals”; and “noodles, pasta, and potatoes” categories, the carbohydrate-based items, were reported most precisely (total match rates: 68%-76%). More than half of the “snack and dessert” items were omitted (omission rate: 54%). The side dishes that tended to be omitted by the participants were “vegetables and mushroom,” “eggs and tofu,” “meat and fish,” and “curry” (omission rates: 42%-46%). The food categories of “milk, cheese, and yogurt”; “snacks and desserts”; and “drinks” intruded most often (intrusion rates: 37%-46%).

Table 3. Percentage of matches, omissions, and intrusions observed between photographed meals and self-reported individual food and drink items in My E-Diary for Activities and Lifestyle (MEDAL) by food groups.

Food groups	Total observed items[a], n (%)	Total reported items[b], n (%)	Matches, n (%)			Omissions[c], n (%)	Intrusions[d], n (%)
			Total[e]	Approximate[f]	Exact[g]		
Rice and porridge (n=215)	195 (90.7)	168 (78.1)	148 (75.9)	10 (5.1)	138 (70.8)	48 (24.6)	20 (11.9)
Fast food (n=36)	32 (89)	28 (78)	24 (75)	2 (6.3)	22 (68.8)	8 (25)	4 (14.3)
Breads, spreads, and cereals (n=82)	73 (89)	61 (74)	53 (72.6)	2 (2.7)	51 (69.9)	21 (28.8)	8 (13.1)
Noodles, pasta, and potatoes (n=82)	75 (91)	58 (71)	51 (68)	3 (4)	48 (64)	24 (32)	8 (13.8)
Soups (n=38)	34 (89)	27 (71)	23 (67.6)	3 (8.8)	20 (58.8)	12 (35.3)	4 (14.8)
Drinks (n=277)	201 (73)	209 (75)	131 (65.2)	10 (5)	121 (50.2)	68 (33.8)	78 (37.3)
Milk, cheese, and yogurt (n=47)	31 (66)	35 (74)	19 (61.3)	0 (0)	19 (61.3)	12 (38.7)	16 (45.7)
Fruits (n=71)	58 (82)	48 (68)	34 (58.6)	0 (0)	34 (58.6)	23 (39.7)	14 (29.2)
Curry (n=24)	19 (79)	16 (67)	11 (57.9)	4 (21.1)	7 (36.8)	8 (42.1)	5 (31.3)
Meat and fish (n=196)	187 (95.4)	116 (59.2)	108 (57.8)	13 (7)	95 (50.8)	79 (42.2)	9 (7.8)
Eggs and tofu (n=95)	90 (95)	54 (57)	50 (55.6)	0 (0)	50 (55.6)	41 (45.6)	4 (7.4)
Vegetables and mushrooms (n=191)	174 (91.1)	112 (58.6)	96 (55.2)	9 (5.2)	87 (50)	80 (46)	16 (14.3)
Snacks and desserts (n=125)	98 (78.4)	72 (57.6)	45 (45.9)	0 (0)	45 (45.9)	53 (54.1)	27 (37.5)

[a] Number of food items depicted in photographs.

[b] Number of food items reported in MEDAL.

[c] Omission rate = (number of food items reported in MEDAL with omissions/number of food items photographed by parents) [100 = omissions/(omissions + matches)] × 100.

[d] Intrusion rate = (number of food items reported in MEDAL with intrusions/number of food items reported in MEDAL) 100 = [intrusions/(intrusions + matches)] × 100.

[e] Total match rate = (number of food items reported in MEDAL with exact and approximate matches/number of food items photographed by parents) × 100.

[f] Approximate match rate = (number of food items reported in MEDAL with approximate matches/number of food items photographed by parents) × 100.

[g] Exact match rate = (number of food items reported in MEDAL with exact matches/number of food items photographed by parents) × 100.

Discussion

Principal Findings

Overall, the match, omission, and intrusion rates in this study were 62%, 39%, and 20%, respectively. We found that girls reported more total matches and made fewer omissions than boys. At the food-group level, carbohydrate-based items such as “rice and porridge”; “breads, spreads, and cereals”; and “noodles, pasta, and potatoes” were reported most accurately. However, “snack and dessert” items and side dishes of mixed meals such as “vegetables and mushroom,” “eggs and tofu,” “meat and fish,” and “curry” were omitted most often. Furthermore, items from “milk, cheese, and yogurt”; “snacks and desserts”; and “drinks” groups intruded most often.

This study indicated that Malaysian school children aged 10 to 11 years are capable of using the customized MEDAL web-based app to self-report food and drink items, albeit with some inaccuracies. While Tugault-Lafleur et al [18] stated that an acceptable cutoff of ≥85% for match rates and ≤15% for both omission and intrusion rates, this does not mean that the results from this study indicate poor accuracy for self-reported food items. The suggested cutoff was originally developed for meals in the school context. Furthermore, as Baxter and Thompson [23] suggested, children tend to recall food consumed as part of a 24-hour period with lower accuracy than a single meal. Children in this study reported all meals consumed in 24 hours at home and school rather than a single meal in the school context. Therefore, it is reasonable that the match rates would be lower and the omission and intrusion rates would be higher than the suggested acceptable cutoff values.

Furthermore, the total match rates (62%) from this study were slightly higher (better) than the total match rates from the validity study (60%) conducted in Singapore [21], although only school meals were included in the validity study conducted in Singapore and more meals were included in this study.

However, food photography by parents was used as the reference measure, and thus there might be a possibility that the children in this study referred to the food photographs taken by their parents while self-reporting their meals in MEDAL. In addition, the match rates from this study were slightly higher than those from other studies that used web-based dietary assessment tools, for example, studies conducted in Brazil (43%) [16], Denmark (59%) [12], and the United States (42%) [24]. These studies used direct observation as the reference measure. Moreover, the slightly higher match rate in this study might be attributable to the fact that older children were recruited (aged 10 to 11 years) instead of the younger children (aged 7 to 9 years), as older children have better recall than younger children [25]. Furthermore, direct observation was used as the reference measure. In contrast, a Malaysian study [7] conducted among children aged 7 to 9 years demonstrated a higher match rate (89%) than this study, which might be attributable to the fact that the participants only needed to recall a single recess meal, whereas in this study, participants were asked to recall all their meals in a day.

The omission (39%) and intrusion rates (20%) in this study are higher than the cutoff value of ≤15% [18]. In general, children might have recorded their dietary intake in MEDAL the following day or later, instead of on the same day. According to Baxter et al [26], the accuracy of omission and intrusion rates declines significantly when the time interval between reporting and eating increases.

In addition, the omission rates (39%) were higher than the validity study conducted in Singapore (25%) [21] and other studies conducted in Malaysia (14%) [7], Brazil (28%) [16], Norway (27%) [17], and the United States (28%) [24]. These studies validated only lunches consumed in a school environment, which are fixed meals with little variation.

However, the increased omission rates in this study might be due to the inclusion of all meals consumed for validation purposes rather than a specific meal in a particular setting. This is further supported by “snacks” being the most omitted meal type in this study (47%). In conjunction with omission rates, “snacks and desserts” (54%) were food items that were omitted most often. This may also explain the higher omission rate in this study because children may be underreporting snacks and desserts, which are deemed to be unhealthy. Children may also forget to report snacks as one of their meals or they may be multitasking (eg, watching television or studying) while consuming snacks.

At the same time, carbohydrate-based items in “rice and porridge”; “breads, spreads, and cereals”; and “noodles, pasta, and potatoes” categories were reported most accurately (total match rates: 68%-76%) in this study. Carbohydrate-based items are usually consumed as main course items during each main meal in Asia, making them more recallable than side dishes or less common foods [5]. Moreover, this study found that the side dishes of mixed meals were commonly omitted, as items from the “vegetables and mushrooms,” “eggs and tofu,” “meat and fish,” and “curry” groups (omission rates: 42%-46%) were commonly consumed as side dishes, together with the carbohydrate-based items (eg, rice, porridge, or noodles) in Asia. Therefore, the results in this study are consistent with the findings of the study by Pérez-Rodrigo et al [5] that carbohydrate-based items are recalled better than side dishes. Children tend to recall salient items, such as main course foods, more easily than less salient items [27]. Side dishes of mixed meals were commonly omitted in this study because children may lack basic knowledge or familiarity with the food, food preparation, added ingredients, and components of side dishes in mixed meals [5]. Therefore, they omitted these food groups in their self-reports of dietary intake.

Furthermore, the intrusion rates in this study are slightly higher than those in the validity study conducted in Singapore (20% vs 15%) and a study conducted in Malaysia (3%) [7]. However, the intrusion rate is lower than those in studies conducted in Brazil (29%) [15,16] and the United States (30%) [24]. The food groups of “milk, cheese, and yogurt”; “snacks and desserts”; and “drinks” intruded most (intrusion rates: 37%-46%) in this study. These food groups intruded most because they are consumed along with the main meal or during snacking. These results are consistent with those of a study conducted in Brazil, where the intrusion rates are the highest for dairy products [16]. Furthermore, the results are supported by a study conducted in Norway, in which the items that intruded most were “yogurt” (56%) and “beverages and other” [17]. Despite this, the result of the intrusion is further influenced by the fact that parents might have forgotten to photograph the food items. Parents might have been unaware of their children consuming food or drink items along with their main meals or snacking and, thus, did not photograph the food.

Moreover, reporting accuracy was linked to gender differences. Girls often reported their dietary intake more accurately than boys [28]. The results in this study are consistent with the results from the study by Lyng et al [28], as the girls recalled better than the boys. The girls had a lower omission rate and a higher match rate than the boys (P=.03). This might be because boys are not as detailed as girls when selecting the food and drinks to report in MEDAL. Furthermore, a previous study demonstrated that compared to boys, girls recalled more details and provided more detailed elaborations on information content [29]. Therefore, the higher accuracy in reporting observed in girls may be attributed to their tendency to provide more detailed information. Furthermore, another study also showed that girls outperformed boys in object recall (recalling a series of pictures presented) and word selective reminding (a verbal free-recall task on word lists) than boys [30]. Consequently, it is plausible that girls exhibit better recall abilities regarding food and drink consumption, which could influence their selection of food and drink items in MEDAL.

Nevertheless, this study has several possible limitations. First, we used the parents’ photographs of the food items as the reference measure. The parents might have forgotten to photograph some food items, drinks, or snacks consumed by their children. Furthermore, parents might be unaware that their child had consumed certain food items, especially if they were working, which could lead to photographs of the food items not being taken. Thus, the intrusion rate was further affected by the forgetfulness or unawareness of parents. Another limitation was that the photographs of the food may serve as a visual-prompting tool for the children, which could increase the match rate. In addition, this study used a convenience sample, which was limited to schools in Kuala Lumpur city and students with internet access and electronic devices. Thus, the results of this study might not be extrapolated due to the limited technology skills in rural areas or other cities. Moreover, study 1 was conducted during the Ramadhan fasting period, which limited the meals reported by children during school recess. Therefore, overall, the results might not be generalizable to the non-Ramadhan fasting period.

Despite these limitations, this study has its strengths. First, it contributes to our understanding of dietary assessment among children aged 10 to 11 years in Malaysia. Furthermore, this is the first study conducted in Malaysia to determine school children's ability to report dietary intake using a web-based diary. The main strength of this study is its validation of all meals consumed by the children in various settings instead of evaluating specific meals in a particular context. This enables the results to be extrapolated to meals consumed outside the school. As a result, numerous food and drink items were reported and analyzed, which increases the generalizability of the findings to the varied eating practices of a multicultural community.

This study has some implications for future research. In order to improve accuracy, children should be encouraged to report their food items in the web-based diary as frequently as possible and preferably on the same day. Furthermore, researchers should remind the children to report on the details of such food items as side dishes and snacks or drinks that are consumed along with meals or during multitasking. Future research should be conducted in different cities or rural areas to further affirm these results.

Conclusions

In conclusion, the overall match (62%), omission (39%), and intrusion (20%) rates suggest that children are able to report their food and drink intake in MEDAL, although some items are omitted or intrude. Thus, MEDAL is a promising tool to assess the dietary intake of Malaysian school children aged 10 to 11 years. Future research should be conducted with a larger sample size and in nonurban areas to provide further insights into the accuracy of MEDAL in capturing the dietary intake of children.

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Data Availability

The data sets used and analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

KMC, NSSB, and JEW conceptualized the study and designed the methodology; KMC and NSSB contributed to data collection; KMC analyzed study data under the guidance of JEW and MFFC; KMC contributed to writing—original draft preparation, while KMC, AC, NSSB, BKP, NAJ, DK, MFFC, and JEW contributed to writing—review and editing.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Flowchart of participants in study 1 and study 2.
[DOCX File , 31 KB - pediatrics_v7i1e53461_app1.docx]

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Abbreviations

MEDAL: My E-Diary for Activities and Lifestyle

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Electronic Communication Between Children's Caregivers and Health Care Teams: Scoping Review on Parental Caregiver's Perceptions and Experience

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Abstract

Background: Asynchronous communication via electronic modes (e-communication), including patient portals, secure messaging services, SMS text messaging, and email, is increasingly used to supplement synchronous face-to-face medical visits; however, little is known about its quality in pediatric settings.

Objective: This review aimed to summarize contemporary literature on pediatric caregivers' experiences with and perspectives of e-communication with their child's health care team to identify how e-communication has been optimized to improve patient care.

Methods: A scoping review following the Arksey and O'Malley methodological framework searched PubMed, CINAHL, Embase, and Web of Science using terms such as "Electronic Health Records" and "Communication" from 2013 to 2023 that discussed caregiver experiences and perspectives of e-communication with their child's health care provider. Studies were excluded if they were abstracts, non-English papers, nonscientific papers, systematic reviews, or quality improvement initiatives, or pertained to synchronous telemedicine. We conducted a two-step screening process by scanning the title and abstract and reviewing the full text by two independent screeners to confirm eligibility. From an initial 903 articles identified via the database search, 23 articles fulfilled all the inclusion criteria and are included in this review.

Results: Of the 23 articles meeting the inclusion criteria, 11 used quantitative methods, 7 used qualitative methods, and 5 used mixed methods. The caregiver sample sizes ranged from 51 to 3339 in the quantitative studies and 8 to 36 in the qualitative and mixed methods studies. A majority (n=17) used the patient portal that was self-categorized by the study. Secure messaging through a portal or other mobile health app was used in 26% (n=6) of the studies, while nonsecure messaging outside of the portal was used 17% (n=4) of the time and email was used 33.3% (n=8) of the time. In 19 of the studies, parents reported positive experiences with and a desire for e-communication methods.

Conclusions: The literature overwhelmingly supported caregiver satisfaction with and desire for e-communication in health care, but no literature intentionally studied how to improve the quality of e-communication, which is a critical gap to address.

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KEYWORDS

electronic communication; patient portal; provider-patient relations; parental caregiver; relational coordination theory; patient-clinician relationship; mobile phone

Introduction

In pediatric health care, effective communication between the caregiver and clinician is pivotal for enhancing illness understanding, promoting treatment adherence, and fostering improved experiences [1-4]. Asynchronous electronic communication (e-communication), through patient portals, secure messaging, email, and SMS text messaging, is increasingly used to supplement synchronous face-to-face medical visits [5]. However, little is known about the quality of e-communication in pediatric settings.

Despite the acceleration of e-communication following the COVID-19 pandemic and the 21st Century Cures Act mandating the sharing of clinical notes with patients, there is limited evidence on the best practices, and what evidence does exist may not be applicable to the specific needs of caregivers of patients with complex needs, of children, or of both [6-10]. Limited research exists on how parental caregivers (hereinafter "caregivers") perceive e-communication, particularly concerning its quality and perceived impact on care delivery [2,6].

The relational coordination theory is well-suited for exploring e-communication between caregivers and health care teams, as it emphasizes the quality of communication and relationships in coordinating complex, interdependent tasks such as caring for a child [11]. The relational coordination theory highlights seven key domains—shared goals; shared knowledge; mutual respect; and communication that is frequent, timely, and accurate, and aids in problem-solving—to support effective teamwork [11,12]. When applied in settings such as pediatric health care, strong relational coordination can improve communication and care outcomes [13]. Thus, incorporating relational coordination into the analysis of e-communication helps to conceptualize caregiver–health care team dynamics and inform improvements in practice.

This review was undertaken to determine contemporary literature on pediatric caregivers' perspectives of e-communication with their child's health care team. We aimed to (1) identify modes of caregiver–health care team e-communication; (2) assess caregiver perspectives on e-communication experiences or expectations; and (3) map findings from such studies to relational coordination domains to better understand its role in effective e-communication and how it may be leveraged to alter delivery of care systems and patient and caregiver satisfaction. The overall purpose of our study was to characterize objectives, therapeutic elements, and delivery characteristics of e-communication as a step to inform intervention development, health care practices/policies, and caregiver and health care team workflows.

Methods

We conducted a scoping review that followed the Arksey and O'Malley [14] methodological framework and the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) checklist (Checklist 1) [15]. We used the communication domains of the relational coordination theory to guide article synthesis [11,12].

Study Identification

The search strategy was iteratively developed in consultation with an experienced medical librarian (Supplement 1 in Multimedia Appendix 1) and conducted in February 2023. We searched PubMed, CINAHL, Embase, and Web of Science using relevant search terms and MeSH (Medical Subject Headings) terms (Supplement 2 in Multimedia Appendix 2).

We included studies within a 10-year period that discussed caregiver experiences and perspectives of e-communication with their child's health care provider. E-communication was defined as web-based technology that allows for asynchronous communication between a caregiver and provider, such as patient portals tethered to electronic health records (EHRs) with or without access to clinical notes, secure messaging, nonsecure messaging (eg, personal mobile, nonsecure SMS text messaging, and WhatsApp), and email. We defined the caregiver as the child's primary caregiver and decision maker. The health care team was defined as medical professionals from various disciplines who provide comprehensive care to children, including registered nurses, nurse practitioners, physician assistants, and physicians. We limited the children's age from 0 through 13 years due to legal, access, and privacy issues for older, adolescent patients [10,16].

Studies were excluded if they were abstracts, non-English papers, nonscientific papers, systematic reviews, or quality improvement initiatives, or if they pertained to synchronous telemedicine.

Article Selection

We used the Covidence literature review software to conduct a two-step screening process by scanning the title and abstract and reviewing the full text by two independent screeners to confirm eligibility. The reviewers applied the inclusion and exclusion criteria to articles, discussed discrepancies as a group to reach consensus, and carefully documented decisions within the software. This method ensured a consistent and thorough review process.

Study Synthesis

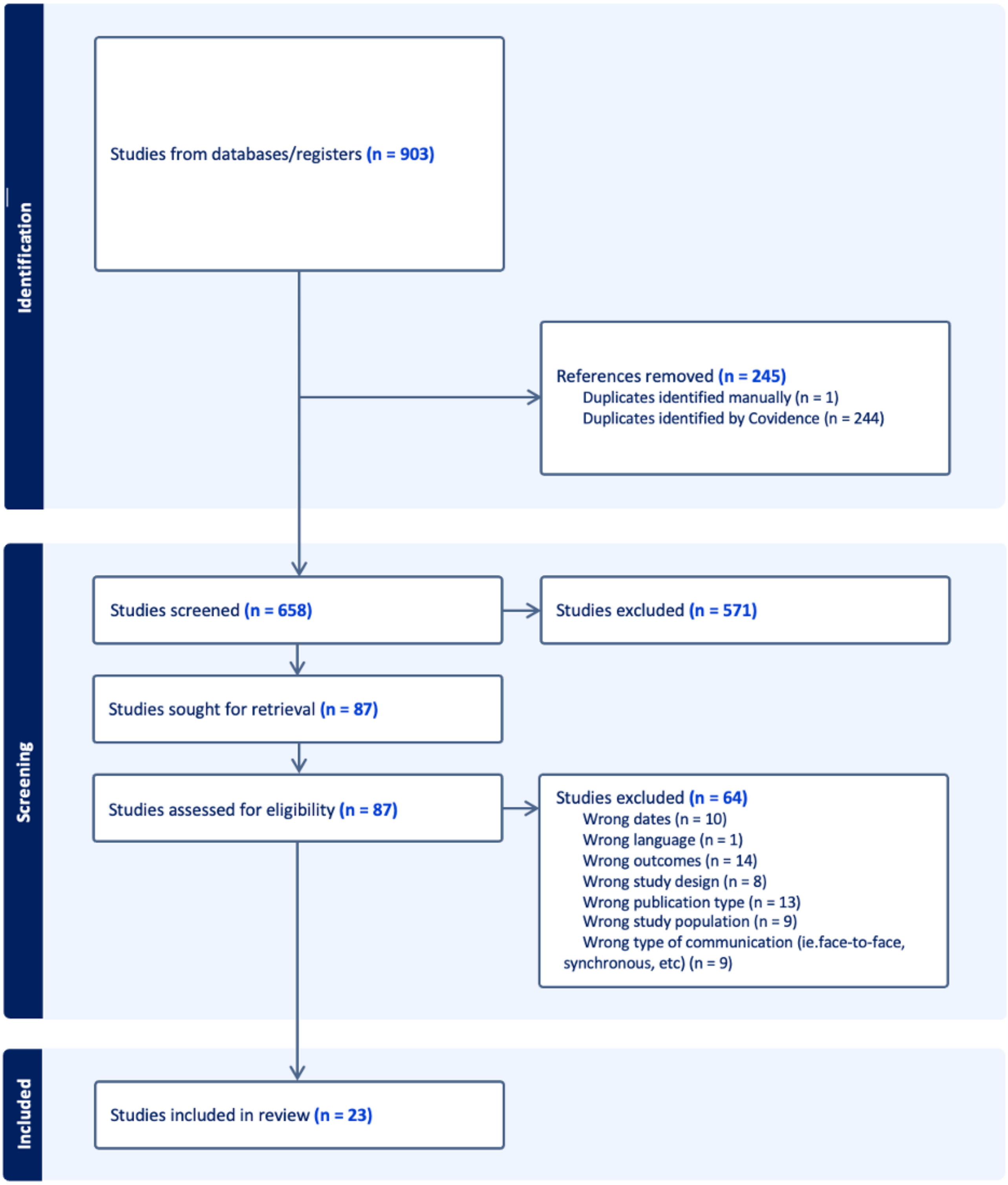
The approach to summarize and report on the findings from the identified articles varied by the research question (RQ). We first compiled articles that assessed caregiver–health care team e-communication (RQ1) by focusing on key parameters, such as the year, setting, population, and mode of e-communication [17]. We then performed a thematic analysis to synthesize information from articles that reported on caregiver satisfaction related to e-communication (RQ2) and the seven relational coordination domains (RQ3). The analysis pertaining to RQ2 and RQ3 involved mapping the findings of the mode of e-communication onto the relational coordination domains, under the hypothesis that the higher the number of relational coordination domains identified per article, the higher the caregiver satisfaction [12].

Results

Overview

In total, 903 articles were identified via the database search. After the duplicates were removed, 658 articles remained for title and abstract screening. Eighty-seven percent (571/659) of the articles were excluded, resulting in 87 full-text studies assessed for eligibility. During the full-text review, 74% (64/87) of the articles were excluded, which resulted in 23 articles included in this review. Figure 1 shows the study selection process in a PRISMA diagram [15].

Figure 1. PRISMA (Preferred Reporting Items and Systematic Reviews) flow diagram showing the literature search and study inclusion.



Basic Characteristics of the Included Studies

The characteristics of the included articles are summarized in Table 1 and individually presented in Supplement 1 in Multimedia Appendix 1. Of the 23 articles included in this review, 11 used quantitative methods, 7 used qualitative methods, and 5 used mixed methods. Sixteen studies (70%) were conducted in the United States, and one-third (n=8, 34.7%) were published after 2020. Half of the studies were conducted in an ambulatory setting (n=13, 56.5%), with the next most frequent location being an inpatient setting (n=8, 34.7%), of which 2 (8%) were in the neonatal intensive care unit. Only 4 (17.4%) were conducted in the community setting. One-third (n=7, 30.4%) of the studies involved populations with chronic illness or complex medical needs. Half (n=12, 52.2%) of the studies included participants in addition to caregivers, such as health care providers, adult patients, and teachers. The caregiver sample sizes ranged from 51 to 3339 in the quantitative studies and 8 to 36 in the qualitative and mixed methods studies. Over half of the 11 caregiver-only studies included 80% or greater female participants.

Table . Basic characteristics of the included studies.[a]

	Overall (N=23), n (%)	EHR[b]/patient portal (n=17), n (%)	Other[c] (n=13), n (%)
Year			
2013 - 2016	8 (34.8)	6 (75.0)	5 (62.5)
2017 - 2020	7 (30.4)	5 (71.4)	4 (57.1)
2021 - 2023	8 (34.8)	6 (75.0)	4 (50.0)
Study Design			
Quantitative	11 (47.8)	8 (72.7)	6 (54.5)
Qualitative	7 (30.4)	6 (85.7)	3 (42.9)
Mixed methods	5 (21.7)	3 (60.0)	4 (80.0)
Participants			
Parents	23 (100.0)	17 (73.9)	13 (56.5)
Health care worker	9 (39.1)	5 (55.6)	6 (66.7)
Adult patient	1 (4.3)	1 (100.0)	0 (0.0)
Teacher	1 (4.3)	0 (0.0)	1 (100.0)
Setting			
Ambulatory	13 (56.5)	11 (84.6)	7 (53.8)
Inpatient/ICU[d]	8 (34.8)	7 (87.5)	4 (50.0)
Community-based	4 (17.4)	2 (50.0)	4 (100.0)
Web-based	1 (4.3)	0 (0.0)	1 (100.0)
Mode of e-communication			
EHR/patient portal	17 (73.9)	—[e]	—
Secure messaging	6 (26.1)	—	—
Email	8 (34.7)	—	—
Nonsecure SMS text messaging	4 (17.4)	—	—
Phone	3 (13.0)	—	—
Other	2 (9.7)	—	—

[a] Individual studies may have more than one category of participants, setting, or mode of e-communication, so the overall percentage corresponds to 23 studies. The columns EHR/patient portal and Other (any mode that is not EHR/patient portal as described by a study) may add up to more than the number of overall studies in a row because studies may include more than one mode of e-communication. The percentage in those columns is the number of studies/number of overall studies in the corresponding row.

[b] EHR: electronic health record.

[c] Other includes secure messaging (n=6), email (n=8), SMS messaging (n=4), phone (n=3), fax (n=1), and web chat (n=1).

[d] ICU: intensive care unit.

[e] Not applicable.

Modes of Communication

The studies were assessed for the mode of e-communication utilized for caregiver–health care team communication and may include more than one mode (Table 2; Supplement 3 in Multimedia Appendix 3). A majority (n=17) used the patient portal that was self-categorized by the study. Secure messaging through a portal or other mobile health app was used in 26% (n=6) of the studies, while nonsecure messaging outside of the portal was used 17% (n=4) of the time and email was used 33% (n=8) of the time. Health care team phone messaging services and facsimiles were cited at 13% (n=3) and 4% (n=1), respectively. Notably, secure messaging was not described in studies prior to 2016; however, patient portals and email were actively referenced throughout the entire study period and could have included secure messaging. Correspondingly, SMS text messaging did not appear in studies after 2021.

Table . Evidence of relational coordination theory concepts in the literature.

Author, year	Mode of communication						7 domains of relational coordination						
	EHR[a]/portal	Secure messaging	Email	SMS text messaging	Phone	Other	Relationships with			Communication with			
							Shared goals (n=11)	Shared knowledge (n=16)	Mutual respect (n=10)	Frequent (n=11)	Timely (n=20)	Accurate (n=14)	Problem-solving (n=6)
Britto et al [18], 2013	✓						✓	✓	✓	✓	✓	✓	✓
Clark and Pledge [19], 2015	✓												
Fiks et al [20], 2015	✓						✓	✓			✓	✓	
Aldekhyyel et al [21], 2018	✓										✓	✓	
Kelly et al [22], 2019	✓						✓	✓	✓	✓	✓	✓	✓
Amirav et al [23], 2020	✓							✓				✓	
Bell et al [24], 2021	✓						✓	✓	✓	✓	✓	✓	
Kelly et al [25], 2021	✓						✓	✓	✓	✓	✓	✓	
Sarabu et al [26], 2021	✓							✓	✓		✓	✓	
Smith et al [27], 2022	✓						✓	✓	✓	✓	✓	✓	✓
King et al [28], 2017	✓	✓						✓			✓		
Kelly et al [29], 2023	✓	✓					✓	✓	✓	✓	✓	✓	
Weatherly et al [30], 2019	✓	✓			✓						✓	✓	
Nadia et al [31], 2022	✓	✓	✓								✓		

Author, year	Mode of communication						7 domains of relational coordination						
	EHR[a]/portal	Secure messaging	Email	SMS text messaging	Phone	Other	Relationships with			Communication with			
							Shared goals (n=11)	Shared knowledge (n=16)	Mutual respect (n=10)	Frequent (n=11)	Timely (n=20)	Accurate (n=14)	Problem-solving (n=6)
Weems et al [32], 2016	✓	✓	✓	✓			✓	✓		✓	✓		
Dudas and Crocetti [33], 2013	✓		✓	✓							✓		
Horsky et al [34], 2014	✓		✓		✓	✓	✓	✓			✓	✓	✓
Parpia et al [35], 2021		✓	✓		✓		✓	✓	✓	✓	✓		✓
Schiller et al [36], 2013			✓				✓	✓	✓	✓	✓	✓	✓
deJong et al [37], 2017			✓								✓		
Adams et al [38], 2021			✓	✓				✓	✓	✓	✓		
Globus et al [39], 2016				✓				✓		✓		✓	
Kaskinen et al [40], 2018						✓					✓		

[a]EHR: electronic health record.

Caregiver Experiences and Expectations for E-Communication in Pediatric Health Care

Overall, when studies are evaluated for positive versus negative caregiver experiences with e-communication use, a majority (n=20, 87%) identified positive experiences, with 3 studies finding more negative impressions of e-communication primarily due to cumbersome electronic system interface, not specifically the quality of communication [30,34,38].

Caregiver utilization of e-communication methods varied widely across studies, but common themes emerged. Particularly, 18 studies highlighted caregiver satisfaction through enhanced access to information, faster communication, and increased preparedness. For example, the ability to access patient information through portals, as noted in both national surveys [19] and qualitative studies [22], empowers caregivers by providing them with immediate, transparent access to their child's health data. The capacity to view laboratory and clinical data, request referrals, or schedule appointments through such systems reduces logistical barriers, offering convenience and a sense of control [19]. Moreover, electronic communication tools, such as portal messaging, email, and texting, reduce caregivers' anxiety by ensuring quicker, more precise interactions with health care teams. For example, mothers in neonatal intensive care unit settings were able to better understand their infant's condition and prepare for postdischarge care through improved clarity and communication speed [41]. However, even as e-communication platforms demonstrate significant benefits, nearly half of caregivers still prefer face-to-face interactions [41]. This suggests that while many caregivers value face-to-face interactions for nuanced discussions, using e-communication in conjunction helps improve access, alleviate burdens, and better equip caregivers for comprehensive conversations, contributing to overall satisfaction [22].

Other studies highlight the importance of a dynamic, two-way exchange of information in e-communication systems. For instance, a qualitative study of parents of children with chronic illnesses found that a secure messaging portal reduced barriers to getting timely answers, which in turn fostered feelings of control, independence, and reassurance [18]. A randomized controlled trial study using the MyAsthma portal demonstrated how ongoing bidirectional communication between families and clinicians supports shared decision-making by enabling real-time adjustments to treatment plans [20]. A cross-sectional survey further revealed that parents are not passive recipients but active participants, frequently initiating communication through messages or requests, emphasizing their active role in managing their child's health care [42].

Three studies focused on the caregivers' perceptions of reading their child's electronic progress notes [24-26]. One survey found that access to their child's clinical progress note positively impacted the caregivers' level of "confidence and trust" in their health care and enabled caregivers to feel like a "part of that team." [24] In qualitative focus groups, an inpatient-facing study found that caregivers believed that communication via access to clinical notes would "enhance the partnership and collaboration" between caregivers and the health care team and support higher standards for communication accuracy and accountability [25]. A survey on the impact of clinical notes being made available online to patients on the patient-physician relationship demonstrated that a parent's perception of their child's physician was generally positive with access to notes and 15% of parents used the ability to contact their provider about something they read in the note [26].

Three studies focused on the impact and satisfaction that SMS text messaging has on parental caregivers. An intervention focused on sending updates to parents via an SMS text regarding clinical updates significantly improved parental satisfaction with the medical treatment, the information provided, and the communication with their neonatal intensive care unit–admitted infants' medical staff. Parents also indicated perceived improvements in medical staff's availability, patience, approachability, and trust after the intervention. In a recent mixed methods study evaluating the use of a non–EHR-tethered secure messaging system compared to emails and phone calls, caregivers enjoyed the "laid-back, casual quick messages" of SMS text messaging; however, they felt email was the most convenient method because they were already logged into their email and they could "communicate with multiple providers at the same time" [35]. In a study involving an intervention of web-based chat consultation with resident physicians, caregivers felt their concerns and questions were "well handled" by the extra time with providers via the web chat, despite it not being face-to-face [40].

Two additional studies focused on attitudes specifically toward emailing the child's health care team. A majority (n=178, 78%) of caregivers from a 2013 cross-sectional study in an urban pediatric primary care clinic showed interest in communicating with their child's providers by this method and attitudes were favorable, with three-quarters of email users reporting that it would improve communication with their provider [33]. A mixed methods study that elicited parents' perspectives on this topic for informing medical student training found that most participants placed high value on a provider's "ability to communicate, respectfully, and empathetically in email." [36]

For the 3 studies that discussed the needs of parents of children with complex needs, the modes of e-communication involved patient portal, secure messaging, email, and SMS text messaging, which were universally believed to enhance the patient/caregiver and health care team relationship [34,35,38]. However, a theme of operational barriers emerged from each study. For example, a lack of integration and interoperability of e-communication systems within and across institutions and professions was found to add considerable effort to both the caregivers and the health care team [34].

Evidence of Relational Coordination Concepts

Of the 7 concepts of the relational coordination theory, "timely" e-communication was identified as a key characteristic in a majority of the studies (n=20) [43], followed by the relationships with "shared knowledge" (n=16; Table 2). Thematic analysis noted "accurate" communication in approximately two-thirds of the studies (n=14), and both "frequent" communication and relationships with "shared goals" were associated with half of the studies (n=11). The relationship with "mutual respect" was detected in fewer than half of the studies (n=10), and "problem-solving" communication was only identified in one-quarter of the studies (n=6). Four references, each quantitative in design, were only coded for the "timely" relational coordination domain [31,33,37,40]. One reference did not demonstrate evidence of relational coordination concepts [19]. These counts help map the prevalence of each concept in the literature and provide insight into the degree to which relational coordination principles have been explored in the context of caregivers' experiences.

Discussion

Key Findings

This scoping review included 23 articles and identified a small body of literature from the last decade focusing on parental caregiver's perspectives on e-communication with their child's health care team. Overwhelmingly parents reported positive experiences with and a desire for e-communication methods. This is particularly relevant to the times as the 21st Century

Cures Act [9] has increased the sharing of clinical notes and test results asynchronously with patients/caregivers. However, there is sparse data on how parents/caregivers perceive such new platforms of communication, given that only 5 out of 23 studies include analysis of access to clinical notes. Overall, the findings suggest positive caregiver experiences with e-communication. Negative perceptions were largely due to technological barriers, including workflow disruptions and underdeveloped communication platforms. These barriers impacted the ease of communication but were not explicitly linked to the quality of the interaction between caregivers and health care team.

The literature spans care settings and illness acuity, and includes chronic, primary, and specialty care. Female caregivers were the most prevalent among the caregiver populations studied. Most studies examined lived experiences of participants, while a small number addressed anticipated expectations [25,32,36]. Although most studies had aims centered around the theme of caregiver perceptions of communication via various modes of e-communication with their child's health care team, the lack of standardized measures for the quality of e-communication made systematically looking across studies for factors to improve the caregiver perception difficult.

Gaps in the Literature

Despite the well-documented growing use of e-communication between patients/caregivers and the health care team, little is known about the characteristics and quality of the conversations that occur and whether the quality of the conversations impacts outcomes [44,45]. In rare instances where the content of e-communication has been analyzed, differences have been identified compared to in-person communication. For example, one study of e-communication via online portals at a large medical center showed a reduction in partnership-building language and supportive talk compared to in-person conversations [46]. Although this study did not measure the effects of this shift, it is possible that such changes could negatively impact the perceived quality of communication. Since evidence exists within nonelectronic communication (ie, face-to-face communication) about how specific content affects perceived quality [6], it is important to determine if those same characteristics and quality preferences apply to e-communication.

Although different modes of communication were studied, trends in preference for mode of e-communication may have changed over time due to increased use of and advances in EHRs and patient portals in the last several years [47]. However, none of the studies necessarily explored whether EHRs and patient portals were the primary modes of communication being routinely utilized. For example, a study may have specifically been asking about patient portals, but the caregiver and health care team may actually communicate most often via nonencrypted texts. SMS text messaging a health care team member's personal cell phone, as opposed to using a secure messaging service through a portal or web-based application, was not evident in this literature search; however, the practice is commonplace [48].

Relational Coordination Theory and Its Relevance

The relational coordination theory emphasizes the importance of shared goals, shared knowledge, and mutual respect in communication. Although the 7 key domains of the theory are present in part in a majority of the studies, both quantitative and qualitative, no study explicitly used the relational coordination theory as a framework to aid in conceptualization, measures of communication, or design of tools or interventions to improve e-communication. However, given the theory's focus on the quality of relationships through communication between team members, it is highly relevant for understanding and improving e-communication between caregivers and health care teams. To strengthen the application of the relational coordination theory, future studies should integrate it into the analysis of caregiver-provider e-communication to better assess how shared goals and mutual respect are fostered or hindered through electronic means, and how these domains affect the quality of care.

Limitations of the Literature

There are limitations to our ability to generalize the findings of this review to the national landscape of patient portals, as the majority of studies were conducted at academic health care institutes. This introduces a potential bias in the sample, as academic health care institutes may have different patient populations, resources to support an EHR/portal, and communication practices compared to other types of health care settings (eg, community hospitals and private practices). There was an absence in the literature on the use of nonsecure SMS text messaging despite its widespread application. Furthermore, not restricting the studies by country enhances the diversity in the review, health care, communication, and e-communication practices that vary across countries, which may also affect generalizability.

Populations in this scoping review were not diverse in sex, with possible underrepresentation of male caregivers in a majority of the studies. The rationale for this sex difference in contemporary research was not explained in any of the studies but likely represented convenience sampling. However, fathers, particularly fathers from disadvantaged backgrounds, have historically been underrepresented in pediatric research, and their lack of recruitment may impede our understanding of paternal effects on children's health and the development of effective family interventions [49].

The participants were not diverse in origins, cultures, or native languages, which appears to be due to language-based inclusion/exclusion criteria cited in some studies, as well as racial and ethnic disparities in technology needed for patient portal offers, access, and use [50]. Workarounds to language barriers might include the use of automated translation software, such as Google Translate, by caregivers or providers to attempt to facilitate asynchronous e-communication; however, the translation is not accurate across languages and only contributes to worsening of health inequity [51,52]. As the perspectives identified in the studies reflect English language speakers, caregivers from other linguistic or cultural backgrounds might have different expectations or priorities for e-communication.

Finally, the lack of representation of the independent child voice in the review is a significant limitation. By primarily focusing on caregivers, the review may not fully capture the perspectives and preferences of the primary participant in pediatric care—the patients themselves who may have high digital literacy. Measurement of children's views in communication, particularly in adolescents and young adults, and their impact on outcomes and experiences is crucial for a comprehensive understanding of pediatric e-communication dynamics.

Conclusions

This review provides a foundation for understanding the evidence base regarding how e-communication may be used to drive improved patient outcomes, experiences, or health care system workflows. The gap in the literature regarding pediatric caregiver and health care team e-communication, specifically the lack of evaluation of the quality of the communication from the caregiver perspective, is urgent to address given the rapid proliferation of e-communication in health care [47]. Investigating this critical void can contribute valuable insights to health care policy and practice guidelines. As e-communication tools become increasingly integrated into health care delivery, understanding the needs, preferences, and experiences of caregivers is essential for optimizing communication quality and enhancing experiences.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Keyword search and strategy.
[DOCX File, 15 KB - pediatrics_v7i1e60352_app1.docx]

Multimedia Appendix 2
Mode of electronic communication sorted chronologically by year of publication.
[DOCX File, 18 KB - pediatrics_v7i1e60352_app2.docx]

Multimedia Appendix 3
Studies on electronic communication between parental caregivers and their child's health care providers.
[DOCX File, 25 KB - pediatrics_v7i1e60352_app3.docx]

Checklist 1
PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) checklist.
[PDF File, 509 KB - pediatrics_v7i1e60352_app4.pdf]

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Abbreviations

EHR: electronic health record
MeSH: Medical Subject Headings
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews

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Original Paper

Exploring the Potential of a Behavior Theory–Informed Digital Intervention for Infant Fall Prevention: Mixed Methods Longitudinal Study

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Abstract

Background: Falls are the most common hospitalized injury mechanism in children aged ≤1 years, and currently, there are no targeted prevention interventions. The prevention of falls in children of this age requires changes in the behavior of their caregivers, and theoretically informed digital behavior change interventions (DBCIs) may provide a unique mechanism for achieving effective intervention. However, user acceptance and the ability of DBCIs to effect the required changes in behavior are critical to their likelihood of success.

Objective: This study aims to evaluate a behavior theory–informed digital intervention developed following a user-centered approach for user experience, the potential for this intervention to prevent infant falls, and its impact on behavioral drivers underpinning fall risk in young children.

Methods: Parents of infants aged <1 year were recruited and asked to use the intervention for 3 months. A pre-post longitudinal design was used to examine the change in the potential to reduce the risk of falls after a 3-month exposure to the intervention. Postintervention data on behavioral drivers for fall prevention, user acceptability, and engagement with the app were also collected. Interviews were conducted to explore user experiences and identify areas for further improvement of the intervention.

Results: A total of 62 parents participated in the study. A statistically significant effect on the potential to reduce falls was observed after the intervention. This effect was higher for new parents. Parents agreed that the intervention targeted most of the target behavior drivers. The impact of behavior drivers and intervention on the potential for fall prevention had a positive correlation. The intervention demonstrated good levels of acceptability. Feedback from participants was mostly positive, and the primary area identified for further improvement was widening the scope of the intervention.

Conclusions: This study demonstrated the promise of a newly developed digital intervention to reduce the risk of infant falls, particularly among new parents. It also showed a positive influence of the DBCI on the drivers of parental behaviors that are important for fall reduction among infants. The acceptability of the app was high, and important insights were gained from users about how to further improve the app.

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KEYWORDS

child injury; digital behavior change interventions; user experience; falls; infant fall; injury; mobile app; digital intervention; users; mixed methods longitudinal study; behavior; development; fall risk; fall prevention; acceptability; app; children; internet; parents; maternal, paternal; accidents; infancy; infant; accidental fall; accidental falls; infant behavior; longitudinal design; mixed methods; parent; mobile phone

Introduction

Children aged ≤1 year, that is, infants, have the highest rate of death owing to fall-related injury, and falls are the most common injury mechanism resulting in emergency department visits and hospitalizations during infancy. The head is the most commonly injured body part owing to infant falls [1-5], and in severe cases, these result in skull fractures, traumatic brain injuries, and long bone fractures [6].

Most of these fall events can be prevented by age-appropriate safe parenting practices and making changes in the child's environment [7-9], but currently, there are no targeted, proven interventions specifically for infant fall prevention [10,11], and there is also evidence that fall injuries have increased in recent years [12].

To fill this gap, the research team created a behavior theory–based digital intervention for infant fall prevention following an iterative user-centered process [13]. As detailed in the first paper, the Behavior Change Wheel (BCW) [14] combined with the person-based approach [15] was used to theoretically inform and develop a user-centered digital intervention. The resulting intervention included 4 modules targeting common fall mechanisms and events occurring within the first year of an infant's life.

The four modules consisted of (1) a safe feeding module targeting the prevention of falls related to feeding, (2) a safe furniture use module targeting infant falls related to furniture, (3) a safe use of baby products module targeting infant falls related to baby products, and (4) a safer environment module targeting stairs-related infant falls. The main features of the app include written articles (13 short articles, reading time per article approximately 3-5 min), trackable “tasks” encouraged by the articles where users can check off tasks as they complete them, a dashboard allowing users to check adherence with suggested tasks, and push notifications to remind users to engage with the app. (see the app screenshots in Multimedia Appendix 1).

The user-centered approach taken to develop this intervention inherently focused on ensuring that the target population comprehended the material provided and that the method of delivery was acceptable to users. However, as detailed in the first paper [13], this development process was undertaken iteratively with each individual module, and there is a need to ensure the acceptability of the overall app that integrates the 4 modules. Although the use of the BCW in designing the app was intended to increase the likelihood that engagement with the app would lead to the adoption of behaviors required to reduce the risk of falls among infants, this is not guaranteed, and there is also a need to evaluate whether the app is likely to have the desired impact and if this impact is consistent across all users. Finally, the app can only realize its desired effect if there is appropriate engagement by users with the app, and there remains the need to assess likely parental engagement and the scope for further improving engagement. This paper presents a 3-month longitudinal study to address these questions. The specific aims of this study were as follows:

1. To determine the overall impact of exposure to the intervention on parents' potential to reduce the risk of infant falls and determine if this is consistent across all users.
2. To examine the behavioral drivers for falls prevention (capability, opportunity, and motivation) among parents after exposure to the intervention and examine the relationship between these factors and the impact of the intervention.
3. To determine acceptability of the app as a whole and engagement with the app.
4. To explore user experience to identify factors driving user acceptability and engagement and scope for further improving the intervention.

Methods

Study Design

This study used a pre-post longitudinal design to examine the change in the potential of parents to reduce the risk of falls after a 3-month exposure to the intervention (part 1). The postexposure survey delivered at 3 months also collected data on behavioral drivers for falls prevention (part 2), user acceptability, and engagement with the app (part 3). User experience was further studied through in-depth interviews with a subset of participants to provide insight into factors driving user acceptability and engagement and to identify the scope for further improvement of the intervention (part 4). Parts 1 to 3 were quantitative and part 4 was qualitative. A mixed methods analysis approach was then used to triangulate the user experience findings from parts 3 and 4.

Ethics Approval

Ethics approval for the study was obtained from the University of New South Wales Human Research Ethics Executive Committee (HC210494).

Study Setting and Participants

Inclusion criteria for participants taking part in this study were as follows: must be aged ≥18 years, a parent of a child aged 0 to 6 months or an expectant parent within 2 months of the due date (mother or father), living in Australia, able to speak and understand English, and have access to a smartphone (iOS or Android). The study duration was 3 months. Participants needed to be in Australia with access to an iOS or Android smartphone because of the availability of the app in relevant app stores. The study duration was selected to cover the relevance of the information within the intervention.

Recruitment

Participants were recruited from an Australian market research company's existing consumer panel of parents between November and December 2021. A screening survey with questions to assess the inclusion criteria was emailed to the members of the consumer panel. Eligible participants who registered their interest in participating were electronically sent the main consent form to read and consent.

Within the main consent form, participants were invited to opt-in for the in-depth interviews, but a decision not to opt-in to this component did not preclude involvement in the main study. The first 10 consenting participants who opted in and provided separate consent for the in-depth interviews were selected.

The participants were given a gift voucher for Aus $100 (US $65) for completing both baseline and poststudy surveys. In addition, participants who took part in the poststudy in-depth interviews were given an Aus $40 (US $26) gift voucher.

Access to the App

Participants were provided with a link to download the app from the Google Play Store or Apple App Store depending on the smartphone they own.

Data Collection

Baseline and poststudy quantitative data were collected via a survey hosted on REDCap (Research Electronic Database Capture; Vanderbilt University) and distributed to participants electronically (Table 1). The baseline survey collected data on participant demographics (such as education level, income level, number of children, and marital status; Table 2) and questions designed to measure participants' potential to reduce the risk of infant falls. The latter consisted of the following four questions:

1. I know how to prevent falls among young children
2. Falls in children aged ≤1 year can be prevented
3. I am confident I can take actions to reduce the risk of my child falling
4. I have taken specific actions to reduce the risk of my child falling

The same 4 questions were also included in the poststudy survey. This set of questions was designed to demonstrate whether exposure to the app had the overall desired impact and was measured using a 5-point Likert scale (strongly disagree to strongly agree). The poststudy survey also included open-ended questions designed to (1) collect data from participants on the behavioral drivers for potential to reduce the risk of infant falls (Table 3) based on the Capability, Opportunity, Motivation–Behavior (COM-B) self-evaluation questionnaire [16] and (2) collect information on user experience. The latter user experience questions were framed in terms of user acceptance and engagement with the app.

User acceptance was measured by asking participants how much they liked the app and to rate the level of agreement (Likert scale: strongly disagree to strongly agree) with the following six statements: (1) I found the app easy to use; (2) I found the information useful; (3) the advice provided was easy to follow; (4) I could act on the advice provided; (5) I like the features of the app; (6) I found the reminders or notifications helpful.

For engagement, participants were asked about their use of the app and its features and to respond to the statements "I used the app" (not at all; once; more than once but not often; often—more than once a month; frequently—more than 4 times a month); "I read all the articles" (Likert scale: strongly disagree to strongly agree); and "I used the task list feature" (Likert scale: strongly disagree to strongly agree).

Poststudy qualitative interviews were conducted with a subgroup of 10 participants to understand parents' user experience with the app and to understand further opportunities to improve the app. In-depth interviews were conducted face-to-face using videoconferencing (Microsoft Teams). A discussion guide was used to structure interviews with each participant. The discussion guide was developed to ensure that participants understood the context of the discussion and to collect more in-depth details about the factors driving their acceptability and engagement with the app than could be collected through a quantitative survey. Similarly, it was also designed to collect more detailed insight into how the material provided in the app influenced the behaviors required to reduce the risk of falls in infants. Before conducting the interviews, the discussion guide was refined through peer-to-peer testing to optimize discussion flow and clarity. The final discussion guide used to frame the 10 in-depth interviews is provided in Multimedia Appendix 2. All the interviews were recorded and transcribed verbatim.

Table 1. Summary table of research variables.

Aim, variable, and source	Data type	Analysis conducted
Aim 1		
Factors assumed related to fall prevention (secondary outcome)		
Response to survey questions: I know how to prevent falls among young children (a)	5-point Likert scale	Difference between before and after using a paired Wilcoxon signed rank test
Falls in children under 1 can be prevented (b)	5-point Likert scale	Difference between before and after using a paired Wilcoxon signed rank test
I am confident I can take actions to reduce the risk of my child falling (c)	5-point Likert scale	Difference between before and after using a paired Wilcoxon signed rank test
I have taken specific actions to reduce the risk of my child falling (d)	5-point Likert scale	Difference between before and after using a paired Wilcoxon signed rank test
Potential to reduce falls (primary outcome)		
Sum of a to d	Continuous variable	Difference in means before and after using a 1-tailed paired *t* test
Intervention impact (“total change”—primary outcome)		
Calculated by postintervention potential to reduce falls minus preintervention potential to reduce falls	Continuous variable	Difference in means between different demographic groups using a 1-tailed paired *t* test
Demographics (independent variable)		
Various levels (Table 2) for relationship to child, age, experience, country of birth, household income, marital status, and education level	Categorical variable	Difference in means between different demographic groups using a 1-tailed paired *t* test
Aim 2		
Intervention impact (“total change”—primary outcome)		
Calculated by postintervention potential to reduce falls minus preintervention potential to reduce falls	Continuous variable	Linear regression used to examine influence of behavior scores on intervention impact while controlling for parental experience
Capability score (independent variable)		
Response to survey questions (Table 3) by Likert scales summed	Continuous variable	Linear regression used to examine influence of behavior scores on intervention impact while controlling for parental experience
Opportunity score (independent variable)		
Response to survey questions (Table 3) by Likert scales summed	Continuous variable	Linear regression used to examine influence of behavior scores on intervention impact while controlling for parental experience
Motivation score (independent variable)		
Response to survey questions (Table 3) by Likert scales summed	Continuous variable	Linear regression used to examine influence of behavior scores on intervention impact while controlling for parental experience
Overall behavior score (independent variable)		
Calculated by the aggregate of capability, opportunity, and motivation scores	Continuous variable	Linear regression used to examine influence of overall behavior score on intervention impact while controlling for parental experience
Experienced parent (confounder)		
Yes=2 or more children; no=1 child	Categorical variable	Linear regression used to examine influence of overall behavior score on intervention impact while controlling for parental experience
Aim 3		
Engagement (outcome)		
Response to survey questions	5-point Likert scale	Descriptive statistics
Likeability (outcome)		

Aim, variable, and source	Data type	Analysis conducted
Response to survey questions	5-point Likert scale	Descriptive statistics
Aim 4		
Barriers and enablers of the intervention		
Poststudy interview	Qualitative data	Qualitative descriptive method

Table 2. Participant demographics (N=60).

	Participants, n (%)	Total change, mean (SD)	*P* value
Relationship to child			.48
Mother	54 (90)	2.35 (2.17)	
Father	6 (10)	1.67 (2.80)	
Age (y)			.41
26-35	40 (67)	2.15 (2.34)	
36-45	19 (32)	2.68 (1.97)	
46-55	1 (2)	N/A[a]	
Number of children (dichotomized to a new parent and experienced parent)			.03
0 (new parent)	20 (33)	3.15 (2.30)	
1 (experienced parent)	40 (67)	1.85 (2.08)	
Parent born in Australia			.57
Yes	49 (82)	2.20 (2.26)	
No	11 (18)	2.64 (2.11)	
Household income (Aus $)			.48
<Aus $ 100,000 (<US $65,000)	15 (25)	1.81 (1.87)	
Aus $ 100,000-Aus $ 150,000 (US $65,000-97,500)	20 (33)	2.40 (2.50)	
≥Aus $ 150,000 (≥US $97,500)	21 (35)	2.29 (2.33)	
Decline to answer	3 (5)	4.00 (0)	
Marital status			.99
Married	43 (72)	2.28 (2.26)	
Single parent	3 (5)	2.33 (2.52)	
De facto (common law marriage)	14 (23)	2.29 (2.23)	
Education level			.66
Primary school, secondary school, and some university or TAFE[b] diploma	20 (33)	2.20 (1.88)	
University or TAFE graduate	25 (42)	2.08 (2.38)	
Postgraduate degree	15 (25)	2.73 (2.46)	

[a] N/A: not applicable.

[b] TAFE: technical and further education.

Table 3. The mean level of agreement with intervention impact on behavioral drivers.

	Values, mean (SD)
The app has improved my knowledge on (capability)	
The importance of getting rest	3.93 (0.94)
How to reduce fall risk while feeding my baby	4.15 (0.84)
How to reduce fall risk while my baby sleeps	4.12 (0.90)
How to reduce fall risk while changing my baby	4.40 (0.79)
How to reduce fall risk when using baby products like chairs and prams	4.17 (0.85)
How to reduce fall risk on stairs	4.30 (0.79)
Overall	4.18 (0.86)
After using the app, I feel (opportunity)	
I have the support I need to get enough rest	3.50 (0.98)
I have everything I need to reduce fall risk while I feed my baby	4.35 (0.60)
I have everything I need to reduce fall risk while my baby sleeps	4.38 (0.56)
I have a safe place to change my baby	4.52 (0.68)
I am able to correctly use safety straps when using baby products like chairs and prams	4.58 (0.53)
I have everything I need to reduce fall risk on stairs	4.20 (0.73)
Overall	4.26 (0.78)
After using the app (motivation)	
Remember to ask for help when feeling tired and feeding my baby	3.90 (1.00)
Have established a routine to reduce fall risk while feeding my baby	4.08 (0.81)
Intend to ensure my baby always sleeps in a cot	3.95 (1.17)
Believe changing my baby on the floor is the best option if I do not have access to a safe change table	4.53 (0.77)
Have established the habit of correctly using safety straps when using baby products like chairs and prams	4.42 (0.74)
Believe stairgates are important in areas accessed by my child	4.68 (0.50)
Overall	4.26 (0.90)

Analysis

The R programming language (R Foundation for Statistical Computing) was used for statistical analysis. In-depth interview data were transcribed and analyzed using NVivo software (Lumivero). Sample characteristics for the 60 participants in the longitudinal study were examined using descriptive statistics. The analytical approaches varied for each part (parts 1-4) of the study. The following section describes the approach adopted for each part.

Part 1: Determining the Overall Impact of Exposure to Intervention to Reduce the Risk of Falls

The primary outcomes studied in part 1 were the change in responses to the 4 questions included in both the pre- and poststudy surveys (ie, I know how to prevent falls among young children; falls in children under 1 can be prevented; I am confident I can take actions to reduce the risk of my child falling; and I have taken specific actions to reduce the risk of my child falling) and change in overall participants "potential to reduce the risk of infant falls." The latter was calculated from both pre- and poststudy responses by summing the Likert values for each of the 4 questions. An "intervention impact" score was then calculated by subtracting the total pre score from the total post score.

The pre-post difference in responses to the 4 questions was examined using paired Wilcoxon signed rank tests. The pre-post difference in the overall "potential to reduce the risk of infant falls" was examined using a 1-tailed paired *t* test.

The influence of exposure to the app on potential to reduce the risk of infant falls for different types of participants (as described by demographic variables: relationship to child, age of parent, 1 or more children, country of birth, household income, marital status, and education level) was examined by testing the difference in mean "intervention impact" between the different demographic groups. For dichotomous variables, independent 1-tailed *t* tests were used, and for variables with ≥2 category levels, ANOVA was used.

Part 2: Behavior Drivers for Fall Prevention After Exposure to the Intervention and the Relationship Between Behavior Drivers and the Impact of the Intervention

To examine the behavioral drivers for falls prevention (capability, opportunity, and motivation) among parents after exposure to the intervention, the mean level of agreement with each of the capability, opportunity, and motivation statements (Table 3) was calculated across the whole sample, together with the overall mean for each group of statements across the whole sample, that is, a mean overall capability, opportunity, and motivation score.

To examine the relationship between the behavioral drivers as self-evaluated by participants and the impact of the intervention, a capability, opportunity, and motivation score was calculated for each participant by summing the level of response provided for each question in each group (Table 3), and an overall "behavioral driver" score for each participant was calculated by summing the level of agreement with each statement listed in Table 3. The association between the behavioral component scores (ie, capability, opportunity, and motivation scores for each participant) and the impact of the intervention was examined using multivariable linear regression. A second linear regression analysis was then conducted to examine the relationship between the overall behavioral driver scores and the impact of the intervention. In both regression models, demographic variables found to be significantly associated with the impact of the intervention were also controlled for parent's experience.

Part 3: Determining Acceptability of the App as a Whole and Engagement With the App

Engagement with the app, as measured using responses to the question "I used the app," and the number of tracked tasks per participant were examined using descriptive statistics.

The acceptability of the app as a whole was determined by calculating the mean levels of agreement for each "app-like" statement across the sample, together with the mean overall level of agreement for this group of "app-like" statements across the sample.

Part 4: Explore User Experience to Identify Factors Driving or Hindering User Acceptability and Engagement and Scope for Further Improvement

The in-depth interview data were analyzed using a qualitative descriptive method to identify barriers and enablers of the intervention in terms of user experience [17].

Sample Size

A sample size of 62 was estimated to be sufficient for the quantitative components of the study based on a power calculation to see a significant change in parents' potential to reduce the risk of falls with an effect size of 0.4 and 80% power at the 5% level, allowing for up to 20% loss to follow-up and rounding up to the next full number.

For the qualitative poststudy in-depth interview, a sample size of 10 was chosen using a rule of thumb that this sample size should be sufficient to reach saturation and is double the minimum sample size recommended for digital intervention usability studies with a sample of 5 [18].

Results

Sample Characteristics

A total of 62 participants were recruited, downloaded the app, and completed the baseline survey, with 2 (3%) lost to follow-up. Therefore, 60 participants completed the poststudy survey. Table 2 presents the sample characteristics. In summary, 54 (90%) were mothers, 40 (67%) were aged 26 to 35 years, 20 (33%) were new parents, and 49 (82%) were born in Australia; 43 (72%) patients were married.

Part 1: Determining the Overall Impact of Exposure to the Intervention to Reduce the Risk of Falls

There was a significant improvement in each measure of the potential to reduce the risk of infant falls from after exposure to the intervention compared with before exposure. For each question, there was a significant increase in the level of agreement with the statements (Figures 1-4; $P<.001$).

There was also a significant improvement in the overall potential of parents to reduce the risk of falls after using the intervention. The mean overall score among participants before exposure was 15.77 (SD 2.24; range 10-20) and 18.05 (SD 1.86; range 14-20) after a 3-month exposure to the app ($P<.001$). Across the entire sample, the mean "total change" in potential to reduce the risk of falls was 2.28 (SD 2.23; range −2 to 8).

Table 2 presents the "total change" according to the different participant demographics. The only significant difference by demographics was a significantly greater "total change" in the potential to reduce the risk of infant falls among participants with only 1 child. Parents with ≥2 children had a mean "total change" of 1.85 (SD 2.08; range –2 to 5) whereas the less-experienced parents with only 1 child had a mean "total change" of 3.15 (SD 2.30; range –1 to 8; $P=.03$).

Figure 1. Level of agreement with “I know how to prevent falls among young children”: before versus after.

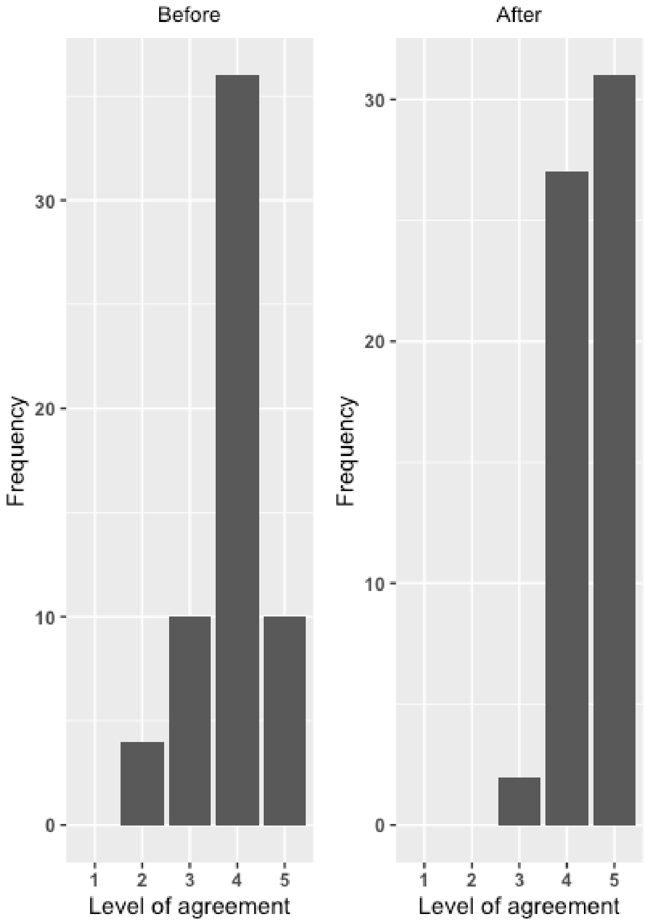


Figure 2. Level of agreement with “Falls in children under 1 can be prevented”: before versus after.

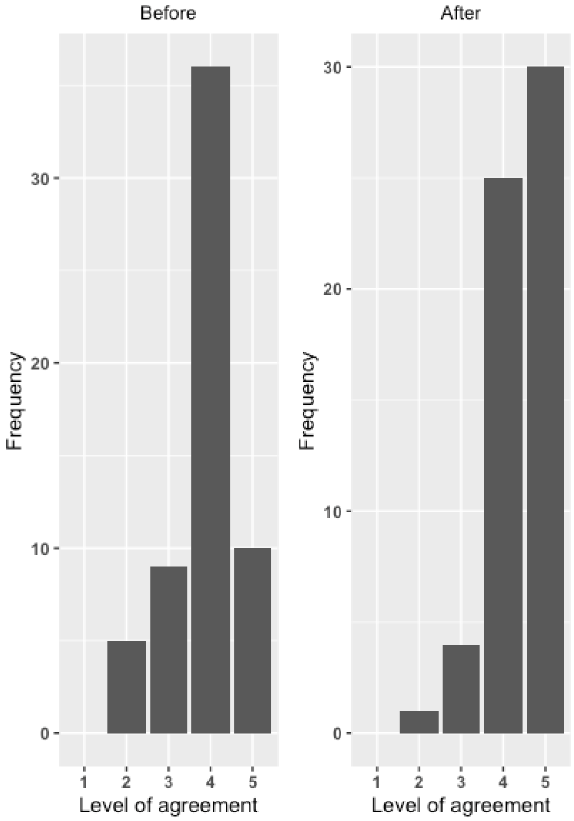


Figure 3. Level of agreement with “I am confident I can take actions to reduce the risk of my child falling”: before versus after.

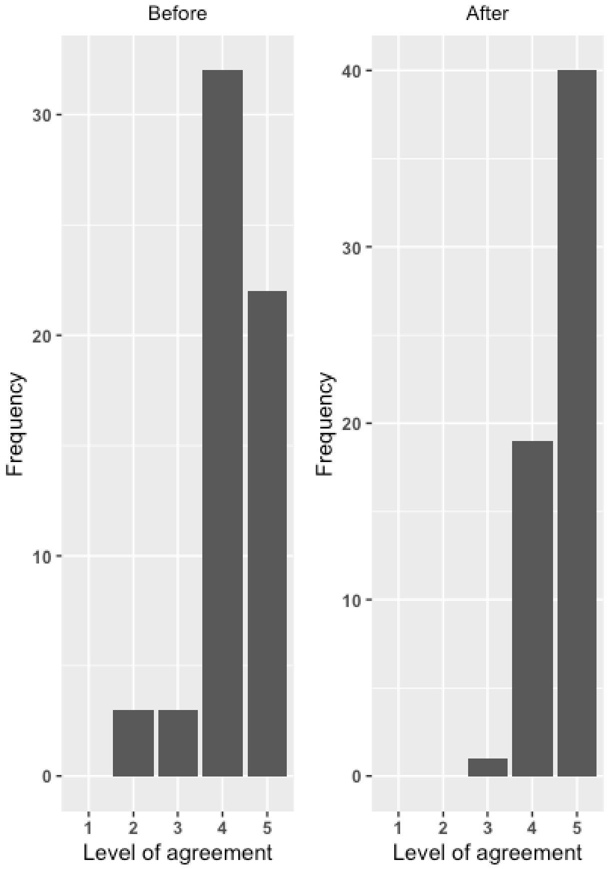
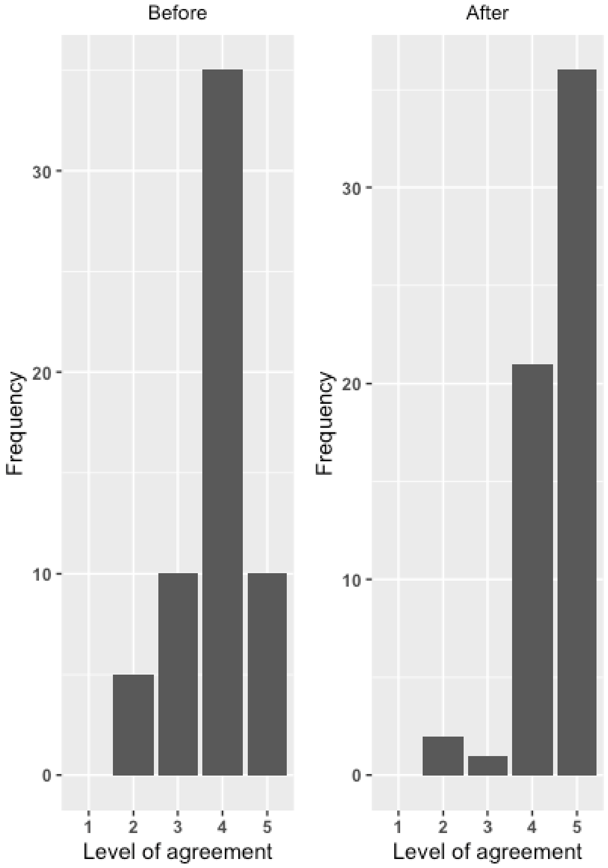


Figure 4. Level of agreement with “I have taken specific actions to reduce the risk of my child falling”: before versus after.



Part 2: Behavior Drivers for Fall Prevention After Exposure to the Intervention and the Relationship Between Behavior Drivers and the Impact of the Intervention

The mean level of agreement with each statement across the sample is shown in Table 3. As shown in Table 3, there was strong agreement with overall capability, motivation, and opportunity as self-evaluated by participants after using the app. The only aspect where there was inconsistent strong agreement was in questions related to getting enough rest where capability, opportunity, and motivation means across the sample remained <4.

Tables 4 and 5 present the results of the linear regression analyses. In the univariate analysis, opportunity and motivation scores were significantly associated with the impact of the interventions, with increasing behavioral component scores associated with increasing impact scores. However, in the multivariable analysis when controlling for parent experience (which was found to be significantly associated with the impact of intervention in part 1), none of the individual behavior components were significantly associated with impact (Table 4).

As shown in Table 5, the overall behavior score was significantly associated with increasing impact scores, even when controlling for parents' experience.

Table 4. Regression analysis modeling the relationship between behavior drivers and intervention impact.

	Univariate		Multivariable	
	Estimate	*P* value	Estimate	*P* value
Capability score	0.127	.07	−0.017	.86
Opportunity score	0.257	.006[a]	0.191	.12
Motivation score	0.207	.01[a]	0.926	.49
Experienced parent (yes or no)	−1.3	.03[a]	−1.196	.04[a]

[a] *P*<.05.

Table 5. Regression analysis modeling the relationship between overall behavior score and intervention impact.

	Univariate		Multivariable	
	Estimate	*P* value	Estimate	*P* value
BD[a] score	0.079	.009[b]	0.075	.01[b]
Experienced parent (yes or no)	−1.3	.03[b]	−1.118	.04[b]

[a] BD: Behavior Drivers Score.

[b] *P*<.05.

Part 3: Determining Acceptability of the App as a Whole and Engagement With the App

Table 6 presents the mean level of agreement of app use statements across the sample of participants, including their app use, whether they read the articles, and used the task tracking feature. The mean number of completed tasks per participant was 24 (SD 24.2052).

Table 7 presents the mean levels of agreement across the whole sample for each of the "app-like" statements and the mean overall, indicating generally strong acceptability (agreement levels over 4) of the app as a whole. The lowest levels of agreement were in the response to the "I like the features of the app" and "I found the reminders/notifications helpful."

Table 6. Participant agreement with the use of the intervention.

App use	Scores, mean (SD)
I used the app	3.53 (0.68)
I read the articles	4.17 (0.98)
I used the task tracking feature	3.75 (1.31)

Table 7. Participant agreement with the acceptability of the intervention.

App-like	Scores, mean (SD)
I found the app easy to use	4.20 (0.71)
I found the information useful	4.05 (0.79)
The advice provided was easy to follow	4.52 (0.60)
I could act on the advice provided	4.22 (0.94)
I like the features of the app	3.67 (0.93)
I found the reminders or notifications helpful	3.68 (0.89)
Overall score	4.05 (0.87)

Part 4: Exploring User Experience to Identify Factors Driving or Hindering User Acceptability and Engagement and Scope for Further Improvement (Qualitative Analysis)

General Understanding of Child Injury and Feedback on the Intervention

Parents expressed that the intervention provided them with important information, which was new. The intervention seemed to be valued more by new parents. It was evident that child injury was not an area that parents gave much attention to ("Injury is not something I had put too much thought into, I guess I just considered a baby didn't move"). Some parents had a general understanding and personal fear about falls due to the experiences of other parents they knew. In addition, safe sleeping practices and safe change table practices were commonly identified as information parents received from antenatal classes ("one of the main ones that I sort of looked at when my first son was born was more pages like SIDS"). However, the consensus was that they had little knowledge of specific preventive actions for most of the common fall events:

> *I learned so much...it brought to light a lot of things that you wouldn't think of...first I was like, you know, but then every time I would read something, I'd learn something.*

Experienced parents (who had more than 1 child) also identified the importance of the intervention. Even in cases where they knew some preventive actions beforehand due to lived experiences ("it was really just some anecdotal stories of my friends babies falling off things and hurting themselves..."), they identified that the intervention was a good reminder to adhere to safe behaviors:

> *I can't remember how I learned the information with my first child, but it was definitely a great reminder and easy access to find the information all in one place.*

Parents liked the style of the articles, which they reported they found engaging and informative and liked that the length was not too long. They also identified that if articles were too long, parents may not bother reading them, particularly as during the first year of a child's life a lot of information is "thrown" at parents:

> *I thought it was really well written. I liked the style of the way that it was written. I thought it was. It was very engaging and informative and I liked the length of it as well. But it wasn't too long. It just made it easy to when you're busy as a mum, sort of dip in and out of just having a bit of a look and yeah, and like getting some information quite quickly rather than reading pages and pages out. It was also quite easy to access different topics with them.*

Parents also identified the importance of the tone of the intervention and appreciated the practical nature of the advice provided:

> *I liked it because it was really straightforward. It's not in any way condescending. I don't think it's like I think sometimes you read resources and they can be like talking down to you. But I found that it was like simple language, but not in a condescending way.*

Credible profiles were valued by parents. They requested more ways to show the credibility of the information such as embedded links below the articles from reputable organizations:

> *And I like it. It's got the...like professors on there.... So it's telling you that there's experts on this.*

The task-tracking and adherence dashboards were features liked by most participants. "Checking things off a list" was well liked. The adherence dashboard was found to be an incentive "to get it all green." Parents understood the rationale of task tracking and expressed its importance in encouraging them to adhere to what was conveyed in the articles. However, there were some issues with the user experience of this feature ("I'm not finding easy to find what the ongoing ones are"). One parent requested access to the task list directly, without going through any related article. Another expressed that they could not get "100%" due to some tasks being not relevant for them. The "if-then" tasks were somewhat disliked:

> *I think that I think that idea of it is good, like having tasks that you can go through and say, yes, we've done this, but just the way it was delivered.*
>
> *I quite like checking things off. At least you know this is quite satisfying to kind of get to the ending. Right. OK, well, you know, I have half a clue about what I'm doing in this area.*

The notifications were found to be helpful. Parents expressed that the notifications made them come back to the app, made them read the articles, and helped them adhere to suggested practices. However, 2 participants mentioned that they did not receive notifications:

> *I liked the little reminders and I do. I do like that ‘cause. I think you get busy and then you don’t think to use it. So I did like the notifications as a way from reminding to dip back in and have information.*

App esthetics was also positively received. Parents liked that the app used real photos rather than drawings. Several “typos” within the content were noticed by the parents and were negatively received (“I’m a bit of a stickler for, you know, the text, I guess so, like typos and things, you know”).

Feedback on 4 Modules

Information provided in the safe feeding module was not practical for some parents. This was because it was dependent on the amount of social support available for mothers.

In addition, some mothers identified the possibility of cosleeping occurring, although this was not suggested by the module. One mother indicated that her initial evaluation of the intervention was not positive because of this inapplicability to her situation:

> *Uhm, I think probably this one was the least effective for me. I think like I like I mean it. I thought it was very helpful for reminding, reminding you of the importance of rest in that, that there it is risky to feed while you are tired. I think like in terms of actually making changes, it was I think the app was less helpful in doing that then the other modules because it was really around like getting support and that sort of thing, which is something that the app can’t necessarily help you with because either you have social support and you have people that can help you or you don’t work down the other modules provided more practical advice which weren’t sort of dependent on social support.*
>
> *Get enough sleep, you know, have your partner or someone to support you to come and do that? Well,... I actually left my job after my first one, and my husband still works and he gets up at 4:00 AM. It’s unrealistic for me to expect that. But for me, the one who doesn’t work to say, Oh no, you need to get up. Or every second night you’re on duty to take over. It’s just not possible.*

Some advice was not practical for parents with more than one child, such as “sleeping while the baby sleeps,” where they have to take care of the other child at the same time (“to sleep when the baby sleeps, I thought, what about my toddler, he doesn’t nap”).

Despite these limitations, parents understood the reasons for the suggested practices. They also expressed that the module made them conscious when they were tired during night feeding and encouraged them to take action to reduce the chance of falling asleep while holding the baby. Some expressed the importance of acknowledging differences in individual experiences within the module to mitigate any negative feelings induced (“it’s one of those things where it’s like ideal situation, right. But the reality is just sometimes so different”).

The parents liked the safe furniture use module. The message “one day the baby is still, and next day they are rolling,” resonated well with the parents. Commonly, parents expressed that they practiced keeping the baby in the cot if they had to move away or “on the floor,” where they could not fall, but some parents still left their baby on a bed, when they are in the prerolling age, in the “middle of the bed”:

> *I really liked this one. It made me yeah, it really made me reconsider that. Uhm, you know, even if you think either in the middle of the bed they are fine, that actually like it, they made that maybe when they roll and so it may be this. So this was helpful for me in thinking actually, although you’re tempted to put them on the bed or put them on the change table, they’re actually safer on the floor like putting them on the carpet actually safer than putting them on the bed. So this one actually really did stick with me. And that’s something that I thought about continually is actually just put him on the floor and he’s safer ’n the floor 'cause he can’t. fall anywhere.*

Parents found safe nappy change practices to be acceptable when using a change table. For some, this was aligned with the information received previously in the antenatal classes, but most mentioned that there are no safety straps in their own change tables, so keeping a hand on the baby was the applicable advice (“I don’t have a change table with straps and I do. I’m not sure that that’s a standard thing”). Changing nappies on the floor “where they can’t fall” was also liked by some, but some expressed this may be not practical in instances where the mother had a cesarean birth (“but as a mom who had two caesareans, I’m not gonna be getting down on the floor with a newborn baby”).

The module for the safe use of baby products was well received. Parents reported that the module made a difference on how they used safety straps with products. Some parents previously did not think of using straps when the baby was “very small” but reported that the module had an influence on changing the practice of using safety straps. One parent found that the information also influenced how they picked secondhand baby products, which seemed to be a common practice:

> *I think it might has made me so that you always say the straps here, but I think it’s just made it. It really reinforced to me how important it is to always do it up and if they look, you know that you think are there sitting there. They look secure, already without the straps on just to make it a habit of doing them up. So that was really good reminder for me that or you always need to just do it up just to just for that safety ‘cause you never know when they’re gonna try and reach for something or rollout or slide out. I think it also made me more aware of When I was buying secondhand baby items, they saw that all of the clips and everything were usable and that and present.*

The use of a wheeled baby walker was well accepted. Parents had commonly received some information on the negatives of baby walkers before the intervention. They understood that wheeled walkers are a fall risk and might also affect a baby's natural ability to stand. One parent mentioned that they still used one, but the duration of use was reduced after the intervention:

> *No, I never did. Somewhere I read early on that they aren't safe 'cause they can get to places they shouldn't be able to get to. Uh,.... So I've never had one. I had a bouncer that didn't move. That's probably not great for their development, but in put them in it too much. But it wasn't their safety thing in terms of, yeah, getting places, they shouldn't get to.*

Parents who had stairs in their homes identified the importance of the information included in the module for creating a safe home. Parents knew about using safe gates but identified the importance of other stair safety practices, but commonly, parents who did not have stairs found this module not relevant to them. They requested relevant information, such as babyproofing the environments:

> *We already knew that we needed to get safety gates. I've got friends with children. So you're already aware of the gates. But I do find the app. Yeah. Helpful from just from the tips around stairs. So, like, sort of saying don't step over the gate. And that's really stuck out to me. Was like, hold onto the rails and like and making sure that you have a free hand because it's so easy with stairs to hold baby in one hand and then be carrying a cup of tea or something else with the other hand. That is something that has changed my behavior, like making sure that I don't have my hands full and nothing to hold onto.*

General Feedback

Most of the interviewed parents expected more from the intervention. Even those who really liked the intervention expected more. Some thought the scope was too narrow, focusing only on falls, compared with multiple injury mechanisms, and mentioned that they may not have used it if they came across it outside the study. In addition, they felt that the intervention should have more engaging features ("It need something to keep you coming back to"). Parents had several suggestions to improve the scope of the intervention, such as providing more information relevant to older children, information on other child injury types, and prevention (babyproofing the house), including first-aid information and tapping into other relevant early childhood information:

> *...And I know this is sort of more a pilot, but I just wanted to see more, but I think that's where you're going with it. I'm, I've got through the modules quite quickly and I thought there's no more. I finished it now.*

> *...but I would really love like a checklist of this is everything that you need to do, you know, to baby proof your house so, you know, draw locks, baby gates like a, you know, like a a nice little comprehensive list for you to sort of do a scan of your house and then, everything you can do to make it injury safe, your baby.*

Parents expressed the importance of receiving the app from reputable agents to find it valuable and for them to use it (eg, via an antenatal class):

> *I think if I'd been aware of it, yeah, I definitely think so. So yeah, if, yeah, if at the hospital or the midwife or if it had been in, you know, the baby bundle that you get if there'd been a little flyer. Yeah, it would be something I'd look at. And definitely if I'd known it.*

Parents reported that they liked mobile apps rather than scanning through websites to obtain relevant information. Similarly, it was evident that although they tended to use social media groups (Facebook groups) to seek childcare information, they preferred reputable sources and sources where they can find professionally backed reputable information:

> *And sometime like when you're looking at websites and stuff, it can get so confusing, whereas like having an app or just one place to look just makes things so much more straightforward.*

> *I've recently got rid of Facebook because they're or maybe within those groups, there tends to be lots of negativity and scaring and I would be, I think it's taken me three kids and this long to realize that it's probably not a space I really want to be in and without an expert moderator, I don't wanna be there 'cause you can get too much information.*

Parents felt that there is a place for digital interventions in the space of early childhood interventions. Several parents shared the opinion that the support provided by the primary health care system reduced after a while and identified the viability of digital health interventions to fill this gap. In addition, they felt that the intervention value would increase if it provided some form of opportunity to connect with a health care professional:

> *Because there is such limited access to midwife and nursing support after having baby now like anything you can access at home...make a difference.*

> *You have lot of contact with the support initially, then you don't really see anyone.*

Triangulation of Quantitative and Qualitative Data

Triangulating the quantitative and qualitative data provided insights for where key improvements could be made to the app going forward. As shown in Table 8, where these are summarized, these largely focus on improvements that would make the app more valuable to parents.

Table 8. Areas to improve and potential improvements.

Areas to improve	Potential improvement
Broadening the scope of the intervention	Intervention could be broadened by including first-aid information and other injury information, including information relevant to a broader age group of children and other early childcare information. Special consideration needs to be given to make the app more valuable for experienced parents.
More autonomy for parents and reframing some advice as "suggestions"	Within intervention content, focus will be given to ensure the advice conveys as suggestions rather than "must follow" advice.
Improving practicality of information	Special consideration will be given to palpability of advice considering a range of individual circumstances of parents.
Improvements to task tracking	The task-tracking feature will be improved by introducing a direct way to access task lists and better ways to identify task ongoing and completion states.
Improvements to if-then plans	If-then tasks will be improved with giving parents a list of options that they can select from to create if-then rules.
Connecting parents to a health care professional	A feature where parents have ≥1 sessions with a health care professional who is experienced in child injury and early childhood could be introduced. This could also be used as a reengaging moment with the intervention for parents.

Discussion

Principal Findings

The findings from this study demonstrate promising potential of the intervention in terms of the impact on reducing the risk of infant falls, particularly among new parents. They also indicate promise in terms of an influence on drivers of parental behaviors important for fall reduction among infants. Acceptability of the app was high, and important insights were gained from users about how to further improve the app.

In this study, the potential to reduce the risk of falls was measured by examining the change in responses to a set of questions asked by the participants before and after the 3-month long exposure to the app. As there was no available validated measure, this set of questions was developed on the basis that knowing falls can be prevented, feeling confident that actions can be taken to prevent falls and taking action to reduce fall risk align with what was hoped would be the desired outcomes from exposure to the app. Although this is self-reported and not a validated measure, the relationship observed between this measure and the participants' responses to questions based on the COM-B self-evaluation questionnaire provides a level of promise that the intervention may work as intended. However, confirmation of the effectiveness of the intervention requires a different methodological approach, such as randomization and use of control, and for this purpose, the use of an objective measure such as reduction in falls would be preferred. Demonstrating the promise of an intervention during the early stages is important, as this reduces the risk of unnecessarily wasting resources in a later, larger, and more resource-intensive randomized controlled trial.

For digital and mobile health interventions, acceptability, usability, and engagement are likely to be as important to effectiveness as the content. The results also demonstrate promise in this regard. Importantly, the users trialing the app appeared to like the app and found it easy to use and useful. More importantly, the feedback from the users identified some areas for further improvement that could be relatively easily actioned, such as improvements to the task-tracking and "if-then" plans, and reframing some of the advice provided to convey more autonomy. However, as identified in user testing during the development phases [13], it was clear from this longitudinal study that in the longer term, the scope of the app needs to be broadened to increase the likelihood of high levels of ongoing engagement.

Concerns raised about the practicality of advice and the relevance of all components of the intervention to all users in this longitudinal study also reflected some of the feedback received during the user testing reported in the study by Cooray et al [13]. As noted in this study [13], issues raised regarding the practicality of advice drawn from best-practice sources indicate a need for further research into practical solutions. However, it may be that it is only certain parents or parents in certain situations who have practical issues, that needs to be explored further. It is possible that the contents of the intervention could be delivered in an individually tailored manner, and this might overcome both the concern of relevance of all information to all users, as well as issues related to the practicality of some advice for certain people or situations. Digital intervention in which injury prevention information is tailored to individuals has been found to be effective in promoting the adoption of safety behaviors relevant to the use of stair gates as well as other childhood injury mechanisms [19]. The potential of this approach should be considered in conjunction with further development of the app.

The potential promise of this behavioral theory–driven app on influencing behavior relevant to falls aligns with the success of other theory-driven digital interventions targeting childhood injury in changing behavior [20-23]. However, this is the first childhood injury intervention developed using the BCW. The significant association between the "behavior score" calculated from responses to the parental COM-B self-evaluation questionnaire and the outcome measure observed in this study also appear to be the first attempt at examining the pathways through which a behavioral theory–driven childhood injury prevention intervention works. Although the approach in this study was rudimentary, consideration should be given to designing future rigorous testing of the app in such a way that the mechanistic pathways can be studied in parallel with the overall effectiveness. The quantitative process evaluation being undertaken by Brown et al [24] in conjunction with the evaluation of their user-driven intervention to reduce the misuse of child restraints is an example of how this might be achieved. This level of evidence for the behavioral underpinnings of the success of digital interventions would further strengthen the case for designing childhood injury interventions using a behavioral theory lens.

The person-based approach to app development is likely to have influenced the high levels of usability and acceptance of the app. However, user feedback indicates that more work is required to increase engagement. The importance of engagement in digital injury prevention interventions has also been identified by other researchers. For example, Ning et al [20] cited poor engagement as a factor that may have reduced the impact of their digital intervention on reducing actual rates of injury. In their study, they measured average hours of engagement and felt that the level of engagement was relatively lower in terms of average hours of engagement than had been reported in other successful digital interventions [20]. However, no attempt has been made to directly study the level of engagement and any outcome. In contrast, Burgess et al [22] examined the direct association between their measure of engagement and an increase in knowledge and found a significant association. Including objective measures of engagement in future attempts to quantitatively evaluate processes underpinning the success of digital interventions would also appear to be useful.

The lack of an objective or quantifiable measure of engagement in this study was a limitation, and tracking engagement is something that should be added to the protocols of any future studies with this app. Other important limitations of this study are as follows: the use of an unvalidated outcome measure for the performance of the app and the pre-post design, which means no causal relationship between exposure to the app and the outcome measure can be confidently claimed. Furthermore, when reviewing the results of this study, it should be noted that recruiting participants via an internet-based panel means that the sample is possibly biased toward inclusion of only those who are already digitally active and computer literate, which may affect the generalizability of the findings. Future studies should aim to assess the intervention across a broader segment of the population. Keeping these limitations in mind, a strength of the study lies in the usefulness of the work as an intermediate step between optimization through user testing and a more resource-intensive controlled trial with a larger population-representative sample.

Conclusions

The 3-month longitudinal user-testing study has demonstrated the potential promise of the behavioral theory–driven, person-based intervention and has highlighted further scope for refinement. Overall, broadening the scope of the app appears to be the most important issue to be addressed in future work.

Conflicts of Interest

None declared.

Multimedia Appendix 1
App screenshots.
[DOCX File , 699 KB - pediatrics_v7i1e47361_app1.docx]

Multimedia Appendix 2
Interview discussion guide.
[DOCX File , 18 KB - pediatrics_v7i1e47361_app2.docx]

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Abbreviations

BCW: Behavior Change Wheel
COM-B: Capability, Opportunity, Motivation–Behavior

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Original Paper

Parent Perceptions of Telemedicine for Acute Pediatric Respiratory Tract Infections: Sequential Mixed Methods Study

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Abstract

Background: Since 2020, parents have had increasing opportunities to use telemedicine for their children, but how parents decide whether to use telemedicine for acute pediatric care relative to alternative sites of care is not clear. One of the most common reasons parents seek acute care for their children is for acute respiratory tract infections (ARTIs).

Objective: This study aims to examine parental expectations of care via telemedicine for pediatric ARTIs, contrasting expectations of care delivered via primary care telemedicine and direct-to-consumer (DTC) telemedicine.

Methods: We performed a sequential mixed methods analysis to examine how parents assess telemedicine for their children's acute care. We used ARTIs as a case study for examining parent perceptions of telemedicine. First, we analyzed semistructured interviews focused on parent responses about the use of telemedicine. Each factor discussed by parents was coded to reflect whether parents indicated it incentivized or disincentivized their preferences for telemedicine versus in-person care. Results were organized by a 7-dimension framework of parental health care seeking that was generated previously, which included dimensions related to care sites (expected access, affordability, clinical quality, and site quality) and dimensions related to child or family factors (perceived illness severity, perceived child susceptibility, and parent self-efficacy). Second, we analyzed responses to a national survey, which inquired about parental expectations of primary care telemedicine, commercial DTC telemedicine, and 3 in-person sites of care (primary care, urgent care, and emergency department) across 21 factors identified through prior qualitative work. To assess whether parents had different expectations of different telemedicine models, we compared survey responses for primary care telemedicine and commercial DTC telemedicine using weighted logistic regression.

Results: Interview participants (n=40) described factors affecting their perceptions of telemedicine as a care modality for pediatric ARTIs. Generally, factors aligned with access and affordability (eg, decreased wait time and lower out-of-pocket cost) were discussed as potential incentives for telemedicine use, while factors aligned with perceived illness severity, child susceptibility, and clinician quality (eg, trustworthiness) were discussed as potential disincentives for telemedicine use. In survey responses (n=1206), primary care and commercial DTC telemedicine were rated similarly on items related to expected accessibility and affordability. In contrast, on items related to expected quality of care, primary care telemedicine was viewed similarly to in-person primary care, while commercial DTC telemedicine was rated lower. For example, 69.7% (weighted; 842/1197) of respondents anticipated their children would be comfortable and cooperative with primary care telemedicine versus 49.7% (weighted; 584/1193) with commercial DTC telemedicine (*P*<.001).

Conclusions: In a mixed methods analysis focused on telemedicine for ARTIs, parents expressed more concerns about telemedicine quality in commercial DTC models compared with primary care–based telemedicine. These results could help health systems better design telemedicine initiatives to support family-centered care.

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KEYWORDS

telemedicine; telehealth; acute care; acute; pediatrics; pediatric; family medicine; family-centered; child; children; parent; parents; attitude; attitudes; opinion; perception; perceptions; perspective; perspectives; expectation; expectations

Introduction

The decision to seek care for a sick child is an increasingly complex one for parents. Parents are faced with a variety of care site options, which include both in-person (ie, primary care, urgent care, and emergency department [ED]) and virtual care modalities (ie, primary care provider [PCP] telemedicine and commercial direct-to-consumer [DTC] telemedicine). In recent years, families have increased experience and opportunity to use telemedicine with both their PCP and DTC telemedicine companies [1-4]. Many studies of prior telemedicine users indicate high parent satisfaction after telemedicine use, including high satisfaction with interpersonal and technical components of these visits, while others note concerns about the quality of interpersonal interaction and concerns about misdiagnosis and privacy [5-8]. Studies of parent perceptions as they anticipate or make decisions about potential telemedicine use are fewer. Some have importantly detailed disparities in general willingness to use telemedicine by sociodemographic characteristics or technology ownership [9,10]. Beyond general willingness to use telemedicine, however, it is important to understand decision factors influencing parents toward or away from telemedicine use at the time of a specific health care need.

One common reason for problem-based visits among children is the cluster of diagnoses known as acute respiratory tract infections (ARTIs), which include viral (eg, viral upper respiratory infection and viral pharyngitis) and bacterial infections (eg, streptococcal pharyngitis and acute otitis media). Before the pandemic, ARTIs accounted for over one-third of acute pediatric primary care visits and nearly 50% of DTC telemedicine visits [4,11]. The volume of pediatric ARTI visits dropped substantially during the early pandemic but increased over time with otitis media, streptococcal sore throat, and acute upper respiratory infection remaining common acute visit diagnoses for both in-person and telemedicine care during the later pandemic period [2,12-15]. These data suggest that deciding whether to seek care for pediatric cough and cold symptoms is one of the more common care-seeking decisions faced by parents. Thus, we focus on ARTIs as an illustrative example of a reason parents may seek care for their child, providing an opportunity to examine care-seeking decision-making processes. Important prior studies uncovered factors that may influence family decision-making about ARTI care-seeking, including site accessibility (eg, timeliness and geographic) and quality (eg, interpersonal and clinical) as well as illness and family factors [16-18], but did not explore how the option of telemedicine informs these decisions. More recent qualitative studies have begun to explore ARTI care-seeking decisions in the context of the option of telemedicine [19,20]. As an example, we recently examined parents decision-making for pediatric ARTIs in the context of the option of telemedicine and identified 7 dimensions that influence parents' decisions: perceived illness severity, perceived child susceptibility, parental self-efficacy, expected accessibility of care, expected affordability of care, expected quality of clinician, and expected quality of site [19]. By applying this framework to qualitative and quantitative data focused specifically on parent perceptions of the potential values and risks of telemedicine use, we seek now to understand how families assess individual factors to decide whether to use telemedicine for a specific ARTI care need. Understanding parent perceptions of telemedicine across these 7 dimensions is important to support health care systems in incorporating telemedicine into the acute care landscape beyond the public health emergency.

Therefore, in this analysis, we investigated current parent views regarding decision factors that potentially influence their intention to use telemedicine and other sites of acute care when their children have ARTI symptoms. Specifically, we sought to better understand parent perceptions of telemedicine models compared with in-person care for pediatric ARTIs using both qualitative and quantitative data to specifically examine potential differences in expectations of telemedicine delivered via PCPs versus telemedicine delivered via commercial DTC providers.

Methods

Overview

We performed a sequential mixed methods analysis to examine how parents approach decisions about the use of telemedicine when care-seeking for commonly experienced acute illness. We first conducted a qualitative analysis of semistructured parent interviews in which we asked parents to discuss prior care-seeking when their children were experiencing ARTI symptoms. Previous analysis of specific portions of these semistructured interviews which focused broadly on the decision to seek care published previously reported on 7 broad dimensions that parents consider when deciding whether and where to seek care for their children (perceived illness severity, perceived child susceptibility, parental self-efficacy, expected accessibility of care, expected affordability of care, expected quality of clinician, and expected quality of site) [19]. In this analysis, we examined parent responses to a specific later portion of the interviews where parents were asked to reflect specifically on the option to use telemedicine, which we analyzed to elucidate factors that might incentivize or disincentivize parents to seek ARTI care through telemedicine. Building on these qualitative findings, we fielded and analyzed a national survey to examine pediatric telemedicine use. Prior analysis examined parent-reported use of primary care telemedicine [21]. In this analysis, we focus instead on parent expectations of the care their child would receive if they presented at each of 5 different sites of care: in-person primary care, in-person urgent care, in-person ED, PCP telemedicine, and commercial DTC telemedicine. We adhered to the standards for reporting quality research guidelines for reporting the qualitative portion of this research [22].

Semistructured Interviews

As described in greater detail elsewhere, we first interviewed 16 pediatric research and clinical professionals to establish a normative expert model of parent care-seeking. Insights from these interviews then informed an interview guide for subsequent semistructured interviews with parents. Prior to launching interviews with a full sample (n=40), we conducted 3 pilot interviews with parents to ensure clarity of our questions and definitions. The first portion of the open-ended interview guide inquired about perceived needs, desires, and care-seeking decisions when seeking care generally for a child's ARTI, with results reported previously [19]. This paper focuses on a portion of the interview guide that inquired about the risks and benefits of telemedicine care for a child's ARTI ("What are your thoughts on the benefits of having a provider see your child while you are in your own house?" and "When, if ever, would telemedicine feel like a good choice for a child with a cold?") and barriers to telemedicine use ("What might make a telemedicine visit difficult for your family?"). Parents of children aged 1-5 years were recruited through a research registry of parents in Western Pennsylvania and beyond. All interviews were recorded, transcribed, and analyzed using thematic content analysis. Team members (SB, KR, and TK) independently coded each sentence in the first 5 transcripts and together reviewed and then developed a preliminary codebook of a priori and emergent codes. For each code present, we noted, when relevant, whether the factor was discussed specifically as a reason to use or avoid telemedicine. Upon achieving consensus, a codebook containing definitions and rules was finalized. The remaining transcripts were coded by a primary coder (SB), and 14 of those were cocoded by a second coder (KR or TK). Dedoose (SocioCultural Research Consultants), a qualitative research software program, was used to code interviews. In this paper, we present parental perceptions of potential factors that might positively or negatively influence their interest in the use of telemedicine organized by the previously identified 7 dimensions [19] to illustrate the degree to which these dimensions influence parental decisions to seek care from telemedicine.

National Survey

As described in greater detail elsewhere [21], we then developed a survey informed by our prior qualitative findings and fielded the survey nationally through the University of Chicago's AmeriSpeak Panel [23], a nationally representative panel. The survey included items asking about parent priorities and expectations when seeking care for a child's ARTI, prior telemedicine use, and sociodemographic characteristics. The survey underwent cognitive testing with 3 parents of young children and was offered in English and Spanish. Prior analysis of survey data focused on parent-report of PCP telemedicine use relative to sociodemographic characteristics of the respondent [21]. This analysis focuses on parent expectations of 21 different factors with the potential to influence their care-seeking across 5 different sites of care: in-person primary care, in-person urgent care, in-person ED, PCP telemedicine, and commercial DTC telemedicine. The order in which care sites were presented to respondents was randomized.

In the survey, PCP telemedicine was described as "a telemedicine visit with your child's usual primary care office or clinic. This would be a virtual visit with the provider or group of providers that conduct in-person well and sick care for your child(ren) in the office or clinic." DTC commercial telemedicine was described as "a telemedicine company or group that focuses on telemedicine visits rather than in-person care (also called DTC telemedicine). Providers in these groups do not provide care in-person and are not part of your child's usual care team. In these visits, you connect online and see an available provider in a model that could be thought of as virtual urgent care. Some DTC telemedicine groups or companies are affiliated with health systems but are still separate from primary care clinics who might see their own patients through telemedicine."

The survey was fielded to members of the AmeriSpeak panel, with panel members eligible if they were caregivers of children aged ≤17 years.

This analysis focused on the percentage of respondents who anticipated that the specified care site would meet their expectations "always" or "often" for each of the 21 specific items. For each of the 21 items, we calculated the weighted percentage of respondents who indicated they "always" or "often" expect that item at each site, using weights derived from panel sampling weights along with survey response rates, such that the demographics of the weighted sample align with the US Current Population Survey [24]. Surveys with missing responses to individual items were omitted from denominator for that item. We then used *t* statistics from weighted logistic regression models to compare responses for each item for PCP telemedicine and DTC telemedicine. Finally, we averaged responses to items within each of the 7 dimensions for PCP telemedicine and DTC telemedicine to further synthesize the differences between expectations of PCP and DTC telemedicine.

Ethical Considerations

Semistructured Interviews

The qualitative interview portion of this study was determined exempt from human participants review by the University of Pittsburgh institutional review board (IRB; STUDY20040025). Participants received an IRB-approved introductory script prior to participating in the interview informing them of the goals of the interview, potential risks and benefits, plans to protect their information, and how to contact the research team if they had questions, and they then provided verbal consent to proceed. Identifiable data collected only for payment purposes were stored separately from interview data; interview data were deidentified. Participants received a US $50 gift card through the University of Pittsburgh's Vincent Payment Solutions.

National Survey

The survey portion of this study was determined exempt from human participants review by the University of Pittsburgh IRB and by the National Opinion Research Center at the University of Chicago IRB (STUDY21070080). The University of Pittsburgh research team only received deidentified data from National Opinion Research Center for analysis. Survey respondents were compensated for their time through AmeriSpeak, receiving the cash equivalent of $5 (equivalent of US $17.50/hour) for completing the survey.

Results

Qualitative Interview Results

A total of 40 parents participated in the qualitative interviews, of which 65% (n=26) of parents had more than 1 child, 65% (n=26) of parents had previous experience using telemedicine for a child, and 38% (n=15) of parents had children insured by a commercial or employer-sponsored insurer (Table 1).

Table 1. Demographic characteristics of participants in qualitative parent interviews (n=40).

Characteristics	Interview participants, n (%)[a]
Sex	
Female	38 (95)
Male	2 (5)
Age group (years)	
18-30	12 (30)
31-40	23 (58)
41-50	5 (13)
Interviewee's children's ages[b]	
Interviewees with children <1 year	5 (13)
Interviewees with children 1-5 year	40 (100)
Interviewees with children >5 year	16 (40)
Self-reported race and ethnicity	
African American or Black	6 (15)
African American and Native American	1 (3)
Hispanic or Hispanic and multiracial	3 (8)
White	30 (75)
Prior telemedicine use for their child	
No	14 (35)
Yes	26 (65)
Geographic location	
Urban	23 (58)
Rural	17 (42)
Insurance type	
Commercial or employer based	15 (38)
Medicaid or federal	25 (63)

[a] Percentages may sum to >100% due to rounding.

[b] Categories are not mutually exclusive.

Dimensions Affecting Parental Perceptions of Telemedicine

Interviewees described a range of factors that affect their perceptions of telemedicine care for their children. These factors mapped onto the 7 dimensions influencing care-seeking, including dimensions related to care sites (expected access, affordability, clinical quality, and site quality) and dimensions related to child or family factors (perceived illness severity, perceived child susceptibility, parent self-efficacy) [19].

Expected Accessibility of the Site

Interviewees expressed interest in using telemedicine due to perceived opportunities to increase temporal accessibility, mitigate geographic accessibility, and maximize convenience (Multimedia Appendix 1). In contrast, some spoke about the value of telemedicine only as a last resort option when other sites could not be accessed. One interviewee described how using telemedicine maximizes convenience as follows: "I honestly couldn't see how [using telemedicine] would make anything difficult, 'cause it's saving me time, gas, all of that stuff" (parent 24). In contrast, some interviewees expressed concerns about digital accessibility and how telemedicine might be less optimal for their family or for other families: "You might not even have access to computer. I mean I guess everybody has a cell phone, but, you know, connecting to like a video call on your cell phone isn't always ideal" (parent 06).

Expected Affordability of the Site

Interviewees favored telemedicine use if out-of-pocket costs were less than or equal to in-person options: "I mean you're not getting that one-on-one or face-to-face time necessarily, so, I kind of feel like [telemedicine] should probably be cheaper [laughter] or free" (parent 06). Parents viewed telemedicine favorably if insurance would cover the expense and less favorably if there was a likelihood of needing further in-person evaluation contributing to a possible second visit expense or when costs for telemedicine were out-of-pocket.

Expected Quality of the Site

Interviewees viewed telemedicine positively when they perceived that telemedicine increased their child's comfort level and made seeking care safer: "Well, the kids will be more comfortable [on telemedicine]. I mean, 'cause I know kids...they get anxious when they go to the doctor's office, so they're symptoms might get worse...I mean, they might also pick other stuff up when they go to the doctor's office. So it might just be an ease, so you're not exposing yourself to other things" (parent 39). Parents were split on whether they felt like telemedicine would allow for adequate assessment of ARTI symptoms, noting that evaluation of some symptoms (eg, ear pain) might be more difficult than others (eg, red eyes) over telemedicine without the availability of equipment with remote assessment capabilities. In contrast, some parents were less receptive to the idea of seeking telemedicine, and pointed out that a telemedicine appointment cannot provide comprehensive clinical care: "It's kind of hard—you can't really do immunization [on telemedicine]—I mean, 'cause you would still have to go to the office to get those" (parent 39).

Expected Quality of the Clinician

Interviewees discussed intersections between telemedicine and the expected quality of clinicians. Some interviewees indicated they would be less interested in using telemedicine if they could not visit a familiar provider: "If it was doctor that...didn't know [my child] well, I might not feel 100% comfortable. But because [pediatrician] knows him and his personality...I'd probably feel more comfortable if [telemedicine] was with her" (parent 12). Interviewees were divided on whether they perceived they would receive reassurance over telemedicine. There was a general perception among interviewees that receiving trustworthy care would be less likely over telemedicine. Additionally, parents expressed more interest in telemedicine when the provider was someone with experience in caring for children. One parent described their preference for a provider with pediatric expertise: "I don't want, you know, like, a doctor who just got their degree last week to try and diagnose what my son has, like, with his cold and everything. I would want someone looking at it who has experience with kids" (parent 31).

Perceived Severity of Illness of the Child

Parent interviewees discussed perceptions of telemedicine that mapped along the following 3 primary child and parent dimensions: perceived severity, perceived child susceptibility, and parental self-efficacy (Multimedia Appendix 2). Interviewees primarily viewed telemedicine less favorably when they perceived the high severity of a child's illness and symptom complexity. One interviewee described her care-seeking decision when her child had a cold: "I think if it's just like a normal cold...I feel like I would be pretty comfortable doing telemedicine for that. And then if they thought it was severe enough, then I would go in" (parent 30). Parent's perceptions of using telemedicine based on their child's demeanor and appearance were divided, with interviewees expressing both interest and disinterest in using telemedicine when their child appeared more ill. In contrast, interviewees generally viewed the use of telemedicine favorably when prolonged persistence of their child's symptoms was the primary driver of care seeking.

Perceived Susceptibility of the Child

Interviewees generally expressed less interest in telemedicine use for ARTI acute care when they perceived greater underlying susceptibility of the child, such as if they have a child with medical complexity or younger age. One interviewee described her preference for in-person care because of a perceived vulnerability to the illness of her child: "I need my child to be seen by somebody because I need them to listen to her lungs, and I need them to check her ears. Maybe if the child is not prone to having ear infections, and she's not asthmatic, then it would be a little different" (parent 33). In contrast, interviewees showed more interest in telemedicine use when trying to avoid community-based exposure: "I'm thinking now I probably should have done [telemedicine] instead of having to take him in, and like possibly exposing him" (parent 12).

Perceived Self-Efficacy of the Parent

Parent self-efficacy factors identified by interviewees included achieving the goal of the visit, antibiotic expectations, and easing uncertainty, all of which interviewees generally viewed as achievable through telemedicine care. For individual interviewees, however, self-efficacy factors, such as parent health literacy and worry, were discussed as individual reasons to seek and not to seek care through telemedicine. Concerns about the ability to protect their child's privacy (ie, information privacy and physical location privacy) and negotiate power differentials (ie, equity and patient-clinician power dynamics) contributed to parental worry about using telemedicine. One parent described these worries: "They [provider on telemedicine] could catch you at a really bad time whenever, you know, 'cause when a kid is sick...things in the house just kind of—everything falls into chaos, so they could be seeing a snapshot and judging your entire life by that" (parent 03).

Survey Results

Survey invitations were sent to 6015 AmeriSpeak panelists, with 1599 (26.6%) of those invited completing the screener; of the 1599 individuals screened, 1297 (81.1%) met the eligibility requirements; and of the 1297 individuals who were eligible, 1206 (93.0%) completed the survey. The majority (1136/1206; 96% weighted) of respondents took the survey in English, and 60% (weighted; 714/1206) had children insured through a private employer or purchased directly (Table 2).

Table 2. Demographic characteristics of participants (n=1206) and weighted percentages in a quantitative national survey.

Characteristics	Survey respondents, n (weighted %)[a]
Sex	
Female	786 (55.3)
Male	420 (44.7)
Age group (years)	
18-29	158 (11.8)
30-44	761 (59.2)
45-59	258 (26.3)
>60	29 (2.6)
Race and ethnicity	
Asian, non-Hispanic	34 (6.4)
Black, non-Hispanic	109 (11.3)
Hispanic	375 (22)
White, non-Hispanic	634 (56.6)
Other, non-Hispanic	54 (3.7)
Census division	
South Atlantic	233 (19.5)
Pacific	195 (16.7)
East North Central	172 (14.3)
West South Central	136 (13.2)
Mountain	129 (8)
Mid-Atlantic	103 (11.4)
West North Central	102 (6.6)
East South Central	77 (6)
New England	59 (4.4)
Survey language	
English	1136 (96.1)
Spanish	70 (3.9)
Previous telemedicine use for a child	
Yes	516 (41)
Child insurance type	
Employer or Commercial	714 (60.2)
Medicaid or federal	460 (37)
Uninsured	32 (2.8)

[a] Percentages may sum to >100% due to rounding.

Parents were asked to indicate how often they expect to find each of the 21 specific items across 5 different care sites. For most items, respondents most commonly expected to experience that item at an in-person primary care visit compared with the 4 other sites. The 2 virtual sites of care carried higher expectations than in-person primary care for items related to accessibility and not being near other sick children (Multimedia Appendix 3). For example, out of 1200 respondents answering the item, 56.3% (weighted; n=679) expected to avoid a long wait through a primary care visit, compared with 60% (weighted; 740/1195) through commercial DTC telemedicine and 64.1% weighted (790/1200) through PCP telemedicine. The 2 virtual sites carried lower expectations than all 3 in-person sites for "being able to complete all tasks" (within the expected quality of site dimension) and "ability to care for severe symptoms" (within the perceived illness severity dimension; Table 3 and Multimedia Appendix 3).

Parents reported high expectations for PCP telemedicine across several system dimensions (Table 3), with three-quarters indicating expecting to be able to usually or always see a provider with experience caring for children (919/1195; 76.5% weighted) and to receive care in a way that protects the child's privacy (932/1198; 76.2% weighted). Parents largely had higher expectations for PCP telemedicine than commercial DTC telemedicine for items related specifically to their perception of their child's illness and susceptibility with 75.7% (weighted; 915/1198) always or often expecting the ability to receive care across the 0-17 years age range at PCP telemedicine (Table 4 and Multimedia Appendix 4).

Comparing expectations specifically for the 2 telemedicine options, responses were relatively similar for accessibility items and were the most discrepant for quality of clinician and child susceptibility items. For example, a similar percentage of parents expected to always or often receive care that does not disrupt their schedule for PCP telemedicine (723/1200; 60.2% weighted) and DTC telemedicine (696/1195; 59.1% weighted; *P*=.57), which is an item under the accessibility dimension. In contrast, parents' expectations to often or usually receive care from a "provider who they trust to make choices in their child's best interest" varied from 72.4% (weighted; 885/1199) for PCP telemedicine to 54.3% (weighted; 664/1192) for DTC telemedicine (*P*<.001). Similarly, parents' expectations to always or often receive care from a "provider with full access to their child's medical history" ranged from 71.3% (weighted; 857/1194) for PCP telemedicine to 46.5% (weighted; 541/1190) for DTC telemedicine (*P*<.001).

Survey results were averaged within each of the 7 dimensions and mapped onto the previously identified health care–seeking decision model (Figure 1), with line weight illustrating the difference in parent expectations of PCP and DTC telemedicine.

Table 3. Percentage of caregiver respondents (n=1206) who "always" or "often" expect the factors listed relating to expected accessibility, affordability, and quality at the 2 telemedicine sites (primary care provider [PCP] telemedicine and direct-to-consumer [DTC] telemedicine).

Factors[a]	PCP telemedicine, n/N (weighted %)	DTC telemedicine, n/N (weighted %)	*P* value
Expected accessibility			
Fits schedule	723/1200 (60.2)	696/1195 (59.1)	.57
Minimal hassle	892/1199 (73.9)	843/1195 (70.4)	.045
Minimal wait	790/1200 (64.1)	740/1195 (60.0)	.04
Expected affordability			
Minimal costs	676/1197 (54.5)	553/1196 (46.2)	<.001
Expected quality of the site			
Knows child	726/1198 (60.5)	416/1196 (35.9)	<.001
Pediatric experience	919/1195 (76.5)	672/1193 (55.9)	<.001
Record access	857/1194 (71.3)	541/1190 (46.5)	<.001
Can trust	885/1199 (72.4)	664/1192 (54.3)	<.001
Expected quality of the site			
Protects privacy	932/1198 (76.2)	756/1196 (61.8)	<.001
Comprehensive tasks	656/1194 (56.1)	505/1196 (42.3)	<.001
Avoid exposures	890/1197 (73.4)	856/1192 (72.4)	.54
Child comfort	842/1197 (70.3)	584/1193 (50.2)	<.001

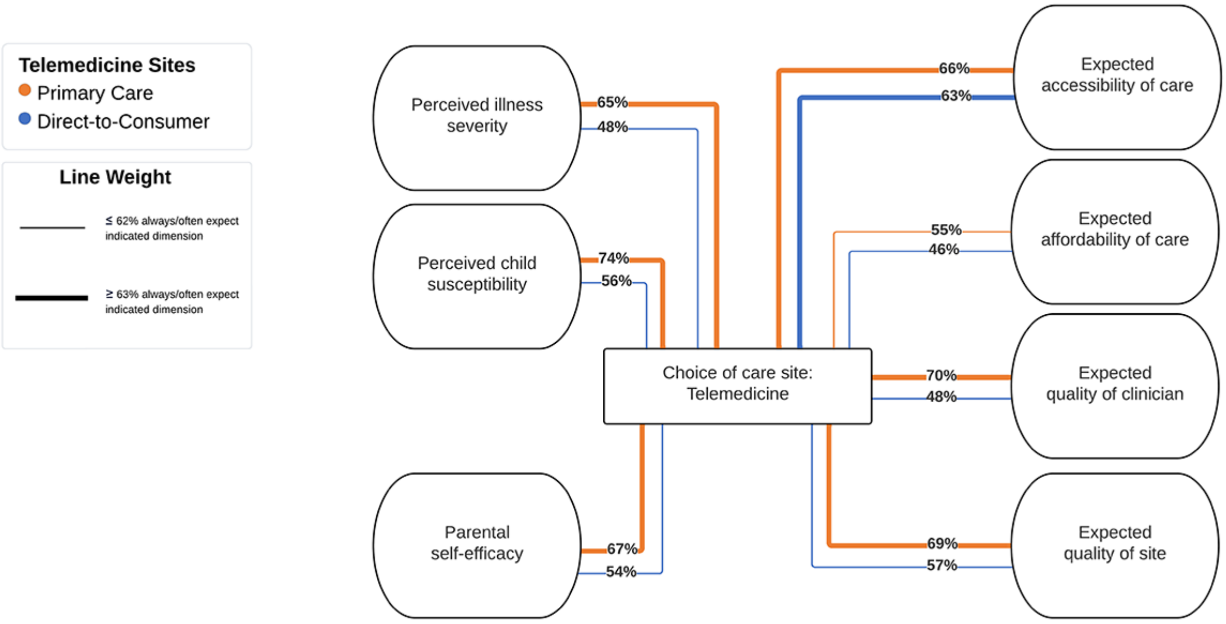
[a] For each item, we calculated the weighted percentage of nonmissing responses indicating that the item was expected "always" or "often" at the specified site. We determined statistical significance using *t* statistics from weighted logistic regression models to compare responses for each item for PCP telemedicine and DTC telemedicine.

Table 4. Percentage of caregiver respondents (n=1206) who "always" or "often" expect the factors listed relating to perceived illness severity, perceived child susceptibility and parental self-efficacy factors at the two telemedicine sites (primary care provider [PCP] telemedicine and direct-to-consumer [DTC] telemedicine).

Factors[a]	PCP telemedicine, n/N (weighted %)	DTC telemedicine, n/N (weighted %)	*P* value
Perceived illness severity			
Severity responsive	773/1199 (63.1)	585/1198 (48.3)	<.001
Duration responsive	792/1196 (65.3)	576/1194 (48.1)	<.001
Multiple symptom responsive	814/1199 (67.9)	634/1198 (51.6)	<.001
Seriousness responsive	762/1199 (63.3)	553/1196 (46.0)	<.001
Mood responsive	790/1196 (64.4)	579/1190 (47.6)	<.001
Perceived child susceptibility			
Considers history	902/1193 (73.1)	646/1195 (52.6)	<.001
Age responsive	915/1198 (75.7)	718/1193 (58.4)	<.001
Parental self-efficacy			
Will understand	892/1200 (73.1)	703/1198 (57.9)	<.001
Obtain doctor forms	754/1199 (61.8)	609/1198 (50.6)	<.001

[a] For each item, we calculated the weighted percentage of nonmissing responses indicating that the item was expected "always" or "often" at the specified site. We determined statistical significance using *t* statistics from weighted logistic regression models to compare responses for each item for PCP telemedicine and DTC telemedicine.

Figure 1. Percent of parents expecting each of 7 dimensions of the influence diagram of health care–seeking decisions when seeking care at primary care provider telemedicine and direct-to-consumer telemedicine. The center rectangle represents the decision "choice of care site." Focusing on the choice to use either of the 2 studied telemedicine models (primary care telemedicine and commercial direct-to-consumer telemedicine), this choice is surrounded by dimensions affecting this decision in ovals with averaged expectations of survey respondents of primary care telemedicine (orange) and direct-to-consumer telemedicine (blue). Line weight indicates the average percentage of respondents expecting the factors within the indicated dimension always or often at the indicated telemedicine site.



Discussion

Through semistructured interviews, parents expressed positive assessments of telemedicine accessibility but voiced concerns about telemedicine quality. In a structured survey informed by these results, we found continued positive expectations of telemedicine accessibility and less concern about quality for PCP telemedicine relative to commercial DTC telemedicine. Respondents anticipated that both models of telemedicine would minimize hassle, wait time, schedule disruption, and exposure to other ill children. However, respondents had higher expectations of clinician and site quality and the ability to treat severe illness from PCP telemedicine compared with DTC telemedicine. The strengths of this analysis include a mixed methods approach with qualitative interviews conducted until saturation was achieved followed by a large nationally representative survey, which was conducted 2 years into the COVID-19 pandemic.

These findings first provide an illustration of the applicability of our health care–seeking decision model [19], which incorporates elements represented in prior models representing both health beliefs and access to care [25,26]. By using the health care–seeking decision model as a guiding framework for the interpretation of these qualitative and quantitative data, we uncovered differences in parent perceptions of expected quality versus expected accessibility across different models of telemedicine care. The survey data further support the health care–seeking decision model, with these quantitative items showing variation across sites and dimensions.

The relatively high expectations of quality in PCP telemedicine—and the contrast to expectations in DTC telemedicine—comes at an important time for state and federal policy makers as the COVID-19 public health emergency has ended. These findings indicate that parents differentiate between primary care models of telemedicine and virtual-only telemedicine, but this is not a distinction that has made its way into all payment and policy discussions. In states and state Medicaid programs that have not adopted telehealth-supportive legislation or kept up with telemedicine policy changes in Medicare during the pandemic [27], there is a real threat to the financial sustainability of PCP telemedicine [28]. Specifically, if the majority of payers for patients within a pediatric primary care practice do not provide coverage at parity for telemedicine while the child is at home, then primary care clinicians may not be able to continue offering telemedicine to their patient panels [28]. As of June to August 2021, 63% of pediatricians reported that they were continuing to use telemedicine [29]; that number could rise or fall further depending on the ability of payers to signal and provide ongoing support for this modality of care. PCPs with concerns that patients may just as readily seek telemedicine care elsewhere may wish to take note of these results indicating that families value the continuity, pediatric expertise, and access to medical records of telemedicine through primary care practices offer.

While our data suggest that parents have the highest expectations for in-person primary care, it should be noted that parents' expectations of PCP telemedicine approach expectations of in-person primary care for items in dimensions related to quality and even surpass in-person primary care for items related to access. In terms of virtual care options, our data suggest parents may preferentially choose PCP telemedicine for their children over DTC telemedicine, which is supported by the observation that the growth in telemedicine volume for children during the pandemic occurred almost entirely through PCP telemedicine rather than telemedicine-only providers [2]. PCP telemedicine also carries more positive expectations than urgent care or ED for access, quality, and parental self-efficacy dimensions. Thus, maintaining PCP telemedicine as an option may help families choose lower-cost options of care and maintain continuity. PCPs and health systems may also wish to ensure that patients can readily recognize and electronically engage PCP telemedicine, to ensure parents are connecting with the care and the providers that they desire.

Limitations include that results from qualitative interviews may not be generalizable to the population as this sample may over- or underrepresent certain populations when seeking care, such as female caregivers. Our research focuses specifically on how parents perceive telemedicine use in the context of seeking care for ARTI symptoms, and we note that these expectations could vary for other conditions. Interviews were conducted between April and July 2021, during a time when care-seeking decisions may have been influenced by the ongoing COVID-19 pandemic. However, the survey results were fielded in February 2022, a time when COVID-19 vaccines were available and parents had potentially 2 years of experience with telemedicine. We note also that while we had high rates of completion among those screened and determined to be eligible (1206/1297, 93%), there was a sizable number of nonresponders to the initial invitation to complete the screener, which may bias results.

In conclusion, in this mixed methods analysis of parent perceptions of telemedicine when approaching ARTI care-seeking decisions, parents expressed positive assessments of telemedicine accessibility while also voicing more concerns about telemedicine quality in commercial DTC models compared with primary care–based telemedicine. Future work is needed to help support families in making care-seeking decisions when their children are sick, by both supporting family decision-making and aligning in-person and telemedicine care options with child needs and family expectations.

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Data Availability

Deidentified data will be made available on request from authors with appropriate institutional review board and data use agreements in place.

Authors' Contributions

SKB contributed to the survey design, analyzed and interpreted the data, and drafted the manuscript. TK contributed to the design of the study and survey, supervised analysis, interpreted the results, and critically revised the manuscript. TTD and KS interpreted the results and critically revised the manuscript. JMH, AH, and JMK contributed to the design of the study, interpreted data, and critically revised the manuscript. KNR conceptualized and designed the study and survey, acquired and interpreted the data, supervised analysis, and critically revised the manuscript. All authors approved the final version for publication and agreed to be accountable for the work.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Representative quotes from parent interviews (n=40) related to system-level dimensions.
[DOCX File , 18 KB - pediatrics_v7i1e49170_app1.docx]

Multimedia Appendix 2
Representative quotes from parent participants (n=40) related to parent or child factor dimensions.
[DOCX File , 18 KB - pediatrics_v7i1e49170_app2.docx]

Multimedia Appendix 3
Results from the survey (n=1206) illustrating the percentage that caregivers “always” or “often” expect the factors listed relating to expected accessibility, affordability, and quality at each of 5 sites (in-person PCP, ED, urgent care, PCP TM, DTCTM). DTCTM: direct-to-consumer telemedicine; ED: emergency department; PCP: primary care provider; PCP TM: primary care provider telemedicine.
[PNG File , 101 KB - pediatrics_v7i1e49170_app3.png]

Multimedia Appendix 4
Results from the survey (n=1206) illustrating the percentage that caregivers “always” or “often” expect the factors listed relating to child and parent-level factors at each of 5 sites (in-person PCP, ED, urgent care, PCP TM, DTCTM). DTCTM: direct-to-consumer telemedicine; ED: emergency department; PCP: primary care provider; PCP TM: primary care provider telemedicine.
[PNG File , 85 KB - pediatrics_v7i1e49170_app4.png]

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Abbreviations

ARTI: acute respiratory tract infection
DTC: direct-to-consumer
ED: emergency department
IRB: institutional review board
PCP: primary care provider

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Original Paper

Evidence for Changes in Screen Use in the United States During Early Childhood Related to COVID-19 Pandemic Parent Stressors: Repeated Cross-Sectional Study

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Abstract

Background: The COVID-19 pandemic transformed the home lives of many families in the United States, especially those with young children. Understanding the relationship between child and parent screen time and family stressors exacerbated by the pandemic may help inform interventions that aim to support early child development.

Objective: We aim to assess the changing relationship between family screen time and factors related to pandemic-induced remote work and childcare or school closures.

Methods: In the spring of 2021 we administered a survey, similar to one administered in the spring of 2019, to a national sample of parents of young children (aged 6 to 60 months). Using iterative sampling with propensity scores, we recruited participants whose sociodemographic characteristics matched the 2019 survey. Participants were aged >18 years, proficient in English or Spanish, and residing in the United States. The main outcomes were changes in child screen time (eg, mobile phone, tablet, computer, and television) and parenting technoference, defined as perceived screen-related interference with parent-child interactions. Additional survey items reported pandemic-related job loss, and changes to work hours, work location, caregiving responsibilities, day care or school access, and family health and socioeconomic status.

Results: We enrolled 280 parents, from diverse backgrounds. Parents reported pandemic-related changes in child screen time (mean increase of 1.1, SD 0.9 hours), and greater parenting technoference (3.0 to 3.4 devices interfering per day; P=.01). Increased child screen time and parenting technoference were highest for parents experiencing job loss (mean change in child screen time 1.46, SD 1.03; mean parenting technoference score 3.89, SD 2.05), second highest for working parents who did not lose their job (mean change in child screen time 1.02, SD 0.83; mean parenting technoference score 3.37, SD 1.94), and lowest for nonworking parents (mean change in child screen time 0.68, SD 0.66; mean parenting technoference score 2.66, SD 1.70), with differences significant at P<.01. School closure and job loss were most associated with increased child screen time during the pandemic after controlling for other stressors and sociodemographic characteristics (d=0.52, P<.001; d=0.31, P=.01). Increased child screen time and school closure were most associated with increased parenting technoference (d=0.78, P<.001; d=0.30, P=.01).

Conclusions: Work and school changes due to the COVID-19 pandemic were associated with increased technology interference in the lives of young children. This study adds to our understanding of the interaction between technology use at home and social factors that are necessary to support early childhood health and development. It also supports possible enhanced recommendations for primary care providers and childcare educators to guide parents in establishing home-based “screen time rules” not only for their children but also for themselves.

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KEYWORDS

child health; parent-child relationship; screen time; technoference; health equity

Introduction

Use of electronic technologies use may be an important determinant of maternal and child health. Information technology, including its corollary "screen time," has intruded into the everyday lives of the youngest children and the newest parents [1]. Since they became increasingly essential tools to facilitate remote connections, learning, and entertainment during the COVID-19 pandemic, the use of screen-enabled technologies (eg, smartphones, tablets, and laptop computers) increased for both young children and their parents [2-4].

Though not all technology use is detrimental to child health [5-7], increased screen use by young children can interfere with parent-child interactions [8,9]. For infants and young children, their primary interaction partners are their adult caregivers, typically parents. Ecodevelopmental theory proposes that contextual features of a child's environment, including aspects that disrupt their caregiving experiences, are likely to influence socioemotional and cognitive development. Indeed, parents' own use of mobile and other technological devices (termed "parenting technoference") is associated with early childhood problem behaviors, delayed language acquisition, and poor healthy eating habits [10-13]. In particular, studies show that parent use of mobile devices interferes with their ability to respond to child cues and bids for attention [13-15]. This phenomenon was made even more complex during the pandemic when parent or child screen time increased for a variety of reasons [2,16,17].

Parent stress—which increased during the pandemic for multiple reasons, including job loss and related difficulties from lost income, expectations to work full-time from home while simultaneously caring for children, and managing children's schooling at home—may have further increased both child screen time [10] and parenting technoference [15,18]. Examining how the screen time of parents and their young children changed during the pandemic, especially for pandemic-related stressors, may provide useful insights into how mobile technology use by both young children and their caregivers is changing parent-child interactions and child development. This in turn is critical to informing policies, programs, and parents with meaningful guidance regarding their use [13,19].

In this study, we aimed to examine the research question, "How did child and parent screen use and home-based 'parenting technoference' in the United States change since the COVID-19 pandemic, and how were these changes moderated by pandemic-related socioeconomic stressors?" To accomplish this, we conducted a national survey of parents of young children (aged 6 months to 5 years) during the pandemic's first year, modeled on a similar survey administered before the pandemic [20]. The previous survey's parent or child screen time measurement aim overlapped with this study's surveys, while other aims (eg, the relationship between parent screen time and parent desire for help to reduce screen time) did not [20]. We hypothesized that the pandemic would be associated with increases in outcome variables measuring child or parent screen use and technoscience. We also hypothesized that increases in these screen time and technoference outcomes would be most pronounced among families that encounter more socioeconomic stressors (eg, job loss, food insecurity, and family dysfunction). To our knowledge, the unique interrelationship between parenting technoference, child screen time, and pandemic-induced remote work and reduced childcare has not been studied in a representative US sample. This is especially relevant to emerging issues regarding dual responsibilities of childcare supervision while simultaneously working for pay.

Methods

Study Design

In March and April of 2021, we conducted an observational repeated cross-sectional study by administering a population-based web-based survey of US parents of children younger than 5 years previously administered in May and June of 2019 [20]. Recruitment and administration of this open, voluntary, web-based survey were performed using CloudResearch (TurkPrime; Prime Research Solutions LLC) and Qualtrics (Qualtrics). As in the 2019 survey, participants could choose to take the survey in English or Spanish (details of translation in Glassman et al [20]). Participants were provided reminders for unanswered questions and were able to review responses via a back button before submission.

Ethical Considerations

All participants were provided an informed consent form, discussing survey length and anonymity of responses, before being taken to the first survey question. All procedures were approved by Stanford's Human Subjects Research Office (institutional review board protocol 57720).

Participants

Inclusion criteria were adults aged >18 years with primary caregiving responsibility for at least 1 child aged >6 months and <5 years in the household. Exclusion criteria were the inability to read English or Spanish or completing the survey outside of the United States. For the survey, the index child was defined as the youngest child in the household. We sought a sample of participants whose sociodemographic characteristics matched that of the 280 participants in the 2019 survey. To accomplish this, CloudResearch oversampled participants, and we used iterative, propensity score matching until we were able to create a matched sample. As noted in the Limitations section, the present study's sample therefore carried the same generalizability strengths and weaknesses as the sample obtained for the 2019 survey [20]. For example, we aimed to match how participants in the original survey were distributed across the 4 census regions of the United States (Midwest: 52/280, 19%;

Northeast: 54/280, 19%; South: 119/280, 42%; and West: 55/280, 20%).

Survey Items

We used the same survey items about parent perceptions of their own technology use, parent perceptions of their technology use in the presence of their young child (parenting technoference), and sociodemographic factors, as described in detail in the publication of the 2019 survey results [20]. Additionally, we added items that assessed parents' perceptions of changes in their child's average daily screen time, as well as items capturing pandemic-related stressors. Wording for all items and construct coding is provided in detail in the web-based supplementary material and summarized (see Multimedia Appendix 1). The survey was translated into Spanish by a trained, bilingual research associate and back-translated from Spanish to English by another independent, trained bilingual research associate; differences between the original and back-translated versions were resolved in Spanish by a third bilingual research coordinator.

Outcome Measures

The primary outcomes were (1) the extent to which parents perceived their child's screen time to have increased since the pandemic began, (2) the extent to which parents perceived their mobile device use as interfering in their interactions with their young children [21], and (3) parents' perceptions of the degree to which their own mobile device use was problematic in general (eg, reported inability to resist checking text messages) [21]. Outcome 1 (change in child screen time) was assessed by asking how many more hours per day the index child used each of the following 6 devices: television, computer, smartphone, tablet, other handheld device (eg, iPod Touch), and video game console. Response options were 0, <1, 1, 2, 3, 4+ more hours per day and were coded as 0, 0.5, 1, 2, 3 and 4, respectively. Outcome 2 was measured using the parenting technoference index, which is a count from 0 to 6 of the number of devices (eg, smartphone and tablet) that interrupted a conversation or activity between the parent and index child at least one time on a typical day [18]. Outcome 3 was assessed using the parent problem technology use scale, which is an average of responses to 3 questions such as "when my mobile electronic device alerts me to indicate new messages, I cannot resist checking them," with 6-point Likert scale response options ranging from strongly disagree to strongly agree [18].

Measures of Pandemic-Related Stressors

Independent variables representing pandemic-related stress were measured using new and previously validated items and scales assessing whether parents experienced the following potential stressors during the first year of the pandemic: job loss (yes, no, or did not have a job before the pandemic), reduction in job hours (yes, no, or not applicable [N/A]), change to remote work (yes, no, or N/A), child day care or preschool or school closure (yes, no, or N/A), change in caregiving time (decreased, increase by 1, 2, 3, 4+ hours, coded as –1 to 4), and reduced ability to meet family health and socioeconomic needs (3-point scale from less difficult to more difficult across 4 domains—health care, food, utilities, and housing). We also examined how the pandemic-related increase in child screen time outcome was related to the technoference and parent problem technology use outcomes.

Measures of Sociodemographic and Household Characteristics

The sociodemographic and household characteristics were selected because they have been hypothesized to be confounding variables in similar studies of child and parent screen time. They included self-report of age (parent and child), sex, race or ethnicity, language spoken at home, marital status, number of children, education level, and income level. A proxy measure of the geographic region in which the participant resided was derived from the longitude or latitude values of the survey respondent's computer captured by CloudResearch survey administration. Geographic region was categorized into the 4 US census regions defined by West, South, Northeast, and Midwest.

Data Analysis

We first conducted data distribution and quality assessments to identify potential missing values and outliers. We removed outliers defined as "speeders" (those who answer unreasonably fast) and "straightliners" (those who answer with identical values for each survey item in a block) as described for the 2019 survey [20,22,23]. All returned surveys were analyzed.

Propensity Score Matching Procedures

To obtain a 2021 survey sample that matched our 2019 survey sample as closely as possible on the measured covariates, we used optimal pair full matching, which attempts to pair each "treatment" unit—in our case, the observations from the 2021 survey—with one or more "control" units—the observations from the 2019 survey. To accomplish this, a propensity score was estimated for each observation in the 2019 and 2021 survey using a logistic regression of the observation's "treatment" status on the following covariates: parent age, sex, Hispanic ethnicity, language spoken in the home, number of children, education, income, geographic region, and marital status. Each observation from the 2019 survey was then paired with an observation from the 2021 survey such that the sum of the differences between propensity scores across the pairs was minimized. The 2021 survey observations satisfying this criterion were selected as the matched sample. Following this procedure, the *t* tests (2-tailed tests) and chi-square tests used to validate that the differences between the samples on each of the covariates were not significant. We used the *MatchIt* package in R (R Foundation for Statistical Computing) to accomplish the match [24].

Bivariate Analyses

To assess whether parenting technoference and parent problem technology use was higher during the pandemic than in 2019, we used 2-sample *t* tests and Wilcoxon rank sum tests, given that our sample size was only moderate [25]. We report results from the *t* tests since the results were virtually identical.

For the 2021 survey results, the bivariate association between each outcome and pandemic-related stressor or sociodemographic characteristic was assessed using *t* tests. The results of these tests were used to screen for variables to enter into multivariable regression models given the relatively small sample size. We used a stricter screening criterion (*P*.05) than in our prior study because we had a larger pool of potential independent variables and covariates to assess in this study. We did not include the job change (to remote) or job hours reduced variables in multivariable models given they were missing for all parents who were not working before the pandemic. We also elected to include the education and not income variables given their high correlation.

Multivariable Regression Analyses

To evaluate the independent association between the outcomes and pandemic-related stress and sociodemographic characteristics we estimated linear regression models. Separate models were used for each outcome. We assessed the association between a given independent variable and outcome by examining both the statistical significance (at *P*.05) of the Wald test for its regression coefficient as well as a measure of effect size. The effect size was estimated using Cohen *d* and partial η^2. All analyses were conducted using the R (version 3.5.3; R Core Team).

Results

Sample Characteristics and Propensity Score Matching

To obtain a sample of 280 parents of children aged 0-5 years matching the sociodemographic characteristics of the prepandemic sample, 517 consenting participants meeting eligibility criteria were recruited in stages between March and April of 2021. Of these, 468 participants met the data quality criteria. The *MatchIt* algorithm in R requires that there are no missing covariate values, which resulted in a pool of 443 observations for matching. Table 1 shows that the optimal pair matching algorithm was able to select 280 observations from this sample such that all covariate means or percentage distributions matched within 1 point, and there were no statistically significant differences in characteristics between the 2 groups (*P*>.70 for each characteristic). The mean age of respondents was 33 (SD 8) years, with 80% (223/280) female and 20% (57/280) male, 68% (192/280) White, 12% (33/280) Black, and 24% (67/280) Hispanic participants. Almost half (133/280, 48%) had at least a college degree, with 24% (66/280) of them reporting some college, and 29% (81/280) of them having a high school degree or lower educational attainment.

Table 1. Descriptive statistics for study samples (N=280).

Characteristic	First parent survey (spring 2019)	COVID-19 survey (spring 2021)	*P* value[a]
Age (years), mean (SD)	32.8 (8.4)	32.9 (9.5)	.95
Sex, n (%[b])			.99
Female	222 (79)	223 (80)	
Male	57 (20)	57 (20)	
Other	1 (1)	—[c]	
Race, n (%)			N/A[d] (items differed)
Asian	16 (6)	30 (11)	
Black	24 (9)	33 (12)	
Hispanic	40 (15)	—	
Mixed	—	5 (2)	
Other	6 (2)	20 (7)	
White	184 (68)	192 (68)	
Hispanic or Latino, n (%)			.70
Yes	72 (26)	67 (24)	
No	208 (74)	213 (76)	
Language spoken at home, n (%)			.99
English	241 (86)	241 (86)	
Other	39 (14)	39 (14)	
Number of children, n (%)			>.99
1	108 (39)	108 (39)	
>1	172 (61)	172 (61)	
Education, n (%)			.99
≤HS[e]	81 (29)	81 (29)	
Some college	65 (23)	66 (24)	
≥College degree	134 (48)	133 (48)	
Income (US $), n (%)			.99
<25,000	57 (20)	55 (20)	
25,000 to <49,999	68 (24)	68 (24)	
50,000 to <74,999	65 (23)	68 (23)	
75,000 to <99,999	49 (18)	48 (18)	
>100,000	41 (15)	41 (15)	
Geographic area, n (%)			.91
Midwest	57 (20)	52 (19)	
Northeast	49 (18)	54 (19)	
South	117 (42)	119 (43)	
West	57 (20)	55 (20)	
Marital status, n (%)			.84
Single	62 (22.1)	65 (23)	
Not single	218 (77.9)	215 (77)	

[a] *P* value for 2-sided independent samples *t* test.

[b] Percentages add to slightly <100 in some cases due to rounding.

[c] Not available.
[d] N/A: not applicable.
[e] HS: high school.

Bivariate Results: Changes in Screen Time Outcomes

Table 2 shows that while parent reports of their absolute mean level of screen time did not change, mean levels of parents' perceptions of their own parenting technoference and problem device use were higher in the spring 2021 midpandemic sample than the spring 2019 prepandemic sample (3.0, SD 2.1, vs 3.4, SD 2.0; 3.7, SD 1.3, vs 4.0, SD 1.2). Differences for each outcome were statistically significant (*P*<.05). The mean for the change in child screen time variable was 1.1 (SD 0.90) on a scale of 0 to 4, where 0 represented no change, and 4 represented an increase of 4 or more hours.

Table 2. Comparison of outcomes before and during COVID-19.

Outcome (scale)	Pre–COVID-19 pandemic (spring 2019), mean (SD)	During the COVID-19 pandemic (spring 2021), mean (SD)	*P* value[a]
Parenting technoference (0-6)	3.0 (2.1)	3.4 (2.0)	.01
Problem technology use (0-6)	3.7 (1.3)	4.0 (1.2)	.03
Change in child screen time since pandemic[b] (0-4)	Not asked	1.1 (0.90)	N/A[c]

[a] *P* value for 2-sample *t* test.
[b] Child screen time was not asked in the pre–COVID-19 survey.
[c] N/A: not applicable.

Bivariate Results: Association Between Sociodemographic and Pandemic-Related Stressors and Outcomes

Table 3 shows the results of bivariate analyses of the relationships between the outcomes and the sociodemographic and pandemic-related stress variables. Male caregivers (eg, fathers) on average reported higher levels of increased child screen time (1.45, SD 1.07, vs 1.01, SD 0.83; *P*=.01) and higher levels of their own mobile technology use interfering with interactions with their young child (3.91, SD 1.97, vs 3.32, SD 1.97, *P*=.05) since the pandemic. Reports of parenting technoference were greater, on average, for those with a college degree or higher than for those with some college or no college (3.82, SD 2.02, vs 3.21, SD 1.83, and 3.0, SD 1.92, respectively; *P*=.01), and for those with a family income above US $75,000 than for those with an income less than US $75,000 (4.04, SD 1.92, vs 3.16, SD 1.95, *P*<.001). Reports of increase in child screen time and parenting technoference were highest for working parents who lost a job during the pandemic (1.46 and 3.89, respectively), second highest for working parents who did not report losing their job during the first year of the pandemic (1.02 and 3.37, respectively), and lowest for nonworking parents (0.68 and 2.66, respectively), with differences significant at *P*=.01. Among working parents, those whose job changed to remote reported higher levels of pandemic-related increases in child screen time (1.35 vs 1.02; *P*=.01) and parenting technoference (4.18 vs 3.19; *P*<.001) than those whose did not. Reports of increases in parenting technoference and child screen time were higher among parents of children whose day care or preschool or school closed during the pandemic than among those whose child's day care or preschool or school did not close and those whose child did not attend school (4.07 vs 3.29 and 2.65, respectively, *P*<.001; 1.40 vs 0.96 and 0.75; *P*=.002). Change in child screen time was moderately and statistically significantly correlated with parent technoference (*r*=0.44, *P*<.001).

Table 3. Bivariate associations between outcomes and sociodemographic and COVID-19–related family stress measures.

Sociodemographic or COVID-19–related stressor	Outcome		
	Change in child screen time since pandemic (0-4)	Parenting technoference (0-6)	Problem technology use (0-6)
Age (parent)			
r [a]	–0.13	–0.090	–0.057
P value	.03[b]	13	.34
Sex, mean (SD)			
Female	1.01 (0.83)	3.32 (1.97)	3.92 (1.20)
Male	1.45 (1.07)	3.91 (1.97)	4.12 (1.26)
P value	.01[b,c]	.05[b]	.31
Education, mean (SD)			
HS[d] or lower	1.09 (0.92)	3.00 (1.92)	3.79 (1.21)
Some college (no degree)	1.03 (0.84)	3.21 (1.83)	3.91 (1.14)
Lower than a college degree	1.15 (0.93)	3.82 (2.02)	4.10 (1.24)
P value	.70	.01[b]	.19
Hispanic, mean (SD)			
Yes	1.31 (1.01)	3.72 (1.79)	4.09 (1.17)
No	1.04 (0.86)	3.35 (2.03)	3.93 (1.22)
P value	.03[b]	.16	.33
Language spoken at home, mean (SD)			
English	1.10 (0.88)	3.46 (2.0)	3.94 (1.21)
Other (Spanish)	1.14 (1.03)	3.34 (1.88)	4.10 (1.23)
P value	.76	.72	.47
Income (US $) , mean (SD)			
<75,000	1.09 (0.93)	3.16 (1.95)	3.85 (1.24)
≥75,000	1.12 (0.84)	4.04 (1.92)	4.22 (1.11)
P value	.81	<.001[b]	.001[b]
Number of children at home, mean (SD)			
>1	1.02 (0.82)	3.37 (1.95)	3.97 (1.23)
1	1.23 (1.01)	3.56 (2.03)	3.96 (1.18)
P value	.06	.42	.91
Geographic region, mean (SD)			
Midwest	1.05 (0.90)	3.15 (2.05)	3.95 (1.06)
Northeast	1.16 (0.90)	3.75 (1.85)	4.04 (1.37)
South	1.06 (0.88)	3.39 (2.00)	3.96 (1.19)
West	1.18 (0.97)	3.55 (1.99)	3.93 (1.25)
P value	.79	.45	.96
Lost job during the COVID-19 pandemic, mean (SD)			
Did not have a job before the COVID-19 pandemic (n=39)	0.68 (0.66)	2.66 (1.70)	4.00 (1.22)
No (n=158)	1.02 (0.83)	3.37 (1.94)	3.97 (1.23)
Yes (n=81)	1.46 (1.03)	3.89 (2.05)	3.93 (1.19)

Sociodemographic or COVID-19–related stressor	Outcome Change in child screen time since pandemic (0-4)	Parenting technoference (0-6)	Problem technology use (0-6)
P value	<.001[b]	.01[b]	.95
Job changed to remote during the COVID-19 pandemic, mean (SD)			
No (n=127)	1.02 (0.82)	3.19 (1.92)	4.01 (1.19)
Yes (n=99)	1.35 (0.96)	4.18 (1.86)	4.06 (1.23)
P value	.01[b]	<.001[b]	.74
Job hours reduced during the COVID-19 pandemic, mean (SD)			
No	1.02 (0.78)	3.45 (2.04)	4.01 (1.14)
Yes	1.45 (1.04)	3.88 (1.89)	4.00 (1.35)
P value	<.001[b]	.11	.94
COVID-19's impact on meeting family needs, mean (SD)			
High impact	1.11 (0.99)	3.06 (1.84)	3.6 (1.14)
Low impact	1.36 (0.87)	3.77 (1.91)	3.95 (1.18)
Moderate impact	1.14 (0.97)	3.33 (1.92)	4.11 (1.29)
No impact	0.94 (0.85)	3.38 (2.09)	3.99 (1.21)
P value	.02	.35	.32
COVID-19's impact on caregiving hours			
r	0.09	0.061	0.023
P value	.15	.32	.70
Change in child screen time since the COVID-19 pandemic			
r	N/A[e]	0.44	0.15
P value	.02	<.001[b]	.01[b]
School closed during the COVID-19 pandemic, mean (SD)			
Child did not attend school	0.75 (0.78)	2.65 (1.73)	3.93 (1.17)
No	0.96 (0.84)	3.29 (2.00)	3.69 (1.21)
Yes	1.40 (0.91)	4.07 (1.93)	4.13 (1.22)
P value	.002[b]	<.001[b]	.06

[a] Pearson correlation coefficient.

[b] *P* values of <.05.

[c] *P* value for independent samples *t* test.

[d] HS: high school.

[e] N/A: not applicable.

Multivariable Regression Results

In multivariable models (Table 4), having day care, preschool, or school closed during the pandemic and losing a job during the pandemic were most strongly associated with increased child screen time, accounting for 7.23% (*P*<.001) and 3.54% (*P*=.01) of the variance in the outcome after covarying for sociodemographic characteristics. The change in child screen time outcome in turn was most strongly associated with parenting technoference during the pandemic, accounting for 13.5% of the variance (*P*<.001), followed by having day care or preschool or school closed during the pandemic (η^2=2.40%, *P*=.01) after covarying for sociodemographic characteristics. Parents with a high school education or less reported lower levels of perceived technoference than did parents with a college degree or more (η^2=2.4%, *P*=.02).

Table 4. The results of regression models[a] (post bivariate screening) by outcome.

	Coefficient	SE	Cohen *d*[b]	*P* value	η^2[c] (%)
Change in child screen time (scale 0-4; n=277[d])					
Sex (reference: female)					1.93
Male	0.31	0.13	0.28	.02	
Hispanic (reference: no)					0.16
Yes	0.08	0.12	0.08	.51	
Age	–0.01	0.01	–0.32	.01	2.54
Lost job during the pandemic (reference: did not have a job before)					3.54
No	0.13	0.16	0.1	.42	
Yes	0.45	0.17	0.31	.01	
School closed during the pandemic (reference: N/A[e] “child did not attend school”)					7.23
No	0.14	0.15	0.12	.33	
Yes	0.53	0.12	0.52	<.001	
Technoference (scale 0-6; n=276[d])					
Sex (reference: female)					0.11
Male	–0.15	0.27	–0.07	.59	
Education (reference: college degree)					2.40
HS[f] or less	–0.66	0.27	–0.29	.02	
Some college	–0.48	0.27	–0.21	.08	
Lost job during the COVID-19 pandemic (reference: did not have a job before)					0.60
No	–0.05	0.34	–0.02	.89	
Yes	0.27	0.37	0.09	.47	
School closed during the COVID-19 pandemic (reference: N/A child did not attend school)					2.40
No	0.5	0.31	0.19	.11	
Yes	0.68	0.27	0.3	.01	
Change in child screen time since the COVID-19 pandemic	0.82	0.13	0.78	<.001	13.50
Parent problem technology use (scale 1-6; n=280)					
Income (reference:<US $75,000)					2.08
≥US $75,000	0.37	0.15	0.29	.02	
Change in child screen time since the COVID-19 pandemic	0.2	0.08	0.31	.01	2.37

[a] Linear regression model; *P* value for Wald test of significance of regression coefficient.

[b] Cohen *d* effect size interpretation: small=0.2, medium=0.5, and large=0.8 [26].

[c] η^2 effect size interpretation: small=2%, medium=15%, and large=35% [26].

[d] N<280 due to missing values.

[e] N/A: not applicable.

[f] HS: high school.

Discussion

Principal Findings

Serial, national surveys 1 year prior and 1 year into the COVID-19 pandemic revealed increases in child screen time alongside increases in parenting technoference—that is, increases in parents’ perceptions of their own device time interfering with their interactions with their child. Parents reported that their children increased their screen time by approximately 1 hour per day (0.9 hours per day). This finding is consistent with other recent studies [27], including a national survey [3] that found screen time among school-aged children increased by an average of 50 minutes during the early months of the pandemic. The finding of increased parenting technoference is consistent with a recently published study that found an increase in maternal use of mobile devices while parenting during the pandemic lockdowns [16].

We found a strong association between technology use and changes in a child's schooling, parent work, and remote options for school or work. We also found higher rates of reported technoference among parents with higher levels of educational attainment, as well as among male (vs female) caregivers. These findings are consistent with recent evidence suggesting that increases in child screen time were directly associated with decreased childcare availability [28]. Day care or school closure—which constitutes not just a change in routine but a challenge to supervision requirements for young children, especially if the parent is expected to work while being responsible for children's needs—was related to increases in parenting technoference as well as child screen time. Another recent study suggested that there was an important interrelationship between parent stressors, the pandemic, and negative parenting techniques such as coercive parenting [29]. Further, there is now a body of literature showing that parenting technoference negatively affects child development through mechanisms such as delayed language acquisition [10,13,18]. The factor most strongly associated with the parenting technoference outcome was the change in child screen time outcome itself. Other studies have shown a strong relationship between parent screen time and child screen time [30,31].

Together these findings suggest that future research and development on interventions designed to mitigate the negative effects of technology on parent-child interactions should consider extrinsic factors and how those may affect the potential feedback loops involved in parent and child device time. These findings may also be critical to informing new consumer health interventions designed for home-based implementation [32,33].

Parent job status was an important contributor to pandemic-related increases in child screen time and technoference. In particular, working parents who experienced job loss during the first year of the pandemic were more likely to report increased child screen time and increased technoference than nonworking parents and parents who did not lose their jobs. Further, working parents (regardless of job loss) were more likely to report technoference than nonworking parents. Several mechanisms may explain these findings. A job-stressed parent may be more likely to use a mobile device as a stress-reduction tool [10,19]. It is also possible that a job-stressed parent is more likely to use a mobile device as a "babysitter" to keep their child occupied as they attend to their own needs, such as job interviews or social support [28]. Future research should explore more deeply the complex interplay between parent and child screen time for working compared to nonworking parents. Program and policy considerations to improve early child development may want to consider different strategies tailored to parent work status.

Limitations

This study has several limitations common to repeated, cross-sectional observational studies. First, no causal inferences can be made about the timing of the constructs assessed. Experimental studies may better allow for exploring the causal role of how specific contextual events (eg, remote vs in-person work; availability and types of caregivers to supervise children while parents attend to other tasks, child access to nontechnological play materials) affect patterns of parent and child device use, which may be especially relevant in an age of hybrid work policies.

Second, common limitations and biases associated with web-based surveys include social desirability bias and selection bias. Despite oversampling from traditionally underrepresented groups and the matched design to assure greater alignment with the prior survey, these biases may distort the generalizability of these findings. There were inevitably unmeasured confounders omitted from the propensity score matching model. Specifically, this study's sample included more participants who identified as female, with lower income levels, higher education levels, and a lower prevalence of speaking a language other than English, when compared with the general US population. On the other hand, the results may be generalizable to all 4 census regions of the United States since there was a reasonable representation of respondents from each.

Another limitation was that some items in the prepandemic survey were different, not allowing us to make temporal comparisons. Further, this study was limited by the fact that the measures of parent technoference and child screen time were self-reported and were not externally validated. Parent perceptions of their own technoference and child's screen time may not correspond to actual levels. Future studies in this area could overcome this limitation by including ecological momentary assessment to capture technoference in real time, or by using newly developing AI-based behavioral observation tools for research. Strategies to mitigate the negative effects of technoference and child screen time ideally should consider both actual and perceived levels of these problems. Finally, it is possible that our specific measures of pandemic stress were not sufficiently sensitive. In this context, it may also be that parent-reported measures of pandemic-related changes in child screen time are better at capturing pandemic-related stress than our direct items about childcare burden.

Conclusions

Using a national survey representative of all US parents, we found that the COVID-19 pandemic indirectly accelerated preexisting trends of increasing technology and screen use in the lives of young children. In particular, work and day care or school changes due to the COVID-19 pandemic were associated with increased technology interference in the lives of young children. In concert with a growing body of literature, our study further supports the notion that future parenting technoference research and policy making should consider the causes and context behind parenting technoference [34]. In particular, this study suggests important mechanisms through which certain external stresses on parents, especially concerning dual responsibilities of childcare supervision while simultaneously working for pay, may impact healthy child development. For researchers, it motivates the need for more robust studies examining the interrelationships among other contextual factors not examined in this study (eg, availability and types of caregivers, child access to nontechnological play materials), stress, parent screen time, child screen time, and child development. For practitioners, this study buttresses existing recommendations for primary-care providers and childcare educators to guide parents to establish home-based "screen time rules," not only for their children but also for themselves. To help support families in this effort, our findings add updated context to existing policy recommendations from the American Academy of Pediatrics and other national organizations about the safe use of screens and screen time by young children and their adult caregivers. State and federal policymakers should consider these findings to inform evolving regulations that pertain to child exposure to new media (eg, social media, apps, and virtual-reality headsets), and consider its implications for research funding to strengthen the causal evidence base on the positive and negative impact of these media on parent and child well-being.

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Authors' Contributions

JG and AJ had full access to all of the data in this study and take responsibility for the integrity of the data and the accuracy of the data analysis. JG, LS, KLH, and AM conceptualized and designed the study. Acquisition, analysis, and interpretation of data were undertaken by all authors. Further, critical revision of this paper for important intellectual content was also undertaken by all authors. JG, LS, and KLH drafted this paper. Statistical analysis was performed by AJ and JG. Administrative, technical, or material support was provided by JG, LS, and AM. JG supervised the study.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey administered.
[DOCX File , 44 KB - pediatrics_v7i1e43315_app1.docx]

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Abbreviations

N/A: not applicable

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Online Delivery of Interprofessional Adverse Childhood Experiences Training to Rural Providers: Usability Study

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Abstract

Background: The population health burden of adverse childhood experiences (ACEs) reflects a critical need for evidence-based provider training. Rural children are also more likely than urban children to have any ACEs. A large proportion of providers are unaware of the detrimental effects of ACEs. There is a significant documented need for training providers about ACEs and trauma-informed care, in addition to a demand for that training.

Objective: The objective was to develop, implement, and evaluate an online ACEs training curriculum tailored to Missouri providers, particularly those in rural areas given the higher prevalence of ACEs.

Methods: From July 2021 to June 2022, we conducted literature reviews and environmental scans of training videos, partner organizations, clinical practice guidelines, and community-based resources to curate appropriate and tailored content for the course. We developed the ACEs training course in the Canvas learning platform (Instructure) with the assistance of an instructional designer and media designer. The course was certified for continuing medical education, as well as continuing education for licensed professional counselors, psychologists, and social workers. Recruitment occurred via key stakeholder email invitations and snowball recruitment.

Results: Overall, 135 providers across Missouri requested enrollment, with 72.6% (n=98) enrolling and accessing the training. Of the latter, 49% (n=48) completed course requirements, with 100% of respondents agreeing that the content was relevant to their work, life, or practice; they intend to apply the content to their work, life, or practice; they feel confident to do so; and they would recommend the course to others. Qualitative responses supported active intent to translate knowledge into practice.

Conclusions: This study demonstrated the feasibility, acceptability, and effectiveness of interprofessional workforce ACEs training. Robust interest statewide reflects recognition of the topic's importance and intention to translate knowledge into practice.

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KEYWORDS

adverse childhood experiences; ACE; training; trauma-informed care; provider; rural; adverse; trauma; traumatic; provider; providers; teaching; curriculum; curricula; education; educational; social work; social worker; social workers; psychologist; psychologists; counselor; counselors; interprofessional; pediatric; pediatrics; paediatric; paediatrics; child; children; experience; experiences; continuing education

Introduction

A large proportion of providers are unaware of the detrimental effects of adverse childhood experiences (ACEs) [1]. ACEs are commonly defined as personal abuse that is psychological, physical, or sexual; personal neglect that is emotional or physical; or household challenges that include violence against the mother, divorce, or separation; or living with household members who were substance abusers, mentally ill or suicidal, or had ever been imprisoned [2,3]. Other studies consider additional adversities such as the death of a parent or sibling, poor housing, discrimination, bullying, and poverty, among others [4,5].

If we can reduce intergenerational transmission of ACEs, we have the potential to mitigate ACEs and theoretically make profound improvements in population health outcomes. Overall, 60.9% of US adults experience 1 or more than 1 type of ACE and 15.6% experience 4 or more than 4 types [6]. ACEs increase the risk of adult diseases including heart disease, cancer, chronic lung disease, skeletal fractures, and liver disease via chronic stress and coping behaviors [2,6]. Cumulative exposures to multiple ACEs are associated with an increased risk of substance misuse [2,7,8], including opioids [9-11] and alcohol [12], and an increased risk of suicide [2]. Suicide and other "deaths of despair," ie, deaths from suicide and drug poisoning (including opioids and alcohol) contribute significantly to rising US mortality rates [13]. A 10% reduction in the prevalence of ACEs equates to an annual savings of 3 million disability-adjusted life years or $105 billion US [14]. Illicit drug use had the highest population-attributable fractions associated with ACEs, and population-attributable fractions of causes of ill health were highest for mental illness outcomes: ACEs were attributed to about 30% of cases of anxiety and 40% of cases of depression in North America [14]. The intersection of ACEs, suicide, and overdose is a priority area for the United States Department of Agriculture [15] and the Centers for Disease Control and Prevention (CDC) [16]. Finally, an objective of the US Department of Health and Human Services' Healthy People 2030 is to reduce the number of young adults (aged 18 to 25 years) who report 3 or more than 3 ACEs; this is described as a high-priority public health issue with evidence-based interventions to address it [17].

In addition to the rising US mortality rates mentioned above, there is a place-based mortality penalty, especially for high-poverty rural areas [18]. Rural children are statistically more likely than urban children to experience economic hardship, household substance misuse, household mental illness, household incarceration, and parental separation or divorce, as well as witness neighborhood violence and household violence [19]. Rural children are also more likely than urban children to have any ACEs [19].

There is a significant documented need for training providers about ACEs and trauma-informed care, in addition to a demand for that training [1]. Practical considerations exist with the implementation of training, including time and institutional support, interactive components, practical examples, and not retraumatizing providers who have themselves experienced ACEs [1]. A commentary in 2020 by Campbell [20], suggested that there could be harm to patients from ACEs screening, despite acknowledging there is an evidence base for related clinical preventive services, such as screening for alcohol and drug use disorder and interpersonal violence. A response to this caution coauthored by the investigator of the original ACEs study Felitti stated that "ACEs screening was used as part of a comprehensive health assessment at Kaiser in more than 440,000 adult patients without ever evoking a complaint" [21] and recommended to implement ACEs screening in practice with enthusiasm. Still, the identification of ACEs is only 1 component of translating the science into practice. Providers need to be ready with a planned intervention after ACEs are identified, depending upon a primary, secondary, or tertiary prevention response. Finally, providers need to be aware of positive childhood experiences so they can recognize and encourage these behaviors in parents.

Evaluating the uptake, satisfaction, and effectiveness of ACEs trainings on provider practice is key [1]. The purpose of this project was to develop, implement, and evaluate an online workforce training curriculum tailored to Missouri providers (particularly rural) to improve their capacity to provide evidence-based care to high-needs patient populations in resource-limited settings.

Methods

Setting

Missouri ranks 34th nationwide on ACEs, with 17% of children aged 0 - 17 years having experienced 2 or more ACEs [22]. In Missouri, 99 out of the 115 (86.1%) counties (114 counties plus the city of St. Louis) are rural, and 33.2% of Missouri's population lives in rural counties [23].

Participants

This study is part of a larger project with the overall goal of training physicians who work in rural communities and providing them with the highest level of up-to-date information. Our training was tailored toward interdisciplinary Missouri providers, with the goal of reaching a significant proportion of rural providers. All provider types (including physicians, clinicians, professionals, paraprofessionals, and ancillary service staff) were eligible to enroll so the course would reflect a cross-sector approach and participants could learn from each other in the discussions. We were particularly interested in enrolling rural clinicians. A separate paper details the evaluation of the discussion posts [24].

Course Development

From July 2021 to June 2022, we conducted literature reviews and environmental scans of training videos, partner organizations, clinical practice guidelines, and community-based resources to curate appropriate and tailored content for the course. The content of the course included but was not limited to select published works from Felitti, ACEs videos developed by the CDC [25,26], a TED talk by Harris [27] on how childhood trauma affects health across the lifespan, US Preventive Services Task Force recommendations for screening, and other literature. Resources included but were not limited to Findhelp, Missouri Department of Health and Senior Services' crime victim services, home visiting programs, related partner organizations, screening, and measurement tools. We developed the ACEs training course in the Canvas learning platform with the assistance of an instructional designer and media designer. The designers played a key role in style, usability, design, and best practices for online learning. The course was designed to be asynchronous with interactive elements, such as videos, discussions, and quizzes. Given providers may themselves have experienced childhood adversity, a trigger warning was included on the home page and a mindfulness breathing exercise was included in the instructions.

We pilot-tested the course with health provider colleagues for content, gaps, length, satisfaction, and usability prior to implementation. The final course outline is described in Textbox 1.

Textbox 1. Adverse childhood experiences course outline.

Module 0: Getting started

- This module includes a welcome, introduction of the instructor, demographic survey for participants to complete, an overview of the course and expectations, and a discussion.

Module 1: What are adverse childhood experiences?

- This module includes an overview of the module and explanation of the original adverse childhood experiences (ACEs), expanded ACEs, a discussion, and a quiz.

Module 2: How do adverse childhood experiences impact health?

- This module includes an overview of the module and explanation of ACEs' impact on the developing brain, adult health, depression, substance use disorders, other impacts, increased risk of disease, and population-attributable risk. The module includes a discussion and quiz.

Module 3: How common are adverse childhood experiences?

- This module includes an overview of the module and explanation of how common ACEs are in the United States, Missouri, rural areas, and the status of Missourians' health and wellness outcomes. The module includes a discussion and quiz.

Module 4: How did the COVID-19 pandemic affect adverse childhood experiences?

- This module includes an overview of the module and explanation of the psychological impact of the COVID-19 pandemic, as well as how the COVID-19 pandemic affected ACEs. The module includes a discussion and quiz.

Module 5: What can we do to address adverse childhood experiences?

- This module includes an overview of the module and explanation of the risk factors for ACEs, what can be done at the provider level, what the evidence says about screening, positive childhood experiences and protective factors, what can be done at the organizational, community, and policy levels. The module includes a discussion and quiz.

Module: Wrap up

- This module includes links to resources, explanation of how to enroll in the ACEs listserv, and instructions for completing the course and course evaluation.

Certification

As an incentive to enroll and complete the training, we offered continuing education (CE) credits free of charge to participants. The office of Continuing Education for Health Professions (CEHP) is housed on the University of Missouri campus. CEHP's mission is to provide evidence-based, relevant, and responsive learning activities designed to narrow professional practice gaps with respect to the knowledge, competence, and performance of the health care team.

CEHP reviewed the course content for continuing medical education credits, awarding the course 3 American Medical Association Physician's Recognition Award Category 1 Credits. Upon request from enrollees, the office also reviewed the course for CE for licensed professional counselors, psychologists, and social workers with Missouri licenses. CEHP attested that this course contains 3 clock hours of instructional time. Licensed professionals measuring CE credit based on a 50-minute hour may claim up to 3.6 contact hours for full attendance at this program. Certificates of completion were also available.

To qualify for CE credit or a certificate of completion, trainees were required to complete (1) a demographic survey required by the funder and available in the introductory course pages; (2) six discussion assignments; (3) five quizzes, receiving a grade of at least 80% on each; and (4) the end-of-course evaluation. The course evaluation is linked to a separate page in Qualtrics (Qualtrics, LLC). We chose to make the course evaluation anonymous to protect the respondents' identity and to improve the integrity of the responses while recognizing we would not be able to individually validate trainees' completion of this course requirement. Some of the demographic survey questions (eg, do you consider yourself disadvantaged or the level of rurality of their hometown setting) are reflective of self-identity and self-report rather than objective indicators.

Recruitment, Enrollment, and Tracking

The course was launched via key stakeholder email invitations in late November 2022 with snowball recruitment thereafter. Email invitations included a statewide listserv focused on responding to the opioid crisis, as well as to a network of rural providers. The recruitment email included that the course is an asynchronous online course available through June 30, 2023, free of charge to participants, offers free CE credit, and a basic course outline. Interested individuals sent an email with a request to enroll in the training. The individual was then sent instructions for creating a Canvas account, with technical support available for troubleshooting challenges. Once the Canvas account was created, the individual was subsequently invited into the ACEs training. Course requests, enrollment, and completion were tracked in Microsoft Excel. Periodically throughout the course implementation period, study personnel sent email reminders to those enrolled regarding the end date for the training.

Data Analyses

The data used for analysis in this study included the course enrollment tracking data, the demographic survey data, and the course evaluation survey data. Frequencies and percentages were calculated for quantitative data; missing responses were not included in the calculations. Age was approximated by subtracting birth year collected in the sponsor demographic survey from 2023. Short-answer open-ended questions were qualitatively coded into major themes independently by 2 authors and then reviewed for divergence. Reported quotes were lightly copyedited.

Ethical Considerations

The University of Missouri Institutional Review Board reviewed and approved this project (#2096686).

Results

Enrollment and Completion

Overall, 135 individuals requested enrollment into the ACEs training. Of those, 98 (72.6%) completed the steps for enrollment and accessed the course. Among the individuals who enrolled and accessed the course, 70 (71.4%) completed the demographic survey, and 48 (49%) completed all course requirements.

Participant Characteristics

The setting in which participants worked varied (Table 1). The majority of participants worked in “other” settings (n=28, 40%), followed by clinical sites (n=12, 17.1%); academic medical centers (n=8, 11.4%); federally qualified health centers or Look-Alikes (n=6, 8.6%; Look-Alikes are community-based health center programs that meet program requirements but do not receive health center program funding); government (n=6, 8.6%); private practice or industry (n=4, 5.7%); and public community, rural, or migrant health centers (n=4, 5.7%). Responses for the employment setting location included 27.1% (n=19) rural areas, 25.7% (n=18) health professional shortage areas, 18.6% (n=13) medically underserved communities, and 12.9% (n=9) primary care settings. Most (n=30, 42.9%) participants reported their hometown setting as rural, with 34.3% (n=24) suburban and 18.6% (n=13) urban.

Regarding participant characteristics, 84.3% (n=59) reported their gender as female, with a balanced distribution across age groups 20 to 59 years. The majority of participants reported White race (n=62, 88.6%), and a minority (n=11, 15.7%) considered themselves disadvantaged (defined as growing up in an area that was medically underserved or had insufficient access to social, economic, and educational opportunities). Respondents’ professional disciplines consisted of 50% (n=35) behavioral health, 18.6% (n=13) nursing, 14.3% (n=10) other, 10% (n=7) public health, 4.3% (n=3) student, and 2.9% (n=2) medicine. Enrollee fields and degrees included bachelors (BS, BA, and BSPH), nursing (RN, FNP, BSN, DNP, and CPNP), social work (MSW, LMSW, and LCSW), licensed professional counselors (MA, MAC, MS, MEd, and PLPC), others with master’s degrees (MPH, MS, and MPA), doctorates (PhD), and physicians (MD).

Table . Characteristics of adverse childhood experiences course participants who completed the demographic survey (n=70).

Variable			Values, n (%)
Personal attributes			
	Gender		
		Female	59 (84.3)
		Male	8 (11.4)
		Nonbinary	1 (1.4)
	Age groups (years)		
		20 - 29	16 (22.9)
		30 - 39	18 (25.7)
		40 - 49	14 (20.0)
		50 - 59	17 (24.3)
		60 - 69	3 (4.3)
	Hispanic, Latino/a/x, or Spanish origin		
		Yes	0 (0)
		No	68 (97.1)
	Race		
		American Indian or Alaskan Native	0 (0)
		Asian	2 (2.9)
		Black or African American	3 (4.3)
		White	62 (88.6)
	Hometown setting		
		Rural	30 (42.9)
		Suburban	24 (34.3)
		Urban	13 (18.6)
	Do you consider yourself disadvantaged? [a]		
		Yes	11 (15.7)
		No	56 (80.0)
	Professional discipline		
		Behavioral health	35 (50.0)
		Medicine	2 (2.9)
		Nursing	13 (18.6)
		Public health	7 (10.0)
		Student	3 (4.3)
		Other	10 (14.3)
Employment attributes			
	Employment setting (check all that apply)		
		Academic medical center	8 (11.4)
		Area health education center	2 (2.9)
		Federally qualified health center or Look-Alike	6 (8.6)
		Government	6 (8.6)
		Nonacademic medical center	1 (1.4)
		Other clinical site	12 (17.1)

Variable			Values, n (%)
		Other health center	2 (2.9)
		Private practice or industry	4 (5.7)
		Public setting—community, rural, or migrant health center	4 (5.7)
		Public setting—health department	2 (2.9)
		Rural health clinic	1 (1.4)
		Other	28 (40.0)
	Employer is located in (check all that apply)		
		Health professional shortage area	18 (25.7)
		Medically underserved community	13 (18.6)
		Primary care setting	9 (12.9)
		Rural area	19 (27.1)

[a] You might consider yourself disadvantaged if you grew up in an area that was medically underserved or had insufficient access to social, economic, and educational opportunities.

Course Evaluation

Of those who completed the training, 42 (87.5%) completed the course evaluation. Quantitative responses are summarized in Table 2. Almost three-fourths of respondents live, work, or serve in rural areas of Missouri.

All respondents (100%) agreed or strongly agreed that the content is relevant to their work, life, or practice; the learning objectives are clear; the resources are helpful; they intend to apply the course content to their work, life, or practice; they feel confident implementing the knowledge gained; and they would recommend the course to others. Most respondents agreed or strongly agreed the length is appropriate (n=41, 97.6%), the videos are informative (n=41, 97.6%), the quizzes provide a helpful self-assessment (n=40, 95.2%), and the discussions are valuable (n=33, 78.6%). Most respondents rated the course overall as excellent or very good (n=39, 92.9%).

A total of 37 respondents answered the question “Please describe the strengths of the course, ie, elements you liked, things that worked well, ‘a-ha’ moments, helpful course content or features.” Responses included a breadth of course components—videos, rural or urban comparisons, statistics, discussion, quizzes, charts or graphs, resources, and online format. Eleven respondents provided suggestions to the question “Please describe opportunities to improve the course, ie, challenges with navigating the course, missing content, barriers to completing the course, etc.” Three respondents did not care for the discussion boards, 2 had technology problems, 1 did not care for the quizzes, and 1 felt the online format was limiting the interaction. The remaining suggestions included incorporating brainstorming technology such as “Jam Boards,” more videos on how to implement the research in the workplace, more emphasis on the role of social workers, and case studies asking people how they would approach a scenario.

Table . Results of adverse childhood experiences course evaluation quantitative questions (n=42).

Question name and response option		Values, n (%)
The content is relevant to my work, life, or practice		
	Strongly agree or agree	42 (100.0)
	Neutral or not sure	0 (0.0)
	Strongly disagree or disagree	0 (0.0)
The learning objectives are clear		
	Strongly agree or agree	42 (100.0)
	Neutral or not sure	0 (0.0)
	Strongly disagree or disagree	0 (0.0)
The length is appropriate		
	Strongly agree or agree	41 (97.6)
	Neutral or not sure	1 (2.4)
	Strongly disagree or disagree	0 (0.0)
The videos are informative		
	Strongly agree or agree	41 (97.6)
	Neutral or not sure	1 (2.4)
	Strongly disagree or disagree	0 (0.0)
The quizzes provided a helpful self-assessment		
	Strongly agree or agree	40 (95.2)
	Neutral or not sure	1 (2.4)
	Strongly disagree or disagree	1 (2.4)
The discussions are valuable		
	Strongly agree or agree	33 (78.6)
	Neutral or not sure	8 (19.0)
	Strongly disagree or disagree	1 (2.4)
The resources are helpful		
	Strongly agree or agree	42 (100.0)
	Neutral or not sure	0 (0.0)
	Strongly disagree or disagree	0 (0.0)
I intend to apply the course content in my work, life, or practice		
	Strongly agree or agree	42 (100.0)
	Neutral or not sure	0 (0.0)
	Strongly disagree or disagree	0 (0.0)
I feel confident that I can implement the knowledge I gained		
	Strongly agree or agree	42 (100.0)
	Neutral or not sure	0 (0.0)
	Strongly disagree or disagree	0 (0.0)
Please rate the course overall		
	Excellent or very good	39 (92.9)
	Good	3 (7.1)
	Fair or poor	0 (0.0)
I would recommend this course to others		
	Strongly agree or agree	42 (100.0)

Question name and response option		Values, n (%)
	Neutral or not sure	0 (0.0)
	Strongly disagree or disagree	0 (0.0)
Do you live, work in, or serve individuals in rural areas of Missouri?		
	Yes	31 (73.8)
	No	11 (26.2)

Translation to Practice

A total of 33 respondents answered the question “If you intend to apply the course content to your work, life, or practice, please describe how,” with 26 (78.8%) respondents reporting some level of active intent and 14 (42.4%) respondents suggested using the course content for active organizational planning or changing their practice toward a more advanced trauma-informed care work environment.

> *Apply to current and future practice in the health care field with children and adults.* [Example response 1]
>
> *I want to keep in mind the mother’s ACE score when working with them in parenting classes. Seeing how their own ACE scores affect them and how they can affect their children.* [Example response 2]
>
> *Moving our organization past trauma awareness and into more trauma-informed work.* [Example response 3]
>
> *I will look to implement ACEs screening in our organization and increase trauma informed care.* [Example response 4]
>
> *I work with youth in a school setting. This could be helpful to implement trauma informed care in the school setting, while also being aware of ACEs with clients.* [Example response 5]
>
> *We are currently working on ways to prevent overdose events among youth and have been considering how we can take ACEs into account in preventing overdose and long-term negative health effects related to addiction.* [Example response 6]
>
> *This information is very important to my work with people as well in life. Also, to my organization as we continue to grow towards a trauma-informed organization.* [Example response 7]
>
> *Information will help inform TIC team in evaluating policies.* [Example response 8]

A total of 8 (24.2%) respondents suggested the training will help them actively educate others.

> *Spreading the word on the existence of ACEs and how to use them for positive growth in children.* [Example response 1]
>
> *Psychoeducation in therapy.* [Example response 2]
>
> *Educating my organization and other community partners.* [Example response 3]
>
> *Educating youth and families.* [Example response 4]

Also, 4 (12.1%) respondents reported an intent to screen for ACEs.

> *Have begun utilizing ACEs scoring with incarcerated population.* [Example response 1]
>
> *I work...with clients in the mental health field, so completing the ACEs when they enroll will provide us with more history of the clients and their experiences.* [Example response 2]
>
> *I can use this as I get to know my students. I plan to start using the ACE test as I assess how best I can help my students.* [Example response 3]

Finally, 7 (21.2%) alluded to awareness, which was coded as a passive reaction to applying the course content. Example quotes included:

> *I find it important to be aware of ACEs as a counselor in learning to understand why and how people present as they do in a college setting.* [Example response 1]
>
> *I am aware of the need for more primary care providers to have training in this area.* [Example response 2]
>
> *I work with foster/adoptive families and ACEs are big part of their lives.*
>
> *[Example response 3]*
>
> *I have a new list of resources to utilize, and a better knowledge of what ACEs are and what they might look like in a school setting.* [Example response 4]
>
> *My knowledge of...COVID-19’s effects on ACEs, and [the heightened level of ACEs in rural areas] keeps me more aware of key things to look for.* [Example response 5]

Discussion

Principal Findings

A limited body of literature exists related to educating providers on ACEs and trauma-informed care, as well as evaluating their knowledge, perceived importance, and attitudes toward ACEs in practice [1]. The objective of our study was to develop, deliver, and evaluate an interprofessional, online, asynchronous ACEs training program for interdisciplinary providers across Missouri, especially in rural areas. With a large proportion of providers unaware of the detrimental effects of ACEs, significant need for training providers about ACEs and demand for that training [1], our findings add critical insight to the uptake, satisfaction, and effectiveness of ACEs provider training. Our study additionally addresses a critical gap with its focus on rural providers. Increasing the number of ACEs and trauma-aware providers is a step toward increasing trauma-informed care. The Substance Abuse and Mental Health Services Administration [28] considers being trauma-informed as having a basic realization of trauma and how it impacts families and individuals, recognizing the signs of trauma, responding by applying the principles of a trauma-informed approach, and resisting retraumatizing individuals. These four assumptions work in conjunction with their six key principles and they are (1) safety; (2) trustworthiness and transparency; (3) peer support; (4) collaboration and mutuality; (5) empowerment, voice, and choice; and (6) cultural, historical, and gender issues. The Substance Abuse and Mental Health Services Administration further includes cross-sector collaboration among its implementation practices; an additional strength of our training includes its interprofessional scope of providers.

The overall response to recruitment efforts was stronger than anticipated given we leveraged only a few key communication channels, with 135 individuals statewide requesting enrollment. Additionally, our recruitment and enrollment effort successfully reached the target demographic, with 73.8% (n=31) of participants living, working, or serving in rural areas, despite the broadband challenges. While 90% of rural Missouri counties have broadband internet, Missouri ranks 43rd among states in internet coverage speed and availability [23]. In Missouri, 41 rural counties do not have a hospital [23], making ACEs awareness efforts at the prevention level even more crucial. The course was designed as an asynchronous, online course and technology can sometimes be a barrier, particularly for age cohorts educated prior to the popularity of online courses. However, while the age group distribution for those who completed enrollment was nicely balanced across 20 to 59 years of age, it is possible a selection bias occurred with the 27.4% of individuals who requested enrollment but did not complete enrollment being less comfortable with technology, despite the available assistance. Finally, enrollment by medical providers was modest, despite the asynchronous format to accommodate busy schedules and available continuing medical education.

Among participants completing the course, the course evaluation indicated strong levels of satisfaction with the structure and content. This is particularly encouraging given the interdisciplinary nature of the content, as it was not tailored to a specific discipline by design, yet 100% of respondents agreed the content was relevant to their work, life, or practice; that they intend to apply the content to their work, life, or practice; they feel confident to do so; and would recommend the course to others. Regarding what could be improved, respondents scored the value of the discussions lowest compared to other content questions (78.6% agreed or strongly agreed the discussions are valuable). We attribute this score to the discussion requiring the most active engagement on the part of participants. Active learning is a best practice in online learning, as well as a requirement for these CE credits.

Among the respondents who reported intent to apply the course content in practice, 78.8% suggested active planning, training, or screening, naming specific examples. This is an encouraging indication of effective knowledge transfer and declaration of intention.

Conclusions

This study developed, implemented, and evaluated an online workforce training curriculum tailored to Missouri providers (particularly rural) to improve their capacity to provide evidence-based care to high-needs patient populations in resource-limited settings. This study demonstrated the feasibility, acceptability, and effectiveness of interprofessional online workforce training of ACEs, while also reaching resource-limited rural counties. Robust interest statewide reflects recognition of the topic’s importance and the potential for this training to effect change. Future research is needed to follow up with participants to inquire about knowledge retention and actual implementation in practice, as well as ultimately any benefit to the patient.

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Authors' Contributions

JMK contributed toward the conceptualization, formal analysis, investigation, methodology, project administration, supervision, and writing of the original draft. JMK and RD curated the data. JMK and KQ acquired the funding. JMK, RD, and KQ reviewed and edited the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

ACE: adverse childhood experience
CDC: Centers for Disease Control and Prevention
CE: continuing education
CEHP: Continuing Education for Health Professions

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Red Blood Cell Transfusion for Incidence of Retinopathy of Prematurity: Prospective Multicenter Cohort Study

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Abstract

Background: Retinopathy of prematurity (ROP) is a leading cause of visual impairment and blindness in preterm infants.

Objective: This study sought to investigate the association between red blood cell (RBC) transfusion and ROP in very preterm infants (VPIs) to inform clinical strategies for ROP prevention and treatment.

Methods: We designed a prospective multicenter cohort study that included VPIs and follow-up data from January 2017 to December 2022 at 3 neonatal clinical medicine centers. They were categorized into a transfusion group (infants who received an RBC transfusion within 4 wk) and a nontransfusion group. The relationship between RBC transfusion and ROP incidence was assessed using binary logistic regression, with subgroup analyses based on gestational age, birth weight, sex, and sepsis status. Inverse probability of treatment weighting and propensity score matching were applied to account for all potential confounding factors that could affect ROP development, followed by sensitivity analysis.

Results: The study included 832 VPIs, including 327 in the nontransfusion group and 505 in the transfusion group. The transfusion group had a lower average birth weight and gestational age and a greater incidence of ROP, ≥stage 2 ROP, and severe ROP. Logistic regression analysis revealed that the transfusion group had a significantly greater risk of ROP (adjusted odds ratio [aOR] 1.70, 95% CI 1.14‐2.53, *P*=.009) and ≥stage 2 ROP (aOR 1.68, 95% CI 1.02‐2.78, *P*=.04) but not severe ROP (aOR 1.75, 95% CI 0.61‐5.02, *P*=.30). The trend analysis also revealed an increased risk of ROP with an increasing number of transfusions and a larger volume of blood transfused (*P* for trend<.001). Subgroup analyses confirmed a consistent trend, with the transfusion group at a higher risk for ROP across all subgroups. Inverse probability of treatment weighting and propensity score matching analyses supported the initial findings.

Conclusions: For VPIs, RBC transfusion significantly increases the risk of ROP, and the risk increases with an increasing number of transfusions and volume of blood transfused.

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KEYWORDS

red blood cell transfusion; retinopathy of prematurity; VPI; very preterm infants; ROP; visual impairment; blindness; RBC; red blood cell

Introduction

Retinopathy of prematurity (ROP) is a retinal vasoproliferative disease that occurs in premature and low-birth-weight infants and is the most common cause of blindness and low vision in infants [1,2]. Early detection and treatment are essential for preventing irreversible visual impairment and blindness. The main pathophysiological factor in ROP is an imbalance between proangiogenic and antiangiogenic factors released locally in the retina, resulting in abnormal neovascularization [3].

In premature infants, anemia is caused by multiple factors, including insufficient iron reserves from the mother, nutritional deficiency, a short red blood cell (RBC) lifespan, an immature hematopoietic system, and iatrogenic blood loss. RBC transfusion is one of the main treatments for anemia in premature infants. More than half of premature infants with a gestational age of less than 30 weeks and more than 80% of extremely low-birth-weight infants receive at least 1 RBC transfusion during hospitalization [4]. Although RBC transfusion can significantly improve oxygenation status and promote weight gain in anemic premature infants, the adverse reactions caused by RBC transfusion cannot be ignored. Previous studies have reported that RBC transfusion in premature infants is closely related to the development of necrotizing enterocolitis, bronchopulmonary dysplasia, and abnormal neurological outcomes [5]. However, whether RBC transfusion leads to the development of ROP remains controversial. Prospective and retrospective studies have not provided consistent results [6,7]. ROP may regress naturally or progress to stage 3 or higher, with severe cases requiring laser treatment or intravitreal anti–vascular endothelial growth factor (VEGF) injections [8]. Even for infants with ROP who receive timely treatment and those with ROP below the treatment threshold, there is still a risk of permanent visual impairment [9]. Identifying risk factors that can lead to the development and progression of ROP is crucial for its prevention.

Therefore, the purpose of this study was to determine the correlation between RBC transfusion and the occurrence of ROP, providing new insights for the prevention and treatment of ROP.

Methods

Study Participants

Inclusion and Exclusion Criteria

A multicenter cohort study of very preterm infants (VPIs) who were admitted to 3 neonatal intensive care units in Sichuan was conducted from January 1, 2017, to December 31, 2022. The exclusion criteria for infants were as follows: (1) severe lethal congenital malformations (such as central nervous system malformations, congenital facial malformations, or congenital heart malformations); (2) participation refusal by parents or guardians; (3) incomplete hospitalization and transfusion records; (4) discharge or death before ROP screening; and (5) irregular follow-up after discharge.

Definitions and Diagnostic Criteria for Related Diseases

Early-onset sepsis (≤3 d after birth) and late-onset sepsis (>3 d after birth) were classified based on the timing of onset. The clinical diagnosis of sepsis was based on clinical manifestations and positive results for ≥2 nonspecific blood tests, cerebrospinal fluid examination results consistent with bacterial meningitis, or the detection of bacterial DNA in the blood. A confirmed diagnosis required clinical manifestations and positive blood or cerebrospinal fluid (or other sterile body fluid) cultures [10,11].

Premature rupture of membranes refers to the spontaneous rupture of fetal membranes before labor or before the onset of the first stage of labor [12].

Hypertensive disorders of pregnancy are specific and common diseases in pregnant women and include gestational hypertension, preeclampsia (mild and severe), eclampsia, chronic hypertension with preeclampsia, and chronic hypertension with superimposed gestational hypertension [13].

Gestational diabetes mellitus was defined as meeting any one of the following criteria: a random blood glucose level ≥5.1 mmol/L, a postprandial 1-hour blood glucose level ≥10.0 mmol/L, or a postprandial 2-hour blood glucose level ≥8.5 mmol/L [14].

Small for gestational age (SGA) was defined as a birth weight below the 10th percentile of the average birth weight for infants of the same gestational age and sex according to the Chinese birth weight curve for different gestational ages created by Zhu et al [15,16] in 2018.

Apnea of prematurity was defined as a respiratory pause ≥20 seconds or <20 seconds accompanied by a decrease in heart rate or oxygen saturation [17].

Transfusion Criteria for Premature Infants

There is no unified transfusion guideline for anemia in premature infants. The timing and volume of transfusions are usually determined by physicians based on the clinical manifestations, laboratory parameters, and transfusion standards set by each department. Clinical manifestations include poor weight gain or slow growth, irregular breathing, and hemodynamic disturbances. The laboratory parameters include the RBC count, hematocrit level, hemoglobin content, and central and peripheral oxygen saturation. The transfusion dose is 15 - 20 mL/kg per session, and if repeated transfusions are needed, blood from the same donor should be used whenever possible.

ROP Screening, Diagnosis, and Follow-Up

The initial screening for preterm infants was scheduled between 4 and 5 weeks after birth or at a corrected gestational age of 31 to 32 weeks. The examination was conducted by an experienced ophthalmologist using a RetCam III (Natus Medical Inc), an American-made, wide-angle digital pediatric retinal camera, following a systematic order: the posterior pole, macula, temporal, superior, nasal, and inferior regions.

All the examinations were performed by the same ophthalmologist, who diagnosed and staged ROP according to the severity of the condition; ROP was categorized into stages 1 to 5 [18]. Severe ROP was defined as stage 3 to stage 5 ROP or plus disease in zone I or II [19]. Infants with immature retinal development and no ROP undergo retinal re-examinations every 3 to 4 weeks before peripheral vascularization. The follow-up interval for infants with established ROP was determined according to the severity of the condition.

Methodology

A standardized questionnaire for obtaining basic information for preterm infants was developed, and data from the infants' hospital records were documented. All the data were entered independently by 2 individuals using EpiData software (version 3.1; The EpiData Association), with discrepancies resolved by a third party. The following data were collected: (1) maternal information: mode of delivery, gestational diabetes status, hypertensive disorders of pregnancy status, chorioamnionitis status, and premature rupture of membrane status (defined as rupture occurring more than 18 h before delivery); (2) infant information: gestational age, birth weight, 5-minute Apgar score, and SGA status; (3) postnatal conditions: duration of nasal continuous positive airway pressure (nCPAP), use of invasive mechanical ventilation, highest oxygen concentration (sustained for more than 2 h), apnea status, early-onset sepsis status, late-onset sepsis status, invasive ventilation status, and duration of invasive ventilation; (4) transfusion-related indicators: transfusion status, age at first transfusion, number of transfusions, and total blood volume transfused within the first

4 weeks of hospitalization; and (5) outcomes: ROP status, ≥stage 2 ROP status, and severe ROP status.

Statistical Analysis

Statistical software was used for data description and inference. Categorical data are represented by frequencies and percentages, while continuous data are represented by the mean and SD (for normally distributed data) or median and IQR (for nonnormally distributed data). Chi-square tests were used for group comparisons of categorical data, and independent *2-tailed t* tests or Mann Whitney *U* tests were used for continuous data. Multivariate binary logistic regression was used to adjust for potential confounders and calculate the adjusted odds ratio (aOR) of RBC transfusion in premature infants with ROP. Trend tests (*P* for trend) were used to assess the association between the number of transfusions and the volume of blood transfused in infants with ROP. Subgroup analysis was performed based on gestational age, birth weight, sex, and sepsis status. Forest plots were generated to analyze the impact of RBC transfusions on the incidence of ROP in each subgroup.

To address potential baseline data bias in real-world studies, inverse probability of treatment weighting (IPTW) and 1:1 propensity score matching (PSM) methods were used to balance baseline differences between groups [20]. Sensitivity analysis was conducted using the calculated sample sizes obtained from these postrandomization methods to validate the stability of the results. All the statistical analyses were performed using open-source R packages and SPSS software (version 26.0; IBM Corp). A *P* value <.05 was considered to indicate statistical significance.

Ethical Considerations

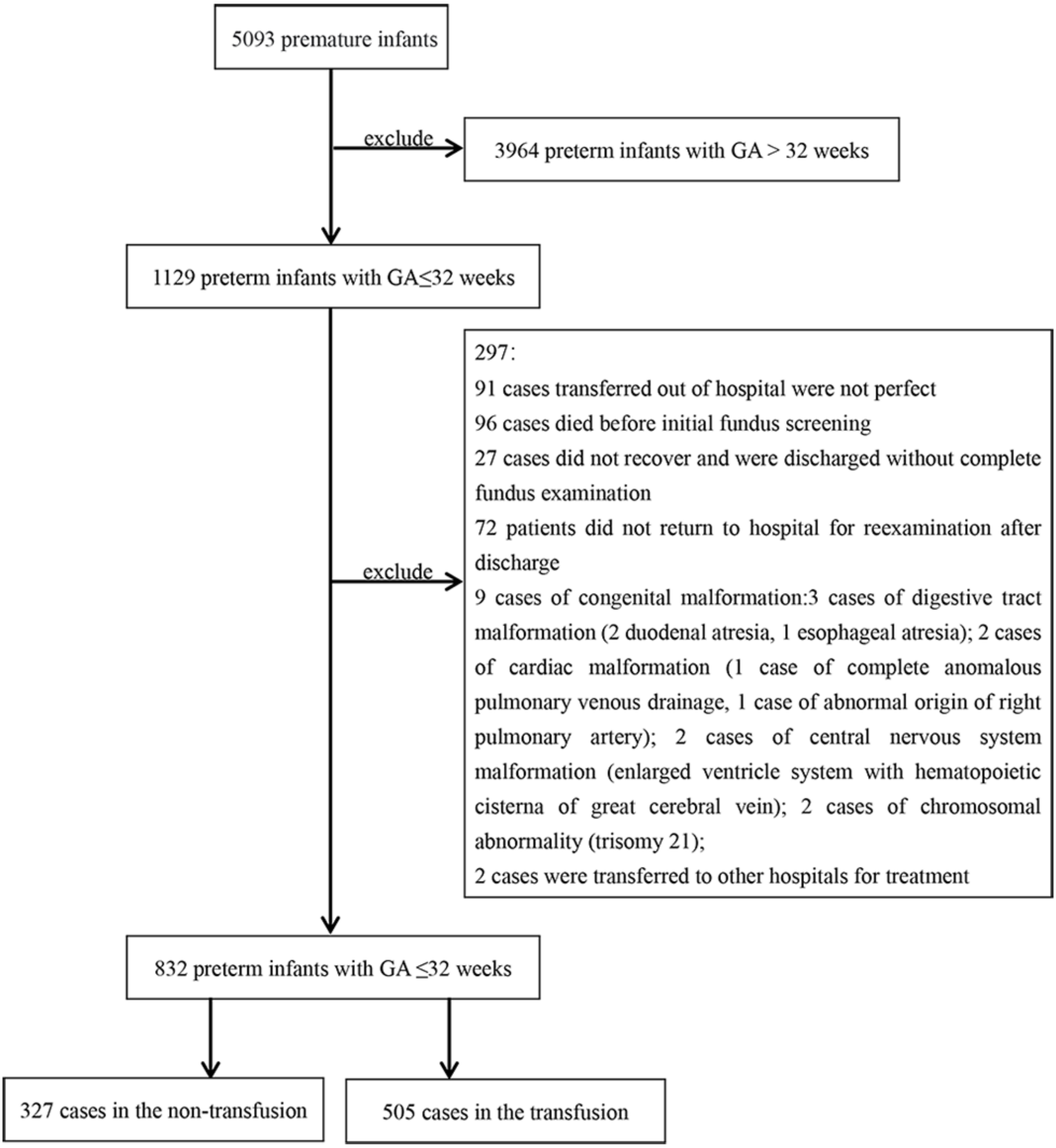
The Clinical Trial Ethics Committee of the Affiliated Hospital of Southwest Medical University approved the study (approval number Y2024124). The study was in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki Declaration and its later amendments. Informed consent was obtained from the legal guardians of all participants included in the study.

Results

Case Selection Process

During the study period, a total of 1129 VPIs were admitted to 3 neonatal intensive care units. After excluding 297 infants, 832 were ultimately included. Since the initial screening for ROP occurs between 4 and 5 weeks after birth, infants who received RBC transfusions within 4 weeks after birth were defined as the transfusion group, and those who did not receive transfusions within 4 weeks or who received transfusions after 4 weeks were defined as the nontransfusion group. The nontransfusion group consisted of 327 (39.3%) infants, and the transfusion group included 505 (60.7%) infants (Figure 1).

Figure 1. Flowchart of the selection of the research participants. GA: gestational age.



Study Results Before Random Matching

Comparison of General Information Between the 2 Groups

Table 1 shows that the preterm infants in the transfusion group had a younger gestational age (median 30.10, IQR 28.90-31.10 wk vs median 31.10, IQR 30.30-31.60 wk, z=−8.77, *P*<.001), a lower average birth weight (mean 1327, SD 251 g vs mean 1543, SD 231 g; *t*=12.50, df=830, *P*<.001), and a lower 5-minute Apgar score (median 8, IQR 7-9 points vs median 9, IQR 8-9 points, z=−6.73, *P*<.001). The highest oxygen concentrations required were greater (median 30%, IQR 28-40% vs median 28%, IQR 25-30%, z=−10.02, *P*<.001); the duration of nCPAP use was greater (median 11, IQR 6-18 d vs median 6, IQR 3-9 d, z=−12.03, *P*<.001); and the incidences of mechanical ventilation (156/505, 30.9% vs 16/327, 4.9%, $\chi^2_1=81.80$, *P*<.001), apnea (280/505, 55.5% vs 87/327, 26.6%, $\chi^2_1=66.96$, *P*<.001), early-onset sepsis (132/505, 26.1% vs 60/327, 18.4%, $\chi^2_1=6.79$, *P*=.009), late-onset sepsis (198/505, 39.2% vs 57/327, 17.4%, $\chi^2_1=44.28$, *P*<.001), and SGA (59/505, 11.7% vs 14/327, 4.3%, $\chi^2_1=13.59$, *P*<.001) were significantly greater in the transfusion group than in the nontransfusion group (Table 1).

Table . Comparison of baseline characteristics between the 2 groups.

General information		Nontransfusion group (n=327)	Transfusion group (n=505)	z, chi-square (*df*), or *t* test (*df*)	*P* value
Maternal data, n (%)					
	Vaginal delivery	183 (56.0)	264 (52.3)	1.09(1)	.30
	Premature rupture of membrane	143 (43.7)	154 (30.5)	15.15(1)	<.001
	Hypertensive disorders of pregnancy	38 (11.6)	72 (14.3)	1.20(1)	.27
	Gestational diabetes mellitus	68 (20.8)	125 (24.8)	1.75(1)	.19
	Chorioamnionitis	120 (36.7)	177 (35.1)	0.24(1)	.63
Neonatal data					
	Male, n (%)	183 (56.0)	282 (55.9)	0.001(1)	.97
	Gestational age (weeks), median (IQR)	31.10 (30.30-31.60)	30.10 (28.90-31.10)	−8.77	<.001
	Birth weight (g), mean (SD)	1543 (231)	1327 (251)	12.50(830)	<.001
	5-min Apgar score, median (IQR)	9 (8-9)	8 (7-9)	−6.73	<.001
	nCPAP[a] duration (days), median (IQR)	6 (3-9)	11 (6-18)	−12.03	<.001
	Invasive ventilation, n (%)	16 (4.9)	156 (30.9)	81.80 (1)	<.001
	Invasive ventilation duration (days), median (IQR)	0 (0-0)	0 (0-2)	−9.21	<.001
	Maximum oxygen concentration (%), median (IQR)	28 (25-30)	30 (28-40)	−10.02	<.001
	Apnea, n (%)	87 (26.6)	280 (55.5)	66.96 (1)	<.001
	Early-onset sepsis, n (%)	60 (18.4)	132 (26.1)	6.79 (1)	.009
	Late-onset sepsis, n (%)	57 (17.4)	198 (39.2)	44.28 (1)	<.001
	SGA[b], n (%)	14 (4.3)	59 (11.7)	13.59 (1)	<.001

[a] nCPAP: nasal continuous positive airway pressure.

[b] SGA: small for gestational age.

The Impact of Transfusion Within 4 Weeks on ROP Incidence

Using the results of univariate analysis as a basis, potential confounding factors were included in a multivariate binary logistic regression model. The results showed that the risk of ROP (aOR 1.70, 95% CI 1.14‑2.53; *P*=.009) and ≥stage 2 ROP (aOR 1.68, 95% CI 1.02‑2.78; *P*=.04) in the transfusion group was significantly greater than that in the nontransfusion group; however, there was no significant difference in the risk of severe ROP between the 2 groups (aOR 1.75, 95% CI 0.61‑5.02; *P*=.30) (Table 2).

Table . The impact of red blood cell (RBC) transfusion within 4 wk on retinopathy of prematurity (ROP) incidence.

	Nontransfusion group (n=327), n (%)	Transfusion group (n=505), n (%)	OR[a] (95% CI)	*P* value	aOR[b] (95% CI)	*P* value
ROP	58 (17.7)	239 (47.3)	4.17 (2.99-5.81)	<.001	1.70 (1.14-2.53)	.009
≥Stage 2 ROP	30 (9.2)	159 (31.5)	4.55 (2.99-6.92)	<.001	1.68 (1.02-2.78)	.04
Severe ROP	5 (1.5)	51 (10.1)	7.23 (2.86-18.33)	<.001	1.75 (0.61-5.02)	.30

[a] OR: odds ratio.

[b] aOR: adjusted odds ratio. Adjusted for gestational age, birth weight, 5-min Apgar score, mechanical ventilation use, maximum oxygen concentration, early-onset sepsis, late-onset sepsis, apnea, and small for gestational age.

The Impact of Different Transfusion Frequencies Within 4 Weeks on ROP Incidence

To clarify the impact of different transfusion frequencies within 4 weeks on ROP incidence, preterm infants in the transfusion group were further divided into a single transfusion group (339 infants) and a multiple transfusion group (166 infants) and compared with those in the nontransfusion group. A single transfusion within 4 weeks increased the risk of ROP (aOR 1.79, 95% CI 1.20 - 2.68; *P*=.005) but did not increase the risk of ≥stage 2 ROP or severe ROP; multiple transfusions within 4 weeks increased the risk of ROP (aOR 2.95, 95% CI 1.67 - 5.21; *P*<.001) and ≥stage 2 ROP (aOR 2.84, 95% CI 1.47 - 5.47; *P*=.002) but did not increase the risk of severe ROP (Multimedia Appendix 1). As the number of transfusions increased, the risk of ROP, ≥stage 2 ROP, and severe ROP gradually increased, with trend test results all less than 0.001, indicating that the higher the number of transfusions was, the greater the risk of ROP.

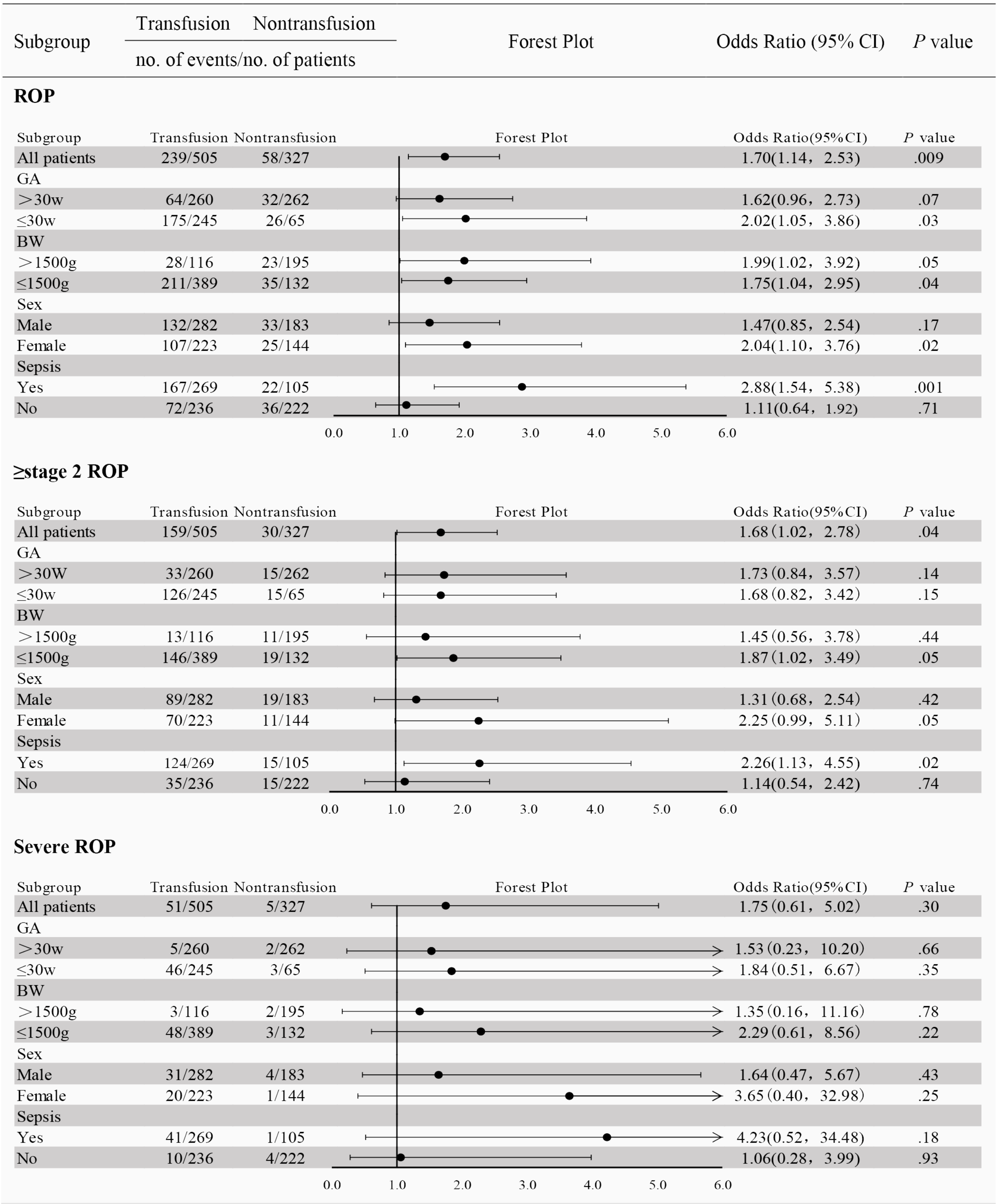
The Impact of Different Transfusion Volumes Within 4 Weeks on ROP Incidence

To clarify the impact of different transfusion volumes within 4 weeks on ROP incidence, preterm infants in the transfusion group were further divided based on the total volume of blood transfused. Due to the nonnormal distribution of the total transfusion volume within 4 weeks, the infants in the transfusion group were divided into the following 3 groups according to the IQR and compared with those in the nontransfusion group: the ≤34 mL/kg group (176 infants), 34 - 42 mL/kg group (159 infants), and ≥42 mL/kg group (170 infants). A total transfusion volume ≤34 mL/kg within 4 weeks did not increase the risk of ROP, ≥stage 2 ROP, or severe ROP; a total transfusion volume of 34 - 42 mL/kg within 4 weeks increased the risk of ROP (aOR 1.67, 95% CI 1.02 - 2.72, *P*=.04) but did not increase the risk of ≥stage 2 ROP or severe ROP; and a total transfusion volume ≥42 mL/kg within 4 weeks increased the risk of ROP (odds ratio [OR] 2.88, 95% CI 1.54 - 5.39, *P*<.001) and ≥stage 2 ROP (OR 3.08, 95% CI 1.53 - 6.23, *P=.002*) but did not increase the risk of severe ROP (Multimedia Appendix 2). As the total transfusion volume increased, the risk of ROP, ≥stage 2 ROP, and severe ROP gradually increased, with trend test results all less than 0.001, indicating that the greater the total transfusion volume was, the greater the risk of ROP.

The Impact of Transfusion on ROP Incidence in Various Subgroups of Preterm Infants

To clarify the impact of transfusion within 4 weeks on ROP incidence in different preterm infant populations, the included preterm infants were divided into 3 subgroups based on gestational age (>30 weeks ≤30 weeks), birth weight (>1500 g, ≤1500 g), sex (male, female) and sepsis status (yes, no). Although there were no significant differences in some outcome indicators between the subgroups, the overall trend was consistent, with the risk of ROP in the transfusion group being greater than that in the nontransfusion group (Figure 2, Multimedia Appendices 3, 4, and 5).

Figure 2. Forest plot of the effect of red blood cell transfusion within 4 wk on the occurrence of retinopathy of prematurity (ROP) in preterm infants in each subgroup. BW: birth weight; GA: gestational age.



Subgroup	Transfusion	Nontransfusion	Forest Plot	Odds Ratio (95% CI)	*P* value
	no. of events/no. of patients				

ROP

Subgroup	Transfusion	Nontransfusion	Odds Ratio(95%CI)	*P* value
All patients	239/505	58/327	1.70(1.14，2.53)	.009
GA				
>30w	64/260	32/262	1.62(0.96，2.73)	.07
≤30w	175/245	26/65	2.02(1.05，3.86)	.03
BW				
>1500g	28/116	23/195	1.99(1.02，3.92)	.05
≤1500g	211/389	35/132	1.75(1.04，2.95)	.04
Sex				
Male	132/282	33/183	1.47(0.85，2.54)	.17
Female	107/223	25/144	2.04(1.10，3.76)	.02
Sepsis				
Yes	167/269	22/105	2.88(1.54，5.38)	.001
No	72/236	36/222	1.11(0.64，1.92)	.71

≥stage 2 ROP

Subgroup	Transfusion	Nontransfusion	Odds Ratio(95%CI)	*P* value
All patients	159/505	30/327	1.68 (1.02，2.78)	.04
GA				
>30W	33/260	15/262	1.73 (0.84，3.57)	.14
≤30w	126/245	15/65	1.68 (0.82，3.42)	.15
BW				
>1500g	13/116	11/195	1.45 (0.56，3.78)	.44
≤1500g	146/389	19/132	1.87 (1.02，3.49)	.05
Sex				
Male	89/282	19/183	1.31 (0.68，2.54)	.42
Female	70/223	11/144	2.25 (0.99，5.11)	.05
Sepsis				
Yes	124/269	15/105	2.26(1.13，4.55)	.02
No	35/236	15/222	1.14(0.54，2.42)	.74

Severe ROP

Subgroup	Transfusion	Nontransfusion	Odds Ratio(95%CI)	*P* value
All patients	51/505	5/327	1.75 (0.61，5.02)	.30
GA				
>30w	5/260	2/262	1.53 (0.23，10.20)	.66
≤30w	46/245	3/65	1.84 (0.51，6.67)	.35
BW				
>1500g	3/116	2/195	1.35 (0.16，11.16)	.78
≤1500g	48/389	3/132	2.29 (0.61，8.56)	.22
Sex				
Male	31/282	4/183	1.64 (0.47，5.67)	.43
Female	20/223	1/144	3.65 (0.40，32.98)	.25
Sepsis				
Yes	41/269	1/105	4.23(0.52，34.48)	.18
No	10/236	4/222	1.06(0.28，3.99)	.93

Sensitivity Analysis Results After IPTW and PSM

Given the numerous factors influencing ROP incidence and the significant imbalance in the baseline data in this real-world study, as shown in Table 2, the ROP data showed considerable changes before and after adjusting for confounding factors, suggesting potential selection bias in the study results. Therefore, the IPTW and PSM methods were applied in this study to evaluate all factors that could affect ROP incidence between the 2 groups. Sensitivity analysis was performed using the calculated sample sizes obtained after IPTW and PSM to validate the stability of the impact of RBC transfusions on ROP incidence. The balance between the groups was significantly improved after IPTW and PSM (Multimedia Appendices 6 and 7). The results obtained after IPTW and PSM were consistent with the original results (Multimedia Appendices 8 and 9).

Discussion

Principal Findings

Previous studies on the association between RBC transfusion and ROP incidence have used a retrospective case-control design to investigate risk factors for ROP development. This is the first prospective multicenter cohort study in which infants were categorized based on whether they received RBC transfusions within the first 4 weeks after birth. The study included all VPIs who were admitted to 3 centers over nearly 6 years, and the correlation between RBC transfusion and ROP incidence was explored. The results indicated that RBC transfusion within the first 4 weeks significantly increases the risk of ROP in VPIs, and this correlation remained consistent across different groups of preterm infants.

Despite various available measures to prevent anemia in preterm infants, the use of RBC transfusion remains inevitable [21]. Studies show that more than 90% of extremely low-birth-weight infants receive at least 1 RBC transfusion during their hospital stay, with the risk of transfusion increasing for infants with younger gestational ages, lower birth weights, and greater immaturity [22,23]. Puia-Dumitrescu et al’s [24] study, which included 54 preterm infants with a gestational age of 30 weeks and a birth weight less than 1000 g, revealed that the average number of RBC transfusions during a 10-week hospital stay was 8. For extremely preterm infants with a gestational age of 23 - 24 weeks, the average number of transfusions was 11, and for those with a gestational age of 27 - 28 weeks, the number could reach 6. Our study revealed that 505 (60.7%) preterm infants with a gestational age ≤32 weeks received at least 1 RBC transfusion within 28 days of hospitalization, with a greater likelihood of transfusion in infants with a younger gestational age. The proportion of transfusions decreased with increasing gestational age and birth weight, which is consistent with previous findings.

ROP is a common complication in preterm infants, and its incidence and severity decrease as gestational age and birth weight increase. In this study, the incidence of ROP in preterm infants with a gestational age ≤32 weeks was 297 (35.6%), and the incidence of severe ROP was 56 (6.7%). The incidence of ROP is greater in infants with younger gestational ages, with those born at less than 28 weeks having an incidence rate of approximately 70%, which is consistent with the reports by Dai et al [25].

The pathogenesis of ROP is multifactorial, with low gestational age, low birth weight, and prolonged exposure to oxygen therapy being the main risk factors for ROP [26]. In addition to these risk factors, RBC transfusion has been suggested to be a risk factor for ROP development in numerous case-control studies [27-29]. However, Lundgren et al [30] reported that the duration of anemia in the first week after birth was an independent risk factor for ROP, while RBC transfusion was not. Given the inconsistent results of retrospective studies, our prospective cohort study aimed to clarify the association between RBC transfusion and ROP incidence. The results indicated that after adjusting for confounding factors such as gestational age at birth, birth weight, and nCPAP use, RBC transfusion within the first 4 weeks of hospitalization significantly increased the risk of ROP and ≥stage 2 ROP in VPIs. However, there was no significant difference in the incidence of severe ROP between the 2 groups, which may have been due to the low incidence of severe ROP and the small sample size. Given that this study was observational, many factors influence ROP development, and there is potential selection bias due to the imbalance of baseline data, we applied the IPTW and PSM methods to account for all potential confounding factors that could affect ROP development. The results still suggested that RBC transfusion increases the risk of ROP in VPIs, and this association remained consistent across different groups of preterm infants.

The risk of ROP increases with an increasing number of RBC transfusions and volume of blood transfused. Ghirardello et al’s [31] study, which included 641 preterm infants with very low birth weight, showed that RBC transfusion is an independent risk factor for ROP development in very low-birth-weight infants, and the risk of complications increases with an increasing number of transfusions, with 3 or more transfusions increasing the risk of bronchopulmonary dysplasia and ROP by 4.88 times. Hengartner et al’s [32] retrospective study of 178 extremely preterm infants showed that infants with ≥stage 2 ROP received more transfusions, had larger volumes transfused, and received earlier treatment. Additionally, Uberos et al’s [19] data indicate that the relationship between the number of RBC transfusions and the risk of ROP and severe ROP is more significant than that between early RBC transfusion (within the first 7 d of life) and the risk of ROP and severe ROP. Our study revealed that the risk of ROP and ≥stage 2 ROP increases with an increasing number of RBC transfusions and volume of blood transfused, which is consistent with the findings of the aforementioned studies.

The mechanism by which RBC transfusion leads to ROP development is not yet fully understood, but it may be related to the replacement of fetal hemoglobin (HbF) with adult hemoglobin after transfusion, which leads to changes in the type and quantity of hemoglobin [33]. Since adult hemoglobin has a decreased affinity for oxygen, developing retinal tissue is exposed to high oxygen levels, leading to oxidative damage to vascular endothelial cells, downregulation of VEGF expression, and stagnation of retinal vascular development [34]. This results in retinal hypoxia, increased VEGF and erythropoietin expression, pathological proliferation of vessels in the retina and vitreous, and the development of ROP [35]. Jiramongkolchai et al’s [36] prospective cohort study showed that infants with the lowest percentage of HbF at a corrected age of 31 weeks had a 7.6-fold increased risk of mild and severe ROP, and this risk increased to 12.3 times by the corrected age of 34 weeks, indicating that a lower HbF percentage is associated with a greater risk of ROP. Prasad et al [37,38] conducted 2 prospective studies to explore the correlation between HbF concentration and ROP, and the results showed that preterm infants with lower HbF levels were at higher risk of developing ROP, and preterm infants with higher HbF concentration were more likely to have ROP spontaneously subside. HbF may play a protective role in the occurrence and development of ROP. Teofili et al investigated the relationship between transfusion-free survival and ROP [39]. The study found that preterm infants receiving RBC transfusions before 28 weeks of gestational age were associated with an increased risk of developing severe ROP, that gestational age at second transfusion was a better predictor of developing severe ROP than gestational age at first transfusion, and that maintaining higher levels of HbF may help reduce the risk of ROP [39].

Preventing anemia and reducing the risk of RBC transfusion are pressing issues for neonatologists. Delayed cord clamping [40], reduced iatrogenic blood loss, and iron supplementation are beneficial interventions for preventing anemia. Research on the RBC source, storage time, and different transfusion thresholds is currently ongoing, but there are no unified results. Kirpalani et al [41] reported that restrictive transfusion strategies did not reduce the incidence of ROP; Glaser et al’s [42] large cohort study revealed that restrictive transfusion strategies could reduce the risk of ROP, while liberal transfusion strategies increased the risk. In recent years, umbilical cord blood (UCB) transfusion has gained increasing attention. The use of UCB from healthy newborns has been proposed to prevent ROP in preterm infants. The main potential advantage of UCB is that it contains the same amount of HbF as newborns in utero. Thus, autologous UCB transfusions would maintain a physiological concentration of HbF during the first weeks of life, which has a greater affinity for oxygen and is more stable in an oxidative environment, maintaining similar oxygen transportation and tissue delivery as in the fetal stage. This fact could optimize the postnatal development of different immature tissues [43].

Limitations

This study has certain limitations. First, as a multicenter observational study spanning 6 years, there may have been changes in the treatment and transfusion strategies for preterm infants across centers, leading to potential bias in the results. Second, although the IPTW and PSM methods were used to control for known confounding factors, unknown confounding factors and other intermediate factors may still have affected the results. Therefore, considering the potential impact of unknown confounding factors, we believe that well-designed, larger-sample randomized clinical trials are needed to further validate the effects of RBC transfusion, different RBC storage times, transfusion intervals, and anemia status on the development of ROP. We also need to learn from the work of Schallmoser et al [44], integrating the medical profession with machine learning to construct a predictive model for the risk of retinopathy of ROP occurrence.

Conclusions

Based on our study results, RBC transfusion increases the risk of ROP, and this effect is consistent across different groups of preterm infants. For VPIs, RBC transfusions are strongly associated with an increased risk of ROP, which escalates alongside the number and volume of transfusions. We recommend that for VPIs with small gestational age, low birth weight, and high risk of sepsis, the indications for RBC transfusion in preterm infants should be strictly controlled and that the number of transfusions and volume of blood transfused should be limited to reduce adverse consequences.

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Data Availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Authors' Contributions

XW was responsible for collecting data, completing data curation, following up with patients, and writing the original draft. RR contributed by collecting data, performing statistical analysis, and revising the manuscript. HL was involved in collecting data and following up with patients. XL and WD conceived the research idea, supervised the research work, and approved and edited the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
The impact of different transfusion frequencies within 4 weeks on retinopathy of prematurity incidence.
[DOCX File, 18 KB - pediatrics_v7i1e60330_app1.docx]

Multimedia Appendix 2
The impact of different transfusion volumes within 4 weeks on retinopathy of prematurity incidence.
[DOCX File, 18 KB - pediatrics_v7i1e60330_app2.docx]

Multimedia Appendix 3
The impact of red blood cell transfusion within 4 weeks on retinopathy of prematurity incidence for different gestational ages.

[DOCX File, 17 KB - pediatrics_v7i1e60330_app3.docx]

Multimedia Appendix 4
The impact of red blood cell transfusion within 4 weeks on retinopathy of prematurity incidence for different birth weights.
[DOCX File, 17 KB - pediatrics_v7i1e60330_app4.docx]

Multimedia Appendix 5
The impact of red blood cell transfusion within 4 weeks on retinopathy of prematurity incidence for each sex.
[DOCX File, 17 KB - pediatrics_v7i1e60330_app5.docx]

Multimedia Appendix 6
Change in standardized mean difference (SMD) values before and after inverse probability of treatment weighting (IPTW) and propensity score matching (PSM). (A) Change in SMD values before and after IPTW; (B) change in SMD values before and after PSM.
[PNG File, 88 KB - pediatrics_v7i1e60330_app6.png]

Multimedia Appendix 7
Propensity score value distribution between groups before and after probability of treatment weighting (IPTW) and propensity score matching (PSM). (A) Propensity score value distribution between groups before random matching; (B) propensity score value distribution between groups after IPTW; (C) propensity score value distribution between groups after PSM.
[PNG File, 65 KB - pediatrics_v7i1e60330_app7.png]

Multimedia Appendix 8
The impact of red blood cell transfusion within 4 weeks on retinopathy of prematurity incidence after inverse probability of treatment weighting.
[DOCX File, 16 KB - pediatrics_v7i1e60330_app8.docx]

Multimedia Appendix 9
The impact of red blood cell transfusion within 4 weeks on retinopathy of prematurity incidence after propensity score matching.
[DOCX File, 16 KB - pediatrics_v7i1e60330_app9.docx]

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Abbreviations

aOR: adjusted odds ratio
HbF: fetal hemoglobin
IPTW: inverse probability of treatment weighting
nCPAP: nasal continuous positive airway pressure
OR: odds ratio
PSM: propensity score matching
RBC: red blood cell
ROP: retinopathy of prematurity
SGA: small for gestational age
UCB: umbilical cord blood
VEGF: vascular endothelial growth factor
VPI: very preterm infant

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Electronic Medical Record Data Missingness and Interruption in Antiretroviral Therapy Among Adults and Children Living With HIV in Haiti: Retrospective Longitudinal Study

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Abstract

Background: Children (aged 0-14 years) living with HIV often experience lower rates of HIV diagnosis, treatment, and viral load suppression. In Haiti, only 63% of children living with HIV know their HIV status (compared to 85% overall), 63% are on treatment (compared to 85% overall), and 48% are virally suppressed (compared to 73% overall). Electronic medical records (EMRs) can improve HIV care and patient outcomes, but these benefits are largely dependent on providers having access to quality and nonmissing data.

Objective: We sought to understand the associations between EMR data missingness and interruption in antiretroviral therapy treatment by age group (pediatric vs adult).

Methods: We assessed associations between patient intake record data missingness and interruption in treatment (IIT) status at 6 and 12 months post antiretroviral therapy initiation using patient-level data drawn from iSanté, the most widely used EMR in Haiti. Missingness was assessed for tuberculosis diagnosis, World Health Organization HIV stage, and weight using a composite score indicator (ie, the number of indicators of interest missing). Risk ratios were estimated using marginal parameters from multilevel modified Poisson models with robust error variances and random intercepts for the facility to account for clustering.

Results: Data were drawn from 50 facilities and comprised 31,457 patient records from people living with HIV, of which 1306 (4.2%) were pediatric cases. Pediatric patients were more likely than adult patients to experience IIT (n=431, 33% vs n=7477, 23.4% at 6 months; *P*<.001). Additionally, pediatric patient records had higher data missingness, with 581 (44.5%) pediatric records missing at least 1 indicator of interest, compared to 7812 (25.9%) adult records (*P*<.001). Among pediatric patients, each additional indicator missing was associated with a 1.34 times greater likelihood of experiencing IIT at 6 months (95% CI 1.08-1.66; *P*=.008) and 1.24 times greater likelihood of experiencing IIT at 12 months (95% CI 1.05-1.46; *P*=.01). These relationships were not statistically significant for adult patients. Compared to pediatric patients with 0 missing indicators, pediatric patients with 1, 2, or 3 missing indicators were 1.59 (95% CI 1.26-2.01; *P*<.001), 1.74 (95% CI 1.02-2.97; *P*=.04), and 2.25 (95% CI 1.43-3.56; *P*=.001) times more likely to experience IIT at 6 months, respectively. Among adult patients, compared to patients with 0 indicators missing, having all 3 indicators missing was associated with being 1.32 times more likely to experience IIT at 6 months (95% CI 1.03-1.70; *P*=.03), while there was no association with IIT status for other levels of missingness.

Conclusions: These findings suggest that both EMR data quality and quality of care are lower for children living with HIV in Haiti. This underscores the need for further research into the mechanisms by which EMR data quality impacts the quality of care and patient outcomes among this population. Efforts to improve both EMR data quality and quality of care should consider prioritizing pediatric patients.

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KEYWORDS

HIV; Haiti; pediatrics; combination antiretroviral therapy; electronic medical record; data quality; child; children; antiretroviral; therapy; longitudinal study; HIV diagnosis; diagnosis; HIV care; patient records; quality of care; treatment; engagement

Introduction

Despite improvements in HIV testing, care, and treatment and reduced HIV incidence over the last 3 decades, Haiti has the largest population of people living with HIV in the Caribbean, with an estimated 1.8% of the population (150,000 persons) having received a positive HIV diagnosis, including nearly 6000 children (aged 0-14 years) living with HIV [1]. Children living with HIV often have lower rates of HIV diagnosis, treatment, and viral load suppression [2]. In Haiti, children living with HIV fare worse across all steps of the care cascade, with only 63% knowing their HIV status (compared to 85% overall), 63% on treatment (compared to 85% overall), and 48% virally suppressed (compared to 73% overall) [1]. Reviews of patient records in Haiti revealed that children living with HIV were significantly less likely to initiate antiretroviral therapy (ART) in a timely manner as compared to adults, and once initiated, were less likely than adults to be retained in ART treatment [3,4].

Electronic medical records (EMRs) can improve HIV patient care and outcomes in multiple ways, including (1) directly informing individual patient care, such as tracking clinical outcomes, ART adherence and retention, as well as patient follow-up; and (2) promoting provider compliance with treatment and care guidelines [5-13]. However, these benefits are largely dependent on providers having access to high-quality data (ie, reliable, timely, and nonmissing data) [14-16]. In the context of EMRs, data missingness is both an element of quality of care (vis-à-vis noncompliance with reporting guidelines) and can itself lead to lower quality of care, as missing data cannot be used to inform clinical decision-making [17]. However, despite the importance of data quality in the value proposition of EMRs, the evidence base exploring the association between data missingness and patient outcomes is limited, especially in resource-limited settings. Although many studies of EMRs include both data quality and patient outcomes as indicators of interest, a direct association between the two is rarely assessed. In addition, no studies reviewed for this paper assessed this relationship by age cohort.

We hypothesize that data missingness will be associated with greater interruption in treatment (IIT) and that this relationship may be larger among children living with HIV. We used ART patient data extracted from the iSanté EMR system to assess the association between age group, data missingness, and IIT.

Methods

Study Design

This was a retrospective longitudinal study using patient-level routine EMR data.

Data Source

We used patient-level clinical and pharmacy data extracted from iSanté—the most widely used EMR in Haiti, which covers over 1.8 million primary care patients and more than 200,000 unique records for people living with HIV [18,19]. iSanté records include data on key HIV care cascade processes (eg, clinical history) and electronic pharmacy data (eg, ART dispensing and continuation).

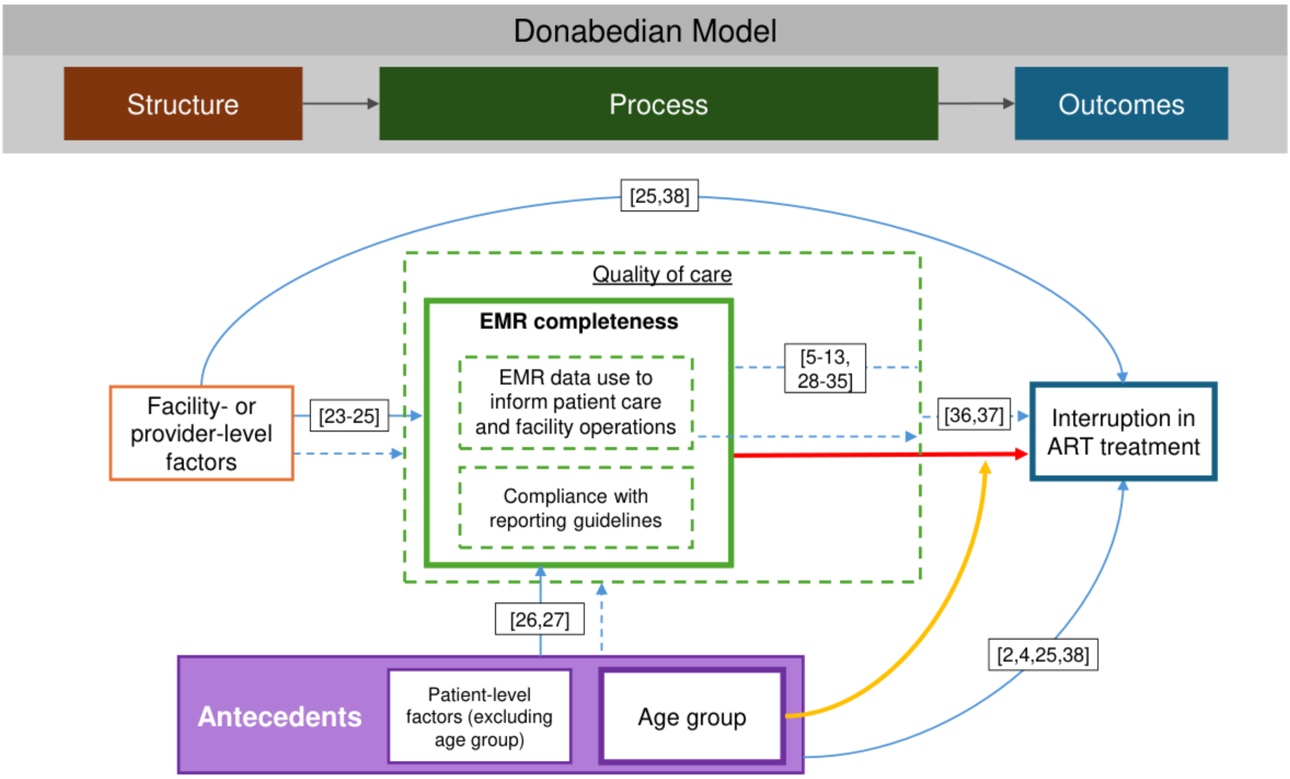
Sample

This analysis included data from 50 facilities and covered individuals who initiated ART between June 2016 and December 2021. Our analyses had a number of data exclusions. A total of 24 facilities were excluded from the analysis due to being prison-based facilities, having >20% of records entered more than 90 days after the visit date, or having a mean number of prescription records per patient less than 5 (suggesting data record input issues). Data before June 2016 were excluded to account for changes in treatment patterns following adoption of the test-and-treat approach to HIV care in mid-2016. Patient records included in the analysis were restricted to patients who initiated ART at least $n+2$ months before the data extraction date (end of July 2022) to allow for sufficient follow-up time to observe the outcome and to account for any delay in the entry of patient files, where n refers to the 6- or 12-month IIT outcome (eg, for the 6 months outcome, data were restricted to those who had initiated ART before December 2021). Individuals without date of birth data (n=1174, 3.2%) were excluded as correct age group categorization was essential for the analysis. Additionally, to better assess the relationship between data missingness at intake and IIT status 6 or 12 months after initiating ART, patients who completed their intake visit more than 3 months prior to initiating ART were excluded from the analysis (n=4083, 11.5%). A CONSORT (Consolidated Standards of Reporting Trials) flow diagram can be found in Multimedia Appendix 1 [20].

Conceptual Model

Figure 1 shows our proposed causal model, which is situated within the Donabedian framework [21] for quality of care, as modified by Coyle and Battles [22] to include medical antecedents. The Donabedian framework divides care into 3 primary components: structure (ie, the context in which care is delivered), process (ie, actual service delivery), and outcome. In the context of HIV care and EMRs, these can be understood as the facility or organizational context in which HIV care is delivered as well as the system aspects of EMRs (eg, accessibility and usability); the provision of HIV care, including the use of EMRs to both document and inform care; and HIV outcomes (eg, IIT). The various pathways in our conceptual model were justified through the published literature [2,4-13,23-38].

Figure 1. Conceptual model [2,4-13,23-38]. The blue lines indicate proposed causal pathways; the red line indicates the observed association of interest; the yellow line indicates effect modification by age; the dashed lines indicate unobserved pathways or variables. ART: antiretroviral therapy; EMR: electronic medical record.



Analysis

Outcome Variable

The primary outcomes of interest were IIT at the current facility at 6 and 12 months post ART initiation, defined as being more than 28 days late in picking up ART medication as of the dates 6 or 12 months after initiating ART. This definition for IIT status has been used in prior research in Haiti and other settings [39-41].

Covariates

Age groups were categorized as pediatric (0-14 years) and adult (>15 years) as of the time of ART initiation, following the age definition used to define pediatric care in Haiti (<15 years).

Data Missingness

Data missingness was defined as an indicator not being collected during the patient's intake visit. Assessment of missingness was restricted to indicators that were shared between both pediatric and adult intake forms, indicators that were clinically meaningful for HIV care, and where missingness could be differentiated from the absence of that issue (eg, the headache symptomology field may be missing due to a patient not presenting with a headache or due to the provider failing to document that issue, whereas the World Health Organization [WHO] HIV stage indicator is expected to be completed for all patients) [42]. Within these stipulations, we assessed missingness for weight, current WHO HIV stage, and current tuberculosis (TB) diagnosis. As the importance and impact of missingness for particular indicators may vary by age group (eg, routine documentation of weight is generally of higher importance for pediatric patients), missingness was analyzed as individual binary outcomes (defined as missing or nonmissing) as well as through a composite score indicator (the number of indicators of interest missing), which was analyzed as both a continuous and categorical outcome.

Models

Associations between data missingness (exposure) and interruption in ART treatment at a patient's current facility (outcome) were assessed through marginal parameters from multilevel modified Poisson models with robust error variances and random intercepts for the facility to account for clustering. Modified Poisson models have been shown to provide unbiased estimates of the risk ratio, important for nonrare binary outcomes where odds ratios estimated through logistic regression will overestimate the risk ratio and potentially lead to improper interpretation of the results [43,44]. Patient sex, facility type, ownership, patient volume, and duration of iSanté use were included as fixed effects to control for potential confounding. Models were stratified by age group to understand the relationship between data missingness and IIT status within each age group. Additional models were run with the age group as an interaction term with the continuous composite indicator to assess the statistical significance of the age group as an effect modifier in the association between missingness and IIT status.

Ethical Considerations

The secondary use of deidentified patient data from the iSanté EMR was approved by the University of Washington Human Subjects Division as nonengaged research (STUDY00016591 "Patient Risk Profiles for Interruption in Treatment among People Living with HIV in Haiti: Leveraging Health Information

Systems and Prediction Models to Identify Patients at High Risk"). The research was also reviewed and approved by the Haiti Ministry of Public Health and Population's National Bioethics Committee (reference number 2223-26).

Results

Primary Findings

In total, data were drawn from 50 facilities across 9 departments (of 10 total) in Haiti and comprised 31,457 patient records for people living with HIV. Of these, 30,151 (95.8%) were adult patients and 1306 (4.2%) were pediatric patients. The majority of patients (n=19,544, 62.1%) were female and received care at health centers (n=19,051, 60.6%) or hospitals (n=9883, 31.4%). The median duration of iSanté use at each health facility was 17.5 (IQR 15.8-18.3) years, and the median monthly patient volume was 348 (IQR 172-544). Table 1 further details participant and facility characteristics.

Table . Participant characteristics[a].

Characteristics		Patients		
		Overall (N=31,457)	Adult (n=30,151, 95.8%)	Pediatric (n=1306, 4.2%)
Sex, n (%)				
	Female	19,544 (62.1)	18,855 (62.5)	689 (52.8)
	Male	11,913 (37.9)	11,296 (37.5)	617 (47.2)
Age (years), median (IQR)		35 (27-44)	35 (28-44)	3 (0-9)
Facility type, n (%)				
	Health center	19,051 (60.6)	18,319 (60.8)	732 (56.0)
	Hospital	9883 (31.4)	9406 (31.2)	477 (36.5)
	Dispensary	2523 (8.0)	2426 (8.0)	97 (7.4)
Facility ownership, n (%)				
	Both public and private	7337 (23.3)	7008 (23.2)	329 (25.2)
	Private	11,466 (36.4)	11,109 (36.8)	357 (27.3)
	Public	12,654 (40.2)	12,034 (39.9)	620 (47.5)
Duration of iSanté use, median (IQR)		17.5 (15.8-18.3)	17.5 (15.3-18.3)	18.1 (17.0-18.3)
Monthly patient volume, median (IQR)		348 (172-544)	348 (172-544)	408 (200-626)

[a] Facility-related characteristics are described at the patient level (eg, the proportion of patients initiating antiretroviral therapy at a health center versus a hospital or dispensary).

IIT status and indicator missingness are detailed in Table 2. Across all age groups, the proportion of patients who experienced IIT at 6 and 12 months post ART initiation were 23.8% (n=7477) and 29.3% (n=9222), respectively. Overall, the weight indicator had the highest level of missingness, with 5365 (17.1%) patient records missing weight data, while TB diagnosis had the lowest (n=1417, 4.5%). Both IIT status and data missingness were higher among pediatric patients. Pediatric patients were more likely than adult patients to be IIT at both 6 months (n=431, 33.0% vs n=7046, 23.4%; *P*<.001) and 12 months (n=551, 42.2% vs n=8671, 28.8%; *P*<.001). Only 55.5% (n=725) of pediatric patient records had no indicators of interest missing, compared to 74.1% (n=22,339) of adult patient records. Pediatric patient records were also more likely to have at least 3 (3.1%) indicators missing compared to adult records (n=401, 1.3%; *P*<.001). Variation in missingness across age groups was greatest for the WHO HIV stage, with 32.5% (n=425) of pediatric records missing this indicator compared to 11.1% (n=3355) of adult records (*P*<.001).

Table . Interruption in treatment (IIT) status and indicator missingness.

Characteristics		Patients		*P* value[a]
		Overall (N=31,457), n (%)	Pediatric (n=1306), n (%)	
IIT status				
	6 months	7477 (23.8)	431 (33.0)	<.001
	12 months	9222 (29.3)	551 (42.2)	<.001
Indicator missingness				
	Weight	5365 (17.1)	265 (20.3)	.001
	WHO[b] HIV stage	3780 (12.0)	425 (32.5)	<.001
	TB[c] diagnosis	1417 (4.5)	79 (6.0)	.006
Composite missingness score (number of indicators missing)				
	0	23,064 (73.3)	725 (55.5)	<.001
	1	6666 (21.2)	434 (33.2)	<.001
	2	1285 (4.1)	106 (8.1)	<.001
	3	442 (1.4)	41 (3.1)	<.001

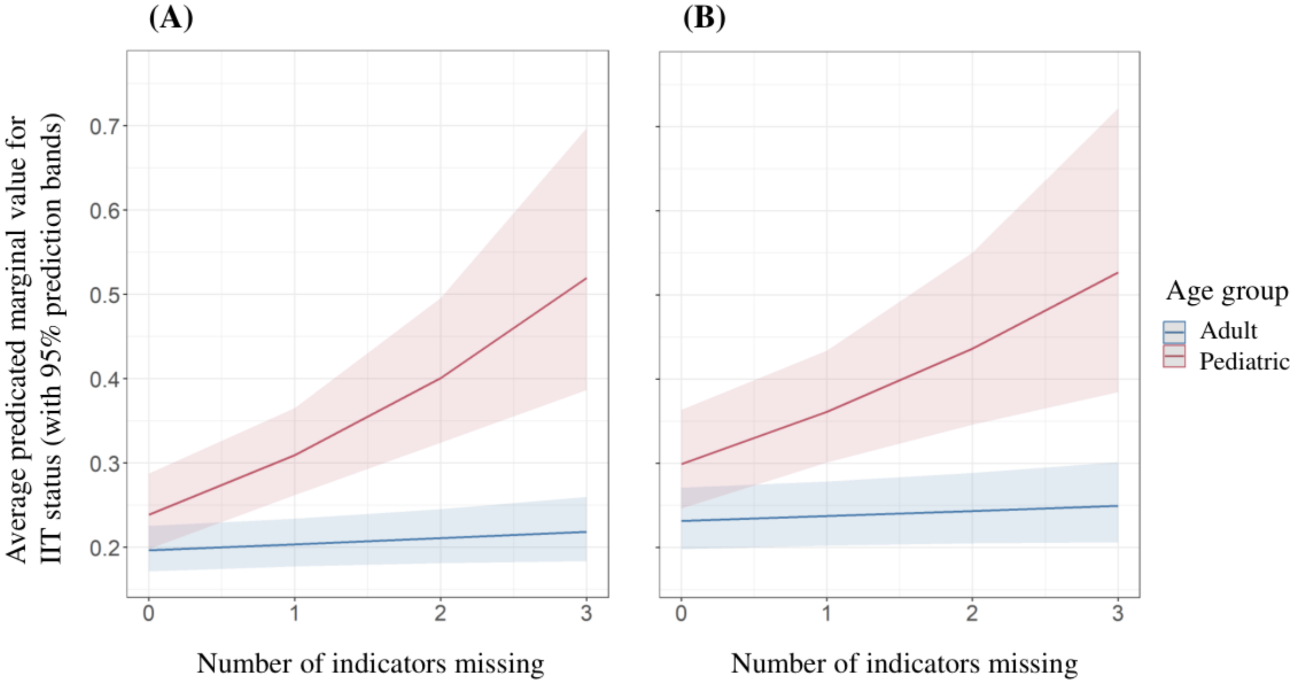
[a] Pearson χ^2 test.

[b] WHO: World Health Organization.

[c] TB: tuberculosis.

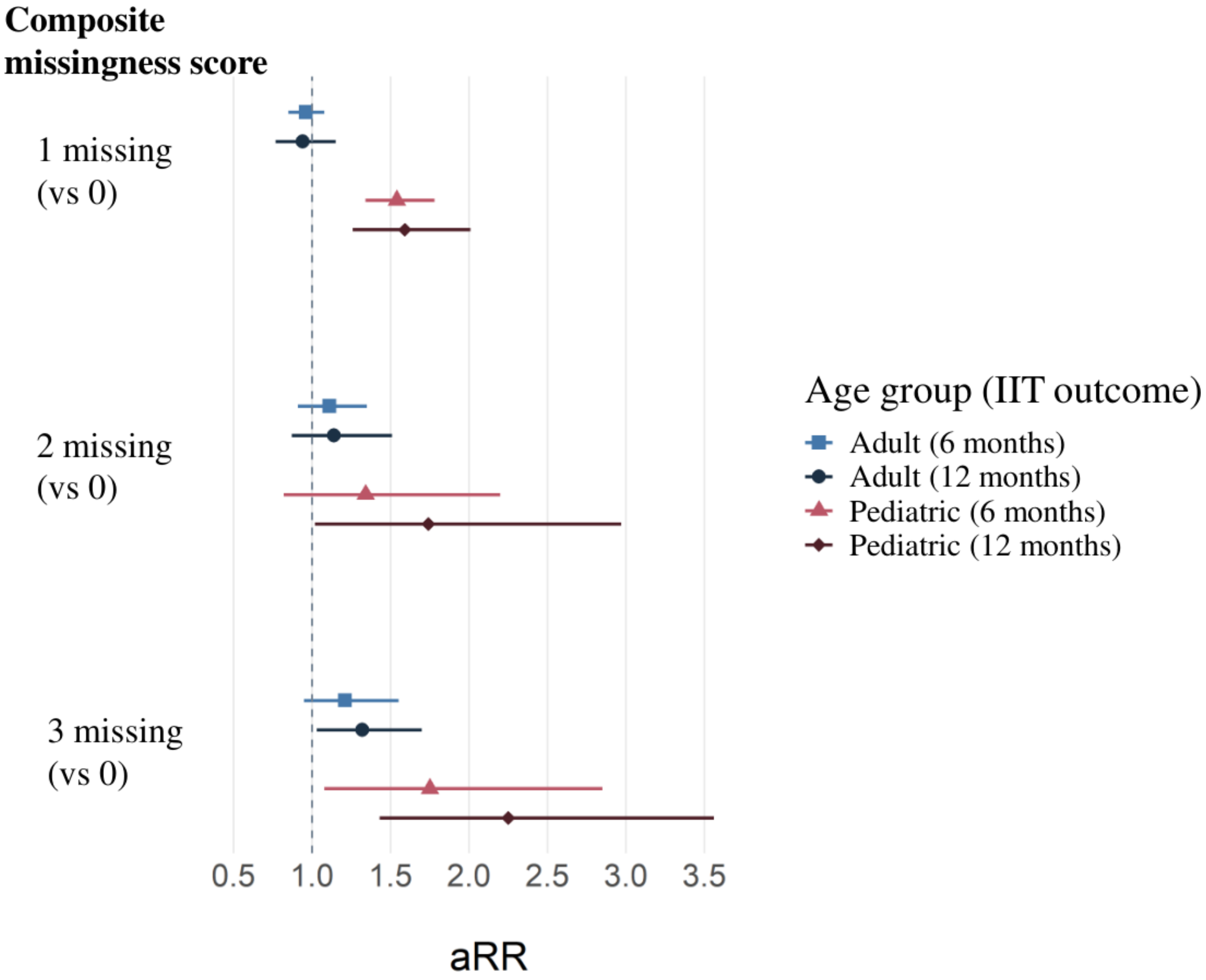
Results from models exploring the association between IIT status and the composite missingness score as a continuous variable are shown in Figure 2 (full multivariable regression results can be found in Multimedia Appendix 2). Statistically significant associations were observed between higher values of the composite missingness score and a greater likelihood of experiencing IIT at both 6 and 12 months among pediatric patients. However, no such association was observed among adult patients for either outcome. Among pediatric patients, each additional indicator missing was associated with a 1.34 times greater likelihood of experiencing IIT at 6 months post ART initiation (95% CI 1.08-1.66; *P*=.008) and 1.24 times greater likelihood of experiencing IIT at 12 months (95% CI 1.05-1.46; *P*=.01). Our interaction models (not shown) revealed that the relationship between the composite score indicator and IIT status was statistically significantly larger among pediatric patients compared to adult patients at both 6 months, where pediatric patients had a 25% greater risk of experiencing IIT for each additional missing element compared to adult patients (95% CI 1.02-1.53; *P*=.03), and 12 months, where pediatric patients had an 18% greater risk of experiencing IIT for each additional missing element compared to adult patients (95% CI 1.01-1.38; *P*=.04).

Figure 2. Multivariable regression of interruption in treatment (IIT) status at (A) 6 months post antiretroviral therapy (ART) initiation and (B) 12 months post ART initiation against composite missingness score (continuous), stratified by age group.



We also assessed the composite missingness score as a categorical variable (Figure 3) to understand the estimates of excess risk in the absence of the assumption of a linear relationship between missingness and IIT status (full multivariable regression results can be found in Multimedia Appendix 2). Compared to pediatric patients with 0 missing indicators, pediatric patients with 1, 2, or 3 missing indicators were 1.59 (95% CI 1.26-2.01; *P*<.001), 1.74 (95% CI 1.02-2.97; *P*=.04), and 2.25 (95% CI 1.43-3.56*; P*=.001) times more likely to experience IIT at 6 months, respectively. At 12 months, pediatric patients with 1, 2, or 3 missing indicators were 1.54 (95% CI 1.34-1.78; *P*<.001), 1.34 (95% CI 0.82-2.20; *P*=.24), and 1.75 (95% CI 1.08-2.85; *P*=.02) times more likely to experience IIT, respectively, although this association was no longer significant for those with 2 indicators missing. Among adult patients, compared to patients with 0 indicators missing, having all 3 indicators missing was associated with being 1.32 times more likely to experience IIT at 6 months (95% CI 1.03-1.70; *P*=.03), while having 3 indicators missing was not associated with IIT at 12 months, and having 1 or 2 indicators missing was not associated with IIT at either 6 or 12 months.

Figure 3. Multivariable regression of interruption in treatment (IIT) status at 6 and 12 months post antiretroviral therapy initiation against composite missingness score (categorical), stratified by age group. aRR: adjusted risk ratio.



For the individual missingness indicators (Multimedia Appendix 2), only the WHO HIV stage indicator was associated with IIT status among pediatric patients, where pediatric patients with missing WHO HIV stage data on their intake form were 2.17 times more likely to experience IIT at 6 months (95% CI 1.79-2.64; *P*<.001) and 1.79 times more likely to experience IIT at 12 months (95% CI 1.54-2.08; *P*<.001), as compared to pediatric patients with nonmissing WHO HIV stage data. Missingness for the WHO stage data among adult patients and missingness for weight and TB status among either age group were not associated with IIT status at either 6 or 12 months.

Sensitivity Analyses

We hypothesized that providers at facilities with a lower proportion of pediatric patients may be less familiar with pediatric care, and therefore, less compliant with treatment and reporting guidelines, which could potentially impact the relationship between data missingness and IIT. However, neither missingness nor IIT status showed a significant association with the proportion of pediatric patients at a given facility, and an interaction model did not show any difference in the relationship between data missingness and IIT status by the proportion of pediatric patients (data are not shown). We additionally explored a more granular definition for age groups 0-9, 10-14, 15-19, 20-24, and >25 years. In age group–stratified models, the association between the continuous composite data missingness score and IIT status at 6 months was only statistically significant for the 0-9 age group, which showed a positive association between greater missingness and likelihood of experiencing IIT (data are not shown).

Discussion

Principal Findings

In this retrospective longitudinal study of patient record data drawn from the iSanté EMR system in Haiti, we found that both data missingness and interruption in ART treatment were higher for pediatric patients compared to adult patients; nearly one-third of pediatric patients had IIT at 6 months compared to just over one-fifth of adults, and nearly half of pediatric patients had missing values for indicators of interest on their intake forms compared to just over one-quarter of adult patients. Data missingness showed a substantial and significant association with greater IIT, with adult patients being 30% more likely and pediatric patients more than twice as likely to have IIT at 6 months when all 3 indicators of interest were missing. The relationship between missingness and IIT status was stronger and more consistent among pediatric patients; pediatric patients showed statistically significantly greater likelihood of experiencing IIT at 6 and 12 months for the composite score indicator both overall (continuous) and across all levels of missingness (categorical), while for adult patients this relationship was only significant at 6 months and for the highest level of missingness in the categorical analysis. Individual indicator missingness showed little association with IIT status, except for the WHO HIV stage among pediatric patients. Within the modified Donabedian quality of care framework, our results show a link between the process of care provision (vis-à-vis compliance with reporting guidelines and data use for clinical decision-making) and patient outcomes (IIT status) after adjusting for structural elements (ie, facility characteristics), with the association being highly dependent on medical care antecedents (ie, patient age group) [21,22].

There is a rich evidence base showing the potential impact of EMR use on HIV service provision and quality of care by promoting adherence to care guidelines, enabling higher quality patient data, improving provider efficiency, and informing patient care, tracking, and follow-up [5-13]. The benefits of EMRs, however, are largely predicated on providers having access to quality data (ie, reliable, timely, and nonmissing) to inform their work, and there is a growing evidence base on the importance and impact of patient record quality (electronic or otherwise) on quality of care, care engagement, or health outcomes [14-16,29,30]. Particularly relevant to this analysis, one study of more than 6000 patient records collected from the National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis found that missing baseline patient data was significantly associated with the odds of timely initiation of treatment being halved [29]. In a qualitative study of health care professionals in South Africa, participants reported viewing data quality as an critical element in the provision of quality health care services, including how poor EMR information integrity can lead “to errors that endanger patient safety or decrease the quality of care” [45]. A systematic review found that data missingness was a commonly cited barrier to the use of EMRs to inform population health efforts [12]. In another systematic review, Albagmi [11] found that EMRs were associated with both better documentation and higher quality of care, although a direct causal relationship between data quality and quality of care was not directly assessed. This limitation is common to much of the literature on EMR data quality; many studies of EMR implementation include both data quality and quality of care indicators as outcomes or indicators of interest, but few directly assess the relationship between data quality and quality of care or patient outcomes. Our results, therefore, contribute to this limited evidence base, providing evidence that EMR data quality is associated with interruption in ART treatment.

Although we have established a temporal sequence for the relationship between data quality and IIT status, the absence of measurements for other elements of quality of care makes it impossible to discern whether the observed association was due to poor data quality itself or data quality as a proxy for broader quality of care. Data quality could be a marker of lower provider competence, poorer supplies and infrastructure at the health facility, higher provider-patient ratio, lower contact time between providers and patients, or other phenomena associated with IIT status. Further research is necessary to understand the role data missingness plays in care provision.

Our finding that overall missingness was higher among pediatric patients and that the association between missingness and IIT status was stronger among pediatric patients supports our hypothesis that there may be differential quality of care among pediatric patients leading to poorer retention in care. Pediatric populations living with HIV have unique care needs, and poorer engagement for pediatric patients across the HIV care cascade is a multifaceted issue, involving behavioral, psychosocial, pharmacokinetic, and structural factors [17,46]. The literature has identified a number of key barriers to pediatric ART adherence, including stigma among caregivers to seek or continue care for children; lack of education or training for caregivers on caring for a child living with HIV; complexities inherent to a patient-caregiver-provider relationship; limited patient agency due to age and patient-caregiver power structures; patient-led treatment refusal, sometimes due to a lack of palatable formulations for younger patients; and lack of providers trained in pediatric HIV care or family-based service delivery [17,47,48]. Relevant to this analysis, prior research has shown direct links between quality of care, care engagement, and patient outcomes for this population. In their analysis of children living with HIV in Nigeria, Ojikutu et al [37] found that higher quality care—measured as a composite score exploring TB screening, adherence measurement and counseling, CD4 and weight documentation, and medication prescription—was significantly associated with a lower likelihood of pediatric and adolescent patients being lost to follow-up and mortality. Improving the quality of care for children living with HIV, including better patient record quality, is necessary to address the gaps in HIV testing and treatment among children living with HIV.

Limitations

At present, it is not possible to track patients between facilities within our analysis data. As such, it is not possible to distinguish patients who transferred to a new facility but remained on ART and those who interrupted or fully discontinued treatment. As a result, our ART retention outcome was defined as an IIT at a patient’s current facility rather than interruption overall. This outcome still fits within our causal model, with lower quality of care being feasibly associated with either an actual IIT or transfer to another facility for higher quality care, and it still represents a meaningful proxy indicator for clinical outcomes, as facility transfer may be associated with ART treatment gaps or discontinuation. Patient transfers are also not a limitation specific to this study; a systematic review of ART retention studies found that nearly 20% of patients classified as lost to follow-up had actually self-transferred to another facility [49].

Additionally, our results may be confounded if the missingness of the indicators is associated with the values of that indicator as well as our outcome. For example, if a higher WHO HIV stage is associated with both a greater likelihood of being missing and a greater likelihood of IIT, the observed association may be due to the latent WHO HIV stage rather than the data missingness. Of note, although integrated with iSanté, pharmacy data used to calculate the IIT outcome variables are collected through different mechanisms and staff. This includes greater data quality oversight, in part due to their inclusion in routine President's Emergency Plan for AIDS Relief (PEPFAR) monitoring, evaluation, and reporting. Therefore, we do not anticipate that misclassification of the IIT outcome due to missing pharmacy data will be highly correlated with our exposure (missingness among indicators of interest), and thus, it will not present a substantial risk of bias. Finally, we were not able to assess associations with clinical outcomes (eg, viral suppression) due to data availability limitations.

Strengths

This was an observational study, and therefore, it could not assess a causal relationship between data missingness and IIT; however, our hypothesis is strengthened by the robust sample size and analytical design; strong association observed between missingness and IIT status; a dose-response relationship wherein greater missingness was associated with greater likelihood of a patient having IIT; and established temporal sequence, as the intake data are completed prior to ART initiation and the IIT outcomes.

Conclusions

Our analysis showed that both patient record data missingness for key indicators and interruption in ART treatment were common among patients, with nearly one-quarter of patients having IIT at 6 months and more than one-quarter of patients missing at least 1 indicator of interest in their patient record. Both IIT status and data missingness were more common among pediatric patients. Greater data missingness was associated with a higher likelihood of being IIT at 6 and 12 months for both pediatric and adult patients, although the association was stronger and more consistent among pediatric patients. Our findings motivate further research into the mechanisms by which EMR data quality impacts the quality of care and patient outcomes, particularly among children living with HIV. Additionally, efforts to improve both EMR data quality and quality of care should consider prioritizing pediatric patients.

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Authors' Contributions

All authors have participated sufficiently in the work to take responsibility for the content, including participation in the conception or design of the work, or the acquisition, analysis or interpretation of data and drafting the work. AMS led on analysis design, conducted the analyses, developed the structure of the manuscript, and wrote the first draft. KC, MJ, and JGH facilitated data access and provided subject matter expertise and content review. ADW, JP, KBS, and NP provided technical review and contributed to analytic methods. NP provided project oversight. All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
The CONSORT (Consolidated Standards of Reporting Trials) flow diagram.
[DOCX File, 123 KB - pediatrics_v7i1e51574_app1.docx]

Multimedia Appendix 2
Multivariable regression tables.
[DOCX File, 65 KB - pediatrics_v7i1e51574_app2.docx]

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Abbreviations

ART: antiretroviral therapy
CONSORT: Consolidated Standards of Reporting Trials
EMR: electronic medical record
IIT: interruption in treatment
PEPFAR: President’s Emergency Plan for AIDS Relief
TB: tuberculosis
WHO: World Health Organization

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Original Paper

Rates of Trauma Exposure and Posttraumatic Stress in a Pediatric Digital Mental Health Intervention: Retrospective Analysis of Associations With Anxiety and Depressive Symptom Improvement Over Time

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Abstract

Background: More than 2 out of 3 children and adolescents in the United States experience trauma by the age of 16 years. Exposure to trauma in early life is linked to a range of negative mental health outcomes throughout the lifespan, particularly co-occurring symptoms of posttraumatic stress (PTS), anxiety, and depression. There has been an increasing uptake of digital mental health interventions (DMHIs) among youths, particularly for anxiety and depression. However, little is known regarding the incidence of trauma exposure and PTS symptoms among youths participating in DMHIs and whether PTS symptoms impact anxiety and depressive symptom treatment response. Moreover, it is unclear whether participation in a DMHI for anxiety and depressive symptoms is associated with secondary effects on PTS symptoms among trauma-exposed youths.

Objective: This study aims to use retrospective data from youths participating in a DMHI to (1) characterize rates of trauma, PTS, and comorbid anxiety and depressive symptoms; (2) determine whether trauma exposure and elevated PTS symptoms impact the improvement of comorbid anxiety and depressive symptoms throughout participation in care; and (3) determine whether participation in a non–posttraumatic DMHI is linked to reductions in PTS symptoms.

Methods: This study was conducted using retrospective data from members (children ages 6 to 12 years) involved in a pediatric collaborative care DMHI. Participating caregivers reported their children's trauma exposure. PTS, anxiety, and depressive symptom severity were measured monthly using validated assessments.

Results: Among eligible participants (n=966), 30.2% (n=292) reported at least 1 traumatic event. Of those with trauma exposure and elevated symptoms of PTS (n=119), 73% (n=87) exhibited elevated anxiety symptoms and 50% (n=59) exhibited elevated depressive symptoms. Compared to children with no trauma, children with elevated PTS symptoms showed smaller reductions per month in anxiety but not depressive symptoms (anxiety: $F_{2,287}=26.11$; $P<.001$). PTS symptoms also decreased significantly throughout care, with 96% (n=79) of participants showing symptom reductions.

Conclusions: This study provides preliminary evidence for the frequency of trauma exposure and comorbid psychiatric symptoms, as well as variations in treatment response between trauma-exposed and nontrauma-exposed youths, among participants in a pediatric collaborative care DMHI. Youths with traumatic experiences may show increased psychiatric comorbidities and slower treatment responses than their peers with no history of trauma. These findings deliver compelling evidence that collaborative care DMHIs may be well-suited to address mental health symptoms in children with a history of trauma while also highlighting the critical need to assess symptoms of PTS in children seeking treatment.

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KEYWORDS

collaborative care model; telehealth; childhood trauma; DMHI; digital health; mental health; telemedicine; trauma; traumatic; pediatric; pediatrics; paediatric; paediatrics; child; children; youth; adolescent; adolescents; teen; teens; teenager; teenagers; retrospective; anxiety; depression; depressive; co-occurring; comorbid; comorbidity; comorbidities; association; associations; correlation; correlations; correlate

Introduction

More than two-thirds of children have experienced trauma, such as abuse, neglect, natural disasters, and sudden loss of a loved one, by the age of 16 years [1,2]. These rates have been exacerbated by the recent COVID-19 pandemic and associated lockdowns, which appear to have caused a significant increase in child maltreatment globally [3-6]. During the first year of the pandemic, more than 11% of US adolescents reported physical abuse and 55% reported emotional abuse—2- and 3-fold increases compared to prepandemic rates [7,8]. The far-reaching and pervasive effects of childhood trauma are well documented. Those who experience trauma, particularly in childhood and adolescence [9], are at increased risk for a number of maladaptive mental and physical health outcomes throughout the lifespan [10,11] including posttraumatic stress disorder (PTSD). PTSD and symptoms of posttraumatic stress (PTS) develop as a result of a traumatic event and include reexperiencing (eg, flashbacks or memories of the event), avoidance of reminders and feelings related to the event, and elevated arousal and alterations in cognition and mood (eg, negative emotions and feelings, blame, and isolation [12]). Recent estimates suggest that 16% of children and adolescents who experience trauma go on to develop PTSD, although symptom severity is often dependent on age and gender, as well as type, duration, and severity of the trauma experienced [13]. Those with trauma are not only at risk for developing PTSD but also a number of mental health difficulties, particularly anxiety and depression [14]. Indeed, PTS, depression, and anxiety share common symptoms, etiologies, and effective treatment modalities such as cognitive behavioral therapy (CBT) [15,16].

Youths with traumatic experiences are significantly more likely to receive mental health care from a variety of sources, including primary care physicians, therapists, psychiatrists, school counselors, and social workers [17]. With shortages of in-person mental health providers and rates of pediatric mental health disorders increasing, traditional modalities of mental health care are becoming steadily more overburdened, expensive, and inaccessible. These issues of accessibility paired with the lockdowns of the COVID-19 pandemic catalyzed widespread uptake of digital mental health interventions (DMHIs) or those facilitated by technologies such as computers and smartphones. Although a number of DMHIs are available for the treatment of pediatric PTSD [18], these interventions and associated research are limited in significant ways. First, no research has been done to characterize the rates of trauma among youths participating in DMHIs for comorbid symptoms such as anxiety and depression, which are some of the most prevalent mental health disorders among youths. Indeed, most youths who receive mental health services do so for anxiety and depressive symptoms [19-21]. Given the etiological overlap among PTS, depression, and anxiety, there is a high likelihood that many youths with PTS symptoms would experience secondary benefits when receiving mental health care for anxiety and depression. Second, there is little understanding of how traumatic experiences and PTS symptoms impact the treatment response of anxiety and depressive symptoms for youths participating in a DMHI. By exploring these 2 lines of research, pediatric DMHIs will be better equipped to adapt their care programs and modalities to the needs of users with traumatic experiences and posttraumatic symptoms.

The collaborative care model (CoCM), in which primary care providers partner with behavioral care managers (BCMs) and psychiatrists to coordinate patient-centered and measurement-based care, is widely considered the best practice for pediatric mental health care [22]. Researchers have argued that the CoCM, with its use of regular symptom measurement and individualized care, confers better outcomes, particularly for those with trauma who are exhibiting complex and comorbid symptoms of PTS, depression, and anxiety [23,24]. Early evidence indicates that DMHIs using the CoCM are associated with improvements in pediatric mental health problems, including anxiety and depression [10,25,26]. However, no research has been done to understand the use and effectiveness of collaborative care DMHIs for anxiety and depression among trauma-exposed youths.

Therefore, the purpose of this study was to use retrospective data from youths participating in a collaborative care DMHI to (1) characterize rates of trauma, PTS, and comorbid anxiety and depressive symptoms; (2) determine whether trauma exposure and elevated PTS symptoms impact improvement of comorbid anxiety and depressive symptoms throughout participation in care; and (3) determine whether participation in a non–posttraumatic DMHI is linked to reductions in PTS symptoms.

Methods

Participants

Bend Health Inc members aged 6 to 12 years (at baseline, before care started) were eligible for inclusion in the study if they (1) had their first coaching or therapy session with Bend between January 1, 2023, and October 1, 2023 (9 months), and (2) completed the trauma assessment before beginning care (N=979). To more specifically assess symptom outcomes for members receiving care for mental health symptoms other than PTS, members who participated in the trauma care program were excluded from all analyses (n=13, 1.3%). Thus, the final sample included 966 members.

Ethical Considerations

Study procedures were approved by the Biomedical Research Alliance of New York (Study 23-12-034-1374). All participants provided informed consent to their data being used for research purposes upon enrollment, and all data were anonymized and deidentified prior to analysis. Bend Health Inc members were not compensated for their participation in this retrospective research.

Treatment

Treatment with Bend Health Inc has been described previously [25]. Bend Health Inc is a DMHI for youths that uses the CoCM to implement a whole-family approach, involving caregivers in treatment. Each member is assigned a behavioral care manager (BCM) who oversees and manages the child's individual treatment plan and works with primary care providers, psychiatrists, therapists, and coaches to determine the correct treatment plan for each member. The member then meets regularly with either a licensed therapist or a coach, depending on the type and severity of mental health symptoms the member is experiencing. To specifically target a particular symptom domain (eg, anxiety symptoms), children are assigned a care program (by their BCM) based on their symptom severity and care goals. All care programs are designed to be developmentally appropriate for the age of the member, and the primary care programs (eg, anxiety, depression, and attention-deficit/hyperactivity disorder [ADHD]) are intended to take approximately 12 weeks to complete. During sessions, coaches and therapists provide behavioral care that is informed by the components of the care program. The informational contents of all care programs are also available in a digital platform for members and their caregivers to access between sessions (asynchronously). Once a month, caregivers are asked to complete questionnaires regarding their child's symptoms, including PTS, anxiety, and depressive symptoms.

Therapy at Bend Health Inc provides diagnostic clarity, addresses complicated history of trauma and problematic behaviors, and provides clinical treatment for mental health disorders. Coaching provides behavior change tools and improvements in self-efficacy using evidence-based best practices. When appropriate, members' care can escalate to include both coaching and therapy for the treatment of more severe symptoms. Both coaching and therapy at Bend Health Inc are based on CBT, behavioral activation, motivational interviewing, caregiver training, and mindfulness-based practices. Depending on symptom needs and care plan, members may also meet with a psychiatrist at enrollment and throughout care for additional symptoms and medication management.

Assessments

At enrollment into care with Bend Health Inc, caregivers are asked to report their child's demographic information, including date of birth, sex, gender, and race or ethnicity. The response options for sex are "male," "female," and "other." The response options for gender are "male," "female," "transgender," "nonbinary," and "other." From January 1, 2023, to May 26, 2023, only 1 race or ethnicity response could be selected, and the options were "White," "Black or African American," "American Indian or Alaska Native," "Asian," "Hispanic or Latino," and "Other." From May 26, 2023, to October 1, 2023, multiple race or ethnicity responses could be selected, and the options were "White," "Black or African American," "American Indian or Alaska Native," "Chinese," "Vietnamese," "Native Hawaiian," "Filipino," "Korean," "Japanese," "Chamorro," "Other Asian," "Other Pacific Islander," "Some other race or multi-racial," "Mexican," "Mexican American," "Chicano," "Puerto Rican," "Cuban," and "Another Hispanic, Latino, or Spanish origin."

To assess children's mental health symptoms during the enrollment process, caregivers first respond to screener questions. When elevated symptoms are flagged by the responses to the screeners, caregivers are then prompted to complete fully validated assessments. To screen for PTS, caregivers are asked the question: "Has your child ever experienced a traumatic event?" If the response to this question is "Yes," caregivers are then asked to report the nature and timing of the child's most distressing event, and they also complete the entire Child PTSD Symptom Scale (for the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; CPSS-V) validated questionnaire [27]. To assess the nature of the traumatic event, caregivers are asked to describe their child's most distressing event in a free textbox. To assess the timing of the traumatic event, caregivers are asked "How long has it been since that event occurred?" with the following response options: "1-30 days," "1-3 months," "3-6 months," "6-12 months," "1-2 years," "2-4 years," and "4+ years." The CPSS-V consists of 20 items, in which caregivers are asked to report how often their child exhibits behaviors consistent with PTS, such as "trying not to think about it [the distressing event] or have feelings about it" and "trouble having good feelings." Responses to these items are made on a 5-item Likert-type scale, with responses ranging from "not at all" (score=0) to "6 or more times a week/almost always" (score=4).

Screener questions for anxiety and depressive symptoms are taken from the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) cross-cutting measure, which asks caregivers to report the frequency (in the last 2 weeks) that their child exhibits behaviors associated with anxiety and depression [28]. There are 3 anxiety symptom screener questions and 2 depressive symptom screener questions. Responses to the anxiety and depressive symptom screeners are made on a 5-item Likert-type scale with responses ranging from "not at all" (score=0) to "nearly every day" (score=4). If a caregiver responds to any anxiety or depressive screener question with "several days" (score=2) or more frequently, they are prompted to complete the PROMIS (Patient-Reported Outcomes Measurement Information System) anxiety assessment or PROMIS depressive assessment, respectively [29]. The PROMIS anxiety assessment includes 10 questions about common anxiety symptoms (eg, feeling worried). The PROMIS depression assessment includes 11 questions about common depressive symptoms (eg, feeling lonely). For both PROMIS assessments, caregivers report the frequency of their child's behaviors or feelings in the last 7 days, with responses on a 5-item Likert-type scale ranging from "never" (score=1) to "almost always" (score=5). Caregivers were prompted to complete mental health symptom screeners and assessments within the web-based portal every month after enrollment to track mental health symptom severity throughout care.

Statistical Methods

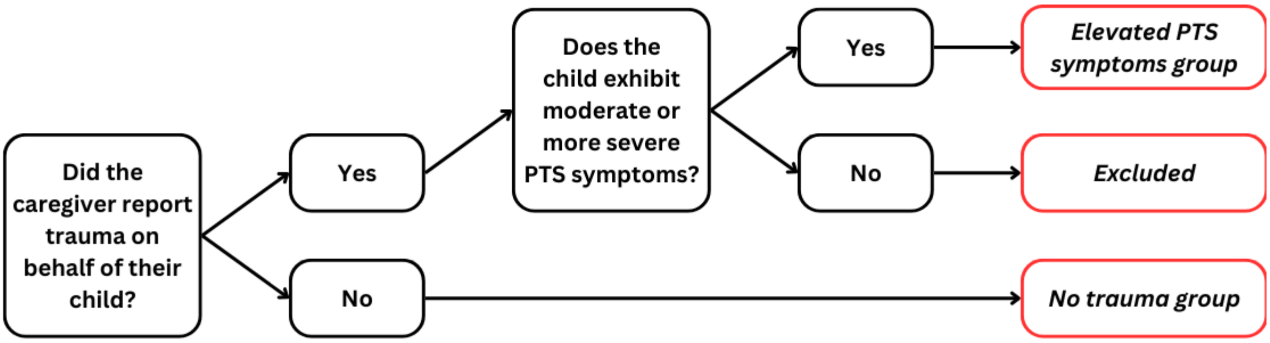
Responses to all items from the CPSS-V were aggregated for a total PTS score of 0 to 80. Using standardized criteria, PTS symptom severity was determined based on CPSS-V scoring norms [27], which are as follows: minimal (scores: 0 to 10), mild (score: 11 to 20), moderate (score: 21 to 40), severe (score: 41 to 60), and very severe (score: 61 to 80). Responses to the items from the anxiety and depression PROMIS assessments were aggregated for a total anxiety score of 10 to 50 and a total depressive symptom score of 11 to 55, respectively. Then, total PROMIS scores were converted to t-scores using standardized criteria [30]. Anxiety and depressive symptom severity were then determined based on t-scores as follows: none to slight (t-score <55), mild (t-score 55-59.9), moderate (t-score 60-69.9), and severe (t-score ≥70). For PTS, anxiety, and depressive symptoms, symptom severity of moderate, severe, or very severe was considered "elevated."

Standard descriptive statistics—including percent, mean (SD), and median (IQR)—are used throughout the "Results" section, as appropriate. For all analyses (outlined in detail below), between-group comparisons for categorical variables were performed using chi-square tests, and comparisons for continuous variables were performed using 2-tailed Wilcoxon signed rank tests or 2-tailed *t* tests, as appropriate based on data distribution (determined by Shapiro-Wilk test). Where between-group comparisons could not be performed given a small representation within a category of interest, only the descriptive statistics are reported.

PTS Symptoms

For all members included in the study (n=966), the rates of reported trauma at baseline (last assessment before care started) were described. For members that had a traumatic event, CPSS-V scores, PTS symptom severity, and the timing of the traumatic event were reported. Members with no traumatic event were included in the no trauma group. Members with both a traumatic event and CPSS-V scores indicating moderate or greater PTS symptoms were included in the elevated PTS symptoms group. Members with a traumatic event and nonelevated PTS symptoms were not included in the primary analyses, and thus all further analyses were applied only to members in the "no trauma" and "elevated PTS symptoms" groups (Figure 1).

Figure 1. Flowchart delineating study group formation and exclusion criteria. PTS: posttraumatic stress.



Member Characteristics and Care Use

Member characteristics and care use patterns were reported for each group. The following member characteristics were assessed: age in years (at baseline), sex (male, female, and nonbinary), gender conforming (conforming and nonconforming), ethnicity (Asian, Black or African American, Hispanic/Latino, White, and Other), and mental health diagnoses by type (anxiety disorder, depressive disorder, and ADHD). Date of birth was used to calculate age in years (at enrollment). If a member's sex at birth and gender identity (reported at enrollment) were not identical, they were classified as gender nonconforming. Otherwise, members were classified as gender conforming. Details on the reporting of race or ethnicity are included in the Multimedia Appendix 1. Rates of elevated mental health symptoms at baseline (moderate or greater severity) were also assessed for anxiety and depressive symptoms. For care use patterns, the duration of care (months between the first session and the last session) and participation in coaching and therapy were reported only for members with at least 1 coaching or therapy session (106 excluded). Between-group comparisons were performed for the following variables of interest: age, female sex (yes or no), gender conformity (conforming or nonconforming), ethnicity (White or non-White), elevated mental health symptom (elevated or nonelevated; all types), months in care, and participation in therapy (yes or no).

Mental Health Symptom Reduction

PTS symptom reduction was assessed for members in the "elevated PTS symptoms" group. Rates of members with symptom reduction were assessed for those with at least 1 coaching or therapy session, and who completed at least one symptom assessment after starting care (37 excluded). Symptom reduction was considered a decrease in score from baseline or screening out of the last assessment. Then, the amount of total change over the duration of care was assessed by delta CPSS-V score from baseline to the last *full* CPSS-V assessment (no screened-out assessments), and delta scores were compared to 0 using a Wilcoxon signed rank test to assess for a significant change in score. This analysis was performed on data from members with at least 1 coaching or therapy session, and at least 1 full symptom assessment after starting care (54 excluded). To determine whether PTS symptoms decreased over months in care, CPSS-V scores were assessed over months in care by a linear mixed effects model with a fixed effect of months in care and a random effect of member ID on the intercept. Potential covariates were added to this basic model, and if a potential covariate improved model fit (based on the likelihood ratio test [LRT]), it was included in the final model. Models with the addition of the following covariates were tested against the basic model: age (at baseline), sex (female vs nonfemale), and race or ethnicity (White vs non-White).

Anxiety and depressive symptoms were assessed over time in care and compared between groups. First, the rates of members with symptom reduction were assessed for members with elevated mental health symptoms at baseline, at least 1 coaching or therapy session, and at least 1 symptom assessment after starting care (anxiety symptoms: 576 excluded; depressive symptoms: 658 excluded). Symptom reduction was considered a decrease in t-score from baseline or screening-out of the last assessment. The rates of members with symptom reduction were compared between groups using chi-square tests. These analyses were performed on data from members with elevated mental health symptoms at baseline, at least 1 coaching or therapy session, and at least one full symptom assessment after starting care (anxiety symptoms: 626 excluded; depressive symptoms: 712 excluded). Then, the total change in t-score (delta t-score) from baseline to the last full assessment was compared between groups using a 2-tailed *t* test or Wilcoxon signed rank test, as determined based on sample distribution. Finally, the rate of anxiety and depressive symptom reduction was compared between groups using linear mixed effects analyses with a fixed effect of group, the interaction of the group with months (in care), and a random effect of the subject on the intercept.

For all linear mixed effects analyses, to ensure that the findings were not skewed by baseline assessments occurring very early before the start of care, members whose baseline assessment occurred greater than 1 month before the first coaching or therapy session were excluded (PTS symptoms: additional 6 excluded; anxiety symptoms: additional 10 excluded; depressive symptoms: additional 4 excluded). A single additional member (n=1) was excluded from the depressive symptom linear mixed effects analysis due to an outlier t-score. For between-group analyses of rates of symptom reduction and total change, we confirmed that each group took their last and *full* last assessments at approximately the same time in care by between-group Wilcoxon signed rank comparisons of assessment timing for each symptom domain.

Results

PTS Symptoms

Of the 966 members included in the study, 30.2% (n=292) had experienced a traumatic event and the remaining 69.8% (n=674) did not have a traumatic event. For members with a traumatic event, CPSS-V scores were a median of 18 (IQR 9-28), with scores ranging from 0 (minimal PTS symptom severity) to 61 (very severe PTS symptoms). Of members with a traumatic event, 86 (29.5%) had minimal symptoms, 87 (29.8%) had mild symptoms, 99 (33.9%) had moderate symptoms, 19 (6.5%) had severe symptoms, and 1 (0.3%) had very severe symptoms. As such, for members with a traumatic event, 59.2% (n=173) had nonelevated PTS symptoms and 40.8% (n=119) had elevated PTS symptoms.

While 63.7% (n=186) of all members with a traumatic event reported that the event occurred 1 or more years before baseline, the timing of the event varied (Table 1). Notably, the rate of children having experienced the event within the last 30 days was nearly twice as high for children with elevated PTS symptoms (n=14, 11.8%) versus nonelevated PTS symptoms (n=10, 5.8%). For all further analyses, 674 were included in the no trauma group (no trauma reported at baseline), 119 were included in the elevated PTS symptoms group (traumatic event and elevated PTS symptoms), and 173 were not included in further analyses (traumatic event and nonelevated PTS symptoms).

Table 1. Timing of trauma, respective to when it was reported at baseline, reported for members in the no trauma and elevated PTS symptoms groups.

Timing of trauma (prior to baseline)	Nonelevated PTS[a] symptoms, n (%)	Elevated PTS symptoms, n (%)
Total	173 (59.2)	119 (40.8)
1 to 30 days	10 (5.8)	14 (11.8)
1 to 3 months	14 (8.1)	11 (9.2)
3 to 6 months	15 (8.7)	10 (8.4)
6 to 12 months	19 (11)	13 (10.9)
1 to 2 years	34 (19.7)	23 (19.3)
2 to 4 years	38 (22)	23 (19.3)
4 or more years	43 (24.9)	25 (21)

[a] PTS: posttraumatic stress.

Member Characteristics

Children with elevated PTS symptoms were a median of 10 (IQR 9-11) years old, 56.3% (n=67) were female, and they were largely gender conforming (n=113, 95%; Table 2). In terms of their race or ethnicity, 44.5% (n=53) were “White” and 35.3% (n=42) were “Other” or multiracial. Compared to members with no trauma, members with elevated symptoms of PTS were older (z=–4.38; P<.001) and more predominantly female (χ^2_1=5.33; P=.02). Rates of elevated mental health symptoms at baseline were higher for children with elevated PTS symptoms compared to children with no trauma. Specifically, 72.6% (n=87) of children with elevated PTS symptoms had elevated anxiety symptoms compared to 33.9% (n=228) of children with no trauma (χ^2_1=63.55; *P*<.001). Approximately 1 in 2 children with elevated PTS symptoms also had elevated depressive symptoms (n=59, 49.6%) compared to 1 in 5 children with no trauma (n=135, 20%; χ^2_1=46.21; *P*<.001). Children with elevated symptoms of PTS had higher rates of participation in the anxiety care program (χ^2_1=7.75; *P*=.005) and depression care program (χ^2_1=3.79; *P*=.05; statistical trend) and lower rates of participation in the ADHD care program (χ^2_1=4.06; *P*=.04).

Table 2. Member characteristics reported for children in the no trauma and elevated PTS[a] symptom groups. Between-group comparisons were performed with chi-square tests unless otherwise specified.

Member characteristics	No trauma (n=674), n (%)	Elevated PTS symptoms (n=119), n (%)	Between-group comparisons	
			Chi-square (*df*=1)	*P* value
Age[b] (years), median (IQR)	9 (7-11)	10 (9-11)	–4.38[c]	<.001[d]
Sex			5.33	.02[d]
Female	299 (44.4)	67 (56.3)		
Male	372 (55.2)	51 (42.9)		
Other	3 (0.4)	1 (0.8)		
Gender conformity			0.21	.64
Conforming	629 (93.3)	113 (95)		
Nonconforming	45 (6.7)	6 (5)		
Ethnicity			0.00	>.99
Asian	38 (5.6)	4 (3.4)		
Black or African American	37 (5.5)	11 (9.2)		
Hispanic or Latino	28 (4.2)	9 (7.6)		
White	301 (44.7)	53 (44.5)		
Other or multiracial	270 (40.1)	42 (35.3)		
Elevated mental health symptom				
Anxiety	228 (33.9)	87 (72.6)	63.55	<.001[d]
Depressive	135 (20)	59 (49.6)	46.21	<.001[d]
Care program				
Anxiety	289 (42.9)	68 (57.1)	7.75	.005[d]
Depression	51 (7.6)	16 (13.4)	3.79	.05[e]
ADHD[f]	231 (34.3)	29 (24.4)	4.06	.04[d]
Behavior	86 (12.8)	13 (10.9)	0.17	.68

[a] PTS: posttraumatic stress.

[b] Between-group comparisons were performed with a 2-tailed Wilcoxon signed rank test.

[c] *z* value for Wilcox signed-rank tests.

[d] *P* values<.05.

[e] *P* values<.10.

[f] ADHD: attention-deficit/hyperactivity disorder.

For members in the no trauma group who began coaching or therapy, they were in care for a median of 3.03 (IQR 1.63-4.50) months; 98.8% (n=479) were in coaching and 23.7% (n=115) were in therapy. For members in the elevated PTS symptoms group that began coaching or therapy, they were in care for a median of 3.03 (IQR 1.89-4.67) months, and 100% (n=102) were in coaching and 25.5% (n=26) were in therapy. The duration of care did not differ between groups (*z*=–1.08; *P*=.28), and the rates of members in therapy also did not differ between groups (χ^2_1=1.27; *P*=.26).

Mental Health Symptom Reduction

The rates of reduction in anxiety and depressive symptoms from baseline to the last assessment did not differ between groups (anxiety: $\chi^2_1=1.33$; $P=.25$ and depressive: $\chi^2_1=0.28$; $P=.59$), with 84.3% (183/217) of all members exhibiting a reduction in anxiety symptom severity and 86.7% (117/135) of all members exhibiting a reduction in depressive symptom severity (Table 3). The amount of change (delta t-score) from baseline to the last *full* assessment also did not differ significantly between groups (anxiety: $z=–0.35$; $P=.73$ and depressive: $t_{51.23}=0.19$; $P=.85$). Specifically, for all children, anxiety t-scores decreased by a median of 5 points (IQR –9 to 0) and depression t-scores decreased by a mean of 3.77 (SD 7.54) points. The number of months between baseline and the last assessment and baseline and the last full assessment did not differ between groups for anxiety and depressive symptoms (all $P>.05$).

Table 3. Change in anxiety and depressive symptoms from baseline. Rates of members with a reduction in symptom severity from baseline to their last assessment and the change in t-score from baseline to the last full assessment are reported for each group.

Mental health symptom	No trauma	Elevated PTS[a] symptoms	Between-group comparisons[b]	
			Chi-square (*df*=1)	*P* value
Percent with reduction in symptom severity (baseline to last assessment)				
Anxiety, n/N (%)	130/158 (82.3)	53/59 (89.8)	1.33	.25
Depressive, n/N (%)	80/94 (85)	37/41 (90)	0.28	.59
Delta t-score (baseline to last *full* assessment)				
Anxiety[c]			–0.35[d]	.73
Median (IQR)	–5.0 (–9 to 0)	–5.0 (–8 to –2.5)		
Participants, n	116	51		
Depressive[e]			0.19[f]	.84
Mean (SD)	–3.65 (7.70)	–4.00 (7.35)		
Participants, n	55	26		

[a] PTS: posttraumatic stress.

[b] Between-group comparisons were performed with chi-square tests, unless otherwise specified.

[c] Between-group comparisons performed with a 2-tailed Wilcoxon signed rank test.

[d] *z* value for Wilcox signed rank test.

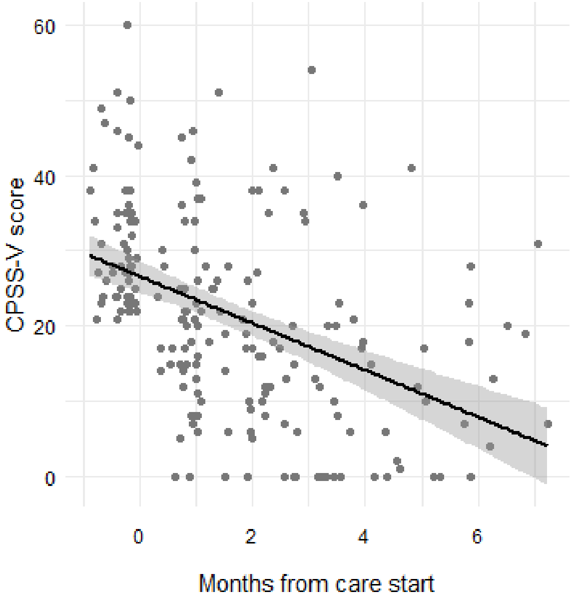
[e] Between-group comparison were performed with a 2-tailed *t* test.

[f] *t* value for *t* test.

In the linear mixed effects model of anxiety symptom severity, the main effect of the group was not statistically significant ($F_{1,155}=2.52$; $P=.11$), indicating that the no trauma and elevated PTS symptoms groups did not differ in anxiety symptom severity. The interaction of the group with months (from care start) was significant ($F_{2,287}=26.11$; $P<.001$), such that children with no trauma had larger anxiety symptom reduction per month (mean –1.23, SD 0.19) than children with elevated PTS symptoms (mean –1.12, SD 0.31). For depressive symptom severity, the main effect of the group was not statistically significant ($F_{1,74}=2.39$; $P=.13$). The interaction of the group with months approached significance ($F_{2,112}=2.86$; $P=.06$), as children with elevated PTS symptoms had slightly larger depressive symptom reduction per month (mean –0.65, SD 0.44) than children with no trauma (mean –0.64, SD 0.34).

For those with elevated PTS symptoms, 96.3% (79/82) exhibited PTS symptom reduction from baseline to the last assessment, with the last assessment having a median of 2.33 (IQR 1.04-3.89) months after the start of care. For members who took the *full* CPSS-V after beginning care (n=65; median 2 months, IQR 1.03-3.50 after the start of care), CPSS-V scores decreased significantly from baseline (median change score –13 points, IQR –19 to –6; $z=–6.35$; $P<.001$). Results from the linear mixed effects model of PTS symptoms, which included a fixed effect of age (LRT: $\chi^2_1=3.97$; $P=.046$) and female sex (LRT: $\chi^2_1=4.92$, $P=.03$), showed that CPSS-V scores decreased significantly over months in care ($F_{1,140}=67.11$; $P<.001$) by an estimated mean of 3.37 (SD 0.41) points per month (Figure 2). The main effects of age ($F_{1,54}=2.07$; $P=.16$) and female sex ($F_{1,54}=1.42$; $P=.24$) were not statistically significant.

Figure 2. CPSS-V score over months in care for members with elevated PTS symptoms. CPSS: Child PTSD Symptom Scale; PTS: posttraumatic stress.



Discussion

Principal Findings

The purpose of this study was to use retrospective data from youths participating in a collaborative care DMHI to (1) characterize rates of trauma, PTS, and comorbid anxiety and depressive symptoms; (2) determine whether trauma exposure and elevated PTS symptoms impact the improvement of comorbid anxiety and depressive symptoms throughout participation in care; and (3) determine whether participation in collaborative care DMHI is linked to reductions in PTS symptoms. We found that trauma, PTS, and psychiatric comorbidity are common among youths participating in a DMHI, and comorbid PTS is associated with variations in rates of improvement for anxiety and depressive symptoms. Moreover, participation in a collaborative care DMHI is linked to improvements in PTS symptoms for most participants. These findings offer valuable preliminary insights into the clinical characteristics and sequelae among trauma-exposed youths participating in a DMHI.

Nearly 1 in 3 members participating in care for depressive, anxiety, or ADHD symptoms had experienced trauma. Many trauma-exposed youths reported symptoms of elevated PTS (n=119, 41%), and children with a traumatic event and elevated PTS had higher rates of elevated anxiety (n=87, 73%) and depressive symptoms (n=59, 50%) than children with no trauma. These observed rates of PTS, which are higher than previous estimates among trauma-exposed youths [13], paired with the high—albeit expected [31]—co-occurrence of anxiety and depression, highlight an acute need for DMHIs to provide both PTS screening and evidence-based treatment for youths with complex trauma-related symptomatology [32]. A slight majority (n=67, 56%) of those with elevated PTS were female, suggesting a limited role of sex in this sample's PTS symptoms. Recent estimates suggest that more than twice as many women develop PTSD in adulthood as men [33], a discrepancy that remains largely consistent when controlling for trauma type [34]. However, these sex-based differences in PTSD prevalence may not arise until adolescence, during which pubertal changes catalyze developments in fear-related neurocognitive processing [35]. Incidence of sexual violence in adolescence may also contribute to sex-based differences in PTS: the majority of youths who experience sexual violence are between 12 and 17 years, and 82% of all sexual assault and abuse victims younger than 18 years are female [36]. Given the relatively young age of our sample, it is understandable that we did not identify such stark sex-based differences in PTS severity. Nevertheless, DMHIs should take into account sex-based differences in trauma and PTS risk factors when providing pediatric mental health care.

PTS symptom severity significantly impacted treatment response for anxiety. Youths with elevated PTS symptoms showed smaller reductions in anxiety symptoms compared to those without PTS symptoms. This is understandable, given the particularly close symptom overlap and etiology of PTS and anxiety [37,38]. Anxiety symptoms may be particularly related to PTSD in the form of anxiety sensitivity or the fear of anxiety-related sensations [39], with previous research suggesting that anxiety sensitivity is both retrospectively and prospectively related to PTSD severity [40,41]. PTS symptoms can also interfere with mental health treatment by exacerbating anxiety and other mental health symptoms, increasing feelings of overall distress, and decreasing receptivity to treatment [42,43]. It should be noted that youths with elevated PTS symptoms showed *larger* reductions in depressive symptoms; however, this effect was small and was not statistically significant. Given the small effect size paired with the limited sample, this finding requires additional study and replication before we interpret it further. In sum, these results suggest that among youths receiving digital mental health care for anxiety and depressive symptoms, screening for and consideration of PTS symptoms are crucial, as PTS may impact the timing and magnitude of treatment response. These findings also emphasize the importance of measurement-based care models such as the CoCM, that is, early and regular screening for PTS symptoms, which is a central aspect of the CoCM, is crucial to proactive treatment and long-term symptom improvement among trauma-exposed youths [32].

Although the intervention did not directly target PTS symptoms, most participants showed significant decreases in PTS symptoms throughout care. This finding likely points to the shared treatment targets (eg, emotion regulation [44]) and evidence-based methods (eg, CBT [15]) across PTS, anxiety, and depressive symptoms. Several DMHIs exist for the treatment of pediatric PTSD [18,45]; however, a recent review found that most are of poor quality and lack evidence- and measurement-based practice in the formation and implementation of the intervention [45]. As the usage of DMHIs for child mental health continues to increase, this study indicates that collaborative care DMHIs, which include high-quality evidence- and measurement-based care, are linked to secondary improvements in PTS symptoms via behavioral health care for depression, anxiety, and other mental health concerns (eg, ADHD). Taken together, these preliminary findings suggest that collaborative DMHIs may confer improvements in symptoms that are related to but outside the scope of treatment targets. Importantly, further experimental research is necessary to compare these effects with active and nonactive controls.

Limitations and Future Directions

Although illuminating, these findings are limited by several notable factors. First, the retrospective nature of the study design limits us from drawing causal conclusions from our results. Further experimental research comparing the current DMHI with a randomized controlled group will offer more conclusive evidence for the effectiveness of the current intervention above and beyond another type of mental health treatment. Another consequence of the retrospective study design is that our results may be biased by participants self-selecting into care, given that nontreatment factors associated with mental health care use may also underlie symptom improvements (eg, family support, increased parental education, and perceived need [46]). Future studies should include a more rigorous study design with a randomized controlled group and data from long-term members.

This study did not address whether particular behavioral intervention methods—including coaching versus therapy and specific symptom target (eg, anxiety or depression)—may be more or less beneficial to mental health outcomes than other methods. Instead, we assessed outcomes associated with participation in the DMHI regardless of intervention methods. In future studies, identification of the behavioral interventions that are most beneficial to mental health outcomes in the context of DMHIs would greatly enhance the quality and efficacy of DMHIs in addressing PTS and comorbid anxiety and depression.

Given the relatively small sample size of children with trauma and elevated PTS symptoms, we were not able to gauge whether the nature of the participants' trauma exposure (eg, type and timing) may have predicted their outcomes. A large body of research suggests that the development of PTS and comorbid psychiatric symptoms following trauma exposure is heavily correlated with the nature of the trauma [11,47]; as such, our analyses are missing a potentially significant covariate. While we reported the timing of trauma for members with an event, we could not assess timing as a potential covariate in further analyses. Future research should continue to assess whether the nature of a child's exposure to a traumatic event may affect their outcomes and symptom trajectory within the context of a DMHI. Nonetheless, the high correlation between participants experiencing a traumatic event and exhibiting elevated PTS symptoms suggests that the trauma measure accurately reflected traumatic exposure.

Conclusions

This study provides preliminary evidence for the frequency of trauma exposure and comorbid psychiatric symptoms, as well as variations in treatment response between trauma-exposed and nontrauma-exposed youths, among participants in a pediatric collaborative care DMHI. Youths with traumatic experiences may show increased psychiatric comorbidities and slower treatment responses than their peers with no history of trauma. These findings deliver compelling evidence that collaborative care DMHIs may be well-suited to address mental health symptoms in children with a history of trauma while also highlighting the critical need to assess symptoms of PTS in children seeking treatment.

Authors' Contributions

LGH and DLS contributed to the conceptualization, methodology, formal analysis, writing the original draft, manuscript reviewing and editing, and visualization of this study. ABB contributed to the writing of the original draft and editing. MR edited the paper and acquired funds. AP and RG reviewed and edited the paper. JH contributed to the conceptualization, writing the original draft, manuscript reviewing and editing, and supervision of this study.

Conflicts of Interest

All authors are employed by Bend Health Inc, which delivered the treatment used in this retrospective study. However, authors' employment status and salary are not dependent upon the results of their research.

Multimedia Appendix 1

Additional details regarding the categorization and analysis of race or ethnicity demographic question responses.

[DOCX File , 13 KB - pediatrics_v7i1e55560_app1.docx]

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Abbreviations

ADHD: attention-deficit/hyperactivity disorder
BCM: behavioral care manager
CBT: cognitive behavioral therapy
CoCM: collaborative care model
CPSS: Child PTSD Symptom Scale
DMHI: digital mental health intervention
DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
LRT: likelihood ratio test
PTS: posttraumatic stress
PTSD: posttraumatic stress disorder

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Original Paper

Parental Assessment of Postsurgical Pain in Infants at Home Using Artificial Intelligence–Enabled and Observer-Based Tools: Construct Validity and Clinical Utility Evaluation Study

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Abstract

Background: Pain assessment in the infant population is challenging owing to their inability to verbalize and hence self-report pain. Currently, there is a paucity of data on how parents identify and manage this pain at home using standardized pain assessment tools.

Objective: This study aimed to explore parents' assessment and intervention of pain in their infants at home following same-day surgery, using standardized pain assessment tools.

Methods: This prospective study initially recruited 109 infant boys undergoing circumcision (same-day surgery). To assess pain at home over 3 days after surgery, parents using iOS devices were assigned to use the PainChek Infant tool, which is a point-of-care artificial intelligence–enabled tool, while parents using Android devices were assigned to use the Observer-Administered Visual Analog Scale (ObsVAS) tool. Chi-square analysis compared the intervention undertaken and pain presence. Generalized estimating equations were used to evaluate outcomes related to construct validity and clinical utility. Receiver operating characteristic analysis assessed pain score cutoffs in relation to the intervention used.

Results: A total of 69 parents completed postsurgery pain assessments at home and returned their pain diaries. Of these 69 parents, 24 used ObsVAS and 45 used PainChek Infant. Feeding alone and feeding with medication were the most common pain interventions. Pain presence over time reduced. In the presence of pain, an intervention was likely to be administered (χ^2_2=21.4; P<.001), with a medicinal intervention being 12.6 (95% CI 4.3-37.0; P<.001) times more likely and a nonmedicinal intervention being 5.2 (95% CI 1.8-14.6; P=.002) times more likely than no intervention. In the presence of intervention, score cutoff values were ≥2 for PainChek Infant and ≥20 for ObsVAS. A significant effect between the use of the pain instrument (χ^2_1=7.2, P=.007) and intervention (χ^2_2=43.4, P<.001) was found, supporting the construct validity of both instruments. Standardized pain scores were the highest when a medicinal intervention was undertaken (estimated marginal mean [EMM]=34.2%), followed by a nonmedicinal intervention (EMM=23.5%) and no intervention (EMM=11.2%). Similar trends were seen for both pain instruments. Pain was reduced in 94.5% (224/237) of assessments where parents undertook an intervention. In 75.1% (178/237) of assessments indicative of pain, the score changed from pain to no pain, with PainChek Infant assessments more likely to report this change (odds ratio 4.1, 95% CI 1.4-12.3) compared with ObsVAS assessments.

Conclusions: The use of standardized pain assessment instruments by parents at home to assess pain in their infants can inform their decision-making regarding pain identification and management, including determining the effectiveness of the chosen intervention. In addition to the construct validity and clinical utility of PainChek Infant and ObsVAS in this setting, feeding alone and a combination of feeding with medication use were the key pain intervention strategies used by parents.

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KEYWORDS

PainChek Infant; Observer-Administered Visual Analog Scale; parents; infant pain; pain assessment; circumcision; infant home assessment; clinical utility; construct validity; artificial intelligence

Introduction

Surgical procedures represent a well-established cause of pain in infants [1]. Good management of pain following various medical procedures, including same-day surgery, is important in infants, considering both short-term and long-term consequences that can arise as a result of a lack of neuronal pathway maturity [2-4]. Literature data suggest that early pain experiences cause activity-induced alterations in pain sensitivity, and these changes continue beyond infancy [3]. In this regard, it is worth noting that the long-lasting effects of suboptimal management of pain in children are more pronounced in comparison to the adult population [5]. Furthermore, in situations where children are exposed to repeated treatment and therefore repeated painful episodes, significant anxiety potentially leading to psychological and emotional consequences for the child and their carers can occur [6].

Despite compelling evidence suggesting the need to better recognize and manage pain in infants, pain in this population group still often remains underestimated and undertreated [4,7]. One of the key contributors to these issues is the fact that infants are unable to self-report pain due to their inability to verbally communicate, therefore making pain identification a major challenge in this population [4,8]. Eccleston et al [4] recently proposed 4 transformative aims with the view of improving pain management in children, one of which was that “pain should be made visible,” highlighting the need to adequately assess pain.

Circumcision is one of the most commonly performed same-day surgical procedures in the world [9,10]. It is estimated that the global prevalence of male circumcision is approximately 38%-39%, and depending on religious beliefs, these figures can reach over 95%, especially in countries with Muslim or Jewish majority [9]. Postoperative pain, such as that associated with circumcision surgery, is by definition acute pain, since it lasts for less than 3 months [4,11]. This pain involves nociceptive mechanisms, and its expected resolution usually occurs as a result of the healing process [4]. It has been suggested that following circumcision (same-day surgery), pain is persistent over a number of days after hospital discharge, which often makes treatment with analgesics necessary [12]. Other studies have also confirmed that children often experience moderate to severe levels of pain following same-day surgery [13-16]. Treatment of this pain generally takes place at home, considering that infants are usually discharged from the hospital on the same day the surgical procedure is performed and parents are then engaged in a number of demanding tasks, including pain assessment and treatment administration [14]. Various issues have been reported in relation to pain management by parents at home, and it has been suggested that the management of children’s postoperative pain at home, following hospital discharge, is generally poor [14,17]. The ability of parents to assess and identify pain and the need for assistance in this aspect have been reported as areas that need to be addressed [14,17,18].

When it comes to pain identification, there are a number of pain assessment scales that have been developed to assess pain in infants and young children, but there is no gold standard [19]. Most of these tools have limited evidence regarding their validity and clinical utility, and they are based on observer identification and evaluation of specific biomarkers indicative of pain [7,20,21]. None of the currently available pain assessment scales use automation to assess pain, and they are all limited by user subjectivity during pain assessment. Moreover, although these tools are used and validated in clinical practice settings, they are usually not used by parents at home. Additionally, there is limited literature reporting the pain assessment–related outcomes of tools specifically designed for use in the infant population (parents conduct pain assessments and use pain assessment tools at home).

This study aimed to explore parents’ assessments of their infants’ pain at home using standardized pain assessment instruments and investigate what pharmacological or nonpharmacological interventions they chose to manage pain following same-day surgery (ie, circumcision). The focus was on exploring the construct validity and clinical utility of 2 pain assessment scales, namely PainChek Infant and Observer-Administered Visual Analog Scale (ObsVAS). PainChek Infant has been designed specifically for use in the infant population and is an example of an automated digital pain assessment scale that uses artificial intelligence (AI) to identify facial indicators of pain [8,22]. ObsVAS is an instrument that has been commonly used to assess and quantify pain and distress [23]. In this regard, we aimed to explore the presence and improvement of pain following different interventions, evaluate how these pain assessment tools track pain levels, and assess their diagnostic accuracy across potential different cutoff points following the intervention and assessment of pain by parents at home.

Methods

Study Design

This prospective study collected data from the parents of infant boys up to 12 months of age undergoing circumcision at Kavaja Hospital in Prishtina in Kosovo from January to December 2023. Infants were excluded from the study if they had any psychiatric or developmental disorders or physical conditions that may interfere with the standard care program, or if their surgeon deemed they should not participate in the study. After undergoing same-day circumcision surgery and following hospital discharge, consenting parents were recruited to conduct pain assessments at home when pain was suspected and then at 30-minute and 60-minute intervals after intervention for a period of up to 3 days after surgery. Parents conducted pain assessments using 1 of the 2 validated pain assessment instruments provided: PainChek Infant or ObsVAS.

Postsurgery Pain Assessment

PainChek Infant

PainChek Infant is a class 1 medical device in the form of a mobile app, which has regulatory clearance for the assessment of procedural pain in Australia and Europe. Assessment takes only 3 seconds to complete [8,22]. PainChek Infant uses AI for the automated recognition and analysis of an infant's face, allowing the detection of 6 facial action units (AUs) indicative of the presence of pain: AU4 (brow lowering), AU9 (wrinkling of the nose), AU15 (lip corner depression), AU20 (horizontal mouth stretch), AU25 (parting lips), and AU43 (eye closure). These facial actions represent specific muscle movements (contractions or relaxations) as classified by the Baby Facial Action Coding System (BabyFACS) [24]. Each of the 6 AUs is scored using a binary scale (0=absent, 1=present), yielding a total potential score of 6 for comparative analysis with ObsVAS scores (standardized to a percentage). PainChek Infant's algorithm to detect the abovementioned AU codes using AI was created on trained images of infants undergoing immunization procedures and corresponding to the age group of infants recruited for this study [8]. Initially, independent coders trained in the facial action coding system analyzed labeled infant images in relation to the presence of AU codes of interest. These labeled images were then used in training the model that is integrated into the mobile app. Using separate independent training and validation datasets, 5-fold cross-validation was employed to create the AI model. The tool has been specifically designed to assess pain in infants (aged 1-12 months), taking into account the facial actions commonly associated with pain in this population. It should be emphasized that prior to assessing facial indicators of pain, the users of PainChek Infant are instructed to rule out other common causes of nonpain-related distress such as the child being hungry, thirsty, frightened, too hot, too cold, tired, or sleepy; requiring a nappy change; wanting comfort; or requiring burping (passing of wind). This functionality comes up as an alert before proceeding to facial assessment. Previous research has found good correlation of scores between these tools (r=0.88, 95% CI 0.85-0.90; P<.001) [8]. However, the focus of this study was on evaluating the use of these tools by parents at home. Furthermore, high accuracy of PainChek Infant, with areas under the curve of 0.964 (standard mode) and 0.966 (adaptive mode), was shown [22]. PainChek Infant was also previously shown to perform well across various feasibility components [22].

ObsVAS Tool

ObsVAS is a tool that is commonly used to measure and quantify pain and distress [8,23]. The scale consists of a 100-mm line. In this line, 0 mm represents no pain or distress and 100 mm represents the worst possible pain or distress. It has been reported that VAS has good to excellent intrarater reliability and strong criterion validity [23]. Additionally, like PainChek Infant, ObsVAS was also previously shown to have good responsiveness in relation to the change of pain scores following a painful procedure [8].

Parent Education and Pain Assessment Diary

All parents who were using an iOS mobile device were approached to use the PainChek Infant app and were also trained on its use before their child was discharged from the hospital. Other parents who did not use iOS devices were approached to use the ObsVAS instrument. All parents participating in this study and consenting to use one of the pain assessment tools at home to assess and monitor their child's pain were educated by their doctor on pain management and use of the pain assessment tool provided. As part of the training process, the correct use of both tools was demonstrated by a research assistant, who was a medical doctor by training and was specifically trained and competent in the use of both tools as well as the protocol of the study. When completing pain assessments at home, parents were also asked to record results in a diary. This was also covered in the training process. In relation to ObsVAS, parents were instructed to mark on the 100-mm line the score that corresponded to their perceived assessment of their child's pain. Considering that PainChek Infant is a digital assessment tool, its results were also recorded automatically and synchronized via a cloud transmission system. For both tools, parents were instructed to perform a pain assessment when they suspected their child was in pain. When conducting a pain assessment, parents were instructed to record the results following a pain assessment in the diary in the morning (between 8:00 AM and 12:00 PM), afternoon (between 12:01 PM and 6:00 PM), or evening (after 6:00 PM), or when required if the assessment was outside of those timeframes. If an intervention was administered (pharmacological or nonpharmacological), parents were asked to record the intervention and then also perform further assessments 30 minutes and 60 minutes after the intervention. Parents were educated by the surgeons on pain intervention and management and were instructed to follow their doctors' recommendations. Additionally, parents were informed that the results from the pain assessment instrument should not be used solely to decide whether to use analgesic therapy or to determine the required analgesic dosing and that this should be based on their doctors' instructions. Moreover, they were told to consult with the doctor if they were not sure. Decisions undertaken by parents to manage postsurgical pain included medication administration (paracetamol or ibuprofen), feeding (breastfeeding, formula, or food), consoling (nursing or toys), and no action. These broad actions were also reclassified as no intervention, medicinal intervention, or nonmedicinal intervention.

Data Analysis

Analysis was conducted using IBM SPSS (version 29) unless otherwise stated. Parents' education levels were described using frequency (n) and percentage (%). Infant age was recorded as the age at admission for the circumcision procedure and was recorded as weeks or months. For 10 infants, the age recorded in weeks was converted to months by multiplying weeks by 0.23. Infant age was described using mean, SD, median, and 25th to 75th IQR. Normality was assessed using the Shapiro-Wilk test with age found not to be normally distributed, and appropriate nonparametric tests were applied. The Mann-Whitney *U* test examined age between pain assessment tool groups (ObsVAS versus PainChek Infant), with the standardized test statistic reported.

The chi-square analysis (or Fisher-Freeman-Halton exact chi-square test where cell counts <5 with exact 2-sided *P* values are reported) was undertaken to compare differences between the intervention used (none, medicinal, or nonmedicinal) and pain presence (absent or present). The test was conducted for the full sample and separately for PainChek Infant and ObsVAS. Binary logistic generalized estimating equations (GEEs) were used to examine if pain was present and assess the likelihood of an intervention occurring (Wald χ^2 and *P* value reported), with parameter-estimated odds ratios (ORs; Exp(β)), 95% Wald CIs for Exp(β), and *P* values reported for medicinal or nonmedicinal intervention compared to no intervention. The model accounted for individuals with repeated measurements and the within-subject variable of time. The confounding effects for age, instrument, and parent education were each examined separately in the basic model, with Quasi-likelihood under the Independence Model Criterion (QIC) goodness of fit indices used to compare models, and a lower number was associated with a better model fit [25]. The GEE method enables regression estimates when analyzing repeated measures with no assumption of the distribution of the response outcome [26,27].

Construct validity was assessed in several ways. First, GEE with standardized pain score as the outcome was evaluated with instrument, intervention, and age as fixed effects, accounting for individuals with repeated measurements and the within-subject variable of time. Model residuals (Q-Q plots) were visually assessed and assumptions were met. Estimated marginal means (EMMs) with 95% CIs were calculated, with Wald χ^2 and *P*-value model effects reported and Bonferroni-corrected pairwise comparisons for instrument and intervention undertaken. Separate models were also analyzed for each instrument on their original measurement scale. Second, we evaluated if pain scores improved after intervention (medicinal, nonmedicinal, or no intervention), with improvement categorized in 2 ways for analysis: pain relief and general pain reduction. For pain relief, a binary (Y/N) response to "did the pain score reduce to no pain" (PainChek Infant <2, ObsVAS=0) was used. For pain reduction, three groups were calculated: (1) no change or worse standardized pain score; (2) small standardized pain score improvement (≤33%); and (3) clinically important pain score improvement (>33%), standardized pain score returned to no pain (PainChek Infant ≤33%, ObsVAS=0%), or pain resolved (no further assessment undertaken at the final recorded timepoint, either 30 or 60 minutes). Receiver operating characteristic (ROC) analysis with sensitivity (true positive rate) and 100-specificity (false positive rate) was conducted using NCSS software (v21.0.14 2021) to assess whether there was a specific pain score where an intervention (generally) or medical intervention (specifically) was undertaken. Youden Index was used to determine the diagnostic accuracy across potential cutoff points (sensitivity + specificity – 1). The summary of area under the curve (AUC) scores overall and for each instrument has been reported. Each time period was a separate data entry for individuals.

Sensitivity analysis was conducted on baseline characteristics (age and education level) between parents who collected pain data versus those who did not. A Kruskal-Wallis test examined between-group differences for age (test statistic reported), while a Pearson chi-square (χ^2) (Fisher-Freeman-Halton exact [cell counts <5]) test examined differences for education level. Two-sided *P* values have been reported throughout.

Ethical Considerations

This study was approved by the research ethics committee of the Faculty of Medicine, University of Prishtina (approval number: 4860/22).

Results

Participant Characteristics

Parents of 109 infant boys undergoing circumcision were recruited in the study before the circumcision procedure and completed baseline measures (infant age and parent education). After surgery, 40 (36.7%) participants did not take any further part in the study (5 assigned to the ObsVAS group and 35 assigned to the PainChek Infant group). Sensitivity analysis did not detect any differences in age across participants who participated in postsurgery activities versus those who did not. A significant difference was detected in parent education, with those who did not return pain diaries coming from among university-educated parents (χ^2_3=12.0; *P*=.005). Of the remaining, 69 participants completed postsurgery pain assessments and returned their pain diaries. Of these, 24 (35%) were allocated to the ObsVAS group and 45 (65%) were allocated to the PainChek Infant group. Infants had a mean age of 5.1 months (SD 3.2 months; median 5.0 months, IQR 2.5-7.0 months). No significant difference in age was detected between the ObsVAS (mean 5.0, SD 3.6 months; median 4.0, IQR 2.0-7.5 months) and PainChek Infant (mean 5.1, SD 3.1 months; median 5.0, IQR 3.0-7.0 months) groups (*U*=–0.4; *P*=.68). Parents were predominantly university educated (50/69, 73%), with the remaining being high school educated or lower (19/69, 28%). There was no significant difference between the ObsVAS (high school: 7/24, 29%; university: 17/24, 71%) and PainChek Infant (high school: 12/45, 27%; university: 33/45, 73%) groups (χ^2_1=0.05; *P*>.99).

Postsurgery Pain Presence and Pain Intervention Results

A summary of pain interventions administered after surgery over 3 days is provided in Table 1, with feeding alone and feeding with medication being the most common interventions reported by parents, followed by the use of medication alone. Parents also chose not to intervene. Among the medications administered, paracetamol was the most commonly reported, with ibuprofen used only in 3 instances.

Pain interventions were further described as no intervention, medicinal intervention, or nonmedicinal intervention (Tables 2-4). At baseline for each timepoint, a comparison was performed between pain present and absent and the pain intervention undertaken. Significant differences were only detected for day 2 afternoon and evening, and day 3 evening. For each, the absence of pain had a higher percentage of no intervention compared to the presence of pain, which had the lowest percentage of no intervention. Similar trends were seen when PainChek Infant and ObsVAS were examined separately. Further details are provided in Tables 2-4.

Pain presence and absence for the total sample and for the PainChek Infant and ObsVAS subsamples are reported in Table 5. From baseline assessments to 30-minute assessments and then 60-minute repeat assessments, there was a general reduction in the proportion of pain assessments, indicating the presence of pain, and there was a concomitant increase in those indicating no pain. A similar trend of decreasing pain presence versus pain absence was seen in assessments performed from day 1 to day 3. Some differences between PainChek Infant and ObsVAS were found across the time points, with PainChek Infant typically reporting a higher percentage of no pain and ObsVAS tending to report a higher percentage of pain present.

Table 1. Pain interventions administered across time after circumcision surgery.

Postsurgery time	Total, n	Intervention, n (%)				
		Consoling	Feeding only	Medications[a]	Medication and feeding	None
Day 1						
Morning[b]	8	0 (0)	4 (50)	1 (13)	2 (25)	1 (13)
Afternoon[c]	52	1 (2)	18 (35)	19 (37)	12 (23)	1 (2)
Evening[d]	61	0 (0)	23 (38)	18 (30)	11 (18)	9 (15)
PRN[e]	14	0 (0)	5 (36)	1 (7)	3 (21)	5 (36)
Day 2						
Morning	62	0 (0)	28 (45)	11 (18)	10 (16)	13 (21)
Afternoon	61	2 (3)	34 (56)	6 (10)	6 (10)	13 (21)
Evening	56	0 (0)	26 (46)	6 (11)	6 (11)	18 (32)
PRN	8	0 (0)	1 (13)	0 (0)	3 (38)	4 (50)
Day 3						
Morning	40	0 (0)	19 (48)	6 (15)	3 (8)	12 (30)
Afternoon	40	0 (0)	17 (43)	1 (3)	5 (13)	17 (43)
Evening	33	1 (3)	13 (39)	2 (6)	5 (15)	12 (36)
PRN	9	0 (0)	5 (56)	0 (0)	1 (11)	3 (33)

[a] Medications include paracetamol and ibuprofen pediatric formulations.

[b] Morning: 8:00 AM to 12:00 AM.

[c] Afternoon: 12:01 PM to 6:00 PM.

[d] Evening: after 6:00 PM.

[e] PRN: required basis outside of those timeframes.

Table 2. Interventions administered at baseline (1st measurement in the time period) for the overall sample.

Postsurgery time	Total, n	Total sample, n (%)			No pain[a], n (%)			Pain[a], n (%)			Pain group comparison[b]	
		None	Medicinal	Non-medicinal	None	Medicinal	Non-medicinal	None	Medicinal	Non-medicinal	χ^2 (*df*)	*P* value
Day 1												
Morning[c]	8	1 (13)	3 (38)	4 (50)	1 (50)	0 (0)	1 (50)	0 (0)	3 (50)	3 (50)	3.2 (2)	.36
Afternoon[d]	52	1 (2)	32 (62)	19 (37)	1 (11)	5 (56)	3 (33)	0 (0)	27 (63)	16 (37)	3.6 (2)	.23
Evening[e]	61	9 (15)	29 (48)	23 (38)	5 (19)	9 (35)	12 (46)	4 (11)	20 (57)	11 (31)	3.1 (2)	.21
PRN[f]	14	5 (36)	4 (29)	5 (36)	4 (67)	0 (0)	2 (33)	1 (13)	4 (50)	3 (38)	5.4 (2)	.10
Day 2												
Morning	62	13 (21)	21 (34)	28 (45)	9 (32)	7 (25)	12 (43)	4 (12)	14 (41)	16 (47)	4.2 (2)	.11
Afternoon	61	13 (21)	12 (20)	36 (59)	10 (36)	4 (14)	14 (50)	3 (9)	8 (24)	22 (67)	6.3 (2)	.047[g]
Evening	56	18 (32)	12 (21)	26 (46)	17 (57)	1 (3)	12 (40)	1 (4)	11 (42)	14 (54)	24.4 (2)	<.001[g]
PRN	8	4 (50)	3 (38)	1 (13)	4 (80)	1 (20)	0 (0)	0 (0)	2 (67)	1 (33)	4.7 (2)	.07
Day 3												
Morning	40	12 (30)	9 (23)	19 (48)	10 (44)	3 (13)	10 (44)	2 (12)	6 (35)	9 (53)	5.5 (2)	.06
Afternoon	40	17 (43)	6 (15)	17 (43)	14 (54)	2 (8)	10 (39)	3 (21)	4 (29)	7 (50)	5.0 (2)	.07
Evening	33	12 (36)	7 (21)	14 (42)	9 (53)	1 (6)	7 (41)	3 (19)	6 (38)	7 (44)	6.3 (2)	.04[g]
PRN	9	3 (33)	1 (11)	5 (56)	2 (50)	0 (0)	2 (50)	1 (20)	1 (20)	3 (60)	1.5 (2)	>.99

[a] PainChek Infant: ≤1=no pain, >1=pain; ObsVAS: 0=no pain, >0=pain.

[b] Fisher-Freeman-Halton exact chi-square test and exact 2-sided *P* value reported.

[c] Morning: 8:00 AM to 12:00 AM.

[d] Afternoon: 12:01 PM to 6:00 PM.

[e] Evening: after 6:00 PM.

[f] PRN: required basis outside of those timeframes.

[g] Statistically significant (*P*<.05).

Table 3. Interventions administered at baseline (1st measurement in the time period) for the PainChek Infant subsample.

Postsurgery time	Total, n	Total sample, n (%)			No pain[a], n (%)			Pain[a], n (%)			Pain group comparison[b]	
		None	Medicinal	Non-medicinal	None	Medicinal	Non-medicinal	None	Medicinal	Non-medicinal	χ^2 (*df*)	*P* value
Day 1												
Morning[c]	4	0 (0)	2 (50)	2 (50)	0 (0)	0 (0)	1 (100)	0 (0)	2 (67)	1 (33)	1.3 (2)	>.99
Afternoon[d]	31	1 (3)	16 (52)	14 (45)	1 (11)	5 (56)	3 (33)	0 (0)	11 (50)	11 (50)	2.6 (2)	.28
Evening[e]	40	4 (10)	22 (55)	14 (35)	3 (15)	8 (40)	9 (45)	1 (5)	14 (70)	5 (25)	3.6 (2)	.23
PRN[f]	5	2 (4)	0 (0)	3 (60)	2 (50)	0 (0)	2 (50)	0 (0)	0 (0)	1 (100)	0.8 (2)	>.99
Day 2												
Morning	39	6 (15)	11 (28)	22 (56)	4 (19)	6 (29)	11 (52)	2 (11)	5 (28)	11 (61)	0.6 (2)	.90
Afternoon	39	8 (21)	9 (23)	22 (56)	6 (29)	4 (19)	11 (52)	2 (11)	5 (28)	11 (61)	1.8 (2)	.47
Evening	35	12 (34)	8 (23)	15 (43)	12 (50)	1 (4)	11 (46)	0 (0)	7 (64)	4 (36)	16.8 (2)	<.001[g]
PRN	3	2 (67)	1 (33)	0 (0)	2 (67)	1 (33)	0 (0)	0 (0)	0 (0)	0 (0)	—[h]	—
Day 3												
Morning	25	7 (28)	4 (16)	14 (56)	6 (38)	2 (13)	8 (50)	1 (11)	2 (22)	6 (67)	2.1 (2)	.44
Afternoon	24	11 (46)	3 (13)	10 (42)	9 (50)	1 (6)	8 (44)	3 (33)	2 (33)	2 (33)	2.8 (2)	.27
Evening	20	6 (30)	4 (20)	10 (50)	4 (36)	1 (9)	6 (55)	2 (22)	3 (33)	4 (44)	1.8 (2)	.60
PRN	3	1 (33)	0 (0)	2 (67)	1 (33)	0 (0)	2 (67)	0 (0)	0 (0)	0 (0)	—	—

[a] PainChek Infant: ≤1=no pain, >1=pain; ObsVAS: 0=no pain, >0=pain.

[b] Fisher-Freeman-Halton exact chi-square test and exact 2-sided *P* value reported.

[c] Morning: 8:00 AM to 12:00 AM.

[d] Afternoon: 12:01 PM to 6:00 PM.

[e] Evening: after 6:00 PM.

[f] PRN: required basis outside of those timeframes.

[g] Statistically significant (*P*<.05).

[h] Not applicable (no statistics computed as 1 pain group had no cases).

Table 4. Interventions administered at baseline (1st measurement in the time period) for the Observer-Administered Visual Analog Scale subsample.

Postsurgery time	Total, n	Total sample, n (%)			No pain[a], n (%)			Pain[a], n (%)			Pain group comparison[b]	
		None	Medicinal	Non-medicinal	None	Medicinal	Non-medicinal	None	Medicinal	Non-medicinal	χ^2 (*df*)	*P* value
Day 1												
Morning[c]	4	1 (25)	1 (25)	2 (50)	1 (100)	0 (0)	0 (0)	0 (0)	1 (33)	2 (67)	3.1 (2)	.50
Afternoon[d]	21	0 (0)	16 (76)	5 (24)	0 (0)	0 (0)	0 (0)	0 (0)	16 (76)	5 (24)	—[e]	—
Evening[f]	21	5 (24)	7 (33)	9 (43)	2 (33)	1 (17)	3 (50)	3 (20)	6 (40)	6 (40)	1.2 (2)	.58
PRN[g]	9	3 (33)	4 (44)	2 (22)	2 (100)	0 (0)	0 (0)	1 (14)	4 (57)	2 (29)	3.8 (2)	.11
Day 2												
Morning	23	7 (30)	10 (44)	6 (26)	5 (71)	1 (14)	1 (14)	2 (13)	9 (56)	5 (31)	7.1 (2)	.03[h]
Afternoon	22	5 (23)	3 (14)	14 (64)	4 (57)	0 (0)	3 (43)	1 (7)	3 (20)	11 (73)	6.2 (2)	.04[h]
Evening	21	6 (29)	4 (19)	11 (52)	5 (83)	0 (0)	1 (17)	1 (7)	4 (27)	10 (67)	10.4 (2)	.004[h]
PRN	5	2 (40)	2 (40)	1 (20)	2 (100)	0 (0)	0 (0)	0 (0)	2 (67)	1 (33)	4.0 (2)	.20
Day 3												
Morning	15	5 (33)	5 (33)	5 (33)	4 (57)	1 (14)	2 (29)	1 (13)	4 (50)	3 (38)	3.5 (2)	.30
Afternoon	16	6 (38)	3 (19)	7 (44)	5 (63)	1 (13)	5 (25)	1 (13)	2 (25)	5 (63)	4.1 (2)	.14
Evening	13	6 (46)	3 (23)	4 (31)	5 (83)	0 (0)	1 (17)	1 (14)	3 (43)	3 (43)	5.9 (2)	.06
PRN	6	2 (33)	1 (17)	3 (50)	1 (100)	0 (0)	0 (0)	1 (20)	1 (20)	3 (60)	2.5 (2)	.50

[a] PainChek Infant: ≤1=no pain, >1=pain; ObsVAS: 0=no pain, >0=pain.

[b] Fisher-Freeman-Halton exact chi-square test and exact 2-sided *P* value reported.

[c] Morning: 8:00 AM to 12:00 AM.

[d] Afternoon: 12:01 PM to 6:00 PM.

[e] Not applicable (no statistics computed as 1 pain group had no cases).

[f] Evening: after 6:00 PM.

[g] PRN: required basis outside of those timeframes.

[h] Statistically significant (*P*<.05).

Table 5. Pain results across time points for the total sample and the tool subsamples.

Sample and postsurgery time	Baseline			30 minutes			60 minutes		
	n	No pain[a], n (%)	Pain[a], n (%)	n	No pain[a], n (%)	Pain[a], n (%)	n	No pain[a], n (%)	Pain[a], n (%)
Total sample									
Day 1									
Morning[b]	8	2 (25)	6 (75)	3	0 (0)	3 (100)	3	1 (33)	2 (67)
Afternoon[c]	52	9 (17)	43 (83)	36	16 (44)	20 (56)	27	16 (59)	11 (41)
Evening[d]	61	26 (43)	35 (57)	40	25 (63)	15 (38)	29	17 (59)	12 (41)
PRN[e]	14	6 (43)	8 (57)	10	6 (60)	4 (40)	8	6 (75)	2 (25)
Day 2									
Morning	62	28 (45)	34 (55)	31	22 (71)	9 (29)	27	21 (78)	6 (22)
Afternoon	62	29 (47)	33 (53)	29	23 (79)	6 (21)	24	20 (83)	4 (17)
Evening	56	30 (54)	26 (46)	33	23 (70)	10 (30)	27	24 (89)	3 (11)
PRN	8	5 (63)	3 (38)	5	3 (60)	2 (40)	4	3 (75)	1 (25)
Day 3									
Morning	41	24 (59)	17 (42)	23	18 (78)	5 (22)	17	14 (82)	3 (18)
Afternoon	40	26 (65)	14 (35)	19	13 (68)	6 (32)	16	12 (75)	4 (25)
Evening	33	17 (52)	16 (49)	18	12 (67)	6 (33)	15	11 (73)	4 (27)
PRN	9	4 (44)	5 (56)	6	3 (50)	3 (50)	5	3 (60)	2 (40)
PainChek Infant subsample									
Day 1									
Morning	4	1 (25)	3 (75)	3	0 (0)	2 (100)	1	1 (100)	0 (0)
Afternoon[f]	31	9 (29)	22 (71)	19	10 (53)	9 (47)	12	9 (75)	3 (25)
Evening[g,h]	40	20 (50)	20 (50)	24	21 (88)	3 (13)	16	13 (81)	3 (19)
PRN	5	4 (80)	1 (20)	3	3 (100)	0 (0)	3	3 (100)	0 (0)
Day 2									
Morning[g]	39	21 (54)	18 (46)	18	16 (89)	2 (11)	16	14 (88)	2 (13)
Afternoon[g]	39	21 (54)	18 (46)	18	17 (94)	1 (6)	15	14 (93)	1 (7)
Evening[f]	35	24 (69)	11 (31)	21	15 (71)	6 (29)	16	15 (94)	1 (6)
PRN	3	3 (100)	0 (0)	2	2 (100)	0 (0)	2	2 (100)	0 (0)
Day 3									
Morning	25	16 (64)	9 (36)	14	13 (93)	1 (7)	11	10 (91)	1 (9)
Afternoon	24	18 (75)	6 (25)	11	8 (73)	3 (27)	10	8 (80)	2 (20)
Evening[g]	20	11 (55)	9 (45)	11	10 (91)	1 (9)	10	9 (90)	1 (10)
PRN[f]	3	3 (100)	0 (0)	2	2 (100)	0 (0)	2	2 (100)	0 (0)
ObsVAS[i] subsample									
Day 1									
Morning	4	1 (25)	3 (75)	1	0 (0)	1 (100)	2	0 (0)	2 (100)
Afternoon[f]	21	0 (0)	21 (100)	17	6 (35)	11 (65)	15	7 (47)	8 (53)
Evening[g,h]	21	6 (29)	15 (71)	16	4 (25)	12 (75)	13	4 (31)	9 (69)
PRN	9	2 (22)	7 (78)	7	3 (43)	4 (57)	5	3 (60)	2 (40)

Sample and postsurgery time	Baseline			30 minutes			60 minutes		
	n	No pain[a], n (%)	Pain[a], n (%)	n	No pain[a], n (%)	Pain[a], n (%)	n	No pain[a], n (%)	Pain[a], n (%)
Day 2									
Morning[g]	23	7 (30)	16 (70)	13	6 (25)	7 (54)	11	7 (64)	4 (36)
Afternoon[g]	23	8 (35)	15 (65)	11	6 (55)	5 (46)	9	6 (67)	3 (33)
Evening[f]	21	6 (29)	15 (71)	12	8 (67)	4 (33)	11	9 (82)	2 (18)
PRN	5	2 (40)	3 (60)	3	1 (33)	2 (67)	2	1 (50)	1 (50)
Day 3									
Morning	16	8 (50)	8 (50)	9	5 (56)	4 (44)	6	4 (67)	2 (33)
Afternoon	16	8 (50)	8 (50)	8	5 (63)	3 (38)	6	4 (67)	2 (33)
Evening[g]	13	6 (46)	7 (54)	7	2 (29)	5 (71)	5	2 (40)	3 (60)
PRN[f]	6	1 (17)	5 (83)	4	1 (25)	3 (75)	3	1 (33)	2 (67)

[a] PainChek Infant: ≤1=no pain, >1=pain; ObsVAS: 0=no pain, >0=pain.

[b] Morning: 8:00 AM to 12:00 AM.

[c] Afternoon: 12:01 PM to 6:00 PM.

[d] Evening: after 6:00 PM.

[e] PRN: required basis outside of those timeframes.

[f] Statistically significant difference between PainChek Infant and ObsVAS for the absence and presence of pain at baseline (chi-square Fisher exact test 2-sided *P* value).

[g] Statistically significant difference between PainChek Infant and ObsVAS for the absence and presence of pain at 30 minutes (chi-square Fisher exact test 2-sided *P* value).

[h] Statistically significant difference between PainChek Infant and ObsVAS for the absence and presence of pain at 60 minutes (chi-square Fisher exact test 2-sided *P* value).

[i] ObsVAS: Observer-Administered Visual Analog Scale.

Regarding the association between pain and intervention, the basic GEE model found that when pain was present, an intervention was likely (χ^2_2=21.4; *P*<.001; QIC=550.5). Specifically, medicinal intervention had the highest odds (OR) of 12.6 (95% CI 4.3-37.0; *P*<.001), followed by nonmedicinal intervention with an OR of 5.2 (95% CI 1.8-14.6; *P*=.002) compared to no intervention when pain was present. The inclusion of a pain instrument in the basic model improved model fit (QIC=513.5), with both intervention (χ^2_2=27.5; *P*<.001) and instrument (χ^2_1=13.10; *P*<.001) being significantly associated with a pain outcome. Higher odds were reported for medicinal intervention (OR 17.5, 95% CI 5.9-51.8; *P*<.001) and nonmedicinal intervention (OR 7.3, 95% CI 2.4-22.1; *P*<.001) compared to no intervention when pain was present. ObsVAS had a higher odds of pain present (OR 4.4, 95% CI 2.0-9.9) compared to PainChek Infant. A model with an interaction term between intervention and instrument did not improve model fit (QIC=517.3), and the interaction term was not statistically significant (χ^2_2=2.1; *P*=.36).

The addition of age to the model improved model fit (QIC=510.9); however, age was not a significant effect (χ^2_1=2.7; *P*=.10), with both intervention (χ^2_2=30.3; *P*<.001) and instrument (χ^2_1=12.1; *P*<.001) being significantly associated with a pain outcome. Slightly higher odds were reported for medicinal intervention (OR 19.2, 95% CI 6.6-56.1; *P*<.001), and nonmedicinal intervention was more likely to occur (OR 6.9, 95% CI 2.3-20.6; *P*<.001) than no intervention. ObsVAS had higher odds of pain present (OR 4.3, 95% CI 1.9-9.9) compared to PainChek Infant. The addition of parent education to the model did not improve model fit (QIC=517.5), with it not having a significant effect (χ^2_1=0.1 *P*=.75).

ROC analysis results are summarized in Table 6, and ROC curves are depicted in Figure 1. Youden Index determined cutoff values for the PainChek Infant and ObsVAS instruments and reported respective cutoff points for intervening values of ≥2 and ≥20 for intervention (medicinal and nonmedicinal) versus no intervention and similarly for medicinal intervention versus no intervention or nonmedicinal intervention. The combination of pain instruments using the standardized pain score Youden Index determined cutoff values of ≥10 for intervention (medicinal and nonmedicinal) versus no intervention; however, it reported values of ≥20 for medicinal intervention versus no intervention or other intervention, indicating a higher pain threshold for medicinal intervention to occur.

Evidence for construct validity assessed via GEE for standardized pain score reported a significant effect for instrument (χ^2_1=7.2; *P*=.007) and intervention (χ^2_2=43.4; *P*<.001) but not age (χ^2_1=1.9; *P*=.17). Pain scores were higher for PainChek Infant (EMM 27.5, 95% CI 22.6-32.3) compared to ObsVAS (EMM 18.5, 95% CI 14.2-22.9). Pain scores were the highest when a medicinal intervention was undertaken (EMM 34.2), followed by a nonmedicinal intervention (EMM 23.5), and were the lowest for no intervention (EMM 11.25). All Bonferroni-corrected intervention pairwise comparisons were significant (Table 7). Similar trends were seen for individual instrument models of PainChek Infant and ObsVAS, with EMM summarized by intervention presented in Table 7. It was noted that Bonferroni-corrected comparisons did not reach significance between medicinal and nonmedicinal interventions (*P*=.20) for the PainChek Infant instrument, and between no intervention and nonmedicinal intervention (*P*=.17) for the ObsVAS instrument.

For a subset of assessments indicative of pain (n=237), we assessed if the pain was relieved (ie, scores reduced to “no pain” levels). Of these, 178 (75.1%) infants recorded a change from pain to no pain. In this group recording an improvement to no pain, 37.6% (n=67) received medicinal intervention, 50.6% (n=90) received nonmedicinal intervention, and 8.9% (n=21) received no intervention. The instruments were also considered separately. For PainChek Infant (subset n=114) regarding improvement to no pain, 42.4% (n=42) received a medicinal intervention, 48.5% (n=48) received a nonmedicinal intervention, and 9.1% (n=9) received no intervention. For ObsVAS (subset n=123) regarding improvement to no pain, 31.6% (n=25) received a medicinal intervention, 53.2% (n=42) received a nonmedicinal intervention, and 15.2% (n=12) received no intervention. GEE reported a significant effect for instrument (χ^2_1=6.32; *P*=.01) and intervention (χ^2_2=7.3; *P*=.03). The PainChek Infant instrument was more likely to report a change from pain to no pain (OR 4.1, 95% CI 1.4-12.3) compared to the ObsVAS instrument.

Further descriptive analysis was used for this subset of assessments where pain was detected (n=237) to assess general pain reduction. Of these initial assessments of pain, 224 (94.5%) were followed by a reduction in pain at 30 minutes or 60 minutes after intervention, with 13 (5.5%) resulting in no change or worse pain. These were observed equally between medicinal intervention (n=100, 44.7%) and nonmedicinal intervention (n=102, 45.5%), with 9.8% (n=22) improving with no intervention. Observationally, similar trends were seen for PainChek Infant and ObsVAS. For PainChek Infant (n=114), when an intervention was undertaken, 110 (96.5%) assessments reported improvement in pain, with 4 (3.5%) reporting no change or worse pain. These were observed equally between medicinal intervention (n=49, 44.5%) and nonmedicinal intervention (n=51, 46.4%), with 9.1% (n=10) indicating improvement with no intervention. For ObsVAS (n=123), when an intervention was undertaken, 114 (92.7%) assessments reported improvement in pain, with 9 (7.3%) reporting no change or worse pain. These were observed equally between medicinal intervention (n=51, 44.7%) and nonmedicinal intervention (n=51, 44.7%), with 10.5% (n=12) indicating improvement with no intervention.

Table 6. Area under the receiver operating characteristic curve data for the pain scores of the tools.

Statistical item	Intervention vs no intervention			Medicinal intervention vs no or nonmedicinal intervention		
	Total	PainChek[a]	ObsVAS[b,c]	Total	PainChek[a]	ObsVAS[b,c]
Total, n	444	268	176	444	268	176
Pain, n	336	80	59	139	80	59
Proportion, %	75.7	29.9	33.5	31.3	29.9	33.5
Youden Index cutoff value	≥10	≥2	≥20	≥20	≥2	≥20
Area under the ROC[d] curve	0.74	0.65	0.78	0.70	0.65	0.78
Standard error	0.03	0.04	0.04	<0.01	0.04	0.04
95% CI lower	0.68	0.58	0.70	0.64	0.58	0.70
95% CI upper	0.79	0.72	0.84	0.74	0.72	0.84
z statistic[e]	8.9	4.2	7.8	7.5	4.2	7.8
P value[e]	<.001	<.001	<.001	<.001	<.001	<.001

[a] PainChek score presented according to the raw scale 0-6.

[b] ObsVAS: Observer-Administered Visual Analog Scale.

[c] ObsVAS score presented according to the raw scale 0-100.

[d] ROC: receiver operating characteristic.

[e] Null hypothesis area under the curve=0.5.

Figure 1. Sensitivity and specificity receiver operating characteristic (ROC) curve for the pain score with an intervention.

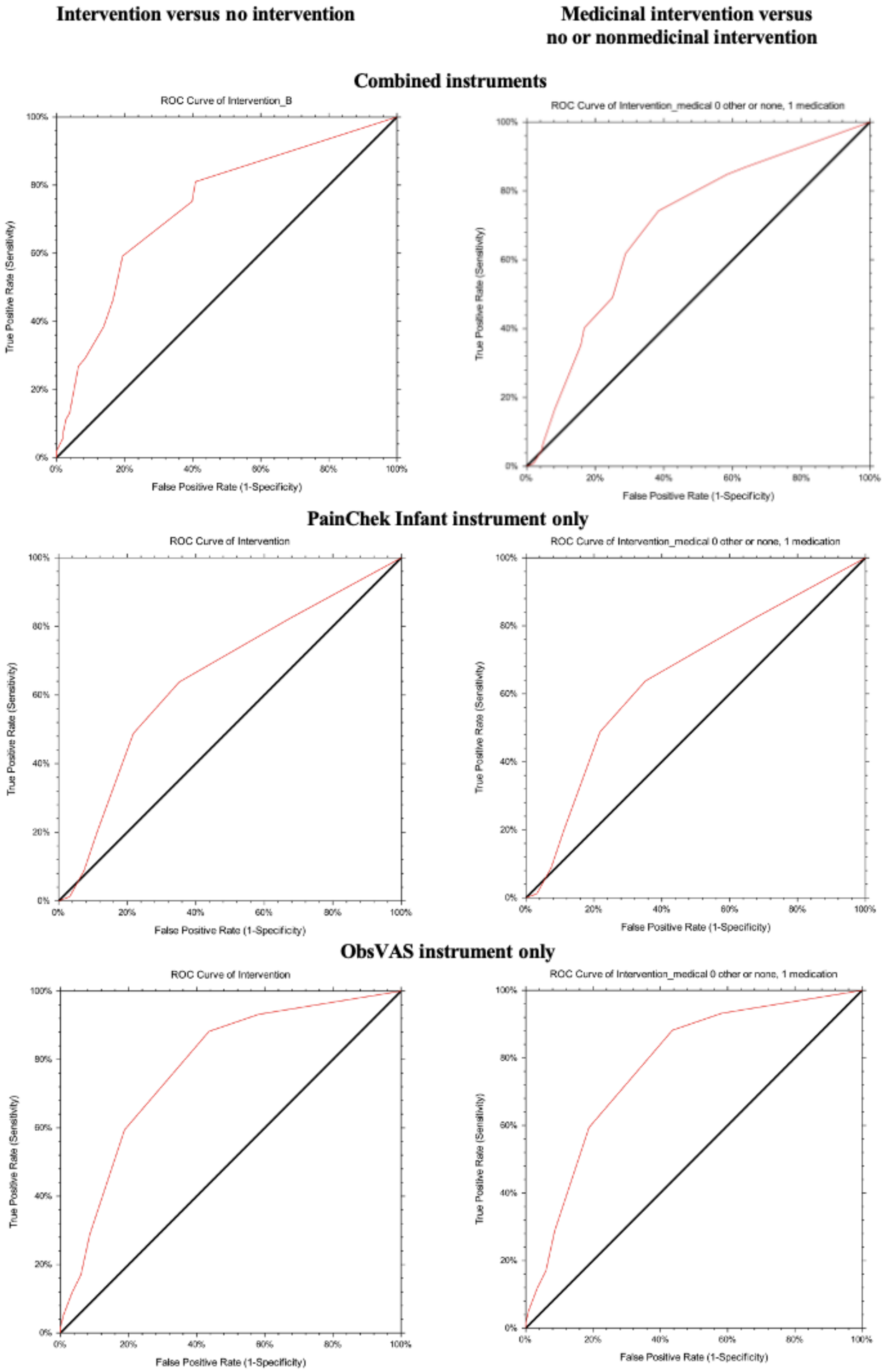

Table 7. Estimated marginal mean pain score from generalized estimating equation models assessing the pain over time and type of intervention undertaken.

Model[a] and intervention	EMM[b]	SE[c]	95% Wald CI	
			Lower	Upper
Combined instrument model (scaled scores)				
Medicinal intervention[d,e]	34.22	2.95	28.44	40.00
Nonmedicinal intervention[d,f]	23.50	2.49	18.62	28.38
No intervention[e,f]	11.25	2.42	6.50	16.00
PainChek model (original 1-6 scale)				
Medicinal intervention[e,f]	2.34	0.31	1.73	2.95
Nonmedicinal intervention[e]	1.69	0.21	1.28	2.10
No intervention[e,f]	0.86	0.17	0.53	1.19
ObsVAS[g] model (original 1-100 scale)				
Medicinal intervention[d,e]	30.49	2.54	25.50	35.47
Nonmedicinal intervention[d]	17.82	2.72	12.48	23.16
No intervention[e]	8.37	4.39	–0.23	16.97

[a] Covariates appearing in the model are fixed for age.

[b] EMM: estimated marginal mean.

[c] SE: standard error.

[d] Statistically significant Bonferroni-corrected comparison between medicinal intervention and nonmedicinal intervention (*P*<.05).

[e] Statistically significant Bonferroni-corrected comparison between medicinal intervention and no intervention (*P*<.05).

[f] Statistically significant Bonferroni-corrected comparison between nonmedicinal intervention and no intervention (*P*<.05).

[g] ObsVAS: Observer-Administered Visual Analog Scale.

Discussion

Principal Findings

In this study, we reported parental assessment and management of pain at home following same-day circumcision surgery after hospital discharge for up to 3 days. Our findings showed that parents usually decided to undertake an intervention when their child was in pain. In this regard, they most commonly opted to choose either feeding alone or using medication together with feeding. Paracetamol was mostly used by parents (as opposed to only 3 cases of ibuprofen use). These results are in line with what was recommended and prescribed by the operating surgeons and what is consistent with recommendations from drug monographs of these medications [28,29]. It was interesting to note that in a number of cases, parents chose not to intervene even when pain was identified. There may be a number of reasons for this, but it is worth noting that fear of using analgesics as well as misconceptions regarding analgesic use by parents have been previously reported in the literature [14,17,18,30]. Nonetheless, our findings confirm that there was a relationship between the presence and absence of pain when an intervention was undertaken by parents (ie, pain assessments with pain as a result, for both PainChek Infant and ObsVAS, had the lowest proportion of no intervention). While similar trends were observed in this regard for both tools throughout various pain assessment timeframes, some differences were identified for day 2 afternoon and evening.

Our findings suggest that both tools were able to demonstrate the effectiveness of the intervention used by parents considering that the number of assessments indicating no pain generally increased over time following the intervention (both the 30- and 60-minute time points) and throughout days 1 to 3. While, as expected, pain presence reduced over this timeframe, our findings are consistent with the results by Freeman et al [12], which suggested that pain is persistent for a few days following circumcision. In cases where there were significant differences between tools, our findings indicated that ObsVAS was associated with reporting a higher proportion of the presence of pain in comparison with PainChek Infant. When it comes to these instrument-specific differences, it should be noted that assessments with different instruments were not conducted on the same subjects. Additionally, PainChek Infant has a clear cutoff (≥2 out of 6) for pain as opposed to ObsVAS, which considers any score above 0 to indicate pain, and a low score in ObsVAS is not necessarily a clinically important score indicative of pain. While it was noted that the aggregated proportion of ObsVAS assessments indicative of pain was higher compared to PainChek Infant, it is important to note that when exploring threshold pain scores in relation to intervention, these were similar (ie, ≥20 out of 100 [20%] for ObsVAS and ≥2 out of 6 [33%] for PainChek Infant). Nonetheless, the determination of the cutoff score for PainChek Infant confirms previous results reported by Hughes et al [22], providing additional evidence on its pain score threshold and clinical utility. Previous validation of the tool was conducted using prerecorded videos of children undergoing immunization, and assessments were undertaken by trained assessors on those video recordings, as opposed to parents conducting assessments in a "real-life" environment at home [8,22]. Another key point of the difference between the instruments used is that PainChek Infant is AI-enabled and fully automated, while ObsVAS relies on the ability of parents to observe and then rate their child's pain. In this regard, variability in parents' judgment related to pain assessment and subjectivity when using observational scales have been reported previously [19,31,32]. Therefore, this should be taken into consideration when interpreting the results obtained when parents use ObsVAS.

Our findings, based on the GEE model, confirm the likelihood of parents undertaking an intervention when pain is identified with either PainChek Infant or ObsVAS. A medicinal intervention, which included pharmacological treatment (mainly paracetamol), was more likely during pain presence as opposed to a nonmedicinal intervention such as breastfeeding or comforting. Additionally, when pain was present, parents were more likely to select a nonmedicinal intervention as opposed to no intervention at all. Furthermore, for both instruments used, there was a clear relationship between higher pain scores and the choice of intervention, with the highest pain scores being more closely associated with medicinal intervention, followed by nonmedicinal intervention. No intervention category was associated with the lowest pain scores. These findings confirm the ability of parents to respond to the presence of pain in their child and to choose a treatment option to manage the pain. This was observed independent of parents' education levels. Our findings confirm the effectiveness of the interventions undertaken by parents considering that the presence of pain, which was indicated by most assessments, improved to no pain. While this trend was observed for both instruments, the use of the PainChek Infant instrument was associated with a higher likelihood of change from pain to no pain compared to ObsVAS. Nonetheless, our results suggest that both instruments assisted parents in identifying pain and making decisions on pain management and helped in rechecking that the pain experienced by their child had diminished.

One of the key strengths of this study is that it provides insights into parents' use of standardized pain assessment tools to identify and make decisions on the management of their child's pain at home. There is scarce literature in this area. However, there are a number of limitations that should be considered overall and that should be taken into account when interpreting our findings. First, the study was conducted with a small number of parents at 1 hospital center only. The issues of small sample size and single-center design limit the generalizability of our findings to a broader audience of parents, and this should be considered when interpreting our findings. Furthermore, other hospitals may have different protocols for managing infant pain following minor surgical procedures, which may affect how parents behave during pain management at home. Second, while ObsVAS was only offered to parents who were using an Android device, it is difficult to judge how this group of parents would have behaved if they were iOS users. Previous studies have already reported on behavioral differences between Android and iOS users [33,34]. At the time when the study was conducted, PainChek Infant was only available on iOS. Moreover, it remains unclear why a higher proportion of those parents using an iPhone device (approached to use PainChek Infant) failed to complete the study despite follow-up attempts. Additionally, it should be noted that the majority of parents who participated in this study were female. The differences may have been driven by greater recruitment of parents using iOS devices, and female individuals have been reported to be more inclined to use iOS devices as opposed to Android devices [34]. Considering this, the recruitment of Android users may have resulted in a higher percentage of male participants conducting pain assessments, which may have impacted the study findings regarding intervention choices. This limitation suggests that there is a need for more research comparing differences between iOS and Android users, especially in the area of postsurgical infant care and specifically pain management. This was not a focus of our study. Another consideration regarding the interpretation of our study findings is parents' education levels, with the majority of parents administering PainChek Infant and ObsVAS having completed tertiary-level education. Nonetheless, our results appear to not have been affected by this particular factor considering that our findings suggest that the ability of parents to respond to the presence of pain in their child was independent of their education. The potential overlap of pain- and nonpain-related distress among parents during the assessment of pain should also be considered. This is a potential limitation that has been acknowledged by a number of other studies reporting on the use of other pain assessment tools [8,35,36]. However, given that in both groups of parents (ie, PainChek Infant and ObsVAS users) the source of pain was known (ie, circumcision procedure), the possibility for this overlap was reduced. To further mitigate this issue, parents using PainChek Infant had the ability to rule out other common causes of nonpain-related distress, such as the child being hungry or tired, as this functionality is built into the PainChek Infant app itself. This could also explain some differences identified between the 2 instruments and may have affected parents' decisions regarding the choice of intervention after ruling out nonpain-related distress. Further studies are needed to explore this issue. The study could have also benefited from the exploration of other available pain assessment tools used in infants, such as the Neonatal Facial Coding System. However, this decision was balanced against potential implications related to recruitment and the need for further training of parents. Further research in this area is recommended.

Although this study had the abovementioned limitations, it provided valuable insights into parents' use of standardized pain assessment tools at home, the selection of interventions when pain is detected in their infants, and the effectiveness of these interventions. Additionally, the study provided further evidence regarding the construct validity and clinical utility of both PainChek Infant and ObsVAS, which were used by parents to assess pain at home for over 3 days after surgery. Both tools were able to inform clinical decision-making and were instrumental in determining the effectiveness of interventions chosen by parents.

Conclusions

Our findings provide insights into parental assessment and management of pain in their infants at home following hospital discharge from same-day surgery (ie, circumcision). Feeding alone and a combination of feeding with medication use were the key pain intervention strategies used by parents after identifying pain using standardized pain assessment tools. We further demonstrated the construct validity and showed that PainChek Infant and ObsVAS have similar clinical utility in assisting parents regarding the selection of pain interventions and the determination of their effectiveness, thus supporting their clinical decision-making.

Acknowledgments

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Authors' Contributions

KH, FS, and JH conceived the idea and designed the study. PC conducted the statistical analyses, and PC, KH, FS, and JH reviewed the outputs. KH drafted the initial manuscript, which was reviewed by all authors. SC engaged in participant follow-up. FS, SS, KU, and SC provided clinical oversight of the study. All authors critically reviewed the manuscript and approved its final version.

Conflicts of Interest

KH and JH are shareholders in PainChek Ltd (formerly known as EPAT Technologies Ltd), which is commercializing PainChek Infant. They are also named as coinventors with Mustafa Atee on the patent entitled “A pain assessment method and system,” which has been granted in the United States, China, Europe, and Japan. KH is employed as a consultant by PainChek Ltd and also serves as a Professor at the University of Prishtina. JH is employed as the Chief Scientific Officer of PainChek Ltd and holds an Emeritus Professor appointment at the Curtin Medical School, Curtin University. PC was engaged through DATaR Consulting and was paid as an independent private consultant to undertake the biostatistical analysis for the project by PainChek Ltd. PC also serves as Manager Research Support and Development, Child and Adolescent Health Service and holds an adjunct appointment at the School of Medical and Health Sciences, Edith Cowan University. FS serves as a Professor at the University of Prishtina and is employed at Kavaja Hospital. SC, SS, and KU are also employed by Kavaja Hospital.

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Abbreviations

AI: artificial intelligence

AU: action unit
EMM: estimated marginal mean
GEE: generalized estimating equation
ObsVAS: Observer-Administered Visual Analog Scale
OR: odds ratio
QIC: Quasi-likelihood under the Independence Model Criterion
ROC: receiver operating characteristic

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Effect of a Web-Based Nutritional and Physical Activity Intervention With Email Support (the EDDY Program) on Primary School Children’s BMI Z-Score During the COVID-19 Pandemic: Intervention Study

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Abstract

Background: COVID-19 mitigation measures enhanced increases in children’s weight and BMI due to decreased physical activity and increased energy intake. Overweight and obesity were major worldwide problems before the pandemic, and COVID-19 increased their severity even more. High BMI directly correlates with health disadvantages including cardiovascular diseases, musculoskeletal disorders, and mental health diseases. Therefore, it is vitally important to develop counteracting interventions to maintain children’s health during exceptional situations like pandemics. However, worldwide data from such interventions are limited, and to our knowledge, no suitable study has been carried out during the pandemic in Austria.

Objective: This study was conducted to examine a 15-week web-based intervention with email support, the EDDY (Effect of Sports and Diet Trainings to Prevent Obesity and Secondary Diseases and to Influence Young Children’s Lifestyle) program and the effect of nutritional education and physical activity on children’s BMI z-score during the COVID-19 pandemic in Vienna, Austria.

Methods: The intervention consisted of 3 weekly videos—2 physical activity and 1 nutritional education video, respectively—and a biweekly email newsletter for the parents. This study was conducted in a Viennese primary school from February to June 2021 by a team of physicians, nutritionists, and sports scientists, including both professionals and students. The study population included an intervention group (who received web-based nutritional and physical activity training) and a control group (who received no intervention), comprising in total 125 children aged 8 to 11 years. Due to COVID-19 mitigation measures, the control group was a comparative group observed during the prior school year (2019-2020). Anthropometric measurements were obtained before and after the intervention in both groups.

Results: Due to a high dropout rate (n=57, 45.6%) because of the mitigation measures, there were 41 children in the intervention group and 27 in the control group. At baseline, the BMI z-score was 1.0 (SD 1.1) in the intervention group and 0.6 (SD 1.2) in the control group (P=.17). After the study period, the BMI z-score decreased by 0.06 (SD 0.21) in the intervention group, whereas it increased by 0.17 (SD 0.34) in the control group (P<.001). Comparing the change in BMI z-scores within BMI categories in the intervention group and control group revealed a statistically significant difference in the normal-weight children (P=.006). Further results showed that the decrease in BMI z-score was significant in the intervention group among both boys (P=.004) and girls (P=.01).

Conclusions: A web-based intervention with combined nutritional education and physical activity training might be an adequate tool to lessen the enhanced increase in body weight during a pandemic. Therefore, additional studies with greater sample sizes and different locations are needed. As the implementation of such intervention programs is essential, further studies need to be established rapidly.

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KEYWORDS

childhood obesity; BMI; prevention intervention; physical activity; nutrition; nutritional; school-based; web-based; COVID-19; diet; child; childhood; children; pediatric; pediatrics; weight; obesity; obese; exercise; school; student; students; youth

Introduction

Since the implementation of COVID-19 restriction measures to reduce the transmission of the disease, the daily routines of adults and children have changed dramatically. As a consequence, an increase in energy intake and a decrease in physical activity (PA) has been reported in schoolchildren [1-3], affecting their BMI and increasing the severity of overweight and obesity [1,2]. In Austria, studies have also reported an increase in body weight and BMI during lockdowns [4-6], affecting boys especially. The restriction of daily activities, the stay-at-home orders, and the closure of playgrounds and sports facilities led to decreased levels of PA in children. Moreover, school PA education classes were interrupted, which may have influenced the observed decrease in cardiorespiratory fitness measurements reported previously [4]. A decline in PA was also described worldwide [3,7], being greater among boys and those who lived in apartments or houses with limited space. Being physically active has proven beneficial in improving physical fitness, BMI [8], and markers of cardiovascular health, as well as bone and mental health [9].

In contrast, obesity is known to have many health disadvantages. There is a direct correlation between elevated BMI and elevated risk for cardiovascular diseases, diabetes, musculoskeletal disorders, cancer, and mental disorders [10,11]. Therefore, implementing programs to prevent and tackle childhood obesity is one of the main research aims of the World Health Organization [12] to maintain children's health.

Further studies suggest that school-based interventions play an essential role in the prevention of childhood obesity [13-16]. The combination of PA and nutritional education is most effective [17]. Additionally, parental involvement in nutrition and PA [3] interventions is crucial to promote healthier lifestyle behavior. Since parenting practices and parent-child interactions are formative in children's health-related behaviors, studies suggest that interventions with parental involvement are more effective [18]. Moreover, parents and children ask for realistic approaches, such as ideas for active games and activities or healthful meals and snacks that families can enjoy [19].

Furthermore, study authors have recommend the opportunity to use web-based interventions to promote healthy behaviors [14]. Online training programs have been suggested to support healthy eating and active movement [5,20-22]. A parent-focused online intervention in Australia led to improvement in dietary-related practices and self-efficacy [23]. Also, evidence indicates that implementing web-based programs at schools could be beneficial, as a high number of people can be reached and they are easy to conduct [24]. Results from web-based studies with other outcome variables, such as alcohol drinking prevention, tobacco knowledge, and eating disorder prevention in children and adolescents, also indicate the usefulness of web-based interventions in children and adolescents [24-26]. Communication tools provide useful means to develop digital health content that can be accessed easily through social media platforms such as YouTube. However, to be effective, this content should be age tailored, involve limited equipment [20], and be able to motivate children [27]. Compared to face-to-face programs, online intervention programs offer advantages such as convenience and self-engagement with PA. On the other hand, family income could be a limitation regarding internet access, mobile device availability, proper space [28], or adequate equipment [29] to perform PA.

Recent studies have called for further investigations focusing on a combination of settings [15,17] and on parents' involvement [30]. As the COVID-19 pandemic and its effects on children increased the severity of childhood overweight and obesity [1,2], it is of major importance to find a way to execute a web-based preventative intervention in this specific setting in order to gather more knowledge, as there is expected to be an increased risk of other infectious disease outbreaks with climate change [31].

Therefore, we aimed to examine the effects of a 15-week web-based nutritional and PA intervention with email support and parental involvement on BMI z-score among children aged 8 to 11 years during a school year that took place in the context of the COVID-19 pandemic in Vienna.

Methods

Study Design

This intervention study was designed to involve children and parents as part of the EDDY (Effect of Sports and Diet Trainings to Prevent Obesity and Secondary Diseases and to Influence Young Children's Lifestyle) program. The EDDY program focuses on nutrition and PA training to prevent childhood obesity and takes place in primary schools in Vienna, Austria. It was founded by the Austrian Academic Institute for Nutrition in Vienna in cooperation with the Institute for Sport Science of the University of Vienna by a professional team consisting of physicians, nutritionists, and sports scientists, as well as students studying for these professions. The EDDY program was implemented in 2012 in the primary school VS (Volksschule; German for "primary school") Haebergasse 1120, Vienna, and is part of the school's fourth-grade curriculum [32]. Thus, all fourth-grade students are candidates to participate in the study with previous consent from their parents or legal guardians. The planned intervention and all anthropometric measurements were performed in the school setting.

In the 2019-2020 school year, a 6-month school-based nutritional and PA intervention was planned. Due to the outbreak of the COVID-19 pandemic, the school-based intervention had to be stopped after 3 weeks in March 2020, but baseline and end measurements could still be obtained. During the 2020-2021 school year, an on-site intervention was difficult to schedule due to the sustained restriction measures. Therefore, a 15-week web-based nutritional and PA intervention program was developed covering areas of knowledge and practices related to healthy meals, snacks, and drinks, as well as PA. Moreover, parents received an informative email newsletter.

Due to the COVID-19 pandemic, the web-based intervention could only be carried out at one school due to mitigation restrictions and the Austrian government being stringent with school studies during that time. To simplify the intervention's feasibility, the intervention sample comprised all 3 of the school's fourth-grade classes.

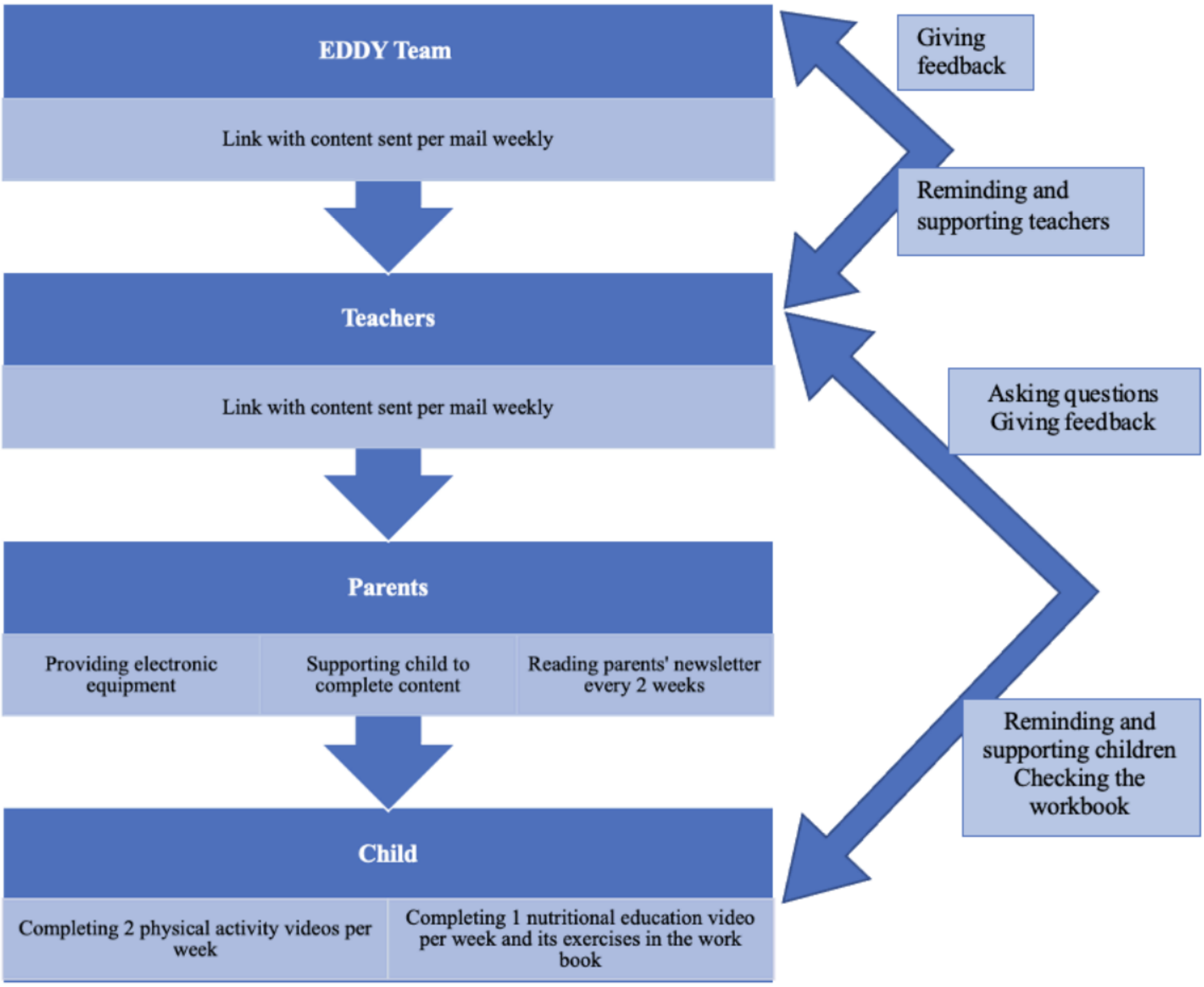
Ethical Considerations

The study was approved by the research ethics committee at Sigmund Freud University in Vienna, Austria (PAFGRW9O@EFQV885378). Legal guardians of all children enrolled in the study provided written informed consent for participating in the study after receiving an informative letter about the procedure of the intervention. The children themselves gave their own consent. The ability to opt out was provided at any point. All gathered data in this study were anonymized. As the EDDY program is part of the school curriculum, compensation was not provided to study participants.

Description of the Intervention

The web-based intervention implemented in this study consisted of 2 main components: (1) nutritional education and (2) stimulating a PA routine during a 15-week period from February to June 2021 with 3 videos per week. Educational and movement content was provided as videos via YouTube. As the videos were not publicly available, the parents received a weekly email with a link to access the content. Therefore, parents needed to instruct their children to watch the videos and support them with electronic equipment. Figure 1 shows a description of the intervention and each participant's role.

Figure 1. Description of the intervention and each participant's role. EDDY: Effect of Sports and Diet Trainings to Prevent Obesity and Secondary Diseases and to Influence Young Children's Lifestyle.



Nutrition

Previous nutritional lessons from the EDDY program have been adapted for web-based training [32]. The educational content was recorded by nutritional scientists and medical school students. It includes both theoretical and practical age-targeted content focusing on food with high nutrient content (vegetables, fruits, and legumes), relevance of timing in eating, and skills to prepare and select healthier food choices, such as recipes for easy, healthy snacks and identification of suitable portion sizes. The content is based on food groups and the healthy plate [33]. Videos were delivered once a week with a duration ranging from 10 to 20 minutes.

Additionally, a workbook with worksheets was provided, including questions about the content of the videos, quizzes, and practical tasks. Progress was monitored for feedback and positive reinforcement.

PA Training

The PA training was designed and conducted by a team of sports scientists, physicians, and students. Since we provided web-based videos and did not have face-to-face contact with the children, the workouts were designed to not require any equipment and use only the participants' own body weight.

Each week, the children received two 25-minute videos via YouTube; one focused on strength training and the other on endurance training. The strength training started with a warm-up phase (coordination exercises and warm-up games) that focused on the correct execution of the subsequent strength exercises. The intensity of the exercises was slow to moderate. The warm-up phase was followed by 10 to 15 minutes of strength training that incorporated 4 to 6 exercises (eg, squats, stretch jumps, push-ups or plank exercises, spider walking, duck walking, sit-ups, and wall sitting) for the entire body. Two series with a repetition count of 15 to 20 repetitions were targeted per exercise. The strength training was taught in a playful way that included the use of children's stories.

The endurance training was structured as follows: The primary focus was to keep children moving continuously over a 25-minute period. The intervention included standing endurance runs, knee runs, heel runs, jumping jacks, frog jumps, boxing exercises, and gymnastic exercises with moderate to high intensity. In addition, dances were choreographed to child-friendly pop music to increase the entertainment factor. All videos ended with a short relaxation and cool-down session. Here, yoga and stretching movements were incorporated and relaxation stories involving fantasy journeys were told in order to achieve better body awareness and to recover from the PA.

The videos were repeated 2 times during the 15-week intervention period to create confidence and enthusiasm for improving physical fitness through the repetition effect.

Intervention for Parents

A major part of the intervention was the inclusion of parents or legal guardians. During the intervention period, the parents received an email newsletter every 2 weeks with healthy lifestyle recommendations, nutrition facts, recipes, and tips on how to increase the amount of time spent physically active. Information on how to increase PA during the period of social distancing and restriction measures (eg, self-use of outdoor gyms and playgrounds and indoor family workouts) was a particular focus. Also, parents received all the intervention videos for the children from their teachers (in the teachers' experience, parents are always more conscientious when being texted by school staff). Therefore, they were in charge of providing electronic equipment and supporting their child in completing the weekly videos.

Involvement of Teachers

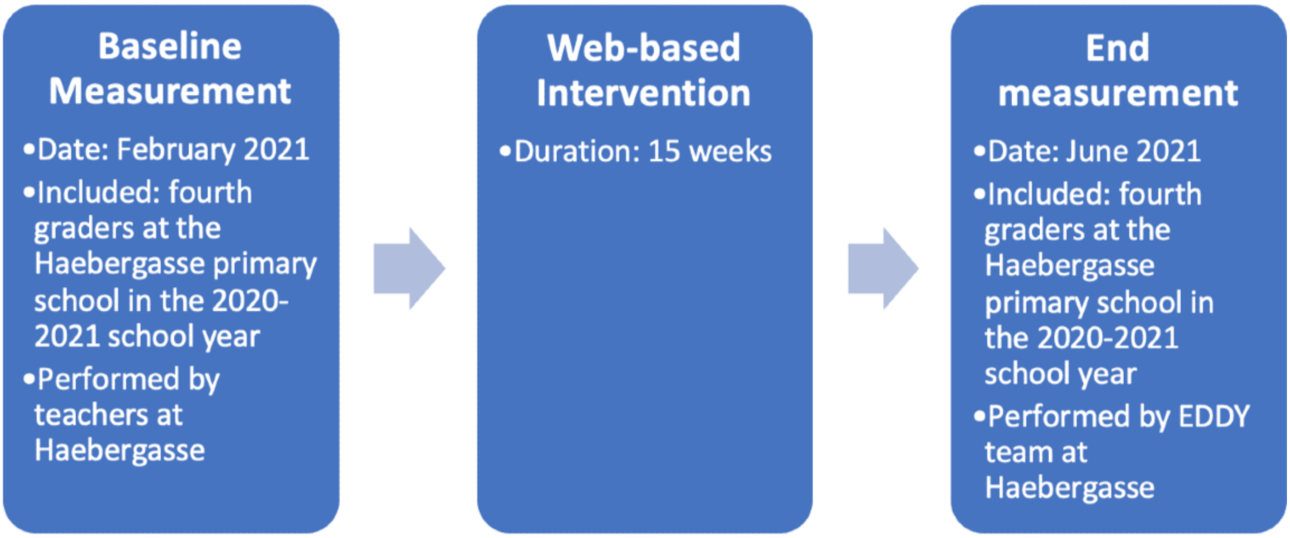
The teachers acted as a link between the children and their legal guardians. At baseline, they received workbooks and distributed them to the children. All videos, newsletters, and information during the 15 weeks of the intervention were sent to the teachers and forwarded to the study participants via email. Teachers interacted closely with the study team, reminded the children to complete the videos, and checked on their workbooks approximately every 2 weeks. Every few weeks, the teachers gave feedback on how the children responded to the content of the intervention.

Participants

Intervention Group

Primary school children from the fourth grade at VS Haebergasse 1120 in the 2020-2021 school year were included and received 15 weeks of web-based nutritional and PA intervention. Anthropometric measurements were performed in February 2021 (before the intervention) and June 2021 (after the intervention) at the school facility. The children were not randomly allocated to the intervention group; instead, all fourth graders in the 2020-2021 school year were eligible for the study to make it more feasible for teachers to organize. As the EDDY program is part of the school's fourth grade curriculum, only children opting out did not receive the weekly videos (Figure 2).

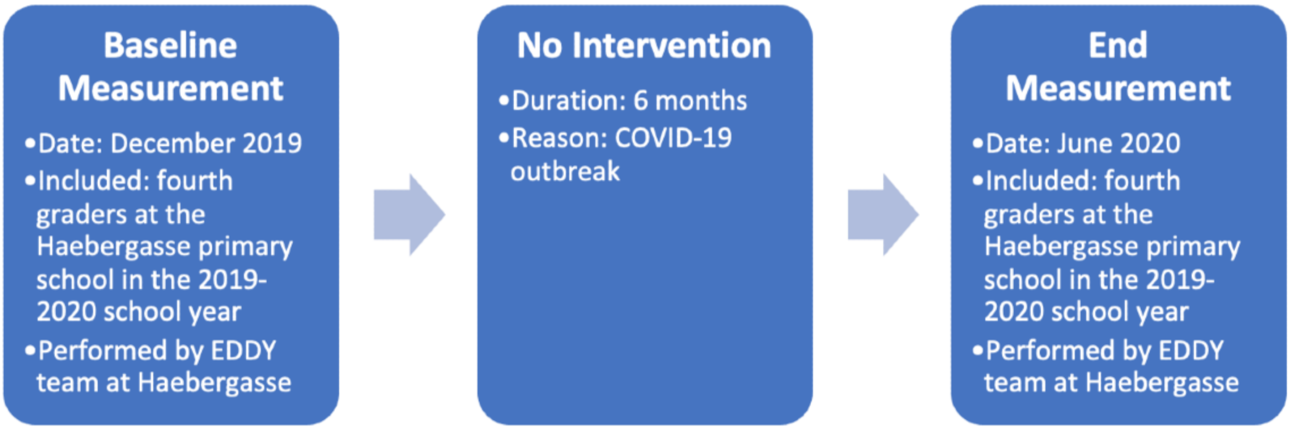
Figure 2. Description of the intervention group's timeline. EDDY: Effect of Sports and Diet Trainings to Prevent Obesity and Secondary Diseases and to Influence Young Children's Lifestyle.



Control Group

For this analysis, primary school children from the fourth grade at VS Haebergasse 1120 in the 2019-2020 school year comprised the control group. During this study year, no repetitions were recorded. Therefore, no children were part of both the control and intervention groups. Anthropometric measurements were performed in December 2019 (before the planned intervention) and June 2020 (after the planned intervention) at the school facility. The planned 6-month intervention could not be carried out due to the outbreak of COVID-19 and state-imposed school closures. The children were not randomly allocated to the control group; instead, all fourth graders in the 2019-2020 school year were eligible for the study to make it more feasible for teachers to organize. Therefore, only children opting out were not included in the measurements (Figure 3).

Figure 3. Description of the control group timeline. EDDY: Effect of Sports and Diet Trainings to Prevent Obesity and Secondary Diseases and to Influence Young Children's Lifestyle.



Inclusion Criteria

To be eligible for this analysis, the participants needed to fulfill the following eligibility criteria: be aged 8 to 11 years, be a student in the fourth grade at the specific primary school where the intervention took place, complete all measurements, and provide written informed consent (both legal guardians and children).

Exclusion Criteria

The exclusion criteria were as follows: be aged <8 or >11 years, not be a student in the fourth grade at the specific primary school where the intervention took place, miss at least one measurement, change class or school during the intervention, and not provide written informed consent (both legal guardians and children).

Outcome Measures

Body weight was measured to the nearest 0.1 kg with a bioelectrical impedance analysis scale (Tanita MC-780MA) without shoes or excessive clothing. Body height was evaluated to the nearest 0.1 cm with a portable stadiometer (Seca) with the participant standing and maintaining their head in the Frankfort horizontal plane position without shoes.

BMI was calculated as weight (kg) divided by square of height (m^2) and classified according to age and sex. BMI z-scores were used for further analysis [34]. SDs for the BMI z-scores were calculated and BMI categories were classified in reference to Kromeyer-Hauschild et al [35]. The obesity category was considered as the sum of obesity and extreme obesity.

Measurements were performed at 2 time points for both groups at the primary school. Due to COVID-19–related school closures in December 2020 and January 2021, baseline measurements of the intervention group were postponed to February 2021. Due to ongoing COVID-19 restrictions and social limitations, the EDDY team could not perform baseline measurements of the intervention group themselves; therefore, they were performed by the teachers at school with the school doctor's equipment. To obtain accurate measures, the EDDY team standardized the measurement procedures among the teachers by giving instructions via video. End measurements of the intervention group were performed by the EDDY team. The control group was measured by the EDDY team at both measurement time points.

Statistical Analysis

For statistical analysis, all data were analyzed with SPSS (version 27; IBM Corp). Continuous variables were expressed as means (range) and categorial variables were expressed as absolute numbers or proportions. Age and sex differences between excluded and included students were determined with the χ^2 test and Mann-Whitney *U* test. Age differences between the study groups were determined using the Mann-Whitney *U* test. Shapiro-Wilk tests were performed to determine standard distribution for BMI, age, weight, height, and BMI z-score at baseline and for BMI z-score differences over the study period. BMI z-score differences in groups and between sex over the study period were assessed using Mann-Whitney *U* tests. For all the above tests, statistical significance was considered as $P<.05$. BMI z-score differences between study groups within the BMI categories were tested with the Mann-Whitney *U* test. Therefore, the Bonferroni test was used as a post hoc analysis, for which statistical significance was considered as $P<.017$.

Results

Study Population at Baseline

At baseline, 125 children (age range 9.25 to 11.75 years) were eligible to participate in the study (n=68 boys and n=57 girls);

there were 56 children in the intervention group and 69 students in the control group. Eventually, 57 children (45.6%) could not be included due to quarantines or absence from school and missing measurements; 15 children in the intervention group and 42 in the control group. The total number of excluded students included 22 girls and 35 boys. The mean age in the dropout group was 10.34 (SD 0.57; range 9.25 ‐ 11.75) years. The excluded and included students did not differ by sex (*P*=.15) but did differ by age (*P*=.02).

Finally, there were 41 children in the intervention group and 27 in the control group. Anthropometric data for the study participants are shown in Table 1.

The mean age in the intervention group was 10.2 (SD 0.5; range 9.41 ‐ 11.17) years and 10.0 (SD 0.5; range 9.33 ‐ 11.08) years in the control group. There was no significant difference in age between the intervention and control groups (*P*=.09).

At baseline, n=8 (20%) children in the intervention group and n=4 (15%) children in the control group were classified as obese, with excessive BMI (≥90th percentile) for their age and sex. In the intervention group, 2 (1 female, 1 male) of 8 children with obesity were classified as extremely obese (≥99.5th percentile). Additionally, in the control group, 1 (female) of 16 children with normal weight was classified as low weight but was represented as normal weight in the figures and tables due to the small number. BMI classification at baseline testing and end testing in each study group is shown in Table 2.

Table . Age and anthropometric data of study participants at baseline.

	Intervention group, mean (SD)			Control group, mean (SD)			*P* value
	Total (n=41)	Female (n=23)	Male (n=18)	Total (n=27)	Female (n=12)	Male (n=15)	
Age (years)	10.2 (0.5)	10.0 (0.4)	10.4 (0.6)	10.0 (0.5)	9.9 (0.4)	10.1 (0.6)	.09[a]
Weight (kg)	43.0 (10.8)	40.4 (8.6)	46.3 (12.6)	39.5 (9.6)	39.3 (11.1)	39.7 (8.6)	.24[a]
Height (m)	142.8 (6.4)	142.3 (6.4)	143.5 (6.5)	142.1 (7.3)	142.0 (7.9)	142.2 (7.1)	.69[b]
BMI (kg/m^2)	21.0 (4.5)	19.8 (3.6)	22.4 (5.2)	19.4 (3.8)	19.3 (4.4)	19.5 (3.4)	.16[a]
BMI z-score	1.0 (1.1)	0.8 (0.9)	1.2 (1.3)	0.6 (1.2)	0.5 (1.4)	0.7 (1.1)	.17[b]

[a] Mann-Whitney *U* test.

[b] Student *t* test.

Table . BMI classification in the study group at baseline testing and end testing.

		Control group participants (n=27), n (%)	Intervention group participants (n=41), n (%)
Baseline testing			
	Normal weight	16 (59)	24 (59)
	Overweight	7 (26)	9 (22)
	Obese	4 (15)	8 (20)
End testing			
	Normal weight	17 (63)	25 (61)
	Overweight	4 (15)	7 (17)
	Obese	6 (22)	9 (22)

Change in BMI z-Score After Intervention

After the implementation of the web-based study, the average BMI z-score decreased by −0.06 (SD 0.21) in the intervention group and increased by +0.17 (SD 0.34) in the control group; this was statistically significant (*P*<.001) (Figure 4).

Within the normal-weight BMI category at baseline, there was a statistically significant difference (*P*=.006) between the control group and intervention group for change in BMI z-score. Within the overweight (*P*=.039) and obese (*P*=.062) BMI categories at baseline, there was no statistically significant difference between the control group and intervention group for change in BMI z-score. In the intervention group, the percentage of participants in the overweight BMI category decreased from 22% (n=9) to 17.1% (n=7), representing a change of −4.95%, and the percentage in the obese BMI category increased from 19.5% (n=8) to 22%(n=9; +2.5%). In the control group, the percentage in the overweight BMI category decreased from 25.9%(n=7) to 14.8% (n=4; −11.8%), and the percentage in the obese BMI category increased from 14.8% (n=4) to 22.2% (n=6; +7.4%).

Figure 5 shows the exact change for BMI z-score within the BMI classification at baseline.

Figure 4. Change in BMI z-score during study period. *Mann–Whitney *U* test: *P*<.001.

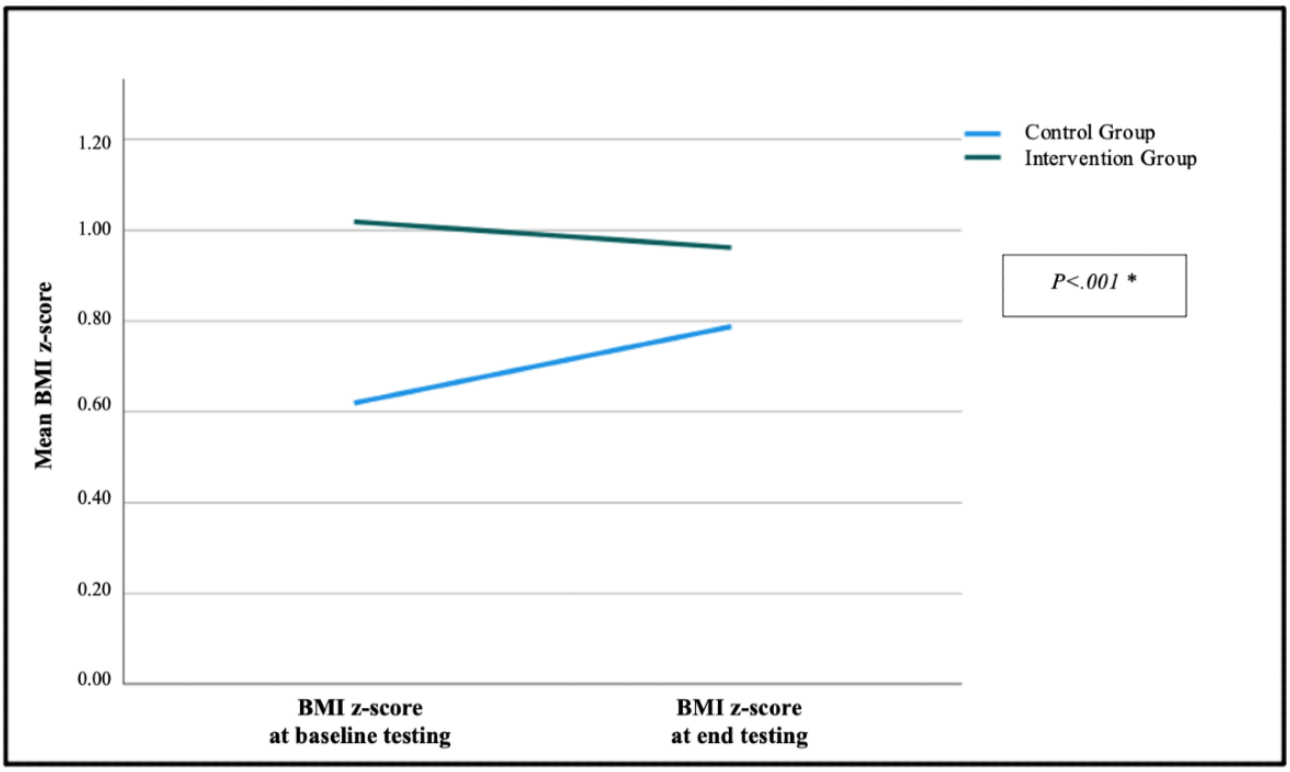
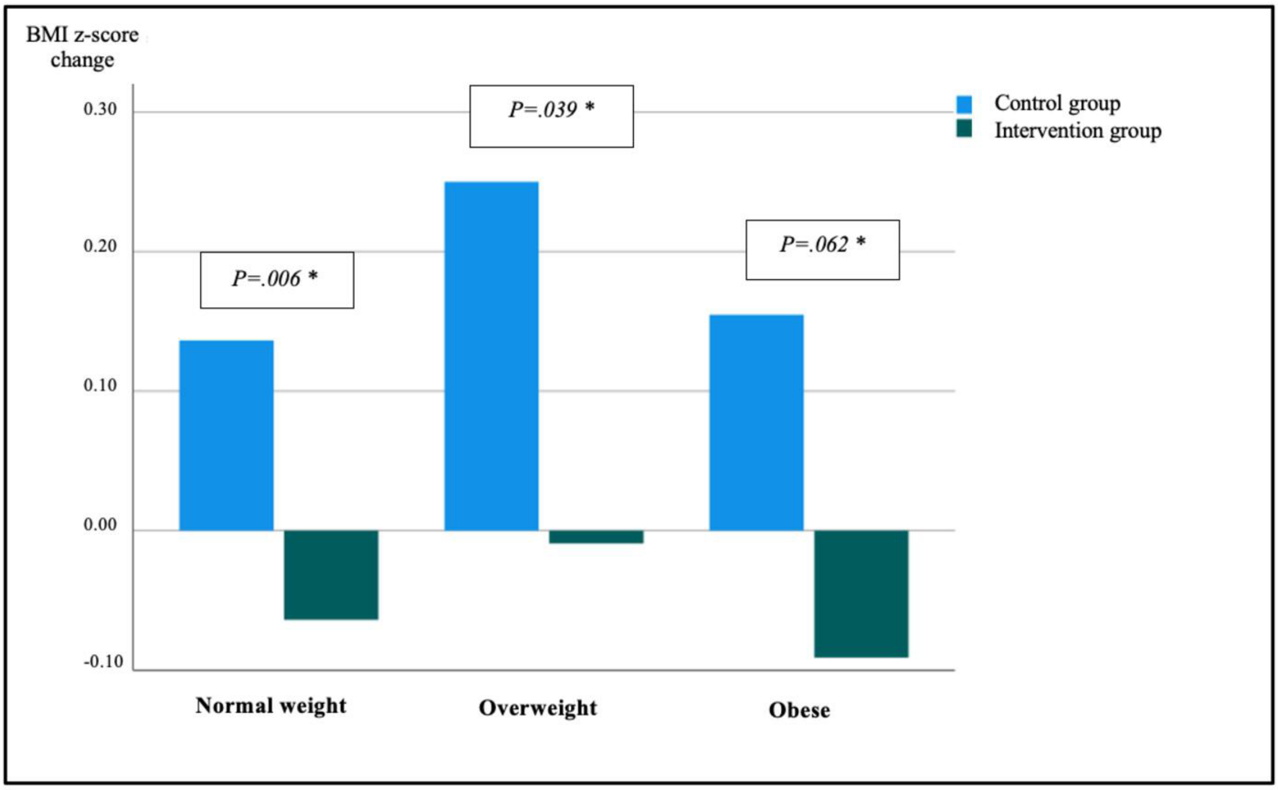


Figure 5. Change in BMI z-score after 15 weeks within the BMI classifications. *Mann–Whitney *U* test for each category: normal weight: *P*=.006; overweight: *P*=.039; obese: *P*=.062. Statistical significance was set after Bonferroni correction at *P*=.017.



Change in BMI z-Score After Intervention According to Sex

Over the study period, the average BMI z-score for girls in the intervention group decreased by −0.04 (SD 0.23) and increased by +0.14 (SD 0.43) in the control group (*P*=.01). Among the boys, BMI z-score decreased by −0.08 (SD 0.19) in the intervention group and increased by +0.19 (SD 0.27) in the control group (*P*=.004). Figures 6 and 7 show the change for BMI z-score over the study period by sex and study group at baseline.

Figure 6. Changes in BMI z-score after 15 weeks in boys according to study group. *Mann–Whitney *U* test: *P*=.004.

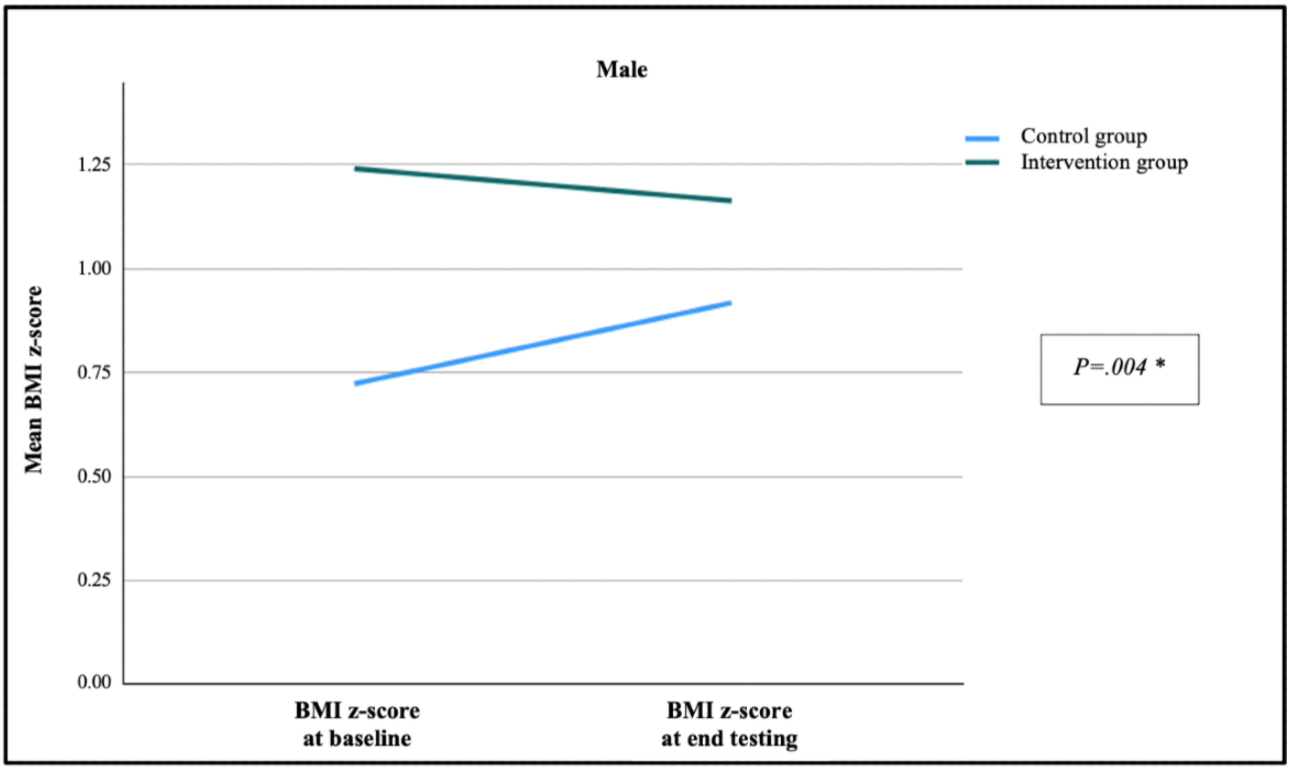
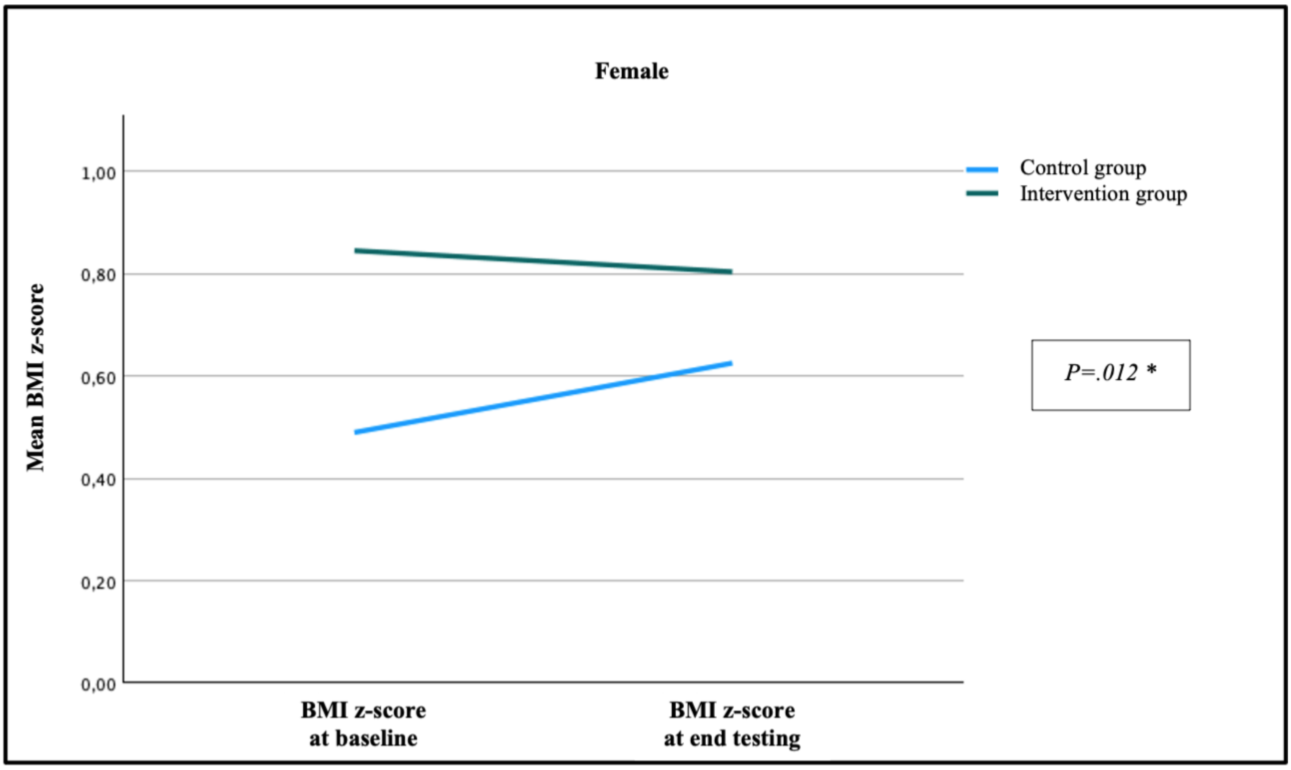


Figure 7. Changes in BMI z-score after 15 weeks in girls according to study group. *Mann–Whitney *U* test: *P*=.01.



Discussion

In Austria, EDDY is one of the few science-based projects for the prevention of childhood overweight and obesity and its secondary causes. When creating the EDDY online program, we aimed to demonstrate the effect of a web-based nutritional education and PA training course with email support on BMI z-score in primary school children during the COVID-19 pandemic. A 15-week nutritional education and PA intervention was performed, and a control group of the same age and at the school, but from the prior school year, was used for analysis. The mean BMI z-score in the intervention group decreased significantly, by 0.06, over the study period. Here, it should be noted that the control group was measured during the first period of the pandemic, which might have affected the results due to different life circumstances. Recent studies from Austria show that the first period of the pandemic had the biggest impact on children's BMI [6,36]. However, Brown et al [37] recently also showed a mean decrease of 0.05 in the BMI z-scores of children aged 6 to 12 years in a systematic review of 20 RCTs, which supports the results of this analysis. However, all studies included took place outside of the context of a pandemic. To our knowledge, there is no other comparable online nutritional and PA program that was carried out during the COVID-19 pandemic. Even outside the pandemic context, online interventions as a method of overweight and obesity prevention have not been widely used. Data from international web-based studies are limited. A positive effect on the eating habits of children and adolescents is often reported [38]. The implementation of an online intervention study, such as the EDDY online program, has numerous advantages. A web-based model, which was used for this intervention, can be used with minimal staffing costs [39]. The COVID-19 pandemic led to difficulties in performing ordinary on-site intervention studies, but led to new ways of teaching, such as distance learning. Thus, the study participants in the EDDY online program were able to take part in the intervention despite school closures and social distancing, which could be beneficial in other exceptional situations, like other pandemics. Moreover, by delivering the intervention content through videos, children with language difficulties had the opportunity to repeat the videos as many times as required and choose their own pace. These could be advantages of an online setting, but further studies are required. As reported by the headmaster, the percentage of children in this primary school with a migratory background and a non-German first language was very high. Studies from Austria indicate that children with non-German first languages have a higher prevalence of obesity [40]. This could be supported by the higher mean BMI (intervention group: 21.0 kg/m^2; control group: 19.4 kg/m^2) in this study group. The latest Childhood Obesity Surveillance Initiative data indicate a mean BMI of 17.2 kg/m^2 in urban children aged 7 to 11 years [41]. This could have led to selection bias; therefore, studies need to be carried out at different schools in different regions with a higher number of study participants.

Moreover, using BMI alone to assess children's body fat has several limitations [42,43]. BMI cannot determine body fat, which is essential to assess cardiovascular and metabolic risk [44]. Adding waist circumference would be a valid way to assess visceral fat [43]. However, recent studies have shown that assessing body composition is the most precise way to determine children's body fat [42,45] and therefore their obesity-related health level. Due to the COVID-19 pandemic and its mitigation measures in Austria, the determination of body composition was not possible in this study, but further studies should use body composition to evaluate childhood interventions.

Furthermore, studies show that the BMI of children has a high correlation with the BMI of their mothers and fathers [46]. Therefore, the inclusion of parents is essential [47,48]. During the EDDY online program, parents were included in 2 main ways: indirectly, by having the chance to join their children's intervention (eg, engaging in PA training together), and directly, by receiving newsletters (eg, healthy meal ideas and outdoor PA ideas). Studies show that parents are interested in online interventions, especially if they have high flexibility [49] and if they use a realistic approach [19]. This study provided flexibility for parents and children, as there was no time limit on accessing the newsletters and children could make their own time schedule within a school week. Some studies have also assessed improved effects when children and parents receive separate interventions [50]. Hence, developing a more enhanced and more extensive intervention (eg, with informative videos and online workshops) solely for parents could have potential.

Additionally, web-based studies make it difficult to analyze participation rates and the duration of attendance [21,51]. As the EDDY team used YouTube as a sharing platform due to easy accessibility [21], it was possible to track the views on videos. As it was also possible to watch videos more than once, to engage with the video together with classmates, or to watch the video but not engage in PA, it was not possible to analyze the exact participation rate or duration of attendance. Also, assessing if and how long parents read the newsletters was not possible. Nonetheless, the teachers reported a high participation rate in the beginning, which slightly decreased over the 15-week intervention. Further studies need to develop tools for children and parents to better analyze the duration of attendance and participation rate per study participant. Furthermore, the content delivered in this web-based intervention for children needs to be evaluated through further studies. Borra et al [19] showed that children request "cool" music. Hence, the EDDY team used popular music (eg, Disney music) for PA content. Children also liked the idea of a website solely for them with chatrooms to communicate with other participants or counsellors [19]. In Austria, schools often use online platforms to communicate with children and parents, check attendance rates, and upload school documents. Using a preexisting school platform and creating an exclusive section for children where intervention content can be delivered could, therefore, have potential. This could lead to easier access and handling. Delivering content via online games could also be beneficial [19,52]. Mack et al [53] concluded that video games as an additional tool could help increase the compliance of study participants. Protecting children is very important for parents [19]; data security needs to be considered carefully when using other technologies.

This study has some limitations that need to be addressed and could have influenced the results. First, the number of participating children was small; therefore, our findings may not generalize to Austria's child population. Our analyses of sex and BMI category should be interpreted with caution due to the even smaller sample sizes. Second, participating children were from a single school that was already familiar with the EDDY program, which could have led to higher feasibility and a better response from the participants and teachers. Third, the number of participants in the intervention and control groups differed, which may have led to limited comparability. Due to the pandemic, many children were missing one measurement point in the control group because of quarantine, sickness, or deregistration from school. Consequently, the results need to be interpreted carefully because of possible selection bias, though the age difference between the 2 study groups was tested statistically prior to the intervention. Fourth, due to mitigation restrictions, the baseline measurements of the intervention group could not be obtained by the EDDY team and were instead obtained by the teachers under close guidance using the school doctor's equipment, which may have led to minor differences in measuring. Fifth, the observation period differed by 10 weeks between the control and intervention groups, and measurements in the control and intervention groups were also obtained in 2 different years. This might also have impacted the results due to possible differences in lifestyle, environment, or mitigation measures. However, a different approach was not feasible in this study.

Due to the COVID-19 pandemic and restricted physical presence at school, health-prevention interventions were not realizable on site, but technology-based interventions could be used to promote age-appropriate health education. The EDDY online nutritional and PA intervention study with email support aligns with the goal of using a multicomponent approach to tackling childhood obesity and preventing excessive weight gain during periods of social distancing. The study demonstrated a significant decrease in the BMI z-scores of a sample of Viennese primary school children, both in the group overall and when they were divided by sex, after an intervention duration of 15 weeks. Furthermore, the study showed a statistically significant change in the children with normal weight at baseline in the intervention group. However, as this study has several limitations, the results need to be interpreted cautiously. Further studies with fewer limitations are needed to determine whether the results generalize to the entire child population.

This study indicates that this could be a new method to improve children's health during a pandemic. In the future, assessing body composition, enhancing interventions for parents, evaluating the intervention content, and, in particular, creating methods for the analysis of participation rate and duration of attendance are highly recommended.

Acknowledgments

We thank all EDDY (Effect of Sports and Diet Trainings to Prevent Obesity and Secondary Diseases and to Influence Young Children's Lifestyle) members that helped create and perform in the video content and who provided technical support for the web-based intervention. We also thank the headmaster and teachers of the primary school Volkschule Haebergasse 1a, 1120, Vienna, for their collaboration and great interest in the prevention of obesity and its secondary diseases.

Data Availability

The data sets generated during and/or analyzed during this study are not publicly available due to no proper open database having been developed in Austria, but they are available from the corresponding author on reasonable request.

Authors' Contributions

AG contributed to writing (original draft), writing (review and editing), project administration, validation, methodology, investigation, formal analysis, data curation, and conceptualization. PM contributed to writing (original draft), writing (review and editing), methodology, investigation, conceptualization, and formal analysis. RN contributed to supervision, writing (original draft), writing (review and editing), validation, methodology, investigation, and conceptualization. CO contributed to writing (review and editing), methodology, investigation, and conceptualization. SC contributed to writing (review and editing), methodology, and investigation. JS contributed to writing (review and editing) and validation. KW contributed to supervision, writing (review and editing), validation, resources, methodology, and conceptualization.

Conflicts of Interest

None declared.

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Abbreviations

EDDY: Effect of Sports and Diet Trainings to Prevent Obesity and Secondary Diseases and to Influence Young Children’s Lifestyle
PA: physical activity
VS: Volksschule (German for primary school)

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Effects of Food Depictions in Entertainment Media on Children’s Unhealthy Food Preferences: Content Analysis Linked With Panel Data

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Abstract

Background: Entertainment media content is often mentioned as one of the roots of children’s unhealthy food consumption. This might be due to the high quantity of unhealthy foods presented in children’s media environments. However, less is known about the role of the centrality of food placement, that is, whether foods are interacted with, consumed, verbally mentioned, or appear unobtrusively. We also lack longitudinal research measuring both children’s unhealthy and healthy food consumption behaviors as outcomes.

Objective: The aim is to connect content analytical data based on children’s actual media diet with panel data in order to explain children’s food preferences. Moreover, this study not only focuses on the amount of healthy and unhealthy foods children are exposed to, but also on how these foods are presented (ie, centrally or not). Furthermore, we looked at the question of how parental coviewing can diminish (or enhance) the effects of unhealthy (or healthy) food depictions, and we measured healthy and unhealthy consumption as dependent variables.

Methods: We conducted a 2-wave panel study with children and one of their parents (of 2250 parents contacted, 829 responded, for a response rate of 36.84%; 648 valid cases, ie, parent-child pairs, were used for analysis), with 6 months between the 2 panel waves. We linked the 2-wave panel data for the children and their parents to content analytical data for movies (n=113) and TV series (n=134; 3 randomly chosen episodes per TV series were used) that children were exposed to over the course of 6 months.

Results: There was no significant relationship between exposure to unhealthy food presentation and unhealthy (b=0.008; *P*=.07) or healthy (b=−0.003; *P*=.57) food consumption over time. Also, healthy food presentation was unrelated to unhealthy (b=0.009; *P*=.18) or healthy (b=0.000; *P*=.99) food consumption over time. However, there was a significant, positive interaction between unhealthy food presentation and presentation centrality on unhealthy food consumption (b=0.000; *P*=.03), suggesting that the effects of unhealthy food presentation rise with increasing levels of centrality. There was no interaction between unhealthy food presentation and presentation centrality on the consumption of healthy foods (b=0.000; *P*=.10). Also, exposure to healthy food presentation interacted with centrality (b=−0.001; *P*=.003). That is, when a healthy product was presented at maximum centrality, it led to less unhealthy food consumption in children. Coviewing did not interact with exposure to unhealthy foods when explaining unhealthy (b=0.003; *P*=.08) or healthy (b=−0.001; *P*=.70) food consumption.

Conclusions: We conclude that simply presenting more healthy foods is not sufficient to combat children’s unhealthy food preferences. Further regulations may be necessary with respect to representations of unhealthy foods in children’s media.

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KEYWORDS

children; health; unhealthy food preferences; food depictions; centrality; coviewing; longitudinal linkage study; child; food; eating; diet; dietary; preference; preferences; nutrition; nutritional; diet; media; entertainment; panel; foods; pediatric; pediatrics; food preference; food preferences

Introduction

Background

There is a great debate among parents, teachers, politicians, and marketers as to how the media contributes to the development of childhood obesity [1]. Recently, meta-analytic data [2-4] and literature reviews [1,5] summarizing a large corpus of empirical studies have suggested that children's confrontation with media content, particularly persuasive content—such as traditional TV commercials [6,7], product placements in movies [8], brand presentations in YouTube videos [9], or online advertisements [10,11]—impacts their food preferences and eating behaviors, particularly regarding the consumption of foods high in fat, salt, or sugar.

Media content creates a very narrow food environment for children. Most of the content children are exposed to presents foods high in fat, salt, or sugar [12-17]. This kind of content is not only shown most often, the characters in children's movies also consume these items most frequently and evaluate them predominantly very positively [15]. The consumption of highly processed products that are high in fat, salt, or sugar but low in nutritional value (ie, minerals or vitamins) is contributing to the development of overweight and obesity and therefore can be categorized as unhealthy. The overrepresentation of these foods in audiovisual media content is indeed worrying [18].

Drawing on the notion of cue reactivity, this paper describes a nonexperimental study linking content analytical data with panel survey data on the food preferences of children. We first review the literature on media effects on children's food preferences and then explain the goals, methods, and findings of the study.

Prior Work

Regarding children's media environment, it has been argued that products integrated within editorial content, interrupting the content, can be more influential on product choices than classical advertisements [19]. This is especially true for children because they are still developing their cognitive abilities and might therefore not be aware of attempts to persuade them that are integrated with the entertainment content [20]. A study on the Reactivity of Embedded Food Cues in Advertising Model (REFCAM) [21] found that when such presentations were integrated within the editorial content, it first led to a kind of cue reactivity. This cue reactivity revealed itself with an increased heart rate [22] or a higher likelihood of thinking about the presented product [23]. In the next step, this cue reactivity influenced children's eating habits [21]. The authors described this pathway as being influenced by individual susceptibility factors, such as children's BMI or age, and also by "the level of integration" of a product [21]. Thus, how a product is presented might influence children's reactions.

Although scholars have theorized that the "food-related media diet" is also represented in children's actual diet, this assumption has never been formally tested to date. The available evidence comes from experimental and survey research focusing on unhealthy [24-28] and healthy foods [28-30]. Whether healthy food presentations have the power to influence healthy food choices is not entirely clear from current empirical evidence [19,31].

It might not be sufficient to only consider what food is presented in media content targeted at children; it will also be necessary to consider how the presented food is shown [32]. Since drawing attention to the food is crucial for arousing appetite, reinforcing appreciation for that food and thus triggering eating behaviors [21,33] is more likely when the depicted food plays a central role in the media content. Therefore, presentation centrality, which is commonly connected to interaction with a product (ie, whether one of the characters on screen handles a product, consumes it, or verbally mentions it) [34], is an important factor that needs to be considered. A study by Charry [30] showed that audiovisual presentations of fruit led to higher intentions of choosing fruit compared to a presentation that was only visual. Similarly, findings by Naderer and colleagues [35] suggest that a character handling or consuming the food elicits higher food consumption for the presented snack compared to the food being only visually presented.

Furthermore, social factors can play a crucial role in influencing obesity in children [36]. Parents heavily shape their children's food environment and thus play a significant role in both establishing children's food preferences and gatekeeping the media food environment of their children [37]. The theory of parental mediation states that parents' behaviors can influence how children access, receive, process, and react to media content and to what extent children adopt behaviors presented in media [38]. Parental mediation encompasses a variety of distinct social behaviors [39] that can be important in the prevention of negative media effects in children [40]. One behavior is called social coviewing, which is the joint viewing of media content by parents and children without necessarily talking about the content [39,41].

Experimental data measuring food choices and eating behaviors shortly after exposure to persuasive content suggest that media depictions do significantly shape unhealthy eating behaviors among children [3,4]. However, as valuable as experimental studies are, they do not allow conclusions about long-term effects, and they typically test specific food depictions, not the food-related media diet as a whole. Cross-sectional data examining the correlation of media consumption and children's BMI indicate that children with factors such as extensive TV viewing also are more prone to be overweight or obese [42]. Some first longitudinal examinations also speak to this relationship [43,44]. However, these studies do not take into account the actual content that children are exposed to.

Goal of This Study

With an extensive and externally valid design, this study aimed to link content analytical data on children's actual audiovisual media content—that is, food depictions in movies and TV series they were exposed to—with their food preferences, measured with survey data. This study used panel data from children and their parents over 6 months. The content analytical data represent the appearance and centrality of unhealthy foods, but also—as another urgent area for research—those of healthy foods. The survey data included parental coviewing measures that may diminish (or enhance) the effects of unhealthy (or healthy) food depictions. As dependent variables, unhealthy, but also healthy, food consumption of children was integrated within the model.

Methods

Ethical Considerations

The study was approved by the ethics committee of the University of Vienna (00343) and the principals of the respective schools. Prior to each wave, the children were asked to take home an information sheet, a consent form, and a survey for their parents. All children who returned a consent form that was signed by one of their parents at the first measurement point (T1) were then asked for their oral consent; if they agreed, we interviewed them individually and measured their weight and their height. Data were anonymized.

Procedure

Overview

This longitudinal linkage study combined survey data from parents and children with content analytical data. A 2-wave panel study was conducted with children and 1 of their parents (n=648) with 6 months in between the 2 panel waves. The study combined this approach with a content analysis of movies (n=113) and TV series (n=134; 3 randomly chosen episodes per TV series) that the children or their parents indicated they had been watching during the last 6 months at the second measurement point (T2).

Panel Survey

The data for this study originated from a larger project for which a 2-wave panel survey was conducted among a convenience sample of children and parents who were recruited via primary schools in Austria.

Parents were told that the purpose of the study was academic and that participation was voluntary. We ensured that both the children and their parents were aware that they could withdraw their consent or choose not to answer at any point in time. All parent surveys that were returned were then matched with the data provided by the children. This procedure was followed for both waves. The data for the first wave were collected from March to May 2019; data for the second wave were collected 6 months later.

Initially, the required documents were handed out to approximately 2250 children in 12 primary schools (n=6, 50% of the schools were in urban areas and n=6, 50% in rural areas). Overall, the response rate was 36.84%; thus, initially, 829 children returned the signed informed consent form. Due to some cases of illness and other issues, 795 children were interviewed at T1; 734 of the children at T1 participated again at T2. Comparing the children who remained with those who dropped out revealed no significant difference with respect to gender (*P*=.96), age (*P*=.66), or BMI (*P*=.29)

Moreover, 778 of the children's parents again returned a questionnaire at T2. For the analysis, our primary interest was the data from the children who participated in both waves (n=734). However, the parents' answers were also important to obtain a good picture of what audiovisual content children watched during the 6 months between the 2 measurement points. Overall, 559 parents at T2 filled out the questions concerning their children's consumption of audiovisual content. To construct a meaningful linkage, only cases with at least 3 named movies or TV series over the past 6 months according to the data provided by children or by their parents were included. Following this procedure, the final analyses were based on the data of 648 children aged between 5 and 11 years (T1: mean age 7.78, SD 0.50 years [n=15 missing]; n=313, 48.3% female [n=17 missing]; T2: mean age 8.26, SD 1.24 years; n=313, 48.4% female).

Content Analysis

To determine the sample for the content analysis, the movies and TV series that were named by children and parents in the open-ended questions about past media consumption and the parents' selections from a list in the parental survey at T2 were combined. All movies and TV series that were watched by at least 5 children were considered. Furthermore, audiovisual content named by a child or a parent was only coded if the child had watched at least 3 different movies or TV series. However, to avoid excessive dropout, movies and TV series were included if they were mentioned by fewer than 5 children if at least 1 of them had not mentioned at least 3 other movies or TV series.

The following criteria were applied to determine whether the movies and TV series were relevant for this study: First, all movies and TV series were excluded that were inappropriate for children according to their age rating (we included age ratings up to 12 years). Second, all media content was excluded that did not have a clear storyline; hence, game shows, educational TV series, and cooking shows were removed. Third, all media content was excluded that was not available in German. Finally, movies and TV series were excluded that were not available on streaming platforms or on DVD/BluRay. If multiple movies from the same movie series had been named, a randomizer selected one, again taking into account their availability on streaming platforms or via the Vienna Public Libraries; also, a randomizer selected 3 episodes from each TV series following the same procedure. The final sample consisted of 113 movies and 3 episodes each from 134 named TV series.

Measures

Exposure to Unhealthy and Healthy Products

To determine the independent variable, that is, the children's audiovisual content exposure (ie, movies or TV series) within the 6 months between the 2 waves, the children and their parents were asked which movies and TV series they had seen during this period. In addition to this open-ended question, the parental survey also contained a list of (at the time) popular audiovisual media content for children, as well as content specifically directed at children that was currently available on Netflix (Netflix, Inc) or Amazon Prime Video (Amazon.com, Inc, from which parents were able to choose.

Then, all food and beverage placements within each scene of the 113 movies and 3 episodes from each of 134 TV series were coded; scenes were defined as 5-minute segments. Five coders were extensively trained and, after completing a total of 2 rounds of reliability testing involving a total of 450 scenes, were deemed reliable (healthfulness of the product: Krippendorff α=0.79; food presentation centrality: Krippendorff α=0.85).

Each food placement (n=12,358) was either deemed healthy, unhealthy, or mixed. This differentiation was based on the recommendations of the World Health Organization [45] and former studies as follows: (1) unprocessed products with a high nutritional value were categorized as healthy, including water, unsweetened tea and juice, and fruit and vegetables (n=2953, 23.9% placements); (2) highly processed products high in fat, salt, and sugar were categorized as unhealthy, including sweets, french fries, and soft drinks (n=4926, 39.7%); and (3) products that included healthy as well as unhealthy ingredients were categorized as mixed products, including combined meals (n=4479, 36.2%). However, this study focused on the exposure effects of healthy or unhealthy products.

The total number of healthy and unhealthy placements within each watched movie or TV series (in the latter case, we added up the data from the 3 episodes we coded) per child was calculated; each child saw a mean 20.87 (SD 9.36) unhealthy products and a mean 11.23 (SD 4.43) healthy products.

Additionally, food placement centrality, that is, whether the placement was a focal point (if one of the characters on screen interacted with the product, consumed it, or verbally mentioned it, it was scored a 1; if it was not a focal point, it was scored a 0) was coded. Overall, 7738 (62.4%) product references appeared as focal points. The total number of focal-point placements within each watched movie and TV series per child was calculated (mean 36.99, SD 13.25 placements).

Coviewing

Based on on the work of Valkenburg and colleagues [41], parental coviewing was measured with 4 items on a 7-point Likert scale at T1 (1=never to 7=very often [in response to the question "How often do you watch a movie/TV series together with your child because you both like it?"]; at T1: Cronbach α=0.82; mean score 4.51, SD 1.47) in the parental survey.

Food Preferences

The dependent variables were measured in the panel survey of the children. We assessed how often the children consumed unhealthy food with 4 items ("How often do you eat [drink] sweets/salty snacks/soft drinks?"; 1=never to 4=very often; at T1: Cronbach α=0.65; mean score 2.20, SD 0.60; at T2: Cronbach α=0.68; mean score 2.19, SD 0.57). Furthermore, the children's healthy food consumption was assessed with 3 items ("How often do you eat [drink] fruit/vegetables/water?"; 1=never to 4=very often; at T1: Cronbach α=0.54; mean score 3.36, SD 0.56; at T2: Cronbach α=0.61; mean score 3.41, SD 0.55). In an additional analysis, water was excluded from the index, which did not affect the findings reported in the Results section.

Control Variables

The children's BMI at T1 was included as a control variable. Therefore, the children's weight and height were measured. For the analyses, their zBMI (SD score of BMI [46]) was calculated to adjust their BMI to their age and their gender (T1: n=628; zBMI: mean 0.09, SD 1.12; n=90, 14.3% overweight; n=33, 5.6% obese; n=20 missing). Furthermore, the children's overall audiovisual media exposure was included as a control variable. Children's media consumption was assessed at T2 using 2 items that respectively focused on movies ("How many movies are you allowed to watch on TV or on the internet at home in one week?"; 1=none, 2=one during the weekend, 3=one per day, 4=as many as I want) and TV series ("How many series are you allowed to watch on TV or on the internet at home in one week?"; 1=none, 2=one episode; 3=several episodes; 4=as many as I want). The items formed a reliable index (Cronbach α=0.63; mean 2.58, SD 0.65). Furthermore, we controlled for the children's age (mean age 7.78, SD 0.50 years; n=15 missing) and gender (n=313, 48.3% female; n=17 missing).

Table 1 provides an overview of variables used in the models.

Table . Description of measured variables.

Variables	Values, mean (SD)
Unhealthy food consumption (score; wave 1)	2.20 (0.60)
Unhealthy food consumption (score; wave 2)	2.19 (0.57)
Healthy food consumption (score; wave 1)	3.36 (0.56)
Healthy food consumption (score; wave 2)	3.41 (0.55)
Age (years; wave 1)	7.78 (0.50)
BMI (score; wave 1)	0.09 (1.12)
Media consumption (score; wave 2)	2.58 (0.65)
Unhealthy food presentations (n; wave 2)	20.87 (9.36)
Healthy food presentations (n; wave 2)	11.23 (4.43)
Focal-point placements (n; wave 2)	36.99 (13.25)
Coviewing (score; wave 1)	4.51 (1.47)

Statistical Analysis

A moderated regression analysis was performed controlling for healthy or unhealthy food consumption as autoregressive paths. All predictors were entered simultaneously and terms were mean-centered prior to computing interaction terms.

Results

The expectations were that exposure to unhealthy food products would be (1) positively related with unhealthy food consumption and (2) negatively related with healthy food consumption. Neither of these expectations found support. There was no significant relationship between exposure to unhealthy food presentations and unhealthy (b=0.008; *P*=.07) or healthy (b=−0.003; *P*=.57) food consumption over time. Moreover, this study examined how healthy food presentations in children’s media would relate to unhealthy and healthy food consumption over time. As indicated in Table 2, there were no significant relationships (unhealthy food consumption: b=0.009; *P*=.18; healthy food consumption: b=0.000; *P*=.99).

We found that exposure to unhealthy food presentations and presentation centrality had a significant positive interaction effect with unhealthy food consumption (b=0.000; *P*=.03). The positive sign of the interaction suggests that the effects of unhealthy food presentation rose with increasing levels of centrality. The probing of the interaction [47] is shown in Figure 1: starting from a level of presentation centrality of 1.65, the relationship is significantly positive (b=0.088; *P*=.05) and rises to an effect of b=.034 (*P*=.03). However, unhealthy food presentation and presentation centrality had no interaction with the consumption of healthy foods (b=0.000; *P*=.10).

When it comes to healthy food presentations, there was also a significant interaction with centrality (b=−0.001; *P*=.003). As can be seen in Figure 2, only for low food presentation centrality, there was an effect of exposure to healthy foods on unhealthy food consumption. Probing of this interaction revealed that for a mean-centered centrality lower than −5.196, the effect of healthy food presentations was significantly positive (*P*<.05) and was largest for the lowest centrality (b=0.40; *P*=.003). For values of centrality higher than 31.434, the effect turned significantly negative (*P*<.05) and was largest for the highest centrality (b=−0.07; *P*=.009). This means that when a healthy product was presented at maximum centrality, it led to less unhealthy food consumption in children. In contrast to expectations, healthy food presentation and presentation centrality had no interaction with healthy food consumption (b=−0.000; *P*=.22). Presentation centrality had no significant relationship with unhealthy food consumption (b=−0.005; *P*=.21) or healthy food consumption (b=0.001; *P*=.71).

Table . Unstandardized coefficients for predicting unhealthy food consumption (n=591; R^2=0.299).

Predictors	Unhealthy food consumption (wave 2)	
	b (SE)	*P* value[a]
Constant	1.608 (0.175)	<.001
Unhealthy food consumption (wave 1; autoregressive)	0.384 (0.037)	*<.001*
Gender	0.087 (0.041)	*.03*
Age (wave 1)	−0.050 (0.017)	*.004*
BMI (wave 1)	−0.014 (0.018)	.43
Media consumption (wave 2)	0.111 (0.034)	*.001*
Unhealthy food presentation (wave 2)	0.008 (0.005)	.07
Healthy food presentations (wave 2)	0.009 (0.007)	.18
Presentation centrality (wave 2)	−0.005 (0.004)	.21
Coviewing (wave 1)	0.044 (0.013)	*.001*
Unhealthy food presentations × presentation centrality	0.000 (0.000)	*.03*
Unhealthy food presentations × coviewing	0.003 (0.002)	.08
Healthy food presentations × presentation centrality	−0.001 (0.000)	*.003*
Healthy food presentations × coviewing	−0.002 (0.003)	.60

[a] Significant *P* values are italicized.

Figure 1. Effects of unhealthy food presentations on unhealthy food consumption by presentation centrality.

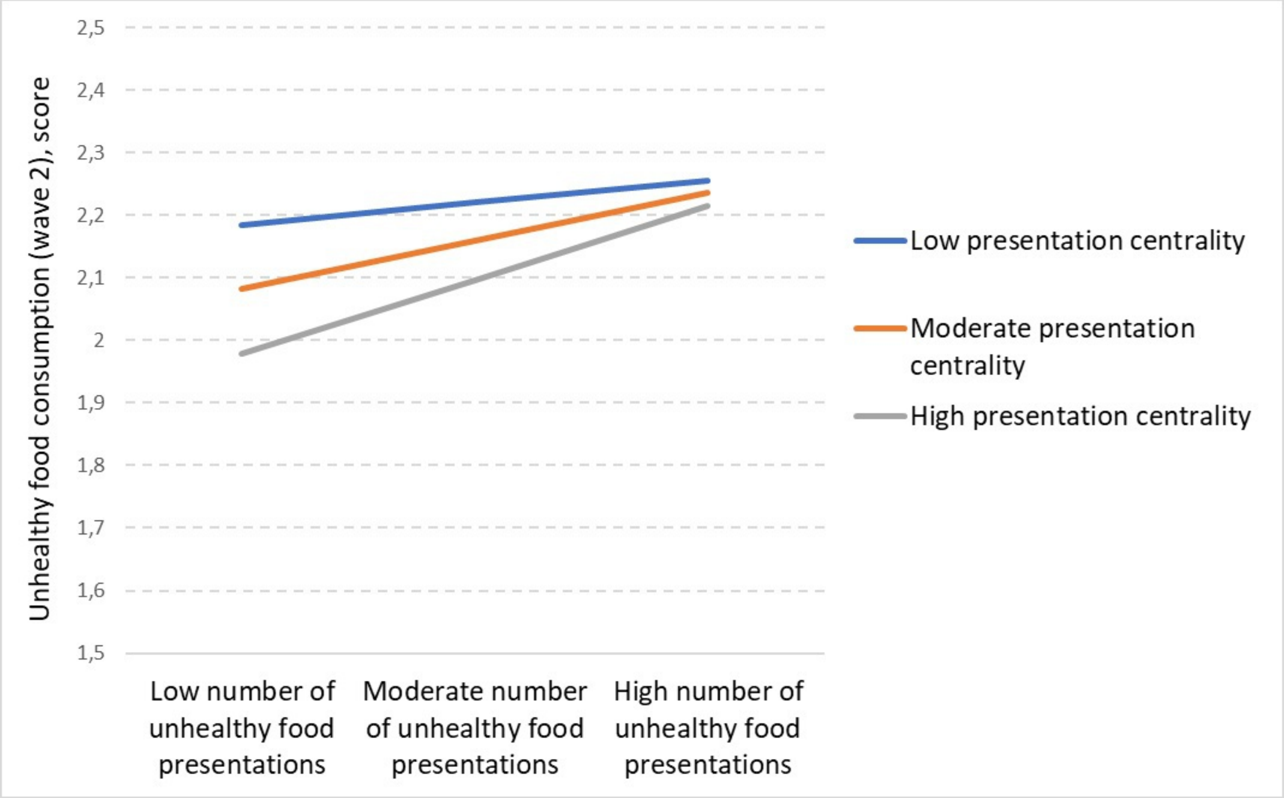
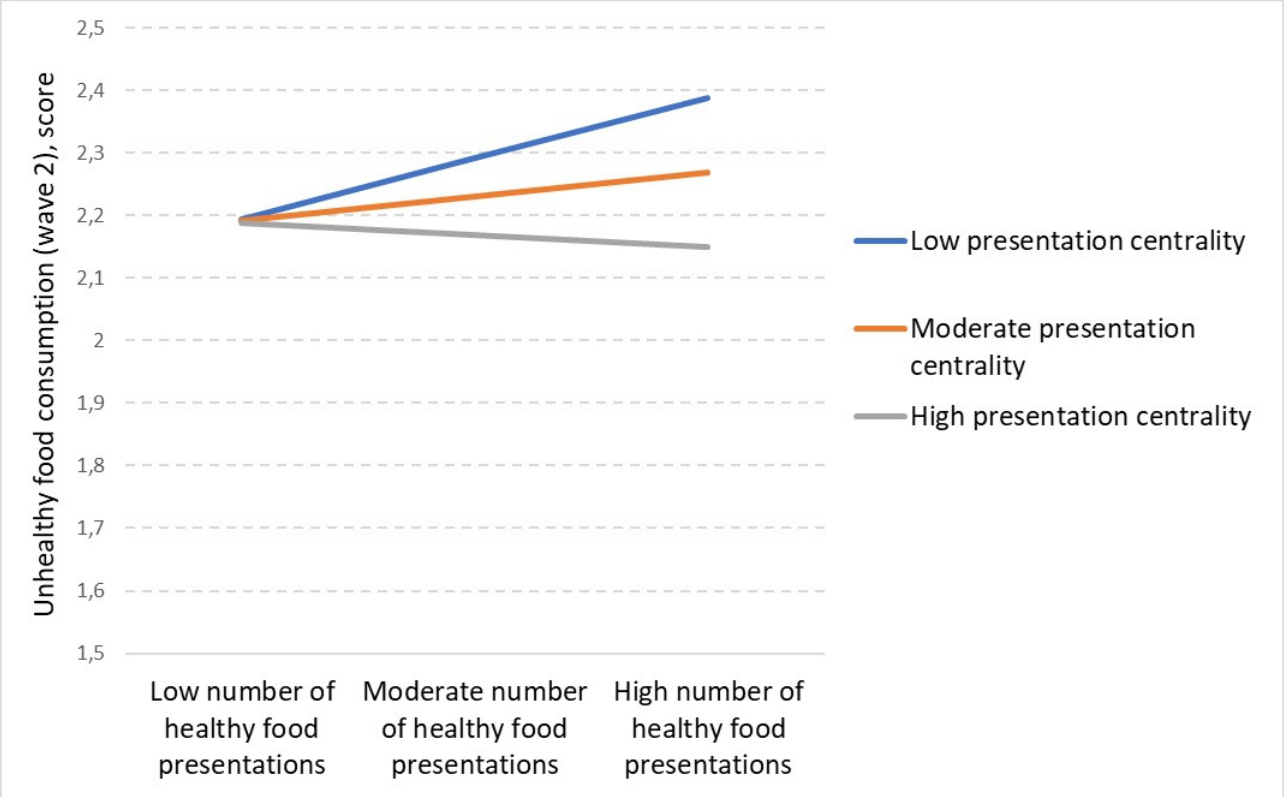


Figure 2. Effects of healthy food presentations on unhealthy food consumption by presentation centrality.



Coviewing did not interact with exposure to unhealthy products in audiovisual media when explaining unhealthy (b=0.003; *P*=.08) or healthy (b=−0.001; *P*=.70) food consumption behavior of children over time. It also did not interact with the presentation of healthy products with regard to unhealthy (b=−0.002; *P*=.60) or healthy (b=0.001; *P*=.74) food consumption. Surprisingly, coviewing was associated with higher unhealthy food consumption over time (b=0.044; *P*=.001), but it was unrelated to healthy food consumption (b=0.005; *P*=.69).

As for the controls, boys were more likely than girls to consume unhealthy foods, and age was positively correlated with unhealthy food consumption. Both gender and age were unrelated to healthy food consumption. Overall media consumption was positively related to the consumption of unhealthy foods and unrelated to healthy food consumption. Children's zBMI had no relationship with either type of food consumption. Tables 2 and 3 show detailed findings from the controls.

Table . Unstandardized coefficients for predicting healthy food consumption (n=591; R^2=.322).

Predictors	Healthy food consumption (wave 2)	
	b (SE)	*P* value[a]
Constant	1.431 (0.175)	<.001
Healthy food consumption (wave 1; autoregressive)	0.537 (0.035)	*<.001*
Gender	0.010 (0.040)	.80
Age (wave 1)	0.021 (0.017)	.21
BMI (wave 1)	−0.015 (0.017)	.40
Media consumption (wave 2)	−0.020 (0.032)	.53
Unhealthy food presentations (wave 2)	−0.003 (0.004)	.57
Healthy food presentations (wave 2)	0.000 (0.006)	.99
Presentation centrality (wave 2)	0.001 (0.004)	.71
Coviewing (wave 1)	0.005 (0.012)	.69
Unhealthy food presentations × presentation centrality	0.000 (0.000)	>.99
Unhealthy food presentations × coviewing	−0.001 (0.001)	.70
Healthy food presentations × presentation centrality	−0.000 (0.000)	.22
Healthy food presentations × coviewing	0.001 (0.003)	.74

[a] Significant *P* values are italicized.

Discussion

Principal Results and Comparison With Prior Work

Evidence is abundant for the effects of unhealthy food presentation in children's media on children's consumption behaviors [4,19,48]. The aim of this study was to revisit this evidence, not only with respect to the presentation of unhealthy foods, but also healthy ones. For the first time in the existing research, content analytical data from movies and TV series that children were exposed to over a time span of 6 months were combined with panel data from children and their parents. With this data linkage design, this study could test how effects evolved over time.

As the findings reveal, even though unhealthy food exposure was much higher overall, exposure to unhealthy and healthy foods alone was not related to children's healthy and unhealthy consumption behaviors. The results show that the centrality with which the products were presented greatly mattered for the relationships. When foods were presented centrally, that is, when they were zoomed in on or when the characters interacted with them, consumed them, or verbally mentioned them, exposure to unhealthy food presentation was positively related to unhealthy food consumption. This effect can be explained by the fact that centrality eases the perception of unhealthy foods, thus increasing cue reactivity, leading to a "wanting" of that product [33]. That is, centrality plays a role in reminding children about their food preferences.

Interestingly, this relationship was different for the presentation of healthy foods. For healthy foods, centrally placed healthy food products were negatively related to unhealthy food consumption. One could argue that children are made aware of the importance of healthy foods for their diet and thus their preference for unhealthy foods decreases. Yet to create such an awareness, a central placement of the food is necessary. Of course, more empirical evidence is needed to corroborate that claim.

However, when healthy foods were placed noncentrally, they were positively related to children's consumption of unhealthy food over time. This finding is in line with a prior study [19] suggesting that healthy food placement can promote unhealthy eating behaviors. Subtle presentation of healthy foods can activate children's inherent preference for unhealthy foods, for instance, by serving as a cue for appetite [32]. When appetite is cued, then children automatically prefer unhealthy over healthy options. However, when the centrality of healthy foods rises, this automatic process may be impeded; children may be reminded about the importance and necessity of healthy food and consume less unhealthy food over time. Again, the precise underlying mechanisms remain to be studied. Overall, even though unhealthy foods were presented more often, the amount of food exposure was not a key element influencing unhealthy food consumption. However, persuasive strategies (ie, centrality) in connection with unhealthy as well as healthy food presentation are more important in that regard.

Against expectations, foods presented in the media that children were exposed to did not show any relationship to healthy food consumption. Healthy food consumption could hardly be explained empirically. One explanation could be that children have an inherent preference for unhealthy foods [49,50]. As a consequence, unhealthy food consumption may be triggered more easily as compared to healthy food consumption. This is also in line with former research testing the effects of different persuasive strategies concerning healthy food consumption [23,51,52]. It seems that more than just a central placement is needed to positively impact children's healthy eating habits [32].

Finally, coviewing by parents did not moderate the effects on healthy and unhealthy food consumption; however, it was positively related to unhealthy food consumption overall. This finding is arguably hard to explain, as theory would suggest the opposite. Perhaps coviewing exerts an indirect effect: when coviewing, parents, too, are exposed to unhealthy food presentations (which are clearly dominant in children's media) [15], and they may also be affected by them. These effects on parents may then, in a second step, facilitate the unhealthy eating habits of their children. In such a scenario, potential effects on children could run via 2 paths: unhealthy food presentation could shape children's eating behaviors directly (ie, by affecting them), and indirectly (ie, by affecting their parents, who then affect their children). This indirect mechanism is certainly speculative and cannot be properly tested in a panel survey; it would thus necessitate strict experimental designs.

Limitations and Future Research

This study relied on self-reported data when assessing the specific movies and TV series that children were exposed to. As always, such self-reported data are prone to perceptual biases, as specific movies and TV series may be more likely to be mentioned for reasons that cannot be measured. However, considering that in this study both children and parents were asked about movies and TV series, and content viewed over 6 months would generally be possible to remember, we are confident that we obtained an account of the content the children were exposed to. Also, when it comes to the dependent variables, self-reported consumption behaviors, which are not the same as actual food choices, were assessed [53]. Related to that, this study can only make correlative conclusions regarding the relationship between mediated exposure to foods and children's consumption behaviors.

The sample relied on the most frequently was movies and TV series. However, this study was unable to include smartphone content or determine the type of screen on which the content was consumed. For the age group of this study (between 5 and 11 years) and their typical content preferences, this seemed reasonable. In addition, the models controlled for overall media consumption to rule out effects of the frequency of exposure to other content not assessed in this study, but future research should take a 360 degree account of children's media diet. This may be challenging for practical reasons, but integrating several types of content in one study is important. Relatedly, we did not predict reciprocal relations (ie, food presentation by consumption), because food presentation refers not only to exposure, but also to content, and the content of the movies cannot be predicted by consumption. However, future research should follow up on this.

This study focused on the centrality of presentation. As important as centrality is [33], it is only one presentation factor that may shape food preferences [32]. Also, this study did not explicitly distinguish between several types of centrality, such as interacting with a product, consuming it, or mentioning it. When it comes to coviewing, several dimensions should also be distinguished in future research, such as intentional versus passive coviewing. Moreover, the age range used in this study deserves further scrutiny. Children younger than 5 years are frequently exposed to media content containing food. These children are, arguably, particularly susceptible to the presentation of unhealthy and healthy food and thus deserve more attention. Finally, no data on the specific schools the children were attending were collected since these would not have been in line with the ethical standards regarding anonymization. Therefore, this study was not able to control for schools in the models.

Conclusions

When discussing the roots of children's unhealthy food consumption and childhood obesity, educators, journalists, and policy makers have been very quick to point their fingers at the media, particularly media that targets a young audience. At first sight, the evidence for the media's role in obesity and unhealthy consumption is overwhelming. Not only are unhealthy foods presented more frequently, more prominently, and more positively as compared to healthy foods [15,54], experimental [19,24,28,48] and survey research [43,44] also suggests that the presentation of unhealthy foods can significantly shape unhealthy consumption habits among children.

This study demonstrates 3 things. First, the findings of this study suggest a more nuanced picture. Linking panel survey data to content analytical data on the content that children were exposed to showed that unhealthy or healthy presentation alone were not related to healthy or unhealthy consumption behaviors. Such relationships may be observable in forced-exposure experimental studies with strong stimuli and measures briefly after stimulus exposure, but not in a longitudinal study sampling actual content [55].

Second, and related to that, this study shows that the way in which foods are presented matters. Centrally placed unhealthy foods do in fact show a positive relationship to unhealthy eating behaviors; centrally placed healthy foods, however, appear to have the opposite effect. Also, healthy foods placed noncentrally seem to prime unhealthy eating habits, not healthy ones.

Third, by and large, children's movies and TV series seem to be more likely to be positively related to unhealthy than healthy eating behaviors. Healthy consumption behaviors were completely unrelated to exposure to media content. Also, when centrality was low, even healthy foods in the media seemed to foster unhealthy consumption.

Overall, these findings inform and qualify the debate about the media's impact on healthy and unhealthy consumption behaviors among children. Most importantly, the call to simply place more healthy foods in children's media may, according to our findings, not be sufficient to combat unhealthy eating and childhood obesity.

Acknowledgments

JM, AB, and BN conceptualized the study, drafted the initial manuscript, and reviewed and revised the manuscript. JM conducted the statistical analysis. MF, IS, HK, and MS administered the study and reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work. The research was partly supported by a grant from the Central Bank of the Republic of Austria (grant 17715).

Conflicts of Interest

None declared.

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Abbreviations

REFCAM: Reactivity to Embedded Food Cues In Advertising Model

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Original Paper

Designing Child Nutrition Interventions to Engage Fathers: Qualitative Analysis of Interviews and Co-Design Workshops

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Abstract

Background: Fathers play a pivotal role in parenting and child feeding, but they remain underrepresented in intervention studies, especially those focused on disadvantaged populations. A better understanding of fathers' experiences and needs regarding support access and child nutrition information in the context of disadvantage can inform future interventions engaging fathers.

Objective: This study aims to explore fathers' experiences; perceived enablers; and barriers to accessing support and information related to parenting, child feeding, and nutrition and to co-design principles for tailoring child nutrition interventions to engage fathers.

Methods: Australian fathers of children aged 6 months to 5 years with lived experience of disadvantage participated in semistructured interviews and co-design workshops, primarily conducted via videoconference. Creative analogies were used to guide the ideation process in the workshops.

Results: A total of 25 interviews and 3 workshops (n=10 participants) were conducted, with data analyzed using reflexive thematic analysis and the Capability, Opportunity, and Motivation–Behavior model. The interview data illuminated factors influencing fathers' initiation in seeking support for parenting, child feeding, and nutrition, including their experiences. It highlighted fathers' diverse information needs and the importance of an inclusive environment and encouragement. Enablers and barriers in accessing support related to parenting and child nutrition were identified at the individual (eg, personal goals and resource constraints), interpersonal (family support and false beliefs about men's caregiving role), organizational (inadequate fathering support), and systemic levels (father-inclusive practice and policy). Digital data collection methods enabled Australia-wide participation, overcoming work and capacity barriers. Videoconferencing technology was effectively used to engage fathers creatively. Key principles for engaging fathers were co-designed from the workshop data. Interventions and resources need to be father specific, child centered, and culturally appropriate; promote empowerment and collaboration; and provide actionable and accessible strategies on the *what* and *how* of child feeding. Fathers preferred multiformat implementation, which harnesses technology-based design (eg, websites and mobile apps) and gamification. It should be tailored to the child's age and targeted at fathers using comprehensive promotion strategies.

Conclusions: Fathers faced barriers to accessing support and information related to parenting and feeding that may not adequately address their needs. Future interventions could integrate the co-designed principles to engage fathers effectively. These findings have implications for health service delivery and policy development, promoting father-inclusive practice.

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KEYWORDS

co-design; fathers; child nutrition; child feeding; intervention design; digital delivery; parenting; participatory; videoconference; communication technology

Introduction

Background

Nurturing care is a central tenet for fostering optimal growth and development in children. This supports children in attaining good health through adequate nutrition, feeling safe and secure, and receiving responsive caregiving and learning opportunities [1]. Child feeding that focuses on the reciprocal positive relationship between the caregiver and the child is an opportunity that integrates all components of nurturing care. Efforts to promote early childhood development recommend incorporating responsive caregiving as part of interventions aimed at optimizing the nutrition of young children [2].

Fathers play a pivotal role in nurturing care, including feeding, and influencing children's eating [1,3]. Although mothers often take on the primary responsibility for feeding children, fathers increasingly participate in various aspects of child feeding, from selecting and preparing foods to sharing family meals [4-6]. Despite an emerging trend of involving fathers in parenting and child health research, there is limited evidence documenting fathers' experiences and needs regarding nutrition and feeding, and they remain underrepresented in intervention studies [7,8]. In a 2017 systematic review of randomized controlled trials (RCTs) targeting child obesity prevention and treatment (n=213), only 10% of participants were fathers, and just 2 studies reported targeted attempts to recruit fathers [9].

A barrier to the inclusion of fathers is their reported reluctance to participate in research even when invited, as they may doubt they have contributions to make to studies on children's eating [10]. On the basis of their own research experience, Moura and Philippe [10] found that fathers with a lower socioeconomic background expressed discomfort with being involved in research, perceiving researchers as *too knowledgeable* to provide additional insight into their work. In another survey study (n=303), >80% of fathers perceived their underrepresentation in child health research as stemming from not being invited to participate in these studies [11]. Fathers living with disadvantage can be considered as *hard to reach* because of structural barriers, including work commitments, limited financial resources, low literacy, or reduced capacity to travel [12]. Consequently, researchers have tended to focus on populations that are easier to reach, typically more advantaged mothers. Targeted strategies are necessary to make participation more accessible and engaging for fathers, particularly those facing disadvantage. Remote and digital data collection methods emerge as promising tools to engage with disadvantaged populations, breaking structural barriers to inclusive participation [13]. The nature of remote technologies, in which participants operate within their settings and control their devices and degree of involvement, also creates a safe environment and balances power dynamics between researchers and participants.

Understanding how to tailor research and service design, including intervention objectives and content, delivery mode, and location, is crucial for the effective engagement of fathers. Moura and Philippe [10] identified practical facilitators to enhance the inclusion of fathers in child nutrition research, including explicitly recruiting *fathers* rather than *parents*, offering web-based participation options, and using interactive methods. However, these suggestions have emerged from reflection and review rather than directly drawing on the lived experiences of fatherhood. To develop tailored interventions that will optimize child nutrition and maximize success in reaching fathers from diverse backgrounds, participatory research, in which fathers are considered experts in their lived experience, may produce more concrete and realistic solutions.

Objectives

Understanding fathers' experiences and needs regarding child nutrition interventions in the context of disadvantage can inform future intervention development. This research aimed to understand the following: (1) fathers' experiences; perceived enablers and barriers in accessing support and information related to parenting, child feeding, and nutrition and (2) how child feeding and nutrition interventions can be effectively tailored to engage fathers through co-design.

Methods

Ethical Considerations

Both studies were approved by the Queensland University of Technology (QUT) Human Research Ethics Committee (2022-5253-7746 and 2023-6687-16117).

Context

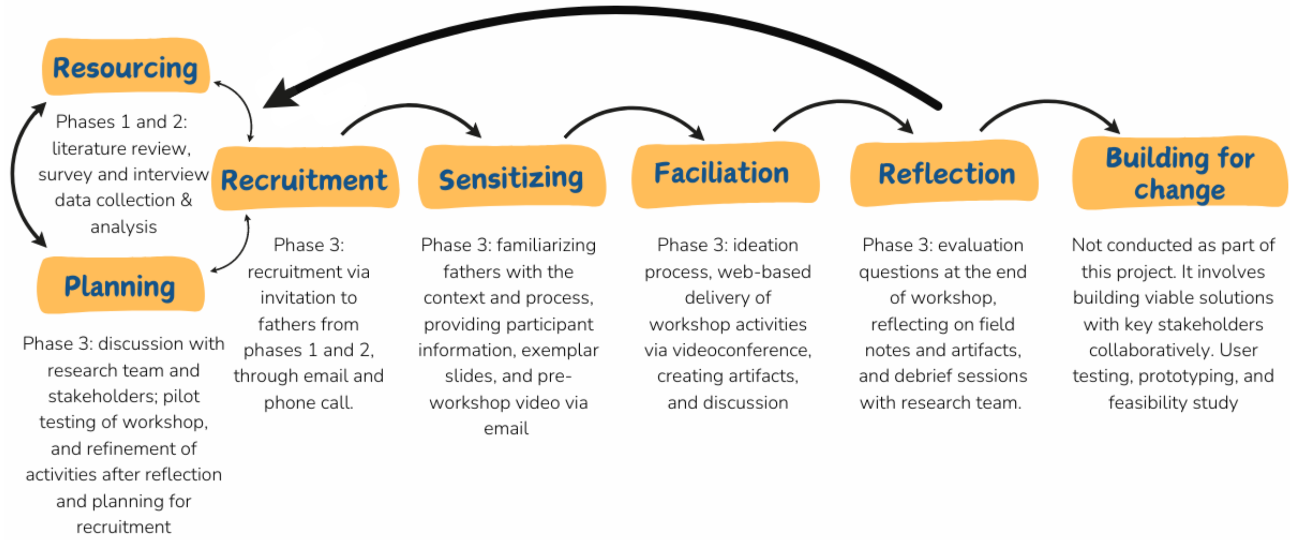
The data presented in this paper come from the research project Dads at Mealtimes (DAM), which consisted of 3 phases: a web-based survey (phase 1), interviews (phase 2), and co-design workshops (phase 3). The overarching research explored the feeding roles and practices of Australian fathers in the context of disadvantage. The survey and interviews were conducted in 2022, informing the subsequent co-design workshops in 2023. All studies primarily used digital tools because of the COVID-19 pandemic, during which digital data collection became more common. This paper focuses on findings from the interview and workshop phases.

The interviews aimed to explore three aspects: (1) paternal roles and contributions in child feeding, (2) enablers and barriers to responsive feeding practices, and (3) experiences and perceived enablers and barriers in accessing support and information related to parenting, child feeding, and nutrition. Objectives 1 and 2 have been reported elsewhere [14]. This paper focuses on data from the interviews, which contribute to objective 3.

The co-design workshops aimed to gain insight into how child feeding and nutrition interventions can be effectively tailored to engage fathers. The workshop uses co-design as a participatory approach, methodology, and method that includes end users in the intervention's conception, development, or evaluation [15]. Underpinned by the principles of equity and partnerships [16], co-design seeks to build capacity, harness creativity, and deepen collaboration between professionals and people experiencing or impacted by the issues [17-19]. Thus, co-design has the potential to create socially and contextually appropriate solutions aligned with the circumstances and contexts of end users [20]. The DAM project aligns with the Kennedy et al [21], extended model of the co-design framework originally developed by Trischler et al [22]. The framework is inherently iterative, with an evolving and flexible design process of resourcing, planning, and recruitment, which is reflective of different study phases and multiple workshops. An overview of the 7 steps and their alignment with the DAM study phases is depicted in Figure 1 [21,22].

Phases 1 and 2 of the DAM study served as the first step (resourcing) in Figure 1 to gain an understanding of the issue. Of the 264 fathers who completed the survey, two-thirds reported having prepared meals (67%) and assisting their child with eating (69%) at least once a day. More than three-quarters (77%) of participants were food insecure, and 55% reported having unmanaged stress [23]. From the interviews (objectives 1 and 2), personal, interpersonal, and systemic enablers (eg, food skills, adequate resources, and support) and barriers (eg, low self-efficacy in feeding, financial and mental strain, food insecurity, and gendered stereotypes) were identified as influencing paternal feeding experiences [14]. The insights from phases 1 and 2 informed the workshop's scope, aim, and activities for engaging fathers in child nutrition interventions. These findings underscored the need for intervention design that harnessed fathers' lived experiences to provide tailored strategies.

Figure 1. Overview of the co-design framework and mapping to the study phases and activities of the Dads at Mealtimes project.



Theoretical Framework

The conceptual framework for the broader study incorporates the Capability, Opportunity, and Motivation–Behavior (COM-B) model of behavior change [24]. This model conceptualizes *capability*, *opportunity*, and *motivation* as the main components for facilitating behavior change. Adopting this behavior change perspective provides a basis for highlighting key attributes in engaging fathers in child nutrition. Consequently, it integrates findings from phases 2 and 3 to inform intervention design.

Positionality

The researchers' positionality is of pivotal importance as coconstructors of meaning in both studies. The first author (JTHS), a male PhD student, conducted recruitment and performed data collection and analyses for both the interview and workshop studies. Not a father himself but involved in caring for young children within an extended family household, he has a background in nutrition and dietetics and completed training in qualitative research. The coauthors (KAB, SN, RB, and DG) are academic dietitian-nutritionists specializing in child nutrition and have experience in qualitative research and co-design. They are mothers of children spanning a broad age range. None of the authors had any prior relationship with the participants.

Interviews

Recruitment

Recruitment procedures for participating in DAM have been detailed previously [14]. Briefly, participants self-identified as fathers or male caregivers with a child aged 6 months to 5 years living with disadvantage. The following question served as an indicator of socioeconomic disadvantage: do you sometimes struggle to pay the bills? The screening question was informed through consultation with parents with the aim of using language that sensitively recruited individuals who were struggling financially and, therefore, at risk of food insecurity [25]. Interview participants were predominantly recruited from a pool of participants who completed the survey (phase 1) and expressed interest in future research. In addition, participants were recruited via promotional flyers distributed to stakeholders, such as family and child services. Consent and demographic information were obtained through a brief web-based questionnaire. All web-based data collection tools were developed using REDCap (Research Electronic Data Capture; Vanderbilt University) [26,27], which was hosted by QUT.

Data Collection

A semistructured interview guide was informed by a literature review and the COM-B model. Pilot testing of the interview questions was completed with 3 fathers to check for comprehension and flow. These questions explored paternal perceptions of their roles and feeding practices, experiences of food insecurity, and accessing support and child nutrition information [14]. Indicative questions relevant to this paper's findings were as follows: (1) Can you tell me any advice you received from anyone or anywhere about child feeding and nutrition? (2) Do you think you received enough support and information about child nutrition? The decision on the sample size is guided by the concept of *information power*, which posits that the greater the relevant information the sample provides, the fewer participants are required [28]. Participants were compensated with an Aus $25 (US $16.6) e-gift card. All interviews were recorded and transcribed verbatim using an automated transcription service, Otter.ai [29]. Participants were invited to review the transcripts. Those who opted to receive the transcripts proposed no alterations. Debriefing sessions were conducted with the research team during data collection and analysis to foster theoretical and reflective thoughts.

Analysis

A detailed description of the data analysis is reported elsewhere [14]. The analysis used the 6-phase process of reflexive thematic analysis [30]. The first author conducted manual coding using inductive and deductive approaches underpinned by a symbolic interactionism lens [31]. Coauthors independently coded a subset of transcripts (n=3) and engaged in discussions to sense check ideas and refine themes. The codes and themes derived from the interview data allowed the researchers to identify enablers and barriers to support access among fathers across individual, interpersonal, and systematic levels. This analysis process was guided by the COM-B model, which was integrated with the workshop findings.

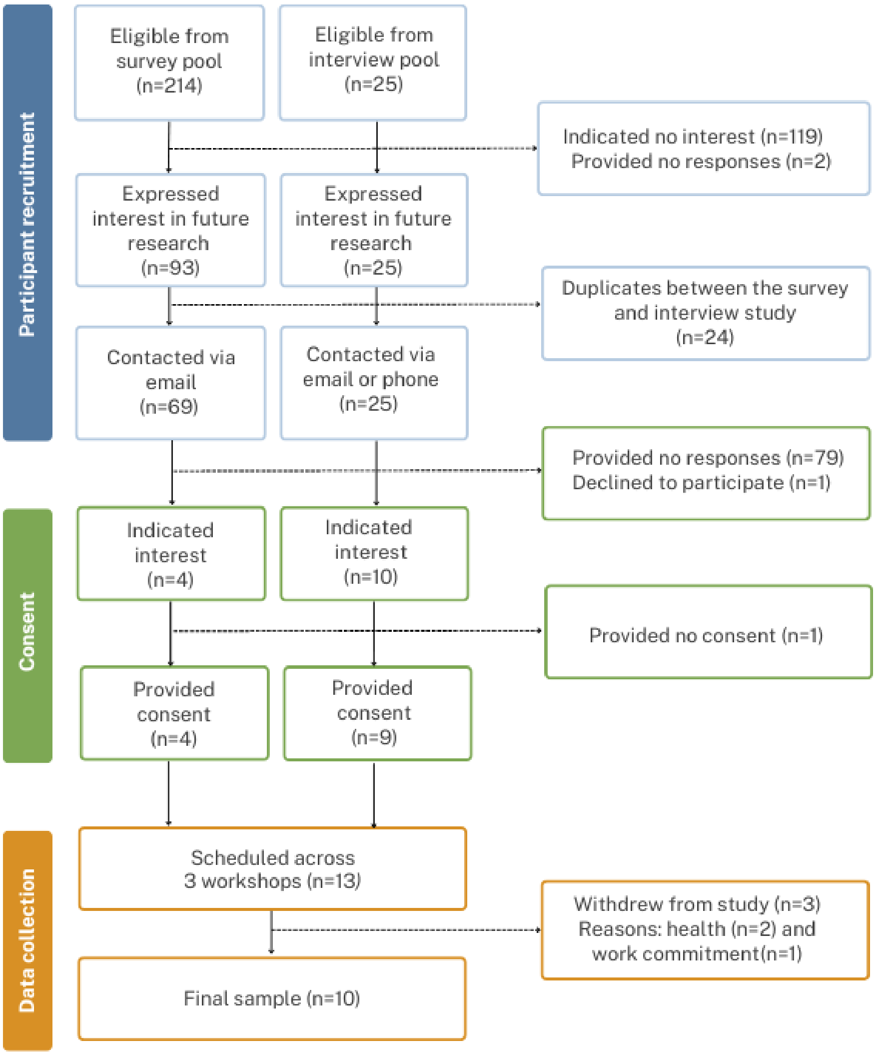
Co-Design Workshops

This section of the paper outlines the recruiting, planning, sensitizing, facilitation, and reflecting steps for the co-design workshops. As part of sensitizing, participants who completed the interview (phase 2) received a summary of findings before phase 3 data collection.

Recruitment

Workshop participants were recruited from a pool of fathers who completed either phase 1, phase 2, or both and expressed interest in further research. Purposeful sampling was adopted to optimize participation from those who completed both phases. Given the sequential design, rescreening for eligibility was not completed. Fathers were invited to participate via email or telephone and were informed that workshops involved several creative web-based activities to design solutions to engage fathers in child feeding and nutrition. Consent and participants' availability were collected via a web-based questionnaire using REDCap [26,27], which was hosted by QUT. The participant flow diagram is presented in Figure 2.

Figure 2. Workshop participant flow diagram, including reasons for exclusion.



Data Collection

The first step in developing the workshop guide was a literature review on fathers' participation in parenting and child nutrition research [10,11,32] and co-design methodologies [19,33]. Discussions were then held among research team members with expertise in child nutrition, socioeconomic disadvantage, and co-design. This was followed by a consultation with a design practitioner-academic with expertise in co-design. After these discussions, a decision was made to conduct workshops of shorter duration and with more streamlined ideation activities focusing on paternal engagement. Drawing on the first author's experience with other co-design studies and sense checking the ideas with other fathers (not part of the final sample), creative analogies that resonate with men were deemed appropriate. The workshop using *superhero* analogies was pilot-tested with 3 fathers (not included in the final sample). These fathers considered the activities and analogies acceptable and enjoyable in eliciting creative ideas. They provided feedback on simplifying the language in the materials (eg, workshop guide, visual slides, and videos) and suggested probes and examples to enhance the concepts and understandability. The workshop overview is provided in Textbox 1.

The preliminary sample size for the workshops was 8 to 10, guided by *information power* [28]. The plan included conducting 2 to 3 workshops, each lasting 70 minutes, with 3 to 4 fathers in each session to facilitate small group discussions. To enable participation across Australia and provide flexibility, workshops were conducted via videoconference using the Zoom platform (Zoom Video Communications) [34]. This reduced barriers to participation and met fathers' preference for web-based activities [10,35]. Features of the platform that were used included screen share, audiovisual recording, and live chat, and it was compatible with mobile or computer use. The *superhero*-themed workshop was complemented by a short preworkshop animated video sent to participants 3 days before the workshop. This video aimed to familiarize fathers with the context, objective, activities, and exemplar personas. These personas were presented as comic characters, incorporating key attributes and findings from phases 1 and 2 (refer to Multimedia Appendix 1 for exemplar personas and related presentation slides).

Each workshop was facilitated by the first author (JTHS), who was one of the coauthors acting as a scribe (DG, KAB, and SN). A presentation slide guided the ideation activities throughout the workshop. Activity 1 involved creating their persons guided by exemplar personas (refer to image C in Multimedia Appendix

1 for 1 father's drawing of their persona). Fathers were asked to ideate their vision and key features of designed solutions in activity 2. Figures 3A and 3B demonstrate the exemplar slides used in this activity. The screen-sharing feature allowed facilitators to share the slides to guide the ideation process and enter responses (provided verbally or via chat) onto these slides in real time for participants to view, validate, and elaborate (refer to Figures 3C and 3D for generated presentation slides). Participants were encouraged to use the live chat function to contribute to the activities or ask questions. At the end of each workshop, the cofacilitator gave a summary of the discussion, providing an opportunity for participants to validate and add further comments. Evaluation questions were posed (ie, What do you like most and least? What would you change?), serving as a short reflection to conclude the workshop. This allowed researchers to refine procedures between the workshops. After the first workshop, this process resulted in a modification to send participants sample slides and questions ahead of time. Participants received an Aus $30 (US $19.9) e-gift card for their involvement.

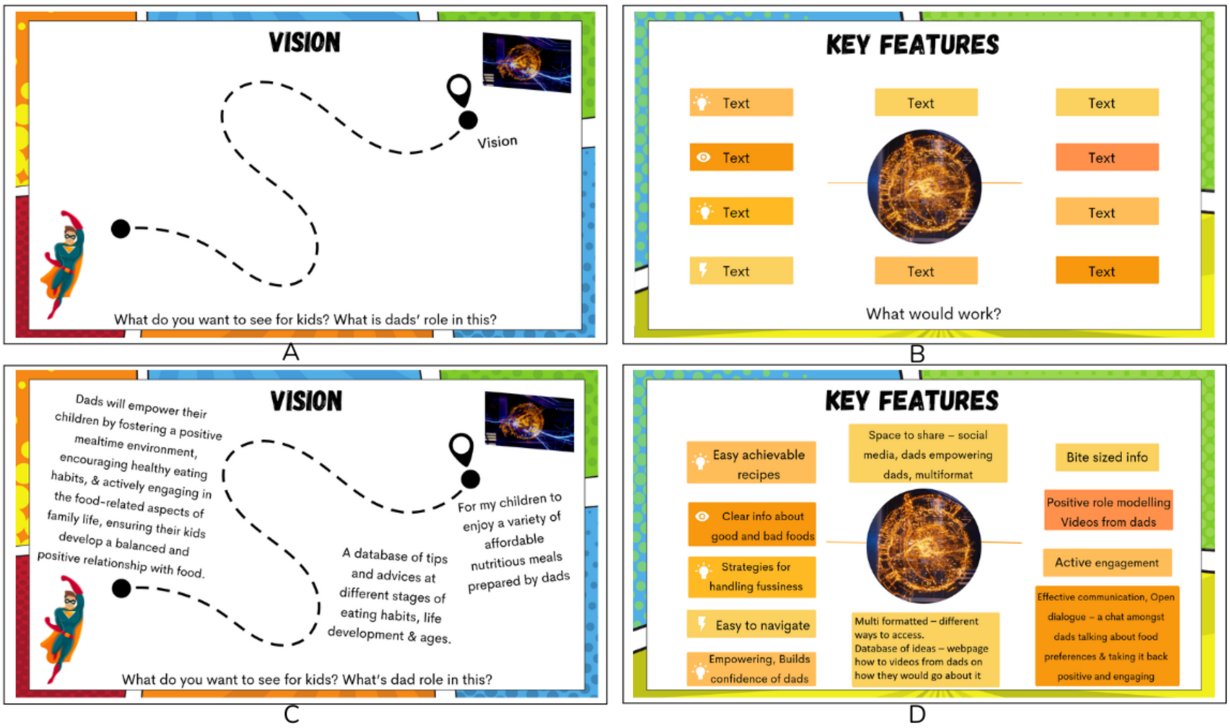
All workshops were video-recorded and transcribed verbatim using Otter.ai [29]. The first author (JS) also completed field notes on each workshop. Artifacts, including drawings, transcripts of chat conversations, and presentation slides (ie, visions and key features created on the slide with fathers), were collated. The research team held debriefing sessions throughout the data collection and analytic process.

Textbox 1. Workshop overview and activities.

Overview

- Study objective: to co-design tailored child nutrition intervention design principles for engaging fathers
- Approach: creative analogies using the *superhero* theme
- Workshop name: Superdads: The New Age of Nourishing Kids
- Workshop activities and indicative questions
  - Activity 1: making superheroes (15 minutes)
    - Description: fathers created their personas, guided by exemplars.
    - Tools: screen sharing of visual slides, drawing, and group sharing.
    - Indicative question: Tell us about yourself (family role, education, cultural background, and life experience), alias (superhero name), your kids, a tip of advice (superpower), challenges (evil nemesis), and information sources.
  - Activity 2: feeding into (fictional artificial intelligence name in the comic) (45 minutes)
    - Description: Participants ideated their vision and brainstormed the key features of the designed solutions; ideas were refined with probes (considerations and challenges informed by phases 1 and 2).
    - Tools: live chat function, group discussion, and presentation slide with real-time responses (ie, facilitator entering words on slides).
- Indicative questions
  - What do you want to achieve for dads and kids regarding child nutrition and eating? (collective vision).
  - What are your ideas for possible solutions for dads, what would work? What are your top 3 design features if we create something for dads about child nutrition? Why are they important?
  - What format could these solutions take on the basis of these features?
- Probes
  - Consider space—where is the best place to reach dads?
  - Consider time—when is the best time to target dads?
  - Consider what empowers dads, their strengths, and challenges. Think about the personas we created.
  - Consider the target group (father only, family focused, and children). Who do you trust to give credible information (male, peer, partner, general practitioner, and health professionals)?

Figure 3. Exemplar slides: (A) template slide for identifying the vision, (B) template slide for identifying key features, (C) completed slide of participants' vision (workshop 1), and (D) completed slide of identified key features (workshop 1).



VISION

Vision

What do you want to see for kids? What is dads' role in this?

KEY FEATURES

Text
Text
Text
Text
Text
Text
Text
Text
Text
Text
Text
Text

What would work?

VISION

Dads will empower their children by fostering a positive mealtime environment, encouraging healthy eating habits, & actively engaging in the food-related aspects of family life, ensuring their kids develop a balanced and positive relationship with food.

A database of tips and advices at different stages of eating habits, life development & ages.

For my children to enjoy a variety of affordable nutritious meals prepared by dads

What do you want to see for kids? What's dad role in this?

KEY FEATURES

Easy achievable recipes

Clear info about good and bad foods

Strategies for handling fussiness

Easy to navigate

Empowering, Builds confidence of dads

Space to share – social media, dads empowering dads, multiformat

Multi formatted – different ways to access.
Database of ideas – webpage how to videos from dads on how they would go about it

Bite sized info

Positive role modelling Videos from dads

Active engagement

Effective communication, Open dialogue – a chat amongst dads talking about food preferences & taking it back positive and engaging

Analysis

Underpinned by the constructivist paradigm that views reality as socially constructed, workshop data (video and chat transcripts, presentation slides, field notes, and artifacts) were analyzed using the same approach as the interviews with inductive coding. Specifically, the enablers and barriers constructed from the interview findings (objective 3) were interpreted together with the workshop data using the COM-B model. In this interpretive process, coauthors were involved in sense checking ideas, generating, naming, and defining the key themes (design principles).

Results

Demographics

A total of 25 fathers participated in semistructured interviews conducted from April to September 2022 (n=24, 96% completed the interviews digitally). Three co-design workshops were held with a sample of 10 fathers (3 or 4 fathers in each workshop) between October and November 2023. The demographics of participants are presented in Table 1. In total, 60% (6/10) of workshop participants completed both phases 1 and 2, and 40% (4/10) completed the survey (phase 1) only.

Table 1. Characteristics of the fathers participating in the interview and workshop studies.

Characteristics	Interviews (n=25)	Workshops (n=10)
Father’s age (years), mean (SD)	35 (6)	35 (4)
Biological father to the index child, n (%)	25 (100)	10 (100)
Days living with the child per fortnight, n (%)		
Full time (14 days)	19 (76)	8 (80)
Part time (7 days)	3 (12)	1 (10)
Less than part time (2-4 days)	3 (12)	1 (10)
Marital status, n (%)		
Married or in a de facto relationship	18 (72)	9 (90)
Separated or divorced	6 (24)	1 (10)
Widowed	1 (4)	0 (0)
Cultural and ethnic group, n (%)		
Australian	18 (72)	8 (80)
New Zealander	1 (4)	1 (10)
Aboriginal or Torres Strait Islander	1 (4)	0 (0)
Other[a]	5 (20)	1 (10)
Education level, n (%)		
University	14 (56)	6 (60)
Certificate or diploma	5 (20)	3 (30)
Year 12	5 (20)	1 (10)
Year 7-9	1 (4)	0 (0)
Employment or study status, n (%)		
Employed[b]	20 (80)	9 (90)
Parental duties	3 (12)	0 (0)
Study or apprentice	2 (8)	1 (10)
Household composition, n (%)		
Single child	9 (36)	5 (50)
2 children	10 (40)	2 (20)
4-7 children	6 (24)	3 (30)
Number of adults[c], n (%)		
1	4 (16)	0 (0)
2	20 (80)	9 (90)
3	1 (4)	1 (10)
Number of children (aged 0-5 years)[c], n (%)		
0	0 (0)	1 (10)
1	13 (52)	7 (70)
2	10 (40)	2 (20)
3-4	2 (8)	0 (0)
Number of children (aged 6-17 years)[c], n (%)		
0	18 (72)	6 (60)
1	3 (12)	1 (10)
2	1 (4)	1 (10)

Characteristics	Interviews (n=25)	Workshops (n=10)
3-6	3 (12)	2 (20)

[a] Cambodian, Chilean, Congolese, Indian, and Indonesian for the interview sample; Cambodian for the workshop sample.

[b] For interviews, of the 25 participants, 14 (56%) were full-time, 1 (4%) was part-time, and 5 (20%) were casual employment. For workshops, employment type was not collected.

[c] The household size is reported for the father's household.

Interviews

Overview

The interview data illuminated fathers' experiences in accessing support and information related to parenting, child feeding, and nutrition. These experiences are reflected by the following themes: (1) factors influencing the initiation of support related to parenting and child feeding, (2) experiences when seeking support, (3) diverse information needs, and (4) inclusive environment and encouragement. ID numbers are assigned to participants' quotes to preserve anonymity.

Factors Influencing the Initiation of Support Related to Parenting and Child Feeding

Fathers reported multifaceted factors that influenced their likelihood to seek and access support *in relation to parenting and child feeding*. These included resource constraints, such as time, location, high mental load, and traditional masculine values, when seeking help might be regarded as a weakness. When asked about their experiences obtaining support around feeding children, 1 father stated the following:

> *As a dad, you don't want to ask for help, it's not a manly thing to do.* [ID64]

How fathers perceived their fatherhood roles and responsibilities regarding caregiving or feeding guided whether and how they sought information. Some fathers believed caregiving to be instinctual (a *gut instinct*) and perceived nutrition as *common sense*. Thus, they are driven by responding to the emotions and behaviors of their child rather than seeking external advice. Others only sought information when they were looking for specific nutrition knowledge. For example, a father indicated the following:

> *When we face questions we didn't know...we tried to solve it early, went to GP, went to nutritionist at the time.* [ID122]

Awareness of available support and gendered expectations, in which fathers perceive and abdicate the responsibility of seeking health and nutrition information to mothers, also influenced whether they sought external support:

> *My wife does like all the research...she drives what we're doing—Okay, we're going to move on to more solid foods or feed her this...she's part of a lot of mother's groups as well, it's a lot of information from there and I just don't have the time so there's no point in doubling up.* [ID61]

Experiences When Seeking Support

When fathers sought child health information and feeding support, experiences were mixed. Although some fathers reported good support from health care workers, others recounted negative experiences in which they received minimal help. One father shared his experience after the birth of his baby:

> *No help for dads...I said—Could you show me how to wash her and all that, my wife couldn't at the time and [the medical staff] said you have to wait until your wife is ready...she got a lot of help but nothing to teach the men how to feed a kid or change a nappy… at the moment I need the help, so teach me.* [ID8]

The stigma of fathers being perceived as uninvolved or unimportant was also raised:

> *There's stigma about dads not being involved as much as they should be. But when you go into an appointment with the mum...you don't exist. It's like mum made the baby and you're just brushed to the side.* [ID118]

In some instances, fathers reported feeling treated as auxiliary parents, in which child health information and systems are geared toward mothers who are designated as primary caregivers:

> *There's information that when you go through the system, the support and consultations. [But] the system is obviously more focused on the mother, so if the mother is not in a state to absorb that information, there's not as much information provided to the father.* [ID74]

Other fathers shared concerns about being judged and harbored distrust toward health professionals when seeking child health information. Information was regarded as *generic* or *overwhelming*. In 1 father's words, he felt coerced and judged by health institutions:

> *You feel a lot of pressure from government agencies that if [the child is] not eating this, you're not doing the right thing.* [ID95]

Highlighting the insufficient father-specific support in caregiving, feeding, and mental health, fathers expressed the importance of services to be sensitive to diverse family structures and care arrangements. One father indicated the following:

> *[I wish I have] more information about feeding, like how often do they feed, because my partner got that information, I got information of looking after [my] partner.* [ID213]

Such experiences could hinder fathers' self-esteem, creating barriers to seeking further support and developing their capabilities in child feeding:

> *No mental health side for the dads. When things got tough, I had to take all the responsibilities on...There's no one to talk to for my side of things.* [ID8]

Diverse Information Needs

Most fathers sought information on child nutrition and feeding from a range of sources, including family, health care providers, mass media (internet, television, and web-based videos) and social media, printed materials (leaflets and books), and community groups. The topics covered a broad spectrum, encompassing breastfeeding and bottle feeding, complimentary food, recipes, child appetite cues and eating behaviors, food safety, and allergies. Fathers often trusted their partners, deeming them as more organized and well informed. Family members, including grandparents and peers, acted as *sounding boards*, providing validation for ideas. Fathers also took measures to assess the reputability of the sources, such as using government websites. In addition, fathers value the expertise of health care workers who have a shared understanding of being a dad:

> *There was a doctor that was a dad, he gave us the rundown...you know, don't worry, it's just a dad thing. It was nice talking to a dad who is also a doctor.* [ID 8]

Inclusive Environment and Encouragement

To address fathers' unique needs and promote paternal involvement in child health, an inclusive environment where fathers feel welcomed is crucial. One father stated the following:

> *A workshop with the kid [would] be beneficial as long as you don't feel judged, [because] you are already feeling really vulnerable.* [ID64]

This vulnerability arises from experiencing financial and food insecurity while navigating fatherhood despite perceived gender stereotypes regarding parenting roles. Although some fathers discussed the need for self-determination in caregiving and feeding, others believed that child health initiatives and professionals should play a role in actively advocating for fathers' involvement, building relationships, and dismantling traditional gender stereotypes:

> *Having an ad campaign [and] for the midwife or paediatrician or obstetrician [to] brought up at the start of the pregnancy that it is going to be helpful if dad comes. When they get letters to attend appointments, have it addressed to the mum and the dad or says dad is encouraged to attend.* [ID118]

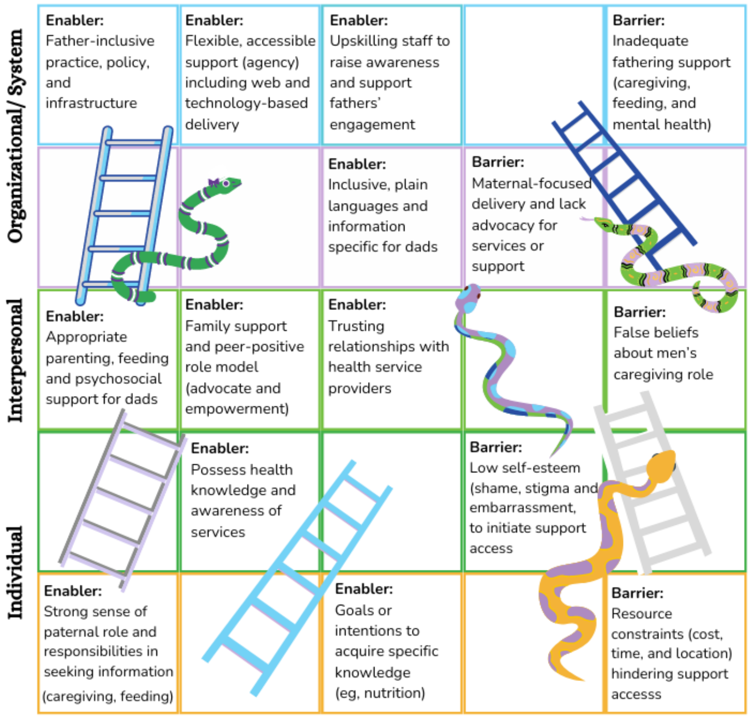
There was also a call for mothers to encourage fathers to fulfill the caregiver role and participate in feeding. For example, a father said the following:

> *If you're a mum, it's okay to tell your partner, that dads are allowed to do things.* [ID3]

Enablers and Barriers to Support Access

Figure 4 presents the interrelated enablers and barriers influencing fathers' access to support across individual, interpersonal, organizational, and system levels. The interviews first provided insights into fathers' enablers and barriers. The workshops allowed for more in-depth exploration, focusing on how to overcome barriers and leverage enablers through co-designed solutions. These factors were embedded into the workshop videos and activities, including the exemplar personas and presentation slides, to facilitate the ideation process.

Figure 4. Enablers and barriers for accessing support: presented as snakes and ladders.

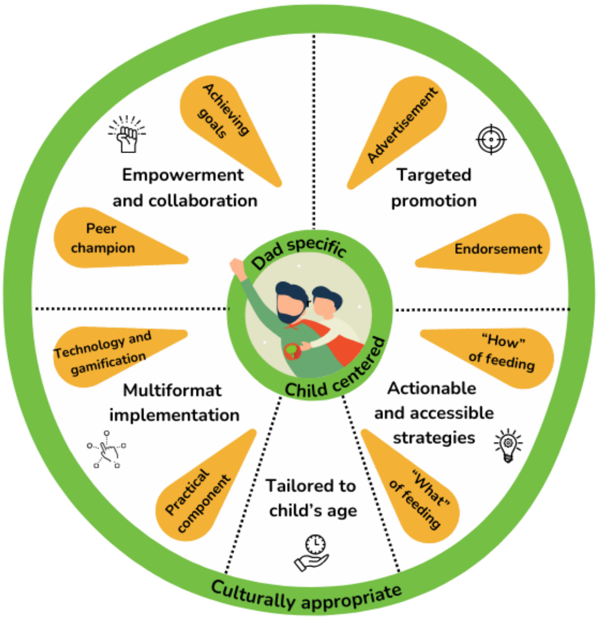


Co-Design Workshops

Overview

From the workshop data, 7 principles for engaging fathers in child nutrition interventions and resources were identified. These include (1) father specific and child centered, (2) empowerment and collaboration, (3) actionable and accessible strategies, (4) multiformat implementation, (5) culturally appropriate, (6) tailored to the child's age, and (7) targeted promotion. Illustrative quotes of each principle, along with the superhero name (if provided) or pseudonym and workshop number, are presented in Multimedia Appendix 2. These design principles encompass various aspects of interventions, from recruitment to content development, and are visually presented in Figure 5.

Figure 5. Design principles for engaging fathers in child nutrition interventions.



Father-Specific and Child-Centered

Fathers identified the need for child-centered interventions specifically designed for fathers themselves, given that most current food and nutrition content predominantly target mothers. Proposed *hooks* for actively engaging fathers in nutrition interventions included strengthening family connections through food, promoting personal growth, and enhancing father-child relationships. This involves supporting fathers to create affordable and nutritious meals, model healthy eating habits, and foster children's positive relationship with food. In 1 father's words, it is important that "dads lead by example [for their child], showing enthusiasm for healthy eating and trying new foods" (W1, Captain Aus). Interventions should involve the child in providing bonding opportunities, such as through "engaging recipes [so] the child can partake in cooking" (W2, Dr Strange). Personalization can support active engagement, which includes providing personalized meal plans and recipes and feedback on performance through using technologies such as mobile apps. Others described web-based tailored support with a moderator who would be able to drive conversations and respond to inquiries within father group chats:

> *Whoever monitors the dad groups—got to keep it positive to try and engage everyone. A lot of people join up to them, but no one comments [or] wants to go first, so if you're there positively backing up comment...The more people comment, you can get an active involved community...* [W1, Hulk]

Empowerment and Collaboration

Interventions should harness peer empowerment and collaboration to facilitate fathers' engagement. Fathers discussed the collective goals of addressing "the stigma that dads are not as good as mums" and being "proud to be a good dad and doing the best for our kids" (W3, Captain Wellness). Creating an interactive fathers' community to exchange ideas about child eating and demonstrate role modeling was thought to be a powerful avenue to build trust and confidence. Seeing other father ambassadors who "do not know how to cook" and realizing "their struggles are the same" was considered valuable:

> *It does [motivate you and empower fathers' identity] if we can create something...I have a family, I'm a father, but I'm independently able to do it...I cook an amazing meal and everyone eats it, it's like "damn right, I did that." It's good for the soul...* [W1, Superdad]

Fathers identified the opportunity for empowerment through self-monitoring and incentivizing behaviors, such as tracking progress and earning badges when mastering a food ingredient and technique or budgeting skills. The ability to act as a peer champion, coaching novice fathers or competing with others, was considered effective in fostering collaboration:

> *I'm always driven to be better than I was yesterday...I see cooking as my own development...In a digital environment, I would look for ways that show progress...like last 12 months, I've made x amount of meals, and gone from beginner to more advanced or*

> *experience more recipes or more ingredients in a way that I can sort of compete with myself and my peers.* [W2, Dr Strange]

Actionable and Accessible Strategies

Fathers described the necessity for bite-sized and actionable strategies regarding the *how* and *what* of child feeding and eating. This includes guidance on teaching nutrition-related information to their child, improving basic food skills (eg, gardening and cooking), and addressing common concerns around infant feeding (eg, allergies and food safety) and fussy eating behaviors:

> *Showing dads how different foods can improve your kids in different ways, like your kids need to have this because it can help with bones or be more active like this. If they don't have it, it may affect them like that.* [W2, Panther]

Fathers highlighted the importance of variety and simple recipes for an enjoyable meal preparation experience for the whole family. They discussed providing clear instructions and using language that resonates with fathers (eg, *recipes presented as a tech manual* and *building a meal*). Accessibility is crucial, considering factors such as time, location, cost, and literacy. Interventions that use technology and build fathers' capacity might overcome these challenges:

> *With time poor, budget constraints and income pressures, [the app, website, or workshop] sort of met the ideas of gaining control...and your competence in making [the meal]. So you sort of alleviate those stresses...* [W2, Flash]

Multiformat Implementation

Fathers sought to move beyond traditional handouts to use technology-based delivery for more personalization. Suggestions included popular social media platforms to host group discussions and websites and mobile apps to provide child nutrition information. These elements should be complemented with behavioral prompts that provide simple educational messages or reminders to prompt action (eg, fridge magnets in prominent places or email reminders). In addition to information provision, practical components, such as video or in-person cooking workshops involving children, remain critical. Gamification could be integrated to enhance engagement, adding an interactive and playful dimension:

> *It would have to be multiformat. One format may not work. The more engagement you can get whether it is one central platform, then you run workshops off the side to get engagement. That's [what] I would enjoy more.* [W1, Superdad]
>
> *I see an app supported by a website, [which] give the same info, but the app would gamify it...This makes it fun, something my son and I can work towards together. He understands games and that keeps him engaged...[like] list of foods to try, get rewards when we try them.* [W3, Thor]

Culturally Appropriate

Food embodies connections, experiences, and culture. Interventions should consider cultural diversity, family dynamics and values, the cost of food, and the skills of those doing the preparation, recognizing that the significance of food extends beyond nourishment to encompass cultural identity and shared experiences. For example, 1 father discussed the need for intervention design to be sensitive to cultural identity:

> *Different cultures, food and family dynamics...It's how you brought up [and] your key beliefs. My wife eats certain foods that I don't eat because of our backgrounds, so my children get to choose what they eat. So saying this is what we're going to eat and this is the recipe, cook on this day wouldn't work for everyone. I'd have to consider different backgrounds and cultures.* [W3, Captain Wellness]

Tailored to Child's Age

Fathers discussed the provision of timely materials tailored to the development stages of children, considering the introduction of complementary foods and eating milestones (eg, supporting breastfeeding, age-appropriate recipes, transitioning food texture, and key nutrients). Some fathers suggested that it would be beneficial to provide resources on food allergies and food safety (eg, choking risks) as well as children's capabilities to engage in different food tasks (eg, holding a knife) at different ages:

> *I guess my vision is a database...of tips, hints, and advice of different stages of eating and what to do or try. Obviously different stages of age and life development they go through different eating habits...* [W1, Superdad]

Targeted Promotion

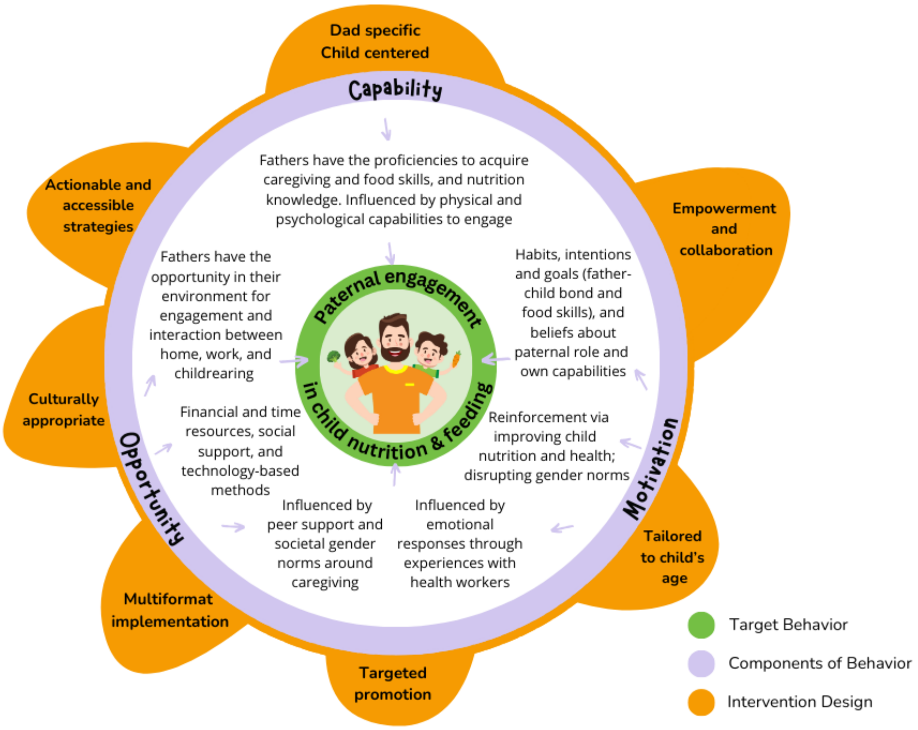
Fathers described a comprehensive, father-targeted promotion strategy using various channels. Marketing was recommended in places traditionally directed at men (eg, hardware and sports venues), web-based platforms (eg, YouTube and Facebook) and community spaces (eg, childcare centers, sports venues, and grocery shops). They acknowledged the influential role of mothers in effectively reaching fathers. Framing of the intervention was key to appealing to fathers, specifically using the word *dads* and father images for promotion purposes. Fathers emphasized the value of endorsement from peers (*someone like me*) and experts (eg, celebrity chefs, health professionals, and academics), who are also fathers, to enhance relatability and trust:

> *I guess like [facilitator's name], PhD, told me something, it's good. I'd go along with it because you got the credential...I'm happy to follow the authorities and the research, peer reviewed studies...well, okay I will do that.* [W1, Hulk]

Integration With the COM-B Model

The COM-B model provided a theoretical lens to integrate findings to inform intervention design that facilitates fathers' engagement in child nutrition. Figure 6 visually illustrates the underlying components of behavior change, encompassing capability (eg, physical and psychological capabilities to acquire food skills and nutrition knowledge), opportunity (eg, material and time resources and social support), and motivation (eg, intentions, goals, and reinforcement). The intertwined design principles can be leveraged to address each component: capacity (eg, through actionable and accessible strategies), opportunity (eg, via multiformat implementation and targeted promotion), and motivation (eg, by being father specific and fostering empowerment and collaboration).

Figure 6. Intervention design: integrating findings with the Capability, Opportunity, and Motivation–Behavior model.



Discussion

Principal Findings

This research offers valuable insight into fathers' experiences when accessing support related to parenting and child feeding and nutrition information, recognizing the enablers and barriers at individual, interpersonal, organizational, and systemic levels. Fathers' intrinsic motivation concerning fatherhood, trusting relationships, social support, and perceived usefulness of information are crucial for active paternal engagement in accessing support related to parenting and child feeding. Conversely, support access is hindered by adverse experiences with health services, fear of judgment, resource constraints (ie, time and location for face-to-face delivery), and gender expectations.

Key principles for child nutrition interventions were identified through co-design. The results indicated that interventions and resources need to be (1) father specific and child centered; (2) leverage empowerment and collaboration; (3) provide actionable and accessible strategies on the *what* and *how* of child feeding; (4) implemented in multiple formats, including technologies; (5) culturally appropriate for diverse practices and values; (6) tailored to child's age and developmental needs; and (7) promoted directly to fathers to engage them effectively.

Drawing from the COM-B model, it is crucial to identify and address barriers when designing interventions to optimize parental feeding and nutrition in children. One significant barrier to fathers' inclusion in public health nutrition initiatives is rooted in gender ideology. Traditional masculinities (reflecting *motivation* of behavior change), characterized by risk taking, invulnerability, plenitude, and autonomous decision-making [10,36], can impede fathers from seeking support in regard to child health and nutrition. These gendered traits may manifest in child feeding, in which the nurturing role or responsibility for child health is typically associated with maternal identity. In this study, some fathers considered healthy eating as *common sense*. Thus, these role expectations and perceptions may deter fathers from seeking information on their children's nutrition.

Qualitative studies with fathers have shed light on the barriers to paternal involvement in child health and nutrition initiatives, such as the Special Supplemental Nutrition Program for Women, Infants, and Children in the United States [37]. The key challenges reported in this study include pride in masculinity, coercion, unacknowledged roles, and feelings of exclusion [37]. Although aiming to improve the health and nutrition of low-income women and children aged <5 years, only a few local offices strive to invite men to participate [38]. The Special Supplemental Nutrition Program for Women, Infants, and Children's name, program structures, and staff-client interactions have been criticized for being unwelcoming and unresponsive to family dynamics and paternal roles [37]. Similarly, fathers in this study stressed the importance of encouragement, inclusiveness, and a father-specific environment (linking both *opportunity* and *motivation* of COM-B) as they navigate their fatherhood role. Thus, intervention designs should engage fathers as a distinct target demographic, using platforms and resources that resonate with men (eg, father imagery and wordings in the promotion and educational materials, technology-based activities, and suitable time outside of regular work hours when providing support).

Many fathers in this study actively sought information on child nutrition from various channels, including health care workers, family, peers, and the internet. Future interventions need to account for the diverse sources fathers seek information from by leveraging these platforms to reach fathers effectively. For instance, health care workers can raise awareness of intervention studies through their services, or mothers can act as agents to promote study information to fathers (*opportunity*). Accessing information through other fathers suggests the potential benefits of mobilizing peer empowerment as a resource to facilitate paternal engagement in child nutrition interventions (*motivation*). Participants in the workshops further expressed an interest in learning about nutrition (*capability*), particularly if their children are the focus. This child-centric approach is consistent with previous research [35,39]. For example, fathers preferred engaging in nutrition intervention with their children and the whole family rather than being targeted themselves [35]. Communicating a clear goal and benefits of fostering father-child bonding has been suggested to be valuable for parenting interventions targeting fathers [40]. This bonding opportunity can be applied to the feeding context, in which emphasizing positive father-child feeding interactions may enhance future intervention uptake.

This study highlights the underlying motivators for paternal engagement in child nutrition, including supporting fathers as role models for their children's eating behaviors and building positive relationships with food (*capability*). Fathers clearly indicated a preference for participating in interventions *with* their children rather than *for* them, whether through in-person programs or technology-based platforms. The success of the *Health Dads, Healthy Kids* (HDHK) and *Healthy Youngsters, Healthy Dads* (HYHD) community-based RCTs in Australia serves as a renowned example internationally [41,42]. Both programs effectively engage fathers and children (aged 5-12 years in HDHK and aged 3-5 years in HYHD) in learning about healthy eating and physical activity [41,42]. Notably, these interventions yielded favorable effects on various outcomes, including improved fathers' and children's weight outcomes, physical activity levels, and dietary intakes [41,43-45]. A core feature of HDHK and HYHD is its family-based approach, which aims to improve men's and children's well-being simultaneously, focusing on fathers as positive role models and implementing effective parenting strategies. Incorporating practical and theoretical components, the programs offered activities and resources for fathers (eg, manual for dads) and children (eg, activity handbook) individually, as well as opportunities for joint participation (eg, rough and tumble play) [41,42]. HDHK and HYHD have been tailored to men using humor, language, and content that cater to their needs. In addition, they used behavior change techniques, such as monitoring, goal setting, and social support. However, these programs have been implemented with older children. Nutrition interventions involving young children may necessitate adaptations to match their developmental stages and warrant further investigation with fathers and other stakeholders.

In-person delivery, such as that offered by the HDHK or HYHD programs, could pose barriers for certain families, such as those with time and geographic constraints and work commitments. Indeed, fathers in this study emphasized there is no one-size-fits-all approach, advocating for multiformat implementation (*opportunity*). Interventions using technology, such as websites, web-based chat groups, social media, and mobile apps, were recognized as providing more pragmatic options while maintaining interactive elements. This is comparable to a survey study examining Australian fathers' preferences for child nutrition interventions, in which web-based programs were deemed the most popular delivery mode, followed by written materials [35]. Similarly, the *Fathers Infant Feeding Initiative* reported paternal preferences for the internet, email, and video as the basis for delivering perinatal programs supporting breastfeeding [46]. Digital delivery offers a cost-effective and scalable format to provide family-based health programs while overcoming accessibility issues [47]. *Milk Man* is a father-focused app that exemplifies using mobile technology to provide social support and information about breastfeeding [48]. In their process evaluation involving 586 fathers, push SMS text messaging notifications and web-based conversation forums were found to be integral to the app's success, prompting fathers to post comments and access articles and external links. One-third of users also indicated gamification as a key motivator for app use [49]. A previous review of RCTs using gamification found promising results in enhancing nutritional knowledge and dietary behaviors among children and adolescents [50]. Fathers in this workshop study similarly favored interactive games and visual content. Therefore, technology-based intervention designs can be expanded to target other areas of child nutrition. Additional research is crucial to examine the acceptability and feasibility of game-based interventions for fathers with young children.

In a systematic review of interventions designed to shift men's attitudes and behaviors in relation to gendered stereotypes, interactive learning, co-design, and peer leadership emerged as cornerstones for maximizing impact [51]. In a recent practice article, Moura and Philippe [10] proposed recommendations for recruitment, focus, and methods to facilitate fathers' engagement in child-feeding research. They advocated for culturally appropriate, child-focused interventions with a clear framing of the *father* and a focus on lived experiences, using participatory web-based activities and tailored and flexible materials. Several studies also recommended peer-based recruitment and messages (*someone like me*) based on fathers' interests and characteristics (ie, small-time commitment and incentives) [10,11,40,52]. The co-designed principles derived from the workshops corroborate with these recommendations, incorporating insights from fathers experiencing disadvantage. An earlier study involving fathers with low-income status emphasized that nutrition education should focus on food as opposed to complex nutritional knowledge, as well as framing basic nutrition information positively [39]. Simple, actionable strategies that translate knowledge into practice were paramount for fathers in this study. Equally important is the provision of evidence-based information, demonstrated by their efforts to seek credible sources and experts' advice. Collaborative input from fathers on content and messages, combined with professional expertise, can create solutions that prioritize relationships and maximize intervention impact.

These findings present new perspectives that diverge from existing research. For instance, Jansen et al [35] reported that fathers preferred a whole-of-family focus over a fathers-only program. This contrasted with this study, in which participants emphasized the need for a father-only community for sharing and peer encouragement. This was rationalized by their shared experience pertaining to fatherhood and their collective goal of addressing gender stereotypes. Although some fathers discussed sharing information with other family members (apps and websites), certain elements of the intervention (eg, chat groups) that remain father exclusive may be beneficial.

An SMS text message–based intervention has been shown to be acceptable in providing men breastfeeding support in Ethiopia [53] and in Australia, where programs such as *SMS4dads* offered perinatal support related to mental health and parenting [54]; this intervention mode was not raised by fathers in this study. However, digital modes of intervention emerged as a common thread in the discussions. Although SMS text messaging may not offer sufficient practicability for certain nutrition topics, such as food skills and recipes, communication through emails, text messages for promotion, and linked information is considered feasible. Intervention design would benefit from building on this co-design study to determine how individual components and formats can complement each other to elicit positive outcomes. This is of great importance for scaling up programs to be embedded into services and informing policies.

Limitations

The interview and workshop studies have limitations that should be considered in interpreting the results. Fathers who took part in this research were less representative of the Australian male population in terms of education levels. National data indicate that approximately 38% of men aged 25 to 44 years held a university degree [55], a proportion lower than the 57% observed in this sample. Most participants were in relationships, resided with their child full time, and identified as Australian. The self-selection nature of the studies may inadvertently exclude fathers who are less involved, less interested in child nutrition, or more susceptible to entrenched disadvantage, such as single fathers, those with lower literacy, individuals who are unemployed and socially isolated, Indigenous Australians, or culturally and linguistically diverse communities. Future studies could use a more comprehensive sampling strategy to ensure diversity, including fathers with varying education levels, ethnicities, relationship statuses, family sizes, and relationships with the child (ie, biological vs social).

Furthermore, the workshop findings should be considered in light of the group setting and technology used. Individuals less inclined toward group discussion or lacking English language proficiency may not have participated. The study design may favor those who are familiar with using videoconference software. Consequently, these factors pose a potential limitation to the generalizability of the findings, particularly concerning preferences for technology-based and interactive interventions. Future research should strive to identify and recruit a more diverse range of male caregivers. Child nutrition interventions would gain from fathers' perspectives from various family dynamics, such as same-sex fathers and nonbiological fathers and diverse cultural backgrounds, to co-design culturally appropriate engagement strategies.

Implications for Research, Practice, and Policy

This research holds implications for practice, research, and policy. Amplifying fathers' voices in child health research recognizes the developmental benefits of paternal involvement in nurturing care and optimal nutrition. Co-design, which harnesses the lived experience expertise of fathers facing disadvantage, strengthens their capacity to contribute to public health initiatives. Future interventions seeking to effectively engage fathers could incorporate the co-designed principles into their planning and delivery.

Although the primary aim of this research was to inform intervention design, the findings have the potential to be extrapolated for health service delivery and policy development. Existing evidence suggests that fathers encounter accessibility barriers when engaging with services. For example, a study on Australian fathers' participation in antenatal care highlighted a gendered approach in providing parenting support, lack of knowledge and decision-making involvement, and paternal anxiety as notable barriers [56]. In addition, paternal depression symptoms were found to be linked to fathers' perceived lack of support and poor father-child and coparent relationships [57]. The design principles identified in our workshops align well with best practice and father-inclusive guidelines, which advocate for a revaluation of how services are planned and delivered to be responsive to fathers' needs and recognize their strengths [58,59]. The enablers and barriers identified provide valuable direction for parenting and child health services, policies, and infrastructure, especially in tailoring child nutrition information for fathers. These findings underscore the importance of a systemic approach to dismantle gender stereotypes, provide feeding and psychosocial support, and strengthen father-child relationships to achieve positive outcomes for children.

Conclusions

Fathers encounter substantial barriers when accessing support and information related to parenting and child feeding, and existing resources are inadequate for their needs. To harness the lived experience of fathers, future interventions could incorporate the co-designed principles developed in this study to effectively engage fathers. These findings hold implications for health service delivery and policy development, advocating for practices that foster fathers' engagement.

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Authors' Contributions

This study was conceptualized by all authors. JTHS collected and analyzed the interview and workshop data and drafted the manuscript. KAB, SN, and DG assisted during the co-design workshops. All authors contributed to the interpretation of results, writing of the paper, and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Exemplar slides on personas: (A) exemplar personas (comic characters) incorporating fathers' characteristics from phases 1 and 2, (B) template slide for guiding making superhero activity, and (C) participants' drawing (artifact) from the making superhero activity (workshop 3).

[DOCX File , 634 KB - pediatrics_v7i1e57849_app1.docx]

Multimedia Appendix 2

Design principles for child nutrition interventions with descriptions and illustrative quotes.

[DOCX File , 17 KB - pediatrics_v7i1e57849_app2.docx]

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Abbreviations

COM-B: Capability, Opportunity, and Motivation–Behavior
DAM: Dads at Mealtimes
HDHK: Health Dads, Healthy Kids
HYHD: Healthy Youngsters, Healthy Dads
QUT: Queensland University of Technology
RCT: randomized controlled trial
REDCap: Research Electronic Data Capture

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Original Paper

Extent and Nature of Television Food and Nonalcoholic Beverage Marketing in 9 Asian Countries: Cross-Sectional Study Using a Harmonized Approach

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Abstract

Background: Rising childhood obesity rates in Asia are adding risk for the future adult burden of obesity and noncommunicable diseases. Weak policies across most Asian countries enable unrestricted marketing of obesogenic foods and beverages to children. Television is the common medium for food marketing to reach this audience.

Objective: This study aimed to assess the extent and nature of television food and nonalcoholic beverage marketing in 9 Asian countries (Bangladesh, China, India, Malaysia, Mongolia, Nepal, the Philippines, Sri Lanka, and Vietnam) with capacity building support from the International Network for Food and Obesity/Non-Communicable Disease Research, Monitoring and Action Support, who enabled harmonization of data collection method and content analyses.

Methods: Advertised foods were categorized as permitted or not permitted based on the nutrient profile models established by the World Health Organization regional offices for South-East Asia (SEARO) and the World Health Organization regional offices for Western Pacific (WPRO). Overall rates of food advertisements (advertisements per hour per channel) and persuasive strategy use were analyzed along with comparisons between children's peak viewing time (PVT) and non-PVT.

Results: Cross-country comparisons, irrespective of country income level, indicated that not permitted food advertising dominated children's popular television channels, especially during PVT with rates as per WPRO or SEARO criteria ranging from 2.40/2.29 (Malaysia) to 9.70/9.41 advertisements per hour per channel (the Philippines). Persuasive strategy rates were also comparatively higher during PVT. Sugar-sweetened beverages, sugar-containing solid foods, and high salt- and fat-containing snacks and fast foods were frequently advertised. Evaluation of the application of WPRO and SEARO nutrient profile models identified inconsistencies due to regional taste and cuisine variations across Asia.

Conclusions: This study clearly showed that unhealthy food marketing through popular children's television channels is widely occurring in Asia and is a clear breach of child rights. Evidence outcomes will benefit advocacy toward stronger policy regulations to control unhealthy food marketing and strengthen strategies to promote a healthier food environment for Asia's children.

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KEYWORDS

children; Asian food marketing; television; unhealthy food; WHO nutrient profile model; World Health Organization; pediatrics; commercial; Asia; unhealthy; nutrition; diet; market; advertisement; food; beverage; consumption

Introduction

Rising childhood obesity rates are a global health issue, with Asia not immune to this trend. Almost half of the world's children younger than 5 years of age who are overweight or obese are living in Asia [1], a region that is also rapidly facing an upsurge in the prevalence of noncommunicable diseases (NCDs) such as diabetes, cardiovascular disease, and hypertension [2]. Even low- and middle-income countries (LMICs) in Asia, dealing with undernutrition as the traditional public health challenge, are not exempt from childhood overweight and obesity, particularly in urban settings [1]. Childhood obesity predicts NCD development in adulthood [3,4].

A systematic review of evidence examining interventions to prevent childhood obesity in the Asian region revealed that interventions tended to focus on children's school settings and targeted behavioral modification through nutrition or health education and physical activity sessions [5]. Focusing on such nutrition and physical activity promotion programs fails to account for the effects of the wider food environment, where unhealthy foods and beverages high in saturated and trans fats, added sugars and sodium (termed as high in fat, sugar, and salt [HFSS]), and usually highly processed [6] are highly available, accessible, and heavily promoted [7,8]. This food environment is consistent with growing transnational and regional food business across Asia [9].

Television advertising of unhealthy foods is a big driver of children's exposure to unhealthy food marketing [10-12]. Without question, children who are highly exposed to powerful marketing of HFSS foods are vulnerable to negative food behaviors that are conducive to overweight and obesity development [13-15]. Increased exposure of children to the marketing of unhealthy foods increases purchase requests [13,14] and develops tastes, preferences, and habits [16-19] for these foods. The habituation of unhealthy foods and beverages in children through advertising exposure is suggested by the World Health Organization (WHO) to be linked to childhood obesity [20].

Expenditure on television advertising rose from the year 2000 in the Asia-Pacific to reach US $55,692 million in 2024 [21]. Free-to-air, cable, or satellite television is a major media source in Asia [22] and comparatively more accessible for low-income households than digital media [23]. Therefore, the dominant influence of food marketing is through children's popular television channels, as observed in Malaysia [24], Thailand [25], and India [26]. Children's exposure to food advertising on television across Asia is largely unchecked because of weak or nonexistent regulations [27]. Slow policy progress is perpetuated by the lack of local research to document the extent of the issue and to hold industries accountable for protecting children from exploitation [8]. Further, current evidence on television food advertising is largely limited to high-income countries, and efforts are needed to support monitoring the nature of this advertising in low-resource settings [28]. Although some data are available for selected countries in Asia, including Malaysia [24,29] and Korea [30], only data from Korea have been able to inform favorable policy design. A major limitation of these Asian studies was the lack of uniform methodology, with researchers adopting varying approaches to categorize nutritional profiles of advertised foods. An Asia-Pacific comparison [31] involving China, Korea, Indonesia, and Malaysia benefited from the use of one standard methodology for data sourcing, recording, and coding but benchmarked nutritional comparisons to core and noncore food criteria rather than a standardized WHO nutrient profile model (NPM).

Acknowledging these gaps, a situational analysis was warranted to explore the extent and nature of unhealthy food and nonalcoholic beverage marketing through television across Asia. Further, the protection of children from exploitation as defined in the Conventions on the Rights of the Child [32] and specifically from unhealthy food marketing [33] constitutes child rights, which emphasizes the need to conduct this research in Asia. Keeping this in mind, we report on the outcomes of a collaboration between 9 Asian countries comprising 7 LMICs (Bangladesh, India, Mongolia, Nepal, the Philippines, Sri Lanka, and Vietnam) and 2 upper- and middle-income countries (China and Malaysia) [34]. This collaboration adopted the International Network for Food and Obesity/Non-Communicable Disease Research, Monitoring and Action Support (INFORMAS) food promotion module's television protocol [35], which harmonized data collection procedures to enable country comparisons on key variables measuring children's exposure to unhealthy food marketing in television. INFORMAS is a global network of public-interest organizations and researchers aiming to monitor, benchmark, and support public and private sectors to foster healthy food environments and combat obesity, NCDs, and their associated inequalities [36]. INFORMAS also served as a research stakeholder by supporting intensive capacity building in implementing a methodology for achieving the project's milestones.

Methods

Study Design

The 9 Asian countries in this collaborative study agreed to adopt the INFORMAS protocol for food promotion [35]. Briefly, this protocol requires country-specific contextual information to be collected through the recording of children's popular television channel broadcasting in order to identify food advertisements embedded between and during programs. This approach did not include other types of marketing such as product placement in shows and sponsorship of television shows. Food advertisements covered both solid foods and nonalcoholic beverages.

The INFORMAS methodology was adapted to enable a standard recording format to fit across the diverse food cultures, seasonal events, and children's schooling and holiday periods of each country. Further, the advent of COVID-19 introduced a disruption to obtaining country clearance, funding disbursements, and data recording schedules. This meant that data recording could not be conducted simultaneously for all countries.

Ethical Considerations

Depending on individual country regulations, some countries were exempted from obtaining ethics approval (India, Malaysia, Nepal, and the Philippines). Ethical clearance was not required for these countries for studies not involving human or animal subjects. Ethics approval was required for Bangladesh (IPH/AW/IRB/2020-21/03, institutional review board of the Institute of Public Health, Dhaka), China (202023, institutional review board of the Chinese Centers for Disease Control and Prevention), Mongolia (253, Ethics Committee under the Ministry of Health), Sri Lanka (EC-20-047, Ethics Review Committee, Faculty of Medicine, University of Colombo), and Vietnam (IRB-VN01057/IORG0008555, institutional review board of the National Institute of Hygiene and Epidemiology).

Sample Selection

Defining Children's Age Limit

Information on audience viewing patterns is usually sourced from media monitoring services and typically reported for children's age limit set <12 years [37,38]. However, for this study's purpose, age was defined according to country-specific regulations and considering the definition of the United Nations's Conventions on the Rights of the Child [6,32]. Most country teams set children's age as up to 18 years, except for India (up to 14 years), Sri Lanka (up to 15 years), the Philippines (up to 17 years), and Malaysia (up to 19 years).

Defining Popular Television Channels

The top 3 children's popular television channels for each country were selected based on children's viewership data [35]. These data were available from commercial media monitoring companies in China (Kuyun), India (Broadcast Audience Research Council), Malaysia (Nielsen), Mongolia (Maxima Consulting), the Philippines (Nielsen), Sri Lanka (Kantar), and Vietnam (Nielsen). Whereas in Bangladesh, popular channels were determined based on expert opinions (n=22), comprising television channel experts, advertising experts, food marketing officials, and caregivers. While in Nepal, expert opinions (n=6) were representative of the Ministry of Information Technology and Communication, national television children's program specialist, cable television service provider, the National Codex committee, and caregiver. Additionally, cross-sectional surveys on television viewing habits were conducted with children and caregivers in Bangladesh and Nepal (n=400 and 51, respectively). In China, findings from a digital survey on parents (n=193) of children and adolescents, aged 3-18 years, were used to validate the commercial data.

Defining Culinary Ingredients

Groceries such as rice, cooking oil, and seasonings were also being advertised in some countries during the sampled day's program broadcasting. These items were targeted to homemakers, as they were also television viewers during children's programs in Asia. Collaborating teams agreed to exclude these items from recorded data, as the intention was to count only packaged food and beverage products cognizant of children's exposure, direct purchasing request, and consumption. A list of these ingredients is provided in Table S1 in Multimedia Appendix 1, and the rates for these ingredients are compared in Table S2 in Multimedia Appendix 1.

Defining Peak Viewing Time

Television viewership data were also used to define peak viewing time (PVT) in each country. PVT represented the top five 1-hour time slots across the broadcast day, separated between weekdays and weekend days [39].

Training

Group training was conducted via videoconferencing by the project management team (PMT) formed by TK, GRO, and SSN with INFORMAS faculty support from SM and BK, to harmonize methodology across countries, prior to data collection.

Recording Protocol

An adapted recording protocol was adopted by all countries, whereby (1) the recording period was within a 3-month period, (2) convenience sampling was used to record for 4 weekdays and 4 weekend days, (3) the 8 recording days were within normal schooling weeks and excluding any public or school holidays and special events (eg, elections), and (4) concurrent recording was performed for 3 selected top channels with a recording duration up to 18 hours per day (6 to 12 AM).

Verification of Recording Procedures

Recording procedures were verified individually by the PMT for each country in one-to-one videoconferencing sessions, with support by faculty to troubleshoot issues. All country teams met the minimum data collection requirement. Some teams completed recording in 2020 (China, Malaysia, and Vietnam). Four teams rerecorded in 2021 (Bangladesh, Mongolia, the Philippines, and Nepal) due to limited viewership data access, school reopening after the COVID-19 lockdown, and data corruption issues. India and Sri Lanka teams completed recording after mid-2022 due to delays in obtaining their country clearance. The recording was performed by most countries using their own research teams, with the exception of outsourcing to providers by China (Kuyun) and Mongolia (Maxima Consulting) teams.

Coding for Healthy Versus Unhealthy Foods

Overview

Each country team assigned at least 2 researchers (student, research assistant, or coinvestigator) to perform the coding of recorded food advertisements. Ongoing support was provided by the PMT and INFORMAS faculty. The primary coding steps involved (1) coding variables for broadcast television channel, date, day, program name or category, and time slot. The time slot variable was classified into PVT or non-PVT. (2) Categorizing all advertisements in the recorded data into food and nonfood items. Advertised food products required brand information (name, description, and parent company). (3) Coding recorded data of advertised foods and beverages according to the NPMs proposed by the World Health Organization regional offices for Western Pacific (WPRO) [40] and World Health Organization regional offices for South-East Asia (SEARO) [41]. The NPMs allow for the classification of foods that should be "permitted" and "not permitted" to be marketed to children based on nutrient thresholds [40,41]. Both models were used, as the participating countries spanned both regions. Additionally, the INFORMAS food classification system was adopted for food products not included in the NPM classifications, such as infant formula, alcohol, and dietary supplements [35]. (4) Coding up to the 3 most prominent food products, as defined by INFORMAS protocol [35], where multiple food products were being promoted in an advertisement. In cases where coders were unable to determine the level of prominence, coding priority was based on the first products shown or coding from the top-left quadrant of the food advertisements for the purpose of sequencing [35]. (5) Conducting market surveys, preferably in physical stores or through digital resources in each country, to retrieve an advertised product's nutrient values to facilitate nutrient profiling. Products without nutrition information were labeled as "insufficient nutrition information panel." Products that were not covered by the WHO NPMs (eg, 1- to 3-year follow-up milk formulae) were identified as "not applicable." (6) Excluding data for banner advertisements and product placements during programs.

Reliability Testing

Intercoder reliability (IRR) testing within each country was performed by researchers who were responsible for the dataset coding. This required a randomly selected hour of television recording for testing reliability between coders according to the formula [35]:

$$\text{Agreement}/(\text{agreement}+\text{disagreement})\times 100$$

The minimum required IRR score was 90% agreement between researchers. If this was not achieved, then additional training was provided to the coder before retesting coding reliability with another television recording sample. Once the minimum IRR was achieved within a country, then IRR testing was conducted between countries. This required each country to submit coded data to the PMT for a random hour of recording. The PMT's coding for this dataset served as a comparator. The minimum required score was 80% agreement, and if this was not achieved, then a second or even a third IRR testing trial was conducted for a different hour of recording, following further training provided to the concerned country's primary coder.

Coding for Persuasive Power Strategies

Additional coding was performed for persuasive power strategies of marketing, comprising the use of power strategies and premium offers [35]. Up to 3 strategies per food advertisement were recorded.

Data Processing

Cleaning

Upon completion of data entry, cleaned Microsoft Excel datasets were provided to the PMT for cross-checking. Country teams corrected datasets based on feedback. Differences were resolved through discussion with the PMT and INFORMAS faculty.

Aggregation

Data were weighted based on weekdays and weekend days. Advertisements were aggregated into hourly time slot intervals. Factors explored for advertisement rate analysis were (1) children's viewing time (PVT vs non-PVT), (2) marketing permissibility (permitted vs not permitted), and (3) the use of persuasive power strategies.

Statistical Analysis

Statistical analysis was performed using SPSS (version 26.0; IBM Corp). A data analysis training workshop (KC, SM, and BK) was conducted for country teams. The PMT checked and consolidated all countries' datasets, before performing the final country comparator analyses.

Outputs for descriptive analysis to understand the extent of television food marketing were reported as mean (SD) for rate parameters (advertisements per hour per channel) applicable to all food advertisements, permitted food advertisements and not permitted food advertisements, and their ratios (permitted:not permitted) derived according to both WPRO and SEARO NPMs. Wilcoxon signed rank tests assessed comparisons between permitted versus not permitted food advertisements. Additionally, the Mann-Whitney *U* test assessed rate comparisons between PVT and non-PVT for not permitted food advertisements. Persuasive marketing strategies engaged for not permitted food advertisements, and interpreted as power strategies and premium offers, were also similarly assessed. Frequency analysis was then performed to understand the popularity of categories of not permitted food advertisements promoted on television according to WPRO and SEARO NPMs. This required coded items to be further consolidated to rank the top 5 most frequently advertised not permitted food categories (%). The significance threshold for all analyses was set at $P<.05$.

Results

Country Comparisons of Food Advertisement Rates for Permitted and Not Permitted Foods

For all 9 Asian countries investigated, food advertisement rates for not permitted foods were significantly higher (all $P<.05$) compared to permitted foods (Table 1). This trend was consistent, whether applying the criteria of the WPRO or SEARO NPMs. Advertisement rates for not permitted foods as per WPRO criteria were highest for the Philippines followed by Sri Lanka>Mongolia>India>Bangladesh>China>Nepal>Vietnam>Malaysia. This trend was also repeated when applying the SEARO criteria, except for not permitted food advertisement rates for China being greater than Bangladesh. However, comparisons between countries regarding the concentration of not permitted food advertisement rates, interpreted as ratio of permitted:not permitted advertisements, indicated that they were lowest for Sri Lanka and China, whereas the ratio of permitted:not permitted food advertisements was highest for Malaysia and Vietnam due to fewer permitted foods being promoted. Of interest, ratios for India and Bangladesh were higher with WPRO criteria than with SEARO criteria.

Table 1. Food advertisement rates for Asian countries as per World Health Organization regional offices for Western Pacific (WPRO) and World Health Organization regional offices for South-East Asia (SEARO) criteria.

Country	All food advertisements[a]	Food advertisement rates (advertisements per hour per channel)							
		WPRO				SEARO			
		Permitted, mean (SD)	Not permitted, mean (SD)	*P* value	Permitted:not permitted	Permitted, mean (SD)	Not permitted, mean (SD)	*P* value	Permitted:not permitted
Bangladesh	8.17 (8.32)	0.43 (1.21)	6.23 (6.67)	<.001	1:14.5	0.72 (1.29)	4.25 (6.00)	<.001	1:5.9
China	11.53 (10.07)	2.13 (2.84)	5.03 (8.57)	<.001	1:2.4	1.57 (2.07)	5.49 (9.60)	<.001	1:3.5
India	9.31 (5.97)	0.46 (0.89)	7.75 (5.36)	<.001	1:16.8	2.08 (2.39)	5.73 (4.56)	<.001	1:2.8
Malaysia	4.07 (6.48)	0.01 (0.11)	2.40 (3.88)	<.001	1:240	0.19 (0.50)	2.29 (3.71)	<.001	1:12.1
Mongolia	11.37 (10.80)	0.72 (1.30)	7.97 (7.67)	<.001	1:11.1	0.72 (1.83)	7.91 (7.46)	<.001	1:11.0
Nepal	4.62 (4.58)	0.11 (0.36)	3.89 (4.06)	<.001	1:35.4	0.11 (0.36)	3.47 (3.64)	<.001	1:31.5
Philippines	15.00 (15.12)	0.75 (1.18)	9.70 (9.85)	<.001	1:12.9	0.93 (1.38)	9.41 (9.47)	<.001	1:10.1
Sri Lanka	16.68 (11.26)	3.43 (3.55)	9.08 (6.84)	<.001	1:2.6	3.15 (3.29)	9.37 (7.16)	<.001	1:3.0
Vietnam	3.34 (6.86)	0.02 (0.15)	2.69 (5.77)	<.001	1:134.5	0 (0)	2.74 (5.90)	<.001	—[b]

[a] All food advertisements include solid foods and beverages advertised. Includes advertisements for culinary ingredients, nutritional supplements, baby food, and follow-up formula. Additionally, the term also covers advertisements for food companies, retailers, and outlets that do not promote specific food products.

[b] For Vietnam, permitted:not permitted could not be determined with SEARO criteria.

Extent of Food Advertisements During PVT and Non-PVT

We further measured the appearance of not permitted food advertisements during PVT and non-PVT for all 9 countries (Table 2). For most countries, not permitted food advertisement rates occurring during PVT were significantly higher compared to rates during non-PVT regardless of both NPMs. For India and Nepal, there was no difference in the rates of not permitted food advertisements between PVT and non-PVT irrespective of both NPM criteria. For China, the rates of not permitted food advertisements when classified using the SEARO model were significantly higher during non-PVT. The difference observed for China as per WPRO (1.45 advertisements per hour per channel) and SEARO (1.29 advertisements per hour per channel) remained comparable but not significant.

Table 2. Appearance of not permitted food advertising during peak and nonpeak viewing times on television.

Country	Not permitted food advertisement rates[a] (advertisements per hour per channel)					
	WPRO[b]			SEARO[c]		
	PVT[d], mean (SD)	Non-PVT, mean (SD)	*P* value	PVT, mean (SD)	Non-PVT, mean (SD)	*P* value
Bangladesh	9.31 (8.00)	5.04 (5.65)	<.001	6.73 (7.11)	3.30 (5.22)	<.001
China	3.98 (5.80)	5.43 (9.40)	.24	4.56 (6.60)	5.85 (10.51)	.02
India	7.54 (4.34)	7.84 (5.70)	.86	5.70 (3.92)	5.75 (4.78)	.38
Malaysia	3.58 (4.76)	1.95 (3.37)	<.001	3.45 (4.72)	1.85 (3.14)	<.001
Mongolia	11.19 (8.60)	6.62 (6.81)	<.001	10.99 (8.33)	6.62 (6.66)	<.001
Nepal	3.67 (3.80)	3.97 (4.15)	.53	3.38 (3.51)	3.50 (3.69)	.84
Philippines	12.26 (10.87)	8.71 (9.24)	<.001	11.84 (10.47)	8.48 (8.89)	<.001
Sri Lanka	11.35 (6.31)	8.21 (6.84)	<.001	11.55 (6.21)	8.53 (7.32)	<.001
Vietnam	5.66 (7.18)	1.54 (4.65)	<.001	5.62 (7.32)	1.63 (4.81)	<.001

[a] Not permitted food advertisements include solid foods and beverages. It excludes advertisements for culinary ingredients, nutritional supplements, baby food, and follow-up formula.

[b] WPRO: World Health Organization regional offices for Western Pacific.

[c] SEARO: World Health Organization regional offices for South-East Asia.

[d] PVT: peak viewing time.

With both NPM criteria, not permitted food advertisement rates during PVT compared to non-PVT were nearly 1.7 times higher for Mongolia (WPRO: mean 11.19, SD 8.60 vs mean 6.62, SD 6.81 advertisements per hour per channel and SEARO: mean 10.99, SD 8.33 vs mean 6.62, 6.66 advertisements per hour per channel), nearly 2 times higher for Malaysia (WPRO: mean 3.58, SD 4.76 vs mean 1.95, SD 3.37 advertisements per hour per channel and SEARO: mean 3.45, SD 4.72 vs mean 1.85, SD 3.14 advertisements per hour per channel) and Bangladesh (WPRO: mean 9.31, SD 8.00 vs mean 5.04, SD 5.65 advertisements per hour per channel and SEARO: mean 6.73, SD 7.11 vs mean 3.30, SD 5.22 advertisements per hour per channel), and nearly 3 times higher for Vietnam (WPRO: mean 5.66, SD 7.18 vs mean 1.54, SD 4.65 advertisements per hour per channel and SEARO: mean 5.62, SD 7.32 vs mean 1.63, SD 4.81 advertisements per hour per channel).

Defining Engagement of Persuasive Strategies in Not Permitted Food Advertisements

We conducted content analyses to probe the nature of engagement used by persuasive strategies for not permitted food advertisements targeting children in the context of power strategies and premium offers, with comparisons during PVT and non-PVT (Table 3).

Rates for power strategies, irrespective of both NPMs, were significantly higher (*P*<.05) for most countries during PVT than non-PVT, with the highest rate observed for the Philippines (WPRO: 8.91 advertisements per hour per channel and SEARO: 8.82 advertisements per hour per channel) and the lowest for Malaysia (WPRO: 1.88 advertisements per hour per channel and SEARO: 1.84 advertisements per hour per channel). In contrast, rates of power strategies for not permitted foods in China and Nepal were significantly higher during non-PVT compared to PVT when classified using WPRO criteria, whereas power strategy rates in India remained similar during PVT and non-PVT irrespective of both NPMs.

When probing premium offers given for not permitted food advertisements, rates were significantly higher (*P*<.05) during PVT compared to non-PVT for most countries by either WPRO or SEARO criteria. Rates were the highest for Bangladesh (WPRO: 1.59 advertisements per hour per channel and SEARO: 1.59 advertisements per hour per channel) and lowest for China (WPRO: 0.06 advertisements per hour per channel and SEARO: 0.05 advertisements per hour per channel) irrespective of both NPMs. No premium offers were broadcast during PVT and non-PVT on Nepal television.

Table 3. Persuasive strategies in not permitted food advertisements during peak and nonpeak viewing times.

Country	Not permitted food advertisement rates[a] (advertisements per hour per channel)											
	Power strategies						Premium offers					
	WPRO[b]			SEARO[c]			WPRO			SEARO		
	PVT[d], mean (SD)	Non-PVT, mean (SD)	*P* value	PVT, mean (SD)	Non-PVT, mean (SD)	*P* value	PVT, mean (SD)	Non-PVT, mean (SD)	*P* value	PVT, mean (SD)	Non-PVT, mean (SD)	*P* value
Bangladesh	5.24 (4.45)	3.28 (3.57)	<.001	3.31 (3.57)	1.97 (3.12)	<.001	1.59 (2.22)	0.58 (1.52)	<.001	1.59 (2.22)	0.58 (1.52)	<.001
China	2.71 (2.92)	3.56 (6.64)	.02	3.71 (4.74)	4.51 (7.60)	.05	0.06 (0.26)	0.05 (0.25)	.13	0.05 (0.24)	0 (0)	<.001
India	5.06 (3.16)	5.21 (4.00)	.88	4.30 (2.74)	4.08 (3.20)	.11	0.49 (0.86)	0.47 (0.92)	.43	0.40 (0.77)	0.33 (0.84)	.005
Malaysia	1.88 (2.87)	0.82 (1.49)	<.001	1.84 (2.90)	0.80 (1.42)	<.001	0.77 (1.14)	0.36 (0.78)	<.001	0.76 (1.10)	0.34 (0.71)	<.001
Mongolia	7.06 (7.30)	4.64 (5.96)	<.001	6.90 (6.89)	4.68 (5.81)	<.001	0.95 (1.64)	0.38 (0.96)	<.001	0.92 (1.42)	0.54 (1.04)	<.001
Nepal	2.06 (2.53)	2.40 (2.71)	.049	1.77 (2.24)	1.94 (2.23)	.12	0 (0)	0 (0)	—[e]	0 (0)	0 (0)	—
Philippines	8.91 (7.88)	6.38 (6.83)	<.001	8.82 (7.77)	6.32 (6.71)	<.001	0.53 (0.76)	0.44 (0.78)	.009	0.53 (0.76)	0.44 (0.78)	.009
Sri Lanka	4.74 (4.02)	3.50 (3.49)	<.001	5.46 (4.07)	4.21 (3.98)	<.001	1.25 (1.67)	0.97 (1.68)	.002	1.14 (1.68)	0.75 (1.60)	<.001
Vietnam	3.98 (5.58)	1.17 (3.65)	<.001	4.17 (5.79)	1.28 (3.87)	<.001	1.10 (1.46)	0.26 (0.77)	<.001	1.07 (1.44)	0.27 (0.79)	<.001

[a] Not permitted food advertisements include solid foods and beverages. It excludes advertisements for culinary ingredients, nutritional supplements, baby food, and follow-up formula.

[b] WPRO: World Health Organization regional offices for Western Pacific.

[c] SEARO: World Health Organization regional offices for South-East Asia.

[d] PVT: peak viewing time.

[e] Not available.

Nature of Most Frequently (%) Advertised Not Permitted Food Categories

We observed that the highest frequency (%) of advertisements for not permitted food categories, irrespective of both NPMs, was driven by HFSS foods and beverages (Figure 1), which varied between countries and likely reflected local popular tastes. When categorized by WPRO criteria, the highest advertisement frequency related to “other beverages” for Nepal, Bangladesh, and Mongolia; “savoury snacks” for China; “chocolate and sugar confectionery, energy bars, and sweet toppings and desserts” for India and Sri Lanka; “ready-made, convenience foods and composite dishes” for Malaysia; and “milk drinks” for Vietnam and the Philippines. When categorized by SEARO criteria, advertisement frequencies were still reflecting local taste preferences for HFSS products as per “water-based flavored drinks” for Bangladesh and Nepal, “milk and dairy based drinks” for Vietnam, the Philippines, and Mongolia; “confectionery” for India and Sri Lanka; “composite foods (prepared foods)” for Malaysia; and “cheese and analogues” for China.

We further appraised the combined share of the sugar and nonsugar sweetener–based beverage products for each country (Figure 2), which were prominent among the top 5 frequently advertised not permitted foods. As per WPRO criteria, this totaled 72.2% (n=2207) for Bangladesh, 67.4% (n=1583) for Vietnam, 66.6% (n=1607) for Nepal, 51.1% (n=3115) for the Philippines, 36.7% (n=1004) for China, 33.8% (n=2237) for Mongolia, 32.8% (n=1403) for India, 29.7% (n=1543) for Sri Lanka, and 24.2% (n=437) for Malaysia. Of note, the WPRO category for “energy drinks, tea and coffee” included beverages marketed without sweetening agents such as teas and coffees, which likely targeted adult consumers. With SEARO criteria, these data changed: 68.3% (n=1527) for Nepal>55.5% (n=1180) for Bangladesh>54.3% (n=1320) for Vietnam>52.9% (n=3506) for Mongolia>43.3% (n=2573) for the Philippines>22.7% (n=1185) for Sri Lanka>19.9% (n=348) for Malaysia>14.2% (n=540) for China>8.4% (n=277) for India.

High sugar-containing foods were also frequently advertised (Figure 3), with the combined share as per WPRO criteria being the highest for Sri Lanka (n=2103, 40.7%)>India (n=1384, 32.3%)>Malaysia (n=1384, 28.1%)>Nepal (n=550, 22.8%)>China (n=472, 17.3%)>Mongolia (n=1105, 16.7%)>Bangladesh (n=474, 15.5%)>the Philippines (n=621, 10.2%)>Vietnam (n=144, 6.1%). With SEARO criteria, some differences were indicated with India (n=1466, 44.6%)>Sri Lanka (n=2093, 40.1%)>Malaysia (n=507, 29%)>Bangladesh (n=474, 22.3%)>Nepal (n=454, 20.3%)>Mongolia (n=1105, 16.7%)>the Philippines (n=869, 14.7%)>China (n=254, 6.7%)>Vietnam (n=141, 5.8%).

Not permitted food advertisements characterized by high-sodium and high-fat content as per both NPM thresholds were among the top 5 frequently advertised foods in China. These were identified as "savoury snacks" (n=931, 34%) under WPRO, whereas "cheese and analogues" (n=1323, 34.8%) and "ready-to-eat savouries (savoury snack foods): potato, cereal or starch-based (from roots, tuber, or legumes) and animal based (from skin)" (n=911, 24%) were products categorized under SEARO (Figure 4). Similarly for Malaysia, Mongolia, and the Philippines, high advertising frequency trends were observed under WPRO criteria relating to "ready-made and convenience foods and composite dishes" and under SEARO criteria relating to "composite foods (prepared foods)."

Figure 1. Top 5 (%) most frequently advertised not permitted foods by WPRO and SEARO criteria. LMIC: low- and middle-income countries; SEARO: World Health Organization regional offices for South-East Asia; UMIC: upper- and middle-income countries; WPRO: World Health Organization regional offices for Western Pacific. *Example of other beverages includes chocolate malt beverages, juice drinks, mineral water, and carbonated soft drinks.

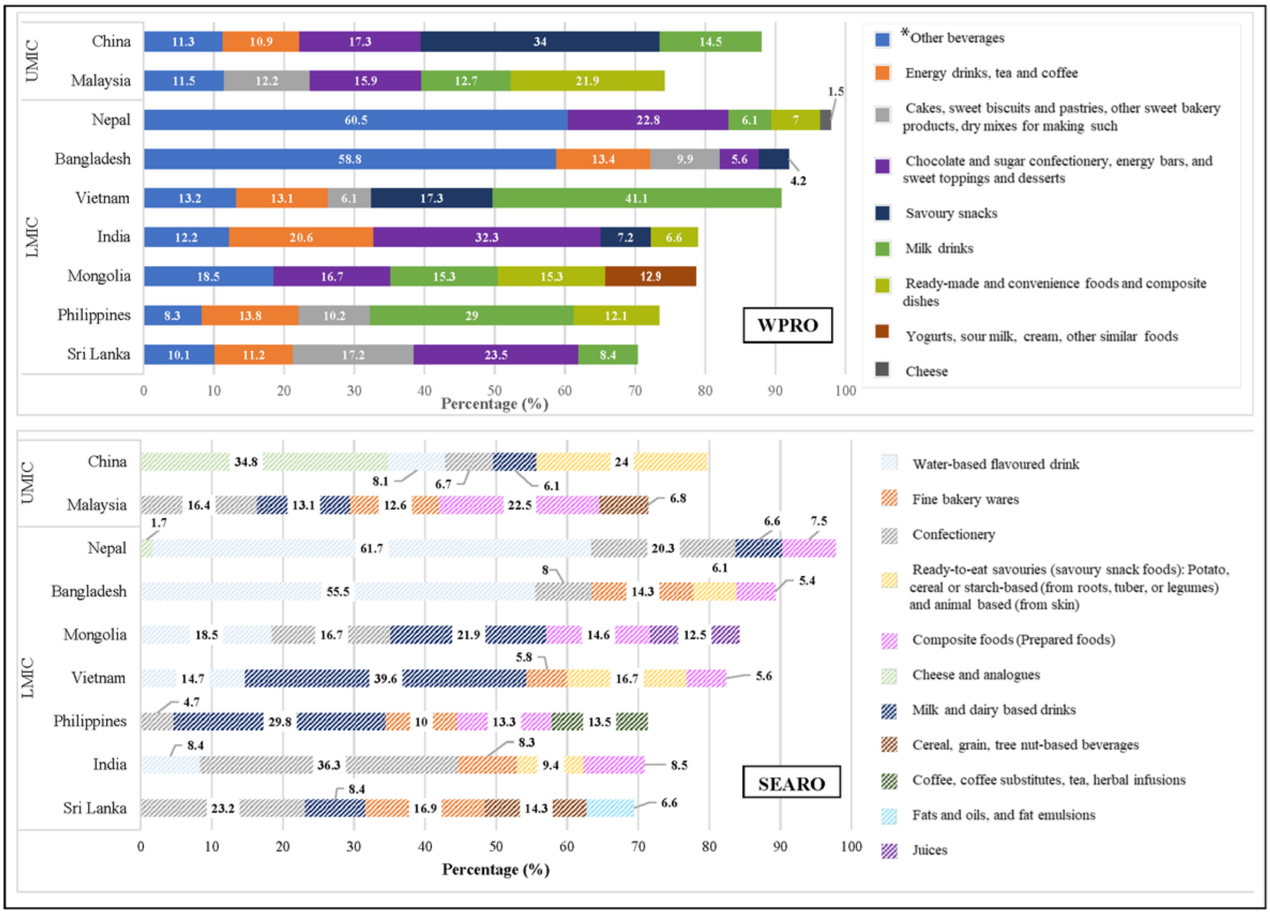


Figure 2. Top 5 (%) most frequently advertised not permitted products by WPRO and SEARO criteria as per combined estimates for sugar and nonsugar sweetener–based beverage products. LMIC: low- and middle-income countries; SEARO: World Health Organization regional offices for South-East Asia; UMIC: upper- and middle-income countries; WPRO: World Health Organization regional offices for Western Pacific.

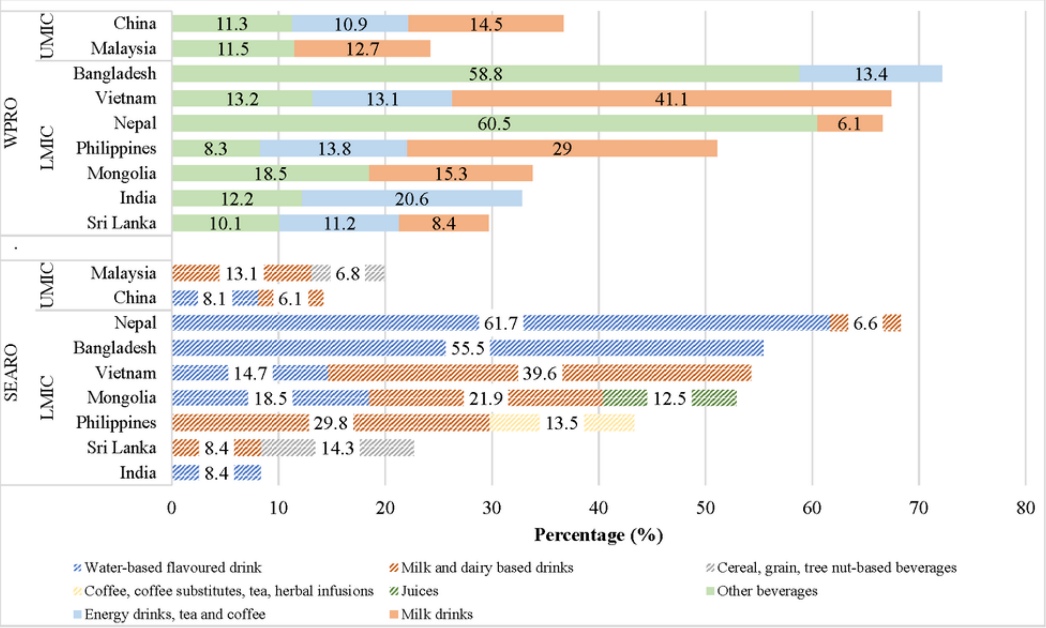


Figure 3. Top 5 (%) most frequently advertised not permitted products by WPRO and SEARO criteria as per combined estimates for sugar-concentrated solid food products. LMIC: low- and middle-income countries; SEARO: World Health Organization regional offices for South-East Asia; UMIC: upper- and middle-income countries; WPRO: World Health Organization regional offices for Western Pacific.

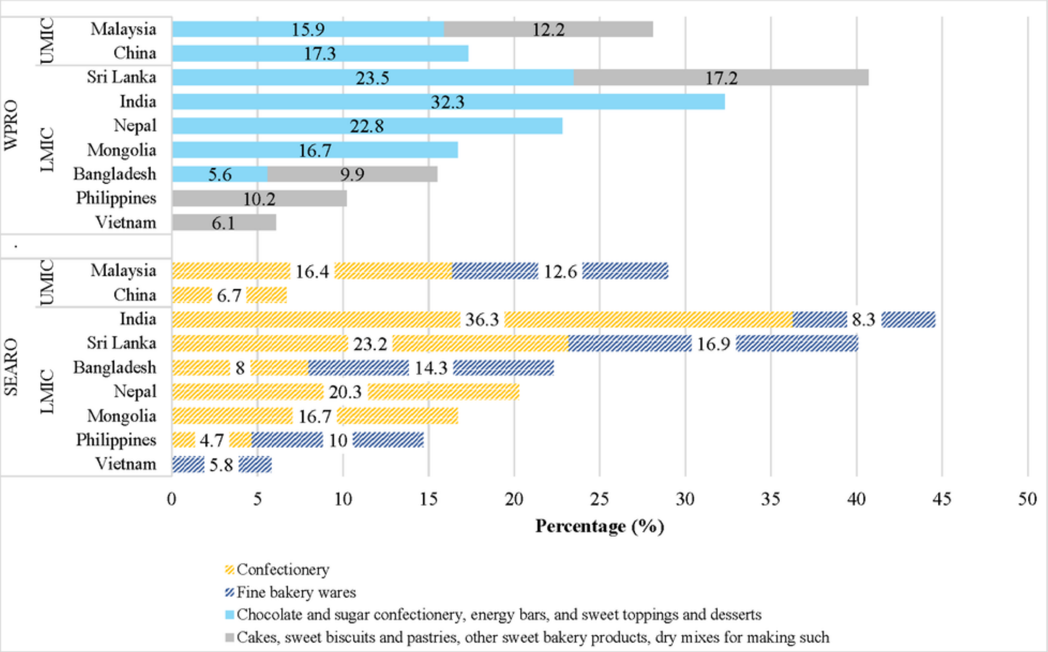
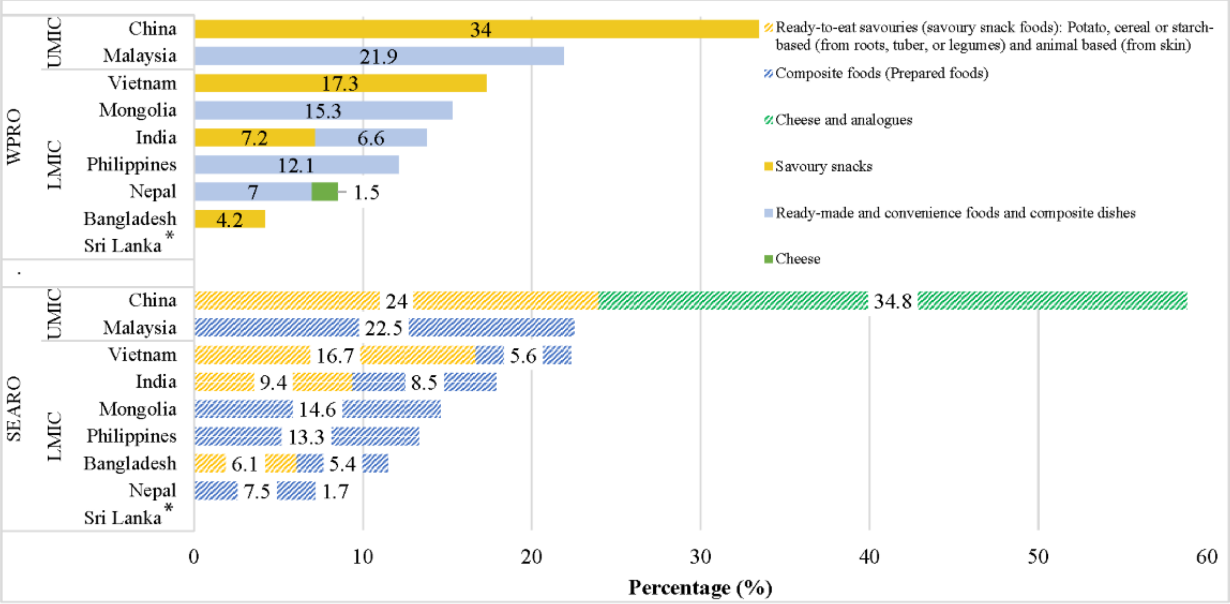


Figure 4. Top 5 (%) most frequently advertised not permitted products by WPRO and SEARO criteria as per combined estimates for high sodium- and fat-containing food products. LMIC: low- and middle-income countries; SEARO: World Health Organization regional offices for South-East Asia; UMIC: upper- and middle-income countries; WPRO: World Health Organization regional offices for Western Pacific. *Relevant products were not recorded.



Discussion

Principal Findings

Rapid economic growth occurring in Asia over the last decades, accompanied by nutrition transition, has unfortunately seeded childhood obesity in many countries. This phenomenon of obesity is driven through the globalization of trade and the growth of transnational and regional food businesses, which nurtured increased access to unhealthy foods and beverages [9,42-44]. Much of the food manufactured for the Asian market promotes HFSS foods and beverages, and the extent of their marketing channeled through children's settings such as popular television was little understood in Asia [11,24,25,29,31,45]. This research provides the first baseline evidence on the extent and nature of unhealthy television food marketing to children and adolescents across 9 Asian countries (Bangladesh, China, India, Malaysia, Mongolia, Nepal, the Philippines, Sri Lanka, and Vietnam) using the uniform approach of INFORMAS [35]. Participating countries representing LMICs at various stages of epidemiological, demographic, and nutrition transitions presented an opportunity to compare and contrast the extent and type of marketing. Policy commitments to regulate unhealthy food marketing on television and other media are not mandatory in most Asian countries [27], and industry commitments to self-regulate appear to be the norm for some of the countries participating in this study.

Using INFORMAS methodology to harmonize measurement approaches, we showed that unhealthy foods, defined as "not permitted" by WHO criteria for the NPMs established for the WPRO and SEARO regions in Asia [40,41], overwhelmingly dominated food advertising through children's popular television channels in the 9 Asian countries studied. The advertisement rate was highly varied between countries, ranging from almost 10 "not permitted" food advertisements per hour in the Philippines and Sri Lanka to 2 per hour in Malaysia. The rates observed in this study were lower than an earlier cross-country study in the Asia-Pacific region in 2014, which used a different food classification system to rate "noncore" (unhealthy) food advertising, reported rates ranging from 2.3 advertisements per hour per channel for South Korea to 16.7 advertisements per hour per channel for Indonesia [31]. This finding aligns with studies from Slovenia, Chile, and Thailand, which, in benchmarking food advertisements to standards of perceived thresholds for the "danger" HFSS nutrients, detected a high concentration of unhealthy food advertisements on children's popular television channels [46-48].

With the exception of India, China, and Nepal, most countries observed higher rates of not permitted food advertisements during the broadcast periods most popular with children compared to non-PVTs. This aligns with earlier studies [31,39,49], which also found higher rates of unhealthy food advertising during children's PVTs. Uniquely, China had significantly lower rates of not permitted food advertisements during children's PVTs compared to non-PVTs based on the SEARO classification. This may be attributed to local advertising regulations in China, which require several advertising slots to be reserved for public service advertisements (including healthy food such as fresh fruit) during these broadcast periods [50].

The use of persuasive marketing techniques embedded in not permitted food advertisements was also significantly higher during children's PVTs in most of the participating countries, which also concurs with previous multicountry studies [31,39] showing higher rates of promotional characters and premium offers during children's PVTs compared to non-PVTs. Taken together, the higher rate of unhealthy food marketing during popular broadcast times for children and the higher use of persuasive marketing techniques that appeal to children during these broadcast times clearly suggest advertisers are targeting children with unhealthy food advertising.

As this study used both the WPRO and SEARO NPM to classify advertised foods, it became possible to explore differences in the performance of these systems in categorizing food marketing across Asian countries. SEARO is the NPM applicable to India, Nepal, Sri Lanka, and Bangladesh, whereas WPRO is applicable to China, Malaysia, Mongolia, the Philippines, and Vietnam. Prior to this study, most studies investigating content analyses [12,39,51] related to the WHO model of the Europe Regional Office [52]. Applicable to the Asian scenario, this study therefore is the first to relate content analyses of food advertising to WPRO [40] and SEARO NPMs [41].

Application of the SEARO model compared to the WPRO model led to a lower ratio of "permitted" to "not permitted" advertised foods for most countries, except China and Sri Lanka, where ratios were comparable between the 2 NPMs. Differences occurred when healthy food and beverage items such as plain mineral water were included under WPRO but not included in the SEARO model. Another reason for higher ratios associated with WPRO was the exclusion of culinary ingredients, which otherwise would be identified as permitted food advertisements.

Upon further comparing WPRO and SEARO criteria, the fewer beverage categories available under WPRO lead to more products to be accommodated within a category. For example, both carbonated and chocolate malt drinks are grouped under "other beverages." Whereas under SEARO, these beverages are grouped separately as carbonated drinks under "water-based flavoured drinks" and chocolate malt beverage products under "cereal, grain, tree nut-based beverages." In scrutinizing the combined share of beverages among the top 5 frequently advertised not permitted foods, we noted higher frequencies for India and China using WPRO criteria for 2 categories, namely "energy drinks, tea and coffee" and "other beverages." However, the single beverage category of the SEARO criteria, vis à vis "water-based flavoured drink," generated lower frequencies when combining the top 5 beverages. Food advertisements categorized under "energy drinks, tea and coffee" as per WPRO criteria would be considered as not permitted with or without sugar content [40]. Whereas a total sugar threshold of up to 2 g would be permitted for categories such as "coffee, coffee substitutes, tea, herbal infusions" and "water-based flavoured drink" (which included energy drinks) or up to 6 g for "cereal, grain, tree nut-based beverages" under the SEARO criteria [41].

Even when considering sugar-concentrated solid food products, differences between NPMs could be explained by categories such as "chocolate and sugar confectionery, energy bars, and sweet toppings and desserts" as well as "cakes, sweet biscuits and pastries, other sweet bakery products, dry mixes for making such" were not allowed to be marketed under WPRO regardless of sugar level [40]. Whereas SEARO allowed a total sugar threshold of up to 6 g [41]. Contrarily, the "cheese" category under SEARO, despite identifying foods with high-sodium and high-fat thresholds as not permitted, includes an additional criterion of "zero" tolerance for added sugar [40,41].

Advertising of fast foods is a concern for Malaysia, Mongolia, and the Philippines with high advertising frequency trends for "ready-made and convenience foods and composite dishes" under WPRO and composite foods (prepared foods) under SEARO criteria. The implication for Malaysia, in particular, is a failure of a self-regulatory policy known as the *Guideline on the Advertising and Nutrition Information Labelling of Fast Foods* [53,54]. This guideline was introduced in 2008 to restrict advertising of fast food during children's programs if ≥4% of children aged 4-9 years comprise the television viewing audience. However, the guideline is not legislated, and government-led monitoring for the guideline is lacking [54].

A trait of television advertising in Asia is featuring culinary ingredients even during PVTs [24,26,45]. It is noted that PVT equates to prime time for Asian families, running between 6 and 11 PM, which also attracts the viewership of the whole family. It is not surprising that this period also carries advertisements for culinary ingredients targeting women, as women traditionally purchase foods for their household, cook foods, and decide what the family consumes [55]. Additionally, labels of culinary items featured in advertisements will not provide serving size, as they are ingredients combined with other ingredients in cooking meals. Unique culinary practices in the Asian region follow recipes prepared in the home requiring many staples (eg, uncooked rice, cooking oil, spices, seasoning powder, uncooked meat, chicken or vegetable stock, recipe premix, plain sugar, stevia, plain flour, breading mix, lentils, and coconut milk). For Malaysia and Vietnam, items such as uncooked rice and soybean cooking oil would otherwise be identified as permitted foods as per WPRO criteria (Table S2 in Multimedia Appendix 1). We, therefore, excluded culinary ingredients from our analyses.

Strength and Limitations

A major strength of this study was the harmonized measurement approaches adopted by all 9 Asian countries, enabled comparisons between countries using 2 WHO NPMs for determining the extent, intensity, and nature of unhealthy food marketing on television. The comparative assessment of WPRO and SEARO NPMs across the 9 Asian countries facilitated the identification of inconsistencies in their application to categorize food advertisements due to regional and cuisine differences, thereby indicating the need for improvement across these 2 models. Overall, the findings from this study contribute evidence of the need to strengthen local regulatory frameworks in each country to stimulate advocacy to stakeholders. Of priority, there is an urgent call for mandatory policy action in Asian countries to restrict children's exposure to unhealthy food marketing on television to protect them from the harmful impact of food marketing [6]. Ultimately, a comprehensive regulatory framework with consistent monitoring over time should enable the reduction of exposure and power of unhealthy food marketing directed to children. A further benefit in conducting this study was that the collaboration achieved between country teams and INFORMAS experts enabled the exchange of technical knowledge and building the capacity of researchers across the 9 Asian countries.

This study's protocol required recording advertisements shown on the top 3 children's popular television channels for each country rather than measuring actual children's media exposure. The latter approach to measure actual targeted media exposure of children to television is experimental, with behavioral research methodology being varied and challenging to execute in multicountry scenarios where a harmonized protocol in low-resource settings is critically required [56]. Second, as this study was initiated during the COVID-19 lockdown occurring in all countries, we adopted convenience sampling to accommodate permitted travel days to the recording site. However, COVID-19 may have changed the nature of advertising, as this period may not have reflected the usual advertising pattern. Coding challenges for food products were encountered where countries lacked mandatory labeling regulation, such as Vietnam. In such cases, researchers would refer to their country's or the neighboring country's food composition database.

Future Directions

Future research on television food marketing in individual countries should consider recording more television channels, such as in India and China. Ideally, randomized sampling for recording days should be adopted, but randomization should be appropriate to the cultural diversity and practices in Asia. Given this successful collaboration between the Asian countries on television food marketing, there is now a need for explorative research on the digital food marketing landscape in Asia, as the food industry has expanded its marketing strategy to digital media platforms.

Conclusions

This project's collaboration and use of harmonized methodology generated country-level evidence for 9 Asian countries on the exposure and power of unhealthy food marketing on television to children. Cross-country comparisons, irrespective of country income level, indicated that unhealthy food advertising dominated children's popular television channels with frequent advertising of sugar-sweetened beverages, sugar-containing solid food and snacks, and fast foods high in salt and fat, especially during PVTs. Clearly, unhealthy food marketing through popular children's television channels is occurring widely in Asia and is a clear breach of child rights. Evidence outcomes could be used to advocate for stronger policy regulations and implementation to control unhealthy food marketing, which will strengthen strategies promoting a healthier food environment for Asia's children.

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Data Availability

The data sets generated and analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

TK, BS, SMMR, JZ, NK, BJ, RKP, EQB, TT, and NTTT conceptualized the project and contributed to the study design. TK, GRO, and SSN served as the project management team in providing training and data management for all participating countries. SM and BK provided a capacity building in the adoption of the International Network for Food and Obesity/Non-Communicable Disease Research, Monitoring and Action Support protocol. They together with KC also provided faculty support in the training involved for data analyses. Data collection and coding were mainly managed by individual countries' principal investigator and coprincipal investigator (TK, MJS, GRO, SMMR, MAU, YT, JZ, NK, NKS, BJ, ED, RKP, RP, EQB, ACR, TT, VPW, NTTT,

and PTH). The project management team consolidated the data from all participating country and conducted the statistical analysis. KC reviewed each country's results. TK, GRO, and SSN developed the first draft of the manuscript. All authors reviewed, revised, and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary tables.
[DOCX File , 19 KB - pediatrics_v7i1e63410_app1.docx]

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Abbreviations

HFSS: high in fat, sugar, and salt
INFORMAS: International Network for Food and Obesity/Non-Communicable Disease Research, Monitoring and Action Support
IRR: intercoder reliability
LMICs: low- and middle-income countries
NCD: noncommunicable disease
NPM: nutrient profile model
PMT: project management team
PVT: peak viewing time
SEARO: World Health Organization regional offices for South-East Asia
WHO: World Health Organization
WPRO: World Health Organization regional offices for Western Pacific

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Parental Autonomy in the Care of Premature Newborns and the Experience of a Neonatal Team: Observational Prospective Study

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Abstract

Background: The European Foundation for the Care of Newborn Infants (EFCNI) has promoted the importance of parental involvement in the care of children.

Objective: The study aimed to examine how the time required by parents to achieve autonomy in the care of their very low–birth weight newborn infants was modified during the implementation of a training program.

Methods: This was an observational prospective study in the context of a quality improvement initiative. The Cuídame (meaning "Take Care of Me" in English) program was aimed at achieving parental autonomy. It was implemented over 2 periods: period 1, from September 1, 2020, to June 15, 2021; and period 2, from July 15, 2021, to May 31, 2022. The days required by parents to achieve autonomy in several areas of care were collected from the electronic health system.

Results: A total of 54 and 43 families with newborn infants were recruited in periods 1 and 2, respectively. Less time was required to acheive autonomy in period 2 for participation in clinical rounds (median 10.5, IQR 5 - 20 vs 7, IQR 4 - 10.5 d; *P*<.001), feeding (median 53.5, IQR 34 - 68 vs 44.5, IQR 37 - 62 d; *P*=.049), and observation of neurobehavior (median 18, IQR 9 - 33 vs 11, IQR 7 - 16 d; *P*=.049). More time was required to achieve autonomy for kangaroo mother care (median 14, IQR 7 - 23 vs 21, IQR 10 - 31 d; *P*=.02), diaper change (median 9.5, IQR 4 - 20 vs 14.5, IQR 9 - 32 d; *P*=.04), and infection prevention (median 1, IQR 1 - 2 vs 6, IQR 3 - 12; *P*<.001).

Conclusions: Parents required less time to achieve autonomy for participation in clinical rounds, feeding, and observation of neurobehavior during the implementation of the training program. Nevertheless, they required more time to achieve autonomy for kangaroo mother care, diaper change, and infection prevention.

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KEYWORDS

family-centered care; neonatal intensive care unit; kangaroo mother care; mother; mothers; parent; parents; parental; ICU; intensive care; training; education; educational; premature; pediatric; pediatrics; paediatric; paediatrics; infant; infants; infancy; baby; babies; neonate; neonates; neonatal; newborn; newborns; intensive care unit

Introduction

The European Foundation for the Care of Newborn Infants (EFCNI) has promoted the importance of parental involvement in the care of children [1]. It has been expected that parental autonomy will result in additional benefits. Some programs have been created [2-4] to achieve such training. However, the time required by parents to become autonomous is unknown, particularly in the case of premature children.

The main objective of this study is to compare the number of days required by parents of very low–birth weight (VLBW) newborn infants to be autonomous in different areas of care during the 2 periods of implementation of a parental training program.

Methods

Overview

This observational prospective study was associated with a quality improvement initiative, aimed at increasing parental autonomy in the care of VLBW newborn infants during the implementation of the Cuídame (meaning "Take Care of Me" in English) program in a IIIC-level Spanish neonatal unit.

Prior to the implementation of this program, in 2020, materials were prepared, and meetings with the most sensitive health care providers to neurodevelopmental-centered care issues were conducted. The program was implemented over 2 periods (Table 1). Period 1 was from September 1, 2020, to June 15, 2021, representing the start of the implementation of the Cuídame program. Period 2 was from July 15, 2021, to May 31, 2022, representing complete implementation along with greater experience of the neonatal team.

Table . Actions carried out in the neonatal unit aimed at the implementation of the Cuídame program over time, as well as the events that could act as barriers to the implementation.

Periods	Actions	Barriers
Prior to the implementation	• The use of family rooms had already begun • Design of the Cuídame program • Approval by the Ethics Committee • Selection of professionals responsible for monitoring the program • Presentation of the program to the professionals	• Family members are restricted due to the COVID-19 epidemic
Period 1: from September 1, 2020, to June 15, 2021	• Start of the implementation of the Cuídame program	• Family members are restricted due to the COVID-19 epidemic
Period 2: from July 15, 2021, to May 31, 2022	• Complete implementation of the Cuídame program	• Family members are restricted due to the COVID-19 epidemic • Summer vacation • Incorporation of new professionals

This program included several areas of care and a paper called a road map, where the parents were encouraged to write down the dates they achieved autonomy under the supervision of the neonatal nursing staff [5]. Health professionals provided information about the Cuídame program at a time close to the admission. There was no standardized day to initiate the information provision. The team adapted to the individual situation of each child and family. A responsible professional was assigned to each family to monitor the autonomy of the parents in caring for their babies. In addition, professionals received file books with the criteria and indicators that parents had to meet to advance in every step.

The families who recorded the dates of autonomy in all areas of care on their road maps were included. Autonomy scores were not based on whether the primary caregiver was the mother or the father. In the context of clinical management, the families of newborns infants with a severe disease focused on caring for children at the end of their life, families with newborn infants who died during the first month of life, or those with important language barriers were excluded.

The autonomy of parents in caring for their VLBW newborn infants during their admission to the neonatal unit and the dependent variables related to the morbidity of VLBW newborn infants were defined based on scientific literature [5]. Autonomy in kangaroo mother care was achieved when parents transferred newborn infants from the incubator to their chest, placed their children properly in the kangaroo position, and then transferred the children back to the incubator. With respect to feeding, autonomy was achieved when parents were able to recognize the signs that their infants were hungry and feed them orally. Autonomy in the observation of neurobehavior was achieved when parents identified their infants' daily achievements and helped them reach the next neurobehavioral step. The parents were considered autonomous in handling, posture, and contact when they created the cradle nest, chose the bedding, placed the infants properly, and executed postural changes in the incubator. Autonomy in diaper change occurred when the infants' diaper were changed by the parents themselves. When parents detected their infants' pain or stress signs and applied nonpharmacological analgesic measures, they were considered autonomous in stress and pain prevention. Autonomy in the prevention of sensory deprivation was achieved when the parents talked to their infants, chose stories to tell them, and conveyed the importance of this initiative to other parents. Autonomy in patient safety involved ensuring that the parents dealt with their babies, were familiar with the monitoring system, and alerted the team about any detected incident. It also involved knowing the medication and the type of milk that the infants were receiving. Parents who cleaned their infants properly according to their corrected age were considered autonomous in cleanliness. Autonomy in the prevention of health care–associated infections involved the removal of bracelets or watches before contact with the infants, the use of hand sanitizer before touching them, and reminding professionals to use hand sanitizer as well. Finally, autonomy in participation in clinical rounds was achieved when the parents provided suggestions to the team during clinical rounds.

Comparisons between the 2 time periods were performed using the nonparametric Mann-Whitney *U* test and the chi-square test or Fisher exact test. Comparative analyses were adjusted for gestational age and birth weight.

Ethical Considerations

The Ethics Committee of the Biomedical Research Institute of the 12 de Octubre University Hospital approved the project (21/123). All participants were sent an information document. No compensation was given to families; they voluntarily participated in the care of their children.

Results

During the study period, a total of 159 VLBW newborn infants were admitted to the neonatal unit. The parents of 107 VLBW newborn infants recorded the dates of complete autonomy in the areas of care at discharge on their road maps. Four families were excluded because of a significant language barrier, and 6 families were excluded because of the death of the newborn in the first month of life. Overall, 54 (72%) out of 75 families were recruited during period 1, and 43 (51%) out of 84 families were recruited during period 2. No statistical differences were found between the infants in periods 1 and 2 (*P*>.50).

The median gestational age and birth weight were 28.7 (IQR 26.8 - 31) weeks and 1080 (IQR 850 - 1270) g in period 1, respectively. In period 2, they were 27.8 (IQR 26.7 - 30.4) weeks and 1000 (800 - 1200) g, respectively. The number of days required by the parents of VLBW newborn infants to be autonomous in the 11 care areas included in this study is described and compared in Table 2. It should be noted that the prevention of health care–associated infection was an area of care where health care providers and parents required fewer days to be autonomous (median 6, IQR 3 - 12 d), and feeding required more days (median 44.5, IQR 37 - 62 d). Additionally, different behaviors can be highlighted when the numbers of days needed to be autonomous were compared between periods 1 and 2. Thus, the number of days required to be autonomous in period 2 decreased for participation in clinical rounds (median 10.5, IQR 5 - 20 vs 7, IQR 4 - 10.5 d; *P*<.001). In contrast, the time required in period 2 was significantly increased in 3 areas of care: kangaroo mother care (*P*=.02), diaper change (*P*=.04), and prevention of health care–associated infections (*P*<.001).

Table . The time required by parents of very low–birth weight newborn infants to acquire the highest degree of autonomy in the 11 care areas of the Cuídame program during the implementation.

Area of care	Days, median (IQR)		*P* value	*P* value adjusted for birth weight and gestational age
	Period 1: from September 1, 2020, to July 15, 2021 (n=54)	Period 2: from July 15, 2021, to May 31, 2022 (n=43)		
Kangaroo mother care	14 (7 - 23)	21 (10 - 31)	*.04*	*.02*
Feeding	53.5 (34-68)	44.5 (37-62)	.39	*.049*
Observation of neurobehavior	18 (9 - 33)	11 (7 - 16)	*.04*	*.049*
Handling, posture, and contact	16.5 (7-36)	22.5 (11-37)	.24	.17
Diaper change	9.5 (4-20)	14.5 (9-32)	*.01*	*.04*
Stress and pain prevention	13 (6 - 26)	12 (7 - 26)	*<.001*	.61
Prevention of sensory deprivation	6.5 (2.5-16)	7 (4.5-9)	.35	.82
Patient safety	9 (4-17)	9 (5-19)	.90	.90
Cleanliness	15.5 (7.5-39)	23.5 (13-37)	.25	.07
Prevention of health care–associated infections	1 (1-2)	6 (3-12)	*<.001*	*<.001*
Participation in clinical rounds	10.5 (5-20)	7 (4-10.5)	*.049*	*<.001*

Discussion

Our study revealed that the implementation of the Cuídame program changed the culture of care in our neonatal unit, resulting in the autonomy of most families in caring for their newborn infants under the supervision of a health care professional during their admission. The prevention of health care–associated infections was the first area where parents achieved the autonomy, and feeding was the last one.

The implementation of a program aimed at achieving parental autonomy in the care of newborn infants does not affect every area of care in the same way. In our case, the time required by parents of VLBW newborn infants to be autonomous in kangaroo mother care, prevention of health care–associated infections, and diaper change increased in the second period. One possible reason for this difference is that health care providers became more demanding during the implementation of the program.

Some limitations should be considered, such as how the COVID-19 epidemic could have acted as a barrier to the implementation of the Cuídame program.

Based on our results, it can be concluded that some areas of care could have different behaviors during the implementation of a training program aimed at achieving parental autonomy. The number of days required by parents to achieve autonomy in kangaroo mother care, diaper change, and the prevention of health care–associated infections increased in our case, even though the team was more experienced. This leads us to believe that achieving parental autonomy is a complex process that depends on several factors in the implementation of a training program.

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Conflicts of Interest

None declared.

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Abbreviations

EFCNI: European Foundation for the Care of Newborn Infants
VLBW: very low–birth weight

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Review

Exploring Maternal and Infant Health App Development and Effectiveness Research: Scoping Review

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Abstract

Background: Globally, high rates of maternal and infant mortality call for interventions during the perinatal period to engage pregnant people as well as their loved ones in care. Mobile health technologies have become ubiquitous in our lives and in health care settings. However, there is a need to further explore their safety and effectiveness to support and improve health outcomes locally and globally.

Objective: The aim of this study was to review and synthesize published literature that described the development process or effectiveness evaluations of maternal and infant apps.

Methods: We applied a methodological framework for scoping reviews as well as the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines; in addition, the systematic review platform Covidence (Veritas Health Innovation Ltd) was used to facilitate the review of included studies. Search terms were developed collaboratively, and health sciences–associated databases were searched for studies conducted between January 1, 2000, and February 4, 2022. We excluded studies about apps that only gathered or tracked data or targeted care providers.

Results: A total of 1027 articles were included for title and abstract screening, of which 87 (8.47%) were chosen for full-text screening. Of these 87 articles, 74 (85%) were excluded with reasons, and 19 (22%) were included. Four articles were added at data extraction from hand searching and 2 others were excluded. Thus, we reviewed and synthesized data from 11 unique studies reported in 21 articles published between 2017 and 2021. The included studies represented 8 different countries. Most of the apps (8/11, 73%) were in English, although apps were also developed in Arabic, Bahasa Indonesia, and Nepali. The articles reviewed revealed the early stage of development of the field of maternal and infant health apps, with modest evidence of app use and achievement of study outcomes. Only 1 (9%) of the 11 apps was endorsed by an independent health care provider society. App development and evaluation processes emerged, and specific app features were identified as vital for well-functioning apps. End-user engagement occurred in some, but not all, parts of app research and development.

Conclusions: Apps to improve maternal and infant health are being developed and launched in enormous numbers, with many of them not developed with mothers' needs in mind. There are concerns about privacy, safety, and the standardization of current apps as well as a need for professional or institution-specific guidelines or best practices. Despite challenges inherent in currently available apps and their design processes, maternal and infant app technology holds promise for achieving health equity goals and improving maternal and child health outcomes. Finally, we propose recommendations for advancing the knowledge base for maternal and infant apps.

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KEYWORDS

maternal and child health; smartphone; mobile health; mHealth; eHealth; app development; app evaluation; app effectiveness; maternal and infant app; pregnancy, postpartum; mothers; mobile phone; artificial intelligence; AI

Introduction

Overview

Achieving the global health goal of health for all requires engaging and empowering individuals, families, and communities for increased social participation and enhanced self-care and self-reliance in health, in addition to universal health coverage (UHC) and primary health care (PHC) [1-4]. Globally, high rates of maternal and infant mortality call for interventions during the perinatal period to engage pregnant people as well as their loved ones to ensure that they remain in care during pregnancy and the postpartum period [5-10]. As mobile health (mHealth) technologies such as smartphone apps emerge and become ubiquitous in our lives and in health care settings, there is a need to further explore their potential to support and improve health outcomes locally and globally. The COVID-19 pandemic demonstrated the capacity for widespread uptake of mHealth technologies in every aspect of life [11,12]. Before the COVID-19 pandemic, there were numerous smartphone apps being developed to support many diverse health goals [7-9,12-14]. However, many maternal and infant health apps are short lived or constrained to specific health care systems or networks, and few of them are evaluated for effectiveness in improving health outcomes for the mother, their children, and families or endorsed or reviewed by health professionals or organizations independent of app development teams [14-19]. Despite the existence of a plethora of apps to support parents, especially during the perinatal and postpartum periods, documented scientific data remain meager. The limited peer-reviewed published evidence about the development process and effectiveness of apps in supporting mothers or parents with the challenges they face during the perinatal or postpartum period makes the content of the available apps questionable, which may influence their efficacy.

Background and Significance

Apps to Prevent Maternal and Infant Morbidity and Mortality

Numerous apps have been developed to support and improve maternal and infant health, including during pregnancy and the postpartum period. These apps can be an efficient means of providing information for parents, and the number of apps is rapidly increasing [20,21]. However, most apps lack the information needed and searched for by mothers with low income and non–English-speaking mothers with low income belonging to minority groups. It is well documented that people with low income, those with low income belonging to minority groups, and non–English-speaking people have a lower rate of pregnancy app use [22,23]. Most maternal and infant apps are not designed for women with low income and culturally diverse non–English-speaking women [24-26]. In the United States, it is estimated that most women (92%-95%) aged between 18 and 34 years own a smartphone [27]. This large proportion of smartphone users may have easy access to apps during pregnancy and the postpartum period when they could benefit from app-based maternal and infant health information. Evidence is emerging that maternal and infant apps have been developed and tested in resource-constrained settings and for use in humanitarian crises [7-9,14,28]. However, most existing pregnancy apps lack commercial regulation and standardization, making their content questionable [29]. Potential harm from several pregnancy mHealth intervention apps have been identified by health professionals [30]. Many apps have not been evaluated for content accuracy, making it difficult for users to assess the reliability of the information presented in them [31,32]. Many apps currently lack information that would be most helpful for women during pregnancy [33,34]. Neither medical nor health care societies have issued guidelines for mHealth apps [18,19,29,35,36]. Few studies exist that report on the outcomes from the use of such apps [29].

Regulatory agencies are constrained under current regulatory frameworks to provide effective and efficient regulation of apps that can be classified as software as medical device (SaMD) [17-19,35]. The US Food and Drug Administration (FDA) takes the position that the regulation of apps needs to be tailored to the risk and benefit profiles of the apps but has *no* standards for apps [35]. The FDA "oversees apps intended to treat, diagnose, cure, mitigate, or prevent diseases or other conditions as medical devices under federal statute" [35]. The FDA seeks to empower patients and clinicians through innovation, including the creation of regulatory frameworks that instills confidence in the performance and reliability of apps [35]. The International Organization for Standardization (ISO) has articulated assessment processes and quality requirements for health apps [17]. There are international standards for product safety and lifecycle processes that are applicable to health apps. However, because of the time investment involved, most health-related apps are not evaluated [17]. This lack of effective regulatory oversight has led to calls for user-centered reforms to improve the accuracy, usability, accessibility, and privacy protection features of apps, especially health apps [18,19].

The current research and regulatory landscape offers little data or regulatory guidance to inform people about the effectiveness of available apps that aim to improve health outcomes among mothers, especially mothers with low income, mothers with low income belonging to minority groups, and non–English-speaking mothers. The lack of regulatory frameworks and guidelines for the development of safe and effective maternal and infant apps limits the confidence of patients and clinicians and may lead to harms derived from the use of currently available apps [18,19,35,36]. Increasing knowledge in this area is important because the population of people with low income and those with low income belonging to non–English-speaking minority groups continues to grow, and these groups tend to have poorer maternal and infant health outcomes. In addition, there is an increased need for maternal and infant apps in languages other than English.

App Searches

Mobile apps are downloaded by end users on their smartphone. However, there are little data on why people search for apps, although major life events seem to be drivers for mobile app installations [37]. People experiencing major life events—change in marital status, moving, job change, pregnancy, or the birth of a child—install 2.5 times more apps than those without any significant life changes. There are studies reporting how end users find apps [37]. More than half of app users (55%) found apps based on recommendations from friends, family members, and colleagues [37]. In addition, 1 in 3 consumers found apps through app store recommendations; searching in an app store; and advertisements on the web, social media, and television. Most consumers (74%) downloaded apps after viewing mobile advertisements for them [38]. There are little data documenting that consumers' app searches and downloads are based on scientific recommendations [38,39].

Brief Overview of Currently Available Parent and Infant Health Apps

An extensive review of currently available maternal and infant apps is beyond the scope of this review. In 2018, a total of 5276 Android maternal and child health (MCH) apps and 877 iOS MCH apps were identified [40,41]. There are estimated to be >350,000 health apps available worldwide, and it is estimated that 250 new health apps are released every daily [42].

Positionality Statement

Our scoping review team includes professionals and researchers with a variety of perspectives that inform our evaluation of the literature reviewed. We represent multiple cultural backgrounds, migrant statuses, sexes, and genders. In addition, our multiple academic disciplines include computer technology and IT, communications, human rights law, informatics, speech-language pathology, medicine, and maternal and child nursing. We have team members from multiple contexts globally. Our varied lived experiences and knowledge support analysis of the literature reviewed from a wider perspective of world views to inform future development of computer-mediated technologies, such as smartphone apps, to improve the health of mothers, their infants, families, and communities.

Objectives

The purpose of this scoping review study was to review and synthesize published literature that described the development process or effectiveness evaluations of maternal and infant health apps, with a specific emphasis on determining the use of the apps by the target population; provided evidence of outcomes with mothers, fathers, infants, or children; and explained whether the apps have been reviewed or endorsed by a health care provider. The research question guiding this scoping review study was as follows: what evidence exists that describes the development and effectiveness evaluation of maternal and infant health apps?

Methods

Scoping Review Approach

Because of the scarce evidence of apps being systematically evaluated for effectiveness, we used a scoping study methodology to review and synthesize the existing literature. The scoping review approach was originally described by Arksey and O'Malley [43] and has since been adapted by Islam et al [44], Levac et al [45], and Westphaln et al [46]. The original scoping review method included 5 steps: identifying the research question (step 1); search strategy (step 2); study selection (step 3); charting the data (step 4); and collating, summarizing, and reporting the results (step 5). Two additional steps were added subsequently: consultation (step 6) [45,46] and quality assessment (step 7) [44]. We used the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines to enhance transparency in our approach to our scoping study [47]. The PRISMA-ScR guidelines checklist is available in Multimedia Appendix 1.

Steps Taken

The identification of the research question (step 1) and the development of our search strategy (step 2) were developed collaboratively during team meetings. The research question addressed by the scoping study was as follows: what evidence exists that describes the development and assessment of the development and effectiveness of parent and infant health apps? Specifically, we sought to identify extant studies that described the use of the apps by the target population; provided evidence of outcomes with mothers, infants, or children; and explained whether the apps have been reviewed or endorsed by a health care provider or health care provider society (eg, American Academy of Pediatrics). Our search strategy included literature published between January 1, 2000, and February 4, 2022. The search terms included "((mother* OR mom* OR matern* OR pregna* OR parent* OR postpart*) AND (infan* OR newborn OR neonat* OR prenat* OR perinat* OR postnat* OR bab*) AND (app OR mobile app OR apps OR mobile device applications OR mobile apps OR smartphone) AND (health*))." The search resulted in 1895 citations being identified. The search process commenced on January 27, 2022, with a preliminary search of Academic Search Complete (EBSCO), Bibliography of Indigenous Peoples in North America (EBSCO), CINAHL, Communication Source (EBSCO), Education Source (EBSCO), and Global Health (EBSCO). The citations identified from this search (163/1895, 8.6%) were imported into the systematic review platform Covidence (Veritas Health Innovation Ltd) [48]. MEDLINE (Ovid) was also searched on January 27, 2022, and the citations identified (398/1895, 21%) were imported into Covidence [48]. Citations from Scopus (64/1895, 3.38%), PubMed (656/1895, 34.62%), and Web of Science (614/1895, 32.4%) were identified in an additional search on February 4, 2022, and added to Covidence [48]. Of the 1895 citations, after screening, 892 (47.07%) duplicates were removed.

Study selection (step 3); charting the data (step 4); and collating, summarizing, and reporting the results (step 5) were facilitated using Covidence [48]. Study selection occurred in 2 stages: title and abstract screening and full-text screening. All articles at each stage were reviewed by at least 2 team members. Any conflicts were resolved during team meetings for title and abstract screening. During full-text screening, any conflicts were resolved by team members who had differing opinions about inclusion discussing their differences and coming to an agreement about whether to include a citation for data extraction. Inclusion and exclusion criteria (Textbox 1) were specified during team meetings and adapted as needed through team consensus. All team members had the opportunity to participate in title and abstract screening, which aligns with our approach to consultation (step 6) that was inclusive of the multiple perspectives of our team members.

Textbox 1. Literature review inclusion and exclusion criteria.

Inclusion criteria

- Published primary research article (eg, completed studies)
- Review article (eg, systematic review or scoping review)
- Apps for pregnant people (people), parents (include fathers if they are part of the app's target audience), postpartum people (people), infants and children, and mothers and infants
- Language: app in any language; articles limited to publications in English
- Any country
- Article describes app development process or how effectiveness was determined (eg, randomized controlled trial or evaluation)

Exclusion criteria

- Study or app focused on pathology or psychopathology (eg, gestational diabetes mellitus, preterm or premature birth, anxiety, and depression)
- Study protocols
- Thesis or dissertation
- Commentaries, editorials, and letters to the editor
- Apps for health care or community services workers only
- Apps for data gathering or tracking
- Computer-mediated platforms: websites, communication platforms (eg, WhatsApp, Facebook Messenger, and FaceTime), and social media or social networking platforms (eg, Twitter, Facebook, and Reddit)

Our team developed a data extraction tool for charting the data (step 4). This instrument was then entered into Covidence to facilitate data extraction. Three authors (JCP, JH, and SZ) completed data extraction. All other team members had access to the data extraction outputs in Covidence [48]. The final outputs of the data extraction process—the charted data—were shared with all team members for review and discussion at a team meeting. Collating, summarizing, and reporting the results (step 5) were completed using the PRISMA-ScR process [47]. To ensure rigor in reporting our findings, we used a 3-stage process [45]. First, we provide numerical summaries of key aspects from the reviewed studies (eg, country where app was designed to be used, app language, and study population). Second, narrative summaries, tables, and figures are used to present our findings and facilitate comparisons between, and contrasts across, the reviewed studies. Finally, in the *Discussion* section, we elaborate on the implications of our findings for the future research and development of maternal and infant apps. We also propose recommendations for improving the development, usability, end-user uptake, evaluation, quality assessment, as well as policies for funders and regulators in the field.

Consultation (step 6) was incorporated into this scoping review by including the multiple personal and professional perspectives of the members of our diverse and inclusive team, which is briefly described in the *Positionality Statement* subsection. We did not consult outside our research team for conducting this scoping review study. Our future research endeavors will include wider community consultations to include the experiences and perspectives of the people who use maternal and infant apps.

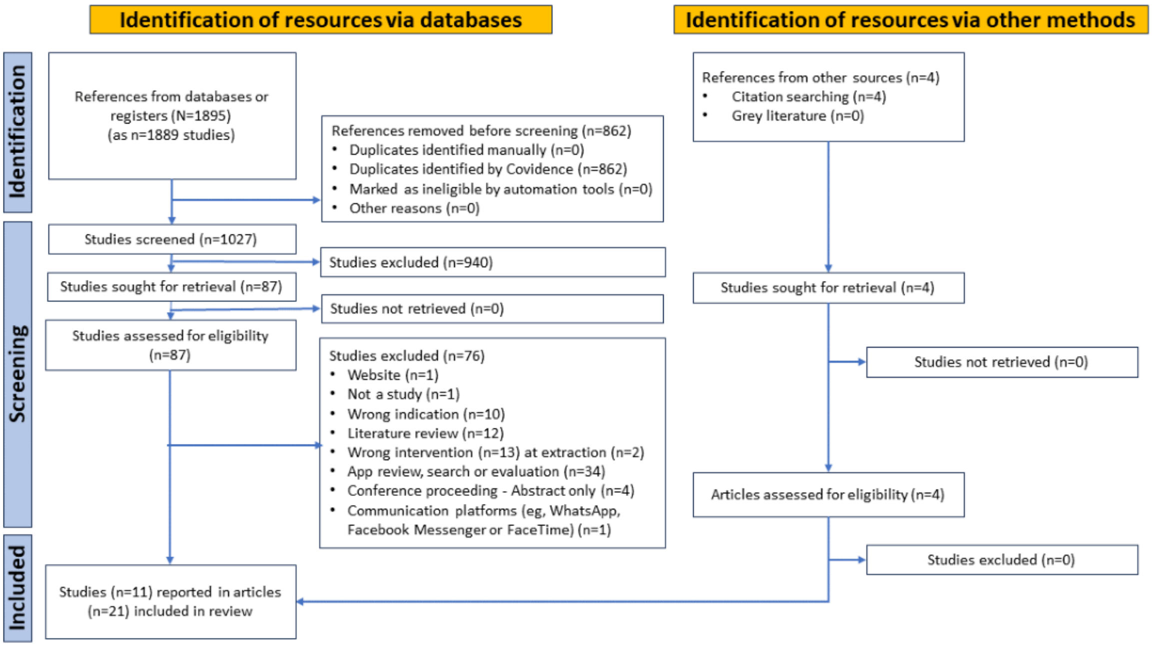
Quality assessment (step 7) is a potentially fraught process for scoping review studies, but efforts are underway to develop an appraisal tool for them [49]. Some researchers have included this step to enhance scoping review quality [44]. For the purposes of our review and given the early developmental stages of the science regarding the development and effectiveness evaluations of smartphone apps, quality assessment was not part of the inclusion criteria for this study. The assessment of the selected studies will be made in a separate study after recommendations for the critical appraisal of scoping reviews have been more formalized [49].

Results

Overview

Of the 1889 studies identified, after removing 862 (45.63%) duplicates, 1027 (54.37%) articles remained. Of these 1027 articles, 940 (91.53%) were excluded during the title and abstract screening. Of the remaining 87 articles that were assessed for eligibility during full-text screening, 74 (85%) were excluded for reasons stated in the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram (Figure 1 [50]), resulting in 19 (22%) articles reporting on 13 distinct studies that were included for data extraction. At data extraction, 4 articles [51-54] describing aspects of 1 (8%) of these 13 studies were added from a hand search of the literature, yielding a total of 23 articles for data extraction. Of the total 23 articles, 2 (9%) were excluded at data extraction; 1 (4%) was excluded because the app is limited to podcasts, which may not offer a range of engagement opportunities and communication modalities for app users and has less potential for use with multiple languages [55]; and 1 (5%) was excluded because the study tested a model of care that included an encrypted digital app that facilitated text-based communication between patients and their care team, not an app with multiple functionalities [56]. Each of these excluded articles reported on a study, which yielded the final total of 11 studies reported in 21 articles included. Of these 11 studies, 2 (18%) were reported in multiple articles, 1 (9%) was reported in 3 (14%) of the 21 articles [7-9], and 2 (18%) studies were each reported in 5 (24%) of the 21 articles [51-54,57-62]. Ultimately, we reviewed and synthesized data from 11 unique studies reported in 21 articles, published between 2017 and 2021.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram.



Characteristics of Included Studies

Table 1 summarizes characteristics across the 11 included studies. The lead authors of the included studies represented 8 different countries, with Australia (3/11, 27% studies reported in 7/17, 41% of the articles) [57,59-64] and the United States (3/11, 27%) [16,65,66] having the greatest representation. The other represented countries included Indonesia (1/11, 9%) [28], Jordan (1/11, 9%) [14], Morocco (1/11, 9%) [67], Nepal (1/11, 9% study reported in 3/21, 14% of the articles) [7-9], and Singapore (1/11, 9% study reported in 5/21, 24% of the articles) [51-54,58]. The health discipline of the primary authors varied, with the most common being medicine (3/11, 27%) and nursing (3/11, 27%). The other disciplines included public health (2/11, 18%), followed by computer technology fields: computing and informatics (1/11, 9%), IT (1/11, 9%), and biomedical engineering (1/11, 9%). Most of the apps were in English (8/11, 73%); other app languages included Arabic (1/11, 9%) [14], Bahasa Indonesia (1/11, 9%) [28], and Nepali (1/11, 9% study reported in 3/21, 14% of the articles) [7-9]. English-language apps were developed for use in Australia (3/11, 27%), the United States (3/11, 27%), Morocco (1/11, 9%), and Singapore (1/11, 9%).

Table 1. Key characteristics of reviewed studies (n=11).

Country (language); authors and year	Studies (n=11), n (%)	Articles (n=21), n (%)	Disciplines	Endorsed by independent HCP[a]
Australia (English)	3 (27)	7 (33)		
Dalton et al [64]; 2018			Anthropology, media, communications, and health (health, arts, and design)	No
Meedya et al [63]; 2021			Medicine, nursing, social work, IT, computer science, and business	No
Scott et al [57]; 2021			Medicine, nursing, IT, dietetics, public health, and population health	No
White et al [59]; 2016			Medicine, nursing, IT, dietetics, public health, and population health	No
White et al [60]; 2018			Medicine, nursing, IT, dietetics, public health, and population health	No
White et al [61]; 2016			Medicine, nursing, IT, dietetics, public health, and population health	No
White and Scott [62]; 2019			Medicine, nursing, IT, dietetics, public health, and population health	No
United States (English)	3 (27)	3 (14)		
Bush et al [65]; 2017			Nursing	No
Cawley et al [66]; 2020			Nursing, public health, and business administration	No
Chaudhry et al [16]; 2019			Medicine, social work, computer science, and trained health workers (prenatal care coordination providers)	No
Indonesia (Bahasa Indonesia)	1 (9)	1 (5)		
Wiweko et al [28]; 2019			Medicine and computer science	No
Jordan (Arabic)	1 (9)	1 (5)		
Nasir et al [14]; 2020			Medicine, international development agencies, UNRWA[b], and World Bank	No
Morocco (English)	1 (9)	1 (5)		
Sardi et al [67]; 2020			Medicine, computer science, and biomedical science	Yes
Nepal (Nepali)	1 (9)	3 (14)		
Kayastha et al [7]; 2021			Social work, IT, and computer science (female community health volunteers were part of the sample studied)	No
Mueller et al [8]; 2020			Social work, IT, and computer science (female community health volunteers were part of the sample studied)	No
Mueller et al [9]; 2020			Social work, IT, and computer science (female community health volunteers were part of the sample studied)	No
Singapore (English)	1 (9)	5 (24)		
Shorey et al [58]; 2017			Nursing and psychiatry	No
Shorey and Ng [51]; 2019			Nursing and psychiatry	No
Shorey et al [52]; 2019			Nursing and psychiatry	No
Shorey et al [53]; 2021			Nursing and psychiatry	No
Shorey et al [54]; 2018			Nursing and psychiatry	No

[a] HCP: health care provider.

[b] UNRWA: United Nations Relief and Works Agency for Palestine Refugees in the Near East.

The studies included a variety of study designs, including randomized controlled trial (2/11, 18% studies reported in 3/21, 14% of the articles) [51,57,58], observational study (1/11, 9%) [66], multisite cross-sectional study (1/11, 9%) [14], diagnostic test accuracy study (1/11, 9%) [16], mixed methods study (1/11, 9%) [63], case study methodology report of a pilot study (1/11, 9%) [65], retrospective review (1/11, 9%) [64], app development reports (2/11, 18%) [28,67], and qualitative articles with participants from the main study (4/11, 36%) [51,53,54,60]. Of the 11 apps, 4 (36%) were designed for use in resource-constrained settings: Indonesia [28], Morocco [67], Nepal (reported in 3/21, 14% of the articles) [7-9], and Palestine refugee camps in Jordan [14].

All studies reviewed reported that they had funding to conduct the research for the study. Of the 11 studies, 7 (64%) were funded by a governmental agency, whereas 1 (9%) was funded by a state Medicaid office [65], 1 (9%) was funded by the United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) [14]; 1 (9%), reported in 5 (24%) of the 21 articles, was funded by a university [51-54,58]; and 1 (9%) was funded by a health system [66]. Funding specific for app development was reported in 5 (46%) of the 11 studies reported in 7 (33%) of the 21 articles [7-9,28,65-67]. Funding to support app sustainability was not specifically reported in any of the studies but could be assumed in 3 (27%) of the 11 studies [14,16,65]. It was not clearly specified whether app development and sustainability funding were obtained for 2 (18%) of the 11 studies [14,16].

Evidence of Apps’ Use, Outcomes, or Endorsement

Characteristics of the study populations from the reviewed studies are summarized in Table 2, and evidence use of the apps by the target population is presented in Table 3. Sardi et al [67] described an app in development and proposed a study to evaluate the effectiveness of the app they developed in collaboration with postpartum people. Evidence of outcomes with mothers, fathers, infants, and children was limited and is summarized in Table 3. Evidence that apps have been reviewed or endorsed by a health care provider is presented in Table 1. Although all studies reviewed included health professionals or health care providers as members of their research and development teams, only 1 (9%) of the 11 apps was endorsed by an independent health care provider or health care provider society not involved in the app’s development or evaluation [67].

Table 2. Participant characteristics.

Authors	Population description	Recruitment method	Sample size, n	Sample characteristics
Sardi et al [67]	Physicians and nurses (app for puerperal women)	Hospital	NR[a]	NR
Wiweko et al [28]	Pregnant and nonpregnant people	Clinic patients	205	NR
Chaudhry et al [16]	Prenatal care coordination providers, social workers, and women	Clinic patients	9	• Age: 20-36 y • Ethnicity: African American (6/9, 67%); Hispanic (1/9, 11%); White (2/9, 22%) • Education: ≤high school (6/9, 67%); college (3/9, 33%) • Income: US $0-US $30,000/y
Meedya et al [63]	Pregnant people	News platform, paper flyers, and social media	7	• Age: 29-37 y • Race or ethnicity: Asian; European; Middle Eastern; White • Education: NR • Income: >US $6000/mo
Bush et al [65]	Pregnant people	Grass roots referrals	85	NR
Shorey et al [58]	Couples (mothers and fathers)	Clinic patients	250 (126/250, 50% [63 couples] received education support via app, whereas 124/250, 50% [62 couples] were in the control group)	• Age: 26-42 y • Ethnicity: Chinese; Malay; other • Education: NR • Income: >SG $6000 (US $4367)/mo
Shorey and Ng [51]	Couples (mothers and fathers)	Clinic patients	250 (126/250, 50% [63 couples] received education support via app, whereas 124/250, 50% [50] couples were in the control group)	• Age: 26-42 y • Ethnicity: Chinese; Malay; other • Education: NR • Income: >SG $6000 (US $4367)/mo
Shorey et al [52]	Couples (mothers and fathers)	Clinic patients	250 (126/250, 50% [63 couples] received education support via app, whereas 124/250, 50% [50] couples were in the control group)	• Age: 26-42 y • Ethnicity: Chinese; Malay; other • Education: NR • Income: >SG $6000 (US $4367)/mo
Shorey et al [53]	Couples (mothers and fathers)	Clinic patients	250 (126/250, 50% [63 couples] received education support via app, whereas 124/250, 50% [62 couples] were in the control group)	• Age: 26-42 y • Ethnicity: Chinese; Malay; other • Education: NR • Income: >SG $6000 (US $4367)/mo
Shorey et al [54]	Couples (mothers and fathers)	Clinic patients	250 (126/250, 50% [63 couples] received education support via app, whereas 124/250, 50% [62 couples] were in the control group)	• Age: 26-42 y • Ethnicity: Chinese; Malay; other • Education: NR • Income: >SG $6000 (US $4367)/mo
Nasir et al [14]	Parents (mothers and fathers)	Clinic patients	1042	• Age • Mothers: 23-33 y • Fathers: 29-39 y • Ethnicity: Palestinian (refugees) • Education: NR • Income: US $0
Cawley et al [66]	Postpartum mothers	Mail	567	• Age: 20-36 y • Race or ethnicity: Asian (74/567, 13%); Hispanic (46/567, 8%); White (360/567, 63%); other (87/567, 15%) • Education: ≤high school (82/567, 14%); college (482/567, 85%) • Income: US $0-US $70,000/y (276/567, 49%); >US $70,000-US $150,000/y (201/567, 35%)

Authors	Population description	Recruitment method	Sample size, n	Sample characteristics
Scott et al [57]	Expecting couples (mothers and fathers)	Clinic patients	1426	- Age - Mothers: 33-34 y - Fathers: NR - Race or ethnicity: African or Middle Eastern (64/1426, 4%); Asian (84/1426, 6%); Australia or New Zealand (724/1426, 51%); United Kingdom or Ireland (129/1426, 9%); other (72/1426, 5%) - Education: ≤high school (409/1426, 29%); college (663/1426, 46%) - Income: NR
White et al [59]	Expecting couples (mothers and fathers)	Clinic patients	1426	- Age - Mothers: 33-34 y - Fathers: NR - Race or ethnicity: African or Middle Eastern (64/1426, 4%); Asian (84/1426, 6%); Australia or New Zealand (724/1426, 51%); United Kingdom or Ireland (129/1426, 9%); other (72/1426, 5%) - Education: ≤high school (409/1426, 29%); college (663/1426, 46%) - Income: NR
White et al [60]	Expecting couples (mothers and fathers)	Clinic patients	1426	- Age - Mothers: 33-34 y - Fathers: NR - Race or ethnicity: African or Middle Eastern (64/1426, 4%); Asian (84/1426, 6%); Australia or New Zealand (724/1426, 51%); United Kingdom or Ireland (129/1426, 9%); other (72/1426, 5%) - Education: ≤high school (409/1426, 29%); college (663/1426, 46%) - Income: NR
White et al [61]	Expecting couples (mothers and fathers)	Clinic patients	1426	- Age - Mothers: 33-34 y - Fathers: NR - Race or ethnicity: African or Middle Eastern (64/1426, 4%); Asian (84/1426, 6%); Australia or New Zealand (724/1426, 51%); United Kingdom or Ireland (129/1426, 9%); other (72/1426, 5%) - Education: ≤high school (409/1426, 29%); college (663/1426, 46%) - Income: NR
White and Scott [62]	Expecting couples (mothers and fathers)	Clinic patients	1426	- Age - Mothers: 33-34 y - Fathers: NR - Race or ethnicity: African or Middle Eastern (64/1426, 4%); Asian (84/1426, 6%); Australia or New Zealand (724/1426, 51%); United Kingdom or Ireland (129/1426, 9%); other (72/1426, 5%) - Education: ≤high school (409/1426, 29%); college (663/1426, 46%) - Income: NR

Authors	Population description	Recruitment method	Sample size, n	Sample characteristics
Kayastha et al [7]	Men and women	By referrals	71	NR
Mueller et al [8]	Men and women	By referrals	71	NR
Mueller et al [9]	Men and women	By referrals	71	NR
Dalton [64]	Pregnant people	Clinic patients	124	• Age: 19-41 y • Ethnicity: Australian White (103/124, 83%); other (21/124, 17%) • Education: ≤high school (83/124, 67%); college (41/124, 33%) • Income: NR

[a] NR: not reported.

Table 3. Target group involvement, app use, and outcomes.

Authors	Target group	Involvement	App use	Outcomes reported
Sardi et al [67]	Mothers and infants	App development	N/A[a] (app in development phase)	• Clinical staff examined app features and functionalities. • A future study with mothers is planned.
Wiweko et al [28]	Mothers	Implementation phase	Mothers	• App provides pregnant people directions to nearest health centers, access to medical staff, and saves patient's medical records to easily obtain professional help needed immediately.
Chaudhry et al [16]	Mothers and infants	App development	Pregnant people	• Low use by both providers and mothers.
Meedya et al [63]	Mothers	App development	Breastfeeding mothers	• App was piloted with, and revised based on, mothers' feedback.
Bush et al [65]	Pregnant people	NR[b]	Pregnant people	• There was a statistically significant increase in the completion of prenatal visits (*P*=.02). • There was an association between the use of the app and lowered incidence of low birth weight infants (*P*=.06).
Shorey et al [58]	Postnatal mothers and fathers	Research process	Postnatal mothers and fathers	• There was an increase in the parenting confidence of new parents, better perceived social support (parents were encouraged to proactively seek help), and greater parenting satisfaction.
Shorey and Ng [51]	Postnatal mothers and fathers	Research process	Postnatal mothers and fathers	• There was an increase in the parenting confidence of new parents, better perceived social support (parents were encouraged to proactively seek help), and greater parenting satisfaction.
Shorey et al [52]	Postnatal mothers and fathers	Research process	Postnatal mothers and fathers	• There was an increase in the parenting confidence of new parents, better perceived social support (parents were encouraged to proactively seek help), and greater parenting satisfaction.
Shorey et al [53]	Postnatal mothers and fathers	Research process	Postnatal mothers and fathers	• There was an increase in the parenting confidence of new parents, better perceived social support (parents were encouraged to proactively seek help), and greater parenting satisfaction.
Shorey et al [54]	Postnatal mothers and fathers	Research process	Postnatal mothers and fathers	• There was an increase in the parenting confidence of new parents, better perceived social support (parents were encouraged to proactively seek help), and greater parenting satisfaction.
Nasir et al [14]	Pregnant people and mothers	No community involvement	Pregnant people and mothers	• The number of participants who downloaded the app was reported. • Having other apps (OR[c] 6.17; *P*<.01), staff knowledge of the app (OR 11.82; *P*<.01), using the Internet as a source of medical information (OR 1.63; *P*=.01) and having internet access at home (OR 1.46; *P*=.05) were associated with app download.
Cawley et al [66]	Mothers and infants	Research process	Pregnant people	• The app provided access to personalized and evidence-based health information. • The app was associated with an increase in healthy behaviors and health knowledge.
Scott et al [57]	Mothers and fathers	Research process	Fathers	• The study did not demonstrate a measurable impact of father-focused support for breastfeeding.
White et al [59]	Mothers and fathers	Research process	Fathers	• The study did not demonstrate a measurable impact of father-focused support for breastfeeding.
White et al [60]	Mothers and fathers	Research process	Fathers	• The study did not demonstrate a measurable impact of father-focused support for breastfeeding.
White et al [61]	Mothers and fathers	Research process	Fathers	• The study did not demonstrate a measurable impact of father-focused support for breastfeeding.
White and Scott [62]	Mothers and fathers	Research process	Fathers	• The study did not demonstrate a measurable impact of father-focused support for breastfeeding.

Authors	Target group	Involvement	App use	Outcomes reported
Kayastha et al [7]	Pregnant people and mothers	App development	Pregnant people and mothers	• Participants gained more knowledge on maternal health than on neonatal health.
Mueller et al [8]	Pregnant people and mothers	App development	Pregnant people and mothers	• Participants gained more knowledge on maternal health than on neonatal health.
Mueller et al [9]	Pregnant people and mothers	App development	Pregnant people and mothers	• Participants gained more knowledge on maternal health than on neonatal health.
Dalton et al [64]	Mothers	App development	Pregnant people	• There was a high rate of noncompletion among study participants.

[a] N/A: not applicable.

[b] NR: not reported.

[c] OR: odds ratio.

App Development and Evaluation Processes

The studies reviewed revealed several approaches to app development. Some of the studies (4/11, 36%) used systematized app development strategies, including software requirements specification [67], rapid iterative testing and evaluation [16,57], and persuasive system design model and principles [63]. Most of the studies (9/11, 82%) included formalized evaluation processes. Standardized approaches to the evaluation of the apps included the Computer System Usability Scale [16], the Mobile Application Rating Scale [57,59,61], and investigator-developed evaluation instruments or processes [7-9,14,59].

App Features

Each app included features intended to improve the end users' experience. A full list of app features described in the studies is beyond the scope and purpose of this scoping review report. Textbox 2 summarizes the key features and functionality reported across the studies.

Textbox 2. Summary of the key app features and functionality reported across the reviewed studies.

Feature and functionality

- Health status tracking: mechanism to record various health indicators and observe changes over time
- Care support and access to information: provides information to guide care and increase knowledge
- Usability: enhances the app user's experience
- Health data protection and privacy: protects the end users' health data gathered by, or shared through, the app
- Data transfer: allows for the sharing of information between patients and providers
- Communication with health care providers: facilitates dialogue and communication between patients and providers
- Behavior change techniques: mechanisms to change health-promoting or risk behaviors

End-User Engagement

End-user engagement in app development was reported in 5 (45%) of the 11 studies, which were reported in 8 (38%) of the 21 articles [7-9,16,28,63,64,67]. Mothers were involved in app development in 7 (64%) of the 11 studies, which were reported in 4 (19%) of the 21 articles [16,28,63,67]. Fathers were involved in app development in 1 (9%) of the 11 studies, which was reported in 3 (14%) of the 21 articles [7-9]. End users were engaged in the research process in 3 (27%) of the 11 studies, which were reported in 11 (52%) of the 21 articles [51-54,57-62,66]. Of the 11 studies, 2 (18%) included mothers and fathers in the research process, as reported in 10 (48%) of the 21 articles [51-54,57-62]; and 1 (9%) included postpartum mothers in the research process [66]. Of the 11 studies, 1 (9%) included pregnant and nonpregnant people in the implementation phase of app development [28], whereas 2 (18%) did not report including end users in any aspect of the study [14,65].

Discussion

Principal Findings

Overview

Our scoping review is consistent with what has been previously reported in the literature. Apps have been developed for, and used in, a variety of settings globally. There are little data and regulatory guidance to inform people about the effectiveness of available apps that aim to improve health outcomes among mothers, especially mothers with low income, mothers with low income belonging to minority groups, and non–English-speaking mothers. This includes geographic locations with constrained resources and humanitarian crises (both human-made and natural disasters) [7-9,14,28]. The studies we reviewed reinforce the importance and usefulness of maternal and infant health apps to support global PHC objectives and confirm that they can be useful tools to facilitate the achievement of UHC [1-4]. However, our findings highlight several research gaps and challenges for the effective and sustainable development, implementation, and evaluation of maternal and infant health apps.

App Development Process

Currently, the development of maternal and infant health apps (including for use during pregnancy and the postpartum period) is on the rise; however, as documented in the literature and the results of this scoping review study, evaluation is lacking. Consistent with previous research, these apps are an efficient means of providing a wide range of health and safety information, and most women and parents, regardless of background or language, own a smartphone [7-9,14,20,21,28]. In fact, >85% of the world's population in advanced economies [68] and >67% of the global population own a smartphone, with >90% owning a mobile phone [69,70]. Smartphone ownership makes health information on pregnancy and perinatal periods easily accessible through maternal and infant health apps. However, as seen in our study, maternal and infant health apps lack commercial regulation and standardization, making their content questionable, which has been previously documented [29]. As there is a lack of regulation and standardization, potential harm has been identified by health professionals with several pregnancy mHealth intervention apps [18,19,30,35]. Our review as well as other studies have found that many apps have not been evaluated for content accuracy, making it difficult for end users to assess the reliability of the information presented in them [31,32]. Some apps also lack information that would be most helpful for women and their families during the perinatal period [33,34]. No medical society has issued guidelines for mHealth apps [29], although the ISO and FDA offer guidance to support further development of guidelines [17,35], and legal scholars have proposed a framework for user-centered approaches to improve the safety and security of all apps, including mHealth apps [18,19].

In this scoping review study, we found that the outcomes reported demonstrated slight increases in behavior and knowledge [9,52,58,63,65,66], whereas other studies reported low use [14,16,64] or were in the development stages with no outcomes reported [28,67]. This is similar to other studies reporting on outcomes regarding the reasons why most apps developed are targeted at English-speaking White women without regard for women of other cultures and non–English-speaking people [8,14,22,23,28,29]. This has been attributed to a lack of app development designed for culturally diverse non–English-speaking women [25,71]. Few studies with culturally diverse women with low income and their use of mHealth apps have been reported or have examined language and cultural issues as potential barriers to app use [8,14,72,73]. Our study indicated that most of the apps (8/11, 73%) were in English. However, our scoping review study documents emerging evidence to support the use of maternal and infant health apps in other languages and cultures [7-9,14,28,51-54,58,67]. Studies have reported high uptake and use of linguistically and culturally tailored apps [74,75].

The findings of our study help in assessing similar conclusions in other recent studies that women using maternal and infant health apps during pregnancy and the postpartum period prefer greater and immediate access to information that is relevant to their local health care context, which includes support offered by health care professionals [25,76].

App Features

A summary of key features to include in future apps are described in Textbox 2. Key features for inclusion in apps include health status tracking, care support and access to information, usability, health data and privacy protection, data transfer, communication with health care providers, and behavior change techniques. Health status tracking facilitates recording various health indicators that can be monitored over time. Care support and access to information build knowledge to improve health outcomes. Usability enhances the end users' experience when using an app. Health data and privacy protection protects the end users' health data gathered by, or shared through, the app. Data transfer allows for sharing information between patients and health care or social services providers. Communication with health care providers facilitates dialogue and communication between patients and health care or social services providers. Behavior change techniques can be embedded in apps to support the achievement of health-promoting or risk behavior reduction goals. Additional information regarding app features is provided in a literature review conducted by Sardi et al [77].

In resource-constrained settings, such as Nepal [7-9], the app served multiple purposes to achieve public health and safety objectives, including maternal health and disaster preparedness. In addition, in refugee settings, an app based on the *Maternal and Child Health Handbook* contains basic MCH information and promotes care-seeking behaviors, improves the continuum of care, and increases users' health-related behaviors [14]. This is evidence that apps can serve multiple health-related objectives, which has been documented in other settings during the COVID-19 pandemic [11,12]. In the context of health and humanitarian crises, the adoption of mHealth apps may be a wise use of scarce resources to address multiple public health–related and safety objectives simultaneously.

Potential risks related to mHealth and privacy exist and have been documented in the literature; for example, apps with the capacity to gather and store health data from end users need to have policies and protocols in place to ensure that the privacy of these data is maintained. These policies and protocols need to be transparent so that end users can be aware of who has access to their health data and for what purposes. In addition, algorithms, artificial intelligence, and machine learning can be used with the data gathered from apps. People who use these apps need to be aware of how these technologies are used with the data they share in apps [36]. Finally, risks can occur related to end users' capability and capacity to read and understand content embedded in apps, even if the app is developed in the end users' native language.

End-User Engagement

A fundamental feature of PHC that effective maternal and infant mHealth apps can offer is engaging people in their health care through empowerment and opportunities for enhanced self-care and self-reliance [1-4]. End-user engagement ought to be an essential part of the development of all maternal and infant health apps as well as other mHealth apps. Including end users in all stages of app development, implementation, scale-up, evaluation, and research across all stages is critical to the sustainability of apps and may enhance app longevity. Strategies for how to engage end users of apps in research have been described previously [78]. None of the studies included in this scoping review included participants in all aspects of app research and development. Most of the studies (9/11, 82%) included end users in part of the app research and development process, including app development, reported in 7 (33%) of the 21 articles [7-9,16,63,64,67]; the implementation of the app [28]; and the research process, reported in 11 (52%) of the 21 articles [51-54,57-62,66].

Quality Appraisal and Risk of Bias

The current state of the science for app development and evaluation limits the ability to evaluate the published studies for risk of bias [49]. Furthermore, there is debate about whether and how to review study quality and risk of bias in scoping reviews [49,79]. As our scoping review included a variety of different research approaches or app development reports, it was difficult to conduct a thorough quality appraisal of the potential for risk of bias, especially because we did not exclude any study based on quality appraisal or risk of bias. Our finding that the current literature may not meet criteria specified in many quality appraisal and risk-of-bias tools aligns with the challenges in the field of mHealth app development and evaluation with which regulatory and standards agencies are currently grappling [18,19,35].

Strengths and Limitations of the Review

This scoping study used a methodological approach that has demonstrated success in other settings. In addition, we used the PRISMA-ScR guidelines to guide our study, which increases the transparency of the processes used to conduct the study. The limitations of this review include the fact that we may have missed some studies by only searching English-language literature. As we excluded studies with a primary focus on mental health outcomes, we may have missed some studies that reported on apps that have demonstrated efficacy and have begun to surmount the concerns with regard to quality and reliability as well as the accuracy, usability, accessibility, and privacy protection features of apps [18,19,35].

Conclusions

In conclusion, this is one of the few studies reviewing the research regarding apps for maternal and infant health. These apps are increasingly being developed and launched in the marketplace in enormous numbers with little to no evaluation criteria in place. Many of the current maternal and infant health apps being launched are not developed with the pregnant person or mother's needs in mind. Although the use of maternal and infant apps in health research is a relatively new area, there are concerns about the safety of these apps for end users. Future initiatives are needed to support health researchers to navigate the landscape of maternal and infant health apps and evaluate the impact of their efforts to develop effective and sustainable apps. Given the concerns related to safety and standardization, future research needs to focus on providing additional direction to health researchers on how to set policies in place. This could include the development of professional or institution-specific guidelines or the development of best practices. Furthermore, there is a need for research to determine the influence and implications of the integration of apps within health care information systems. The integration of apps into health care information systems architecture and environments may pose unique challenges that directly influence the acceptability and usability of these apps for end users and may limit an app's utility, uptake, and sustainability. Despite challenges inherent in currently available apps and their design processes, maternal and infant health app technology holds promise for achieving health equity goals and improving MCH outcomes.

Recommendations

Funders should consider strategies to support the sustainability of effective apps that achieve their stated purpose and are accessible, acceptable, safe, and secure for their end users. This will facilitate the sustainability of apps that have demonstrated effectiveness among pregnant people, parents, and their families. This implies that a quality appraisal or effectiveness evaluation of apps would need to be built into the app development, implementation, and scale-up processes.

We advocate for regulation to ensure that maternal and infant apps support the needs of mothers, fathers, and others who use them to improve health outcomes for mothers, infants, and their families. The regulatory framework proposed by Knox and Tenenbaum [18,19] would be useful to inform and guide regulatory advances in the field, as would the inclusion of strategies to protect the private information of people who use apps [18,19,36]. One aspect of this recommendation is for funders and policy makers to consider requiring end-user engagement in all aspects of app development and research that is consistent with the principles of PHC and UHC [1-4].

Researchers, policy makers, and patient advocates should advocate for the safe and wise use of new technology advances such as the artificial intelligence chatbots ChatGPT and Bard. These technologies may further advance opportunities for computer-mediated approaches that support improvements in MCH. These technologies hold tremendous potential to revolutionize health care but must be used to support goals for improved health outcomes, not for nefarious purposes.

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Data Availability

All data analyzed in this study are cited in this paper and available in the public domain. Data extraction tables are available from the corresponding author.

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) checklist.
[DOCX File , 84 KB - pediatrics_v7i1e46973_app1.docx]

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Abbreviations

FDA: Food and Drug Administration
ISO: International Organization for Standardization
MCH: maternal and child health
mHealth: mobile health
PHC: primary health care
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

SaMD: software as medical device
UHC: universal health coverage
UNRWA: United Nations Relief and Works Agency for Palestine Refugees in the Near East

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Original Paper

Exploring Pregnancy-Related Information-Sharing Behavior Among First-Time Southeast Asian Fathers: Qualitative Semistructured Interview Study

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Abstract

Background: While the benefits of fathers' engagement in pregnancy are well researched, little is known about first-time expectant fathers' information-seeking practices in Southeast Asia regarding pregnancy. In addition, there is a notable gap in understanding their information-sharing behaviors during the pregnancy journey. This information is important, as cultural norms are prevalent in Southeast Asia, and this might influence their information-sharing behavior, particularly about pregnancy.

Objective: This study aims to explore and analyze the pregnancy-related information-sharing behavior of first-time expectant fathers in Southeast Asia. This study specifically aims to investigate whether first-time fathers share pregnancy information, with whom they share it, through what means, and the reasons behind the decisions to share the information or not.

Methods: We conducted semistructured interviews with first-time Southeast Asian fathers in Indonesia, a sample country in the Southeast Asian region. We analyzed the data using quantitative descriptive analysis and qualitative content theme analysis. A total of 40 first-time expectant fathers were interviewed.

Results: The results revealed that 90% (36/40) of the participants shared pregnancy-related information with others. However, within this group, more than half (22/40, 55%) of the participants shared the information exclusively with their partners. Only a small proportion, 10% (4/40), did not share any information at all. Among those who did share, the most popular approach was face-to-face communication (36/40, 90%), followed by online messaging apps (26/40, 65%). The most popular reason for sharing was to validate information (14/40, 35%), while the most frequent reason for not sharing with anyone beyond their partner was because of the preference for asking for information rather than sharing (12/40, 30%).

Conclusions: This study provides valuable insights into the pregnancy-related information-sharing behaviors of first-time fathers in Southeast Asia. It enhances our understanding of how first-time fathers share pregnancy-related information and how local cultural norms and traditions influence these practices. In contrast to first-time fathers in high-income countries, the information-sharing behavior of first-time Southeast Asian fathers is defined by cultural nuances. Culture plays a crucial role in their daily decision-making processes. Therefore, this emphasizes the importance of cultural considerations in future discussions and the development of intervention programs related to pregnancy for first-time Southeast Asian fathers. In addition, this study sheds light on the interaction processes that first-time fathers engage in with others, highlighting areas where intervention programs may be necessary to improve their involvement during pregnancy. For example, first-time fathers actively exchange new information found with their partners; therefore, creating features or platforms that facilitate this process could improve their overall experience. Furthermore, health practitioners should take a more proactive approach in engaging with first-time fathers, as currently there is a communication gap between them.

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KEYWORDS

pregnancy; first-time fathers; information sharing; Southeast Asia; information-seeking behavior; cultural factors

Introduction

Background

In the realm of pregnancy, the traditional focus has predominantly centered on mothers as the primary seekers and bearers of knowledge [1]. However, contemporary perspectives increasingly emphasize the integral role of fathers in the journey to parenthood [2]. Fathers' participation in maternal-fetal health care offers profound benefits; for example, it is associated with a reduction in birth-related risks [3] and improved cognitive outcomes in infants [4]. Consequently, the Cairo Initiative [5] and recommendations from the World Health Organization [6] advocate for the promotion of a father's engagement during pregnancy. The Cairo Initiative emphasized the importance of reproductive health and the shared responsibilities of men and women in family planning and health-related decisions while promoting men's involvement in pregnancy to support maternal health and ensure better pregnancy outcomes.

Fathers have emerged as active participants in the pursuit of pregnancy-related information [7,8]. This is one of the many ways fathers become involved in the pregnancy journey, which involves obtaining information about pregnancy to improve their knowledge [2]. Fathers navigate the vast landscape of the internet and engage with specialized app, websites, blogs, and online support groups [9-12]. This digital terrain resonates particularly with millennial fathers, who readily turn to internet-based resources for guidance and support [13]. While fathers' information-seeking practices have garnered significant attention, it is crucial to acknowledge that the dynamics of this journey transcend mere information acquisition and extend to the pivotal aspect of information sharing. This is because fathers also actively engage with others to exchange information, experiences, insights, and support throughout the pregnancy journey [14].

Information sharing is a multifaceted aspect of human communication, driven by various motivations and yielding both advantages and disadvantages. People engage in sharing to disseminate knowledge, experiences, and insights, fostering collaborative and interactive communication [15,16]. The process is influenced by key variables, such as trust, risk assessment, perceived rewards, and the dynamics of relationships [17,18]. A rapid review study by Naeem et al [18] also emphasizes privacy concerns and the sensitivity of information as the multifactorial nature of an individual's willingness to share health information. Trust plays a pivotal role, as individuals are more inclined to share sensitive information when there is trust in the audience [18]. Assessing the risk associated with sharing and anticipating potential rewards, such as support or advice, further motivates information-sharing behaviors [15,17]. The advantages of sharing include the creation of a supportive community, the exchange of diverse perspectives, and the building of relationships [19]. Sharing can enhance one's understanding, contribute to a collective pool of knowledge, and provide emotional and practical support [10,19]. However, sharing also comes with disadvantages. Individuals may face the risk of judgment or misunderstanding [20] and the potential harm of information misuse or misinterpretation [21]. Striking a balance between the benefits and drawbacks of sharing is a nuanced consideration in various contexts, influencing individuals' decisions to engage in information-sharing behaviors.

In the domain of pregnancy information sharing, results of a research study demonstrate that fathers exhibit a willingness to share information acquired about pregnancy and fatherhood [11]. Fathers actively engage in both online and offline practices [22]. In the context of online information sharing, fathers contribute to discussions and seek advice within their digital communities [11]. They share relevant articles or seek guidance on parenting forums [10]. Some fathers disseminate their knowledge through online forums, while others opt to articulate their experiences via blogs [10]. Within these online forums, fathers recount their journey and provide mutual support [23]. In addition, fathers frequently indicate their participation in online support groups tailored to discussing various aspects of the pregnancy and fatherhood experience [24]. Furthermore, fathers have embraced social media apps as platforms for expressing their emotions and recounting their pregnancy journeys [9]. In these internet-based spaces, fathers actively share pregnancy-related information, fostering their involvement, bolstering their confidence, and encouraging their peers [25,26]. Conversely, offline information sharing predominantly takes place through face-to-face conversations. This emphasizes the significance of interpersonal relationships in the dissemination of information [27]. Fathers engage in discussions about pregnancy-related experiences during casual hangouts or directly seek advice from family members and friends [28]. This practice is driven by the desire to connect, collaborate, and contribute to collective knowledge [19].

While certain fathers actively share information about pregnancy with others [9,11,23], results of other studies suggest that some fathers may refrain from sharing pregnancy-related information [20,29]. First-time fathers, in particular, may seldom share personal experiences about the pregnancy journey, often due to feelings of unfamiliarity with the topic [29]. In addition, they may choose to keep pregnancy matters confidential, adhering to local cultural norms that discourage fathers from discussing such matters with others [29]. As seen in a previous study by Esmaeilzadeh [30], privacy concerns often influence the extent to which individuals are willing to share sensitive information, particularly in online environments like social media. A study by Nash [20] also reveals that, even though fathers share health information about pregnancy, they may withhold their feelings related to pregnancy or fatherhood due to concerns about judgment from other men, indicating a thoughtful risk assessment before sharing the information. These findings illuminate various reasons why fathers may opt not to share information, thereby limiting their potential benefits from engaging in this practice [31].

Studies on fathers' information-sharing behavior in the context of pregnancy information in high-income countries are well-researched [11,23,26]. However, there is a noticeable gap in research studies addressing pregnancy-related information-sharing practices in low- and middle-income countries, particularly in the Southeast Asian context. Southeast Asia is characterized by its diverse cultural norms, traditions, and varying degrees of digital literacy [32-34], providing a unique backdrop for examining how fathers participate in the sharing of pregnancy-related information. In the Southeast Asian context, cultural norms of privacy and reserved communications may impact fathers' information-sharing behaviors [30], influencing whether sharing is performed, what information fathers share, and with whom they share pregnancy-related information [35]. The cultural emphasis on societal expectations within Southeast Asian cultures further directs fathers toward traditional channels, such as consulting with extended family members or seeking advice from older people [36,37].

Adding to this landscape, Southeast Asia exhibits varying levels of digital proficiency, impacting how fathers share information and engage in online information sharing [38]. Specifically, this study was conducted in Indonesia, the most populous nation in Southeast Asia. Indonesia, being part of Southeast Asia, embodies a rich tapestry of diverse cultural norms, traditions, and varying levels of health and digital literacy [38-40]. The country's internal diversity provides a nuanced backdrop for exploring how first-time expectant fathers engage in sharing pregnancy-related information. Indonesia's cultural, linguistic, and contextual elements mirror the broader diversity within Southeast Asia [34,41,42]. The shared cultural threads and regional commonalities offer insights that may extend to other Southeast Asian countries [39,43].

Southeast Asia is a region with various ethnicities, religions, and languages [34]. These differences may impact the information-sharing behaviors of first-time expectant fathers. For example, fathers from Malay, Chinese, or Indigenous communities may have distinct traditions and customs related to pregnancy [36]. These differences may influence their communication patterns and the type of information they prioritize to search and share (or not to share). In addition, religious practices related to Islam, Christianity, Buddhism, and Hinduism may guide the behavior and decision-making process of fathers during pregnancy [44,45]. Finally, linguistic diversity may shape how fathers search for and share pregnancy-related information using their preferred language. Results of a research exploring cross-language information-seeking behavior showed participants implement different strategies and tactics when completing the search process depending on the language they used [44]. Therefore, fathers might have different strategies and approaches when searching and sharing, depending on the language used during the process.

This Study

An exploration of information-sharing practices in these contexts contributes valuable insights to our understanding of how these nuances shape fathers' behavior in the pregnancy journey, as it is likely to be different from the results of research studies conducted in high-income countries. Therefore, this study embarks on an exploration of information-sharing practices of pregnancy information among first-time fathers in Indonesia, a Southeast Asian low- and middle-income country, where cultural traditions and social networks intersect and may shape fathers' behaviors [45]. Our research question and follow-up questions are outlined as follows: Do first-time expectant fathers engage in information sharing about pregnancy? The follow up questions were as follows: (1) If information is shared, with whom is it shared? (2) Through what means the information is shared? (3) Why is the information shared? and (4) If not shared, what are the underlying reasons? This exploration is particularly salient within the temporal confines of the antenatal phase, a pivotal juncture in the transition to fatherhood [46]. Here, we draw a clear distinction between first-time fathers and those with prior parenting experience. The rationale is that first-time fathers bring a unique perspective as they prepare for fatherhood [29]. Furthermore, first-time fathers display heightened sensitivity to their new situation, leading to more pronounced information needs and interaction compared to fathers with prior experience [47]. The results of this study aim to enhance domain knowledge by providing answers to the research questions stipulated earlier.

Methods

Overview

In this study, a grounded theory approach [48] was used to investigate the information-sharing practices of first-time expectant fathers concerning pregnancy-related information. Grounded theory enables the development of theories derived directly from empirical data and provides a neutral perspective on human actions within a social context [49]. The grounded theory approach was used for this study due to the limited knowledge regarding the information-sharing practices of first-time fathers in the context of pregnancy-related information in Southeast Asia. This methodology facilitates the discovery of patterns, capturing lived experiences, exploring the themes, and systematically developing theories grounded in the data itself [50]. This methodological choice is particularly valuable in the context of this study as it allows for the in-depth exploration of the nuanced and context-specific behaviors of first-time fathers beyond surface-level observations. To enhance interpretive validity and intercoder reliability, personal reflexivity practices were implemented [51].

Recruitment

Recruitment notices were placed in health care facilities in Indonesia, community centers, and online social media portals. Participants were required to meet specific inclusion or exclusion criteria. Participants must be aged ≥21 years, first-time fathers, and have sought pregnancy-related information in the past 9 months. Importantly, participants must not be working in or have a formal qualification or be in the process of achieving an academic qualification in the health care or allied health care sectors to eliminate the possibility of health expertise and literacy influencing results.

Data Collection

Data collection involved the use of questionnaires and semistructured interviews. The questionnaire serves to capture information on sociodemographic, digital and health literacy levels, family situations, and pregnancy-related details. This is to provide an overview of the participants of this study and will not be used for analysis. The sociodemographic section encompasses details about participants' social and demographic characteristics. Digital literacy levels are self-assessed to gauge participants' proficiency and comfort with digital technologies. Similarly, health literacy levels are self-assessed to understand participants' capacity to comprehend health-related information effectively. These self-assessments provide insights into fathers' perceived literacy levels related to health and digital matters. Family situations are explored to uncover contextual factors that may influence information-sharing behaviors, considering the role of familial connections in the pregnancy journey. Finally, pregnancy-related details are gathered to gain insights into specific aspects of participants' experiences.

Semistructured interviews were used to collect data, enabling in-depth exploration of participants' thoughts and experiences [52]. The interviews were designed to be open-ended and revolved around the research questions outlined in this study. Participants were queried about their engagement in the sharing or nonsharing of pregnancy-related information. Participants who shared information were asked follow-up questions: (1) with whom the information is shared, (2) through what means the information is shared, and (3) why the information is shared. Participants who did not share pregnancy-related information were asked to elaborate on the reasons for this decision. Participants were allowed to choose whether the interview will be conducted in Bahasa Indonesia or English. An option was provided, as using the mother tongue in interviews can lead to more reliable and valid data [53]. The researcher is Indonesian, so the interview and translation were conducted by the researcher if the participants chose the interview to be conducted in Bahasa Indonesia. If the interview was conducted in Bahasa Indonesia, transcribing was done in Bahasa Indonesia to prevent the loss of meaning of the answers and collect as much culturally localized information as possible [54]. Thereafter, the interviews were translated into the English language [53]. All interviews were recorded and transcribed verbatim, ensuring a robust connection between the data and the researcher [55].

Data Analysis

Open coding technique was used with the grounded theory approach [56]. This method was used to examine participants' responses regarding their information-sharing practices [57]. Initially, a master list of codes was generated through inductive reasoning, with ongoing revisions after every third interview [58]. Subsequently, these codes were condensed into overarching themes using the constant comparative method, which entailed a systematic review of each response to identify prominent patterns and key themes [58,59]. Data analysis commenced immediately following each interview and continued until the study's completion [50]. This method of content analysis provided a comprehensive understanding of fathers' information-sharing practices about pregnancy and the underlying reasons for their behavior [50]. To ensure interpretive validity and intercoder reliability, personal reflexivity practice was undertaken [51].

Ethical Considerations

Before recruitment, ethics approval was obtained from the University of Canterbury, New Zealand (HREC 2022/66). Informed consent was obtained from all participants before their involvement in the study. Participants were provided with a detailed information sheet consisting of the study's objectives, procedures, potential risks, and benefits. They were also informed of their right to withdraw from the study at any time without any penalty. Their consent was recorded electronically. All identifiable information was anonymized, and unique codes were assigned to each participant. Participants were informed about how their data would be stored and used, which is based on the university's regulations. Data were stored securely on password-protected devices to prevent unauthorized access. There was no compensation for participants.

Results

Overview

In this section, we begin with a brief overview of the sociodemographic details of the participants. Following this, we delve into participants' information-sharing behaviors, categorized into those who shared information and those who did not. Information-sharing activities among first-time fathers who shared information are further explored, considering the audience, communication channels used for sharing information, and underlying reasons for sharing. In addition, further examination of first-time fathers who chose not to share information will be provided, revealing their underlying reasons behind this decision.

Sociodemographic Details of Participants

There were 40 participants in this study. Data saturation [60] for this study was achieved with 75% (30/40) participants. The data saturation point is generally reached in 15 interviews, with one-third of the number of interviews being added [61]. Similarly, a study showed that thematic saturation from the conducted interviews will be achieved by completing 30 interviews [62]. Furthermore, other studies exploring information-seeking behavior recruited 40 participants for the interviews to reach data saturation [63,64]. Therefore, in this study, after data saturation was achieved with 30 participants, the researcher added another one-third of the number of interviews, bringing the total to 40 participants.

Most participants fell within the age group of 26 to 30 years, constituting 68% (27/40) of the sample. Urban residency was predominant, with the majority residing in cities (21/40, 52%), while others living in suburbs (10/40, 25%) and rural areas (9/40, 22%). Educational backgrounds were diverse, with 65% (26/40) holding bachelor's degrees, followed by master's degrees (7/40, 18%), and high school qualifications (7/40, 18%). Language preferences for online searches indicated that most used the national language (Bahasa Indonesia; 25/40, 62%), rather than the local languages or dialects (ie, Javanese, Sundanese, Balinese, and Betawi). A national language is a language that is officially recognized and used formally at the country level. By contrast, local languages or dialects are specific to certain communities or regions with specific cultural markers. Most (24/40, 60%) participants worked in the private sector, followed by entrepreneurs (8/40, 20%). Monthly household income varied, with 45% (18/40) falling within the IDR 2-4.99 million (US $120-300) range, followed by the IDR 5-9.99 million (US $325-650) range (14/40, 35%).

In terms of social and familial aspects, 88% (35/40) identified with the Islamic faith. Furthermore, 62% (25/40) of participants perceived their family social systems as equal, including roles and responsibilities between husband and wife. Most (36/40, 90%) participants lived together with their partners. Most participants' partners were in the third trimester (20/40, 50%), followed by the first and second trimesters equally (10/40, 25%). Health and digital literacy levels varied, with 60% (24/40) of participants having moderate health literacy and 28% (11/40) having high health literacy. In terms of digital literacy, 50% (20/40) demonstrated high digital literacy, while 40% (16/40) exhibited moderate digital literacy.

Shared or Did Not Share

Results indicated that 90% (36/40) of the participants shared information, while 10% (4/40) of the participants did not share information with anyone. Within the 36 participants, 55% (22/40) participants only shared information with their partners. Furthermore, 20% (8/40) of the participants shared information solely with their partners, extended family, and the physicians. Results indicated that most (36/40, 90%) first-time fathers were "sharers" of pregnancy information.

Information-Sharing Activities of First-Time Fathers

The Audiences: Who Is Information Shared With?

Table 1 details participants' information-sharing patterns regarding pregnancy. Most (22/40, 55%) participants exclusively shared information with their partners. The second prevalent pattern involved a combination of sharing with partners, physicians, and extended family members (eg, mothers, siblings with pregnancy experience, or siblings with medical qualifications), amounting to 20% (8/40) of the participants. Furthermore, 10% (4/10) of the participants opted to share information with physicians, friends, colleagues, and their partners. Only a small proportion, 5% (2/40), extended their sharing to a social media audience, encompassing participants' social media connections or followers, in addition to partners, physicians, and friends. The findings indicated that fathers primarily share information with their partners only.

Table 1. Information sharing behavior of fathers (N=40).

Activity and audience	Participants, n (%)
Did not share information	4 (10)
Shared information	36 (90)
Shared information with	
Partner only	22 (55)
Partner, physicians, and extended family	8 (20)
Partner, physicians, friends, and colleagues	4 (10)
Partner, physicians, friends, and social media audiences	2 (5)

The Channels: How Is Information Shared?

Participants shared information using offline and online communication channels. Face-to-face communication was the favorite offline method used, as 90% (36/40) opted to share information with this method. As for online communication channels, 65% (26/40) of the first-time fathers used online messaging apps such as WhatsApp (Meta Platforms, Inc) or iMessage (Apple Inc) to share information. With this method, first-time fathers not only shared information using the text format but also sent links and screen captures. Aside from online private messaging platforms, 35% (14/40) of the first-time fathers shared information found on online posts or videos using social media features available on Instagram (Meta Platforms, Inc) and Facebook (Meta Platforms, Inc), such as "direct sharing." However, the "tagging" feature in social media platforms is not a favored method of sharing information, chosen by only 10% (4/40) of the fathers. In addition, only 5% (2/40) leveraged social media "post" features and "comment sections" to disseminate pregnancy information.

The results from Table 2 illustrate the diverse combination strategies used by first-time fathers in sharing pregnancy-related information. The participants in this study used various communication channels to share pregnancy information with their audiences. Face-to-face interactions emerged as the predominant offline method, with 90% (36/40) of the participants engaging with partners, 35% (14/40) with friends, 10% (4/40) with colleagues, and 10% (4/40) with extended family. Phone calls were used by 5% (2/40) of the participants when communicating with extended family. In the online realm, 65% (26/40) of the participants opted for online messaging apps with partners, 18% (7/40) with friends, 10% (4/40) with colleagues, 10% (4/40) with extended family, and 2% (1/40) with physicians or midwives. Online messaging app was used by 10% (4/40) of the participants with their friends and 20% (8/40) of the participants with their extended families. Notably, of the participants, the direct share feature on social media platforms was used by 35% (14/40) with partners, 5% (2/40) with friends, and 5% (2/40) with colleagues. The tag feature on social media was chosen by 10% (4/40) of the participants with partners and 5% (2/40) of the participants with friends. For broader dissemination, 5% (2/40) of the participants utilized the post feature, and 5% (2/40) of the participants engaged in the comment feature on social media platforms when targeting social media audiences.

Table 2. Information sharing strategies (N=40).

Communication channels and audience	Participants, n (%)
Offline	
Face-to-face	
Partner	36 (90)
Friends	14 (35)
Colleagues	4 (10)
Extended family	4 (10)
Physicians or midwives	14 (35)
Phone calls	
Extended family	2 (5)
Online	
Online messaging	
Partner	26 (65)
Friends	7 (18)
Colleagues	4 (10)
Extended family	4 (10)
Physicians or midwives	1 (2)
Online group messaging	
Friends	4 (10)
Extended family	8 (20)
Direct share feature on social media	
Partner	14 (35)
Friends	2 (5)
Colleagues	2 (5)
Tag feature on social media	
Partner	4 (10)
Friends	2 (5)
Post feature on social media	
Social media audiences	2 (5)
Comment feature on social media	
Social media audiences	2 (5)

The Reasons: Why Is Information Shared?

Table 3 presents 3 themes categorizing first-time fathers' reasons for sharing information. These themes are reciprocity and validation of information, compassion and sympathy, and information enhancement. Participants' reasons for sharing information mostly fit in the reciprocity and validation of information theme (14/40, 35%), followed by the compassion and sympathy theme (13/30, 32%). The least number of reasons fit under the information enhancement theme (9/40, 22%).

Table 3. Themes of reasons for sharing information about pregnancy (N=40).

Theme	Participants, n (%)	Quotes
Reciprocity and validation of information	14 (35)	• "I share pregnancy information to initiate a discussion. I also hope to get advice from others based on the discussion results." • "One way to validate the information that I have is by sharing it with others and letting them give feedback on the information given. I can get another perspective by sharing the information obtained." • "During the casual hangout, I share information about pregnancy with my other friends. So in that way, I can compare the information that I have and make it more comprehensive."
Compassion and sympathy	13 (32)	• "I know how confused I was when I dealt with something related to pregnancy problems. So, if my friends facing difficulties or asking for advice, and I have the information, then I will share it with them." • "When I have good or interesting information and I consider it as valid information, I will share it with my partners and my friends so they can also benefit from it." • "Sometimes I share experiences of what I have done based on information obtained from the Internet to others who have similar problems. Or at least, they can take preventive actions based on my experiences."
Information enhancement	9 (22)	• "Sometimes I share information that I obtained with my partners or my families, so they can add or complete the information that I missed." • "What I have in mind when I share the information I obtained from the Internet with my partner is that she can give me a response whether she experiences or feels the same thing or maybe if she hasn't and we need to figure it out further."

In the reciprocity and validation of information theme, participants expressed their motivation to share pregnancy information as a means to initiate discussions and seek advice. Sharing information served as a method for validating the information they possess, obtaining feedback, and gaining additional perspectives. During face-to-face conversations, participants engaged in mutual sharing, fostering a collaborative environment where they compare and enhance their collective understanding of pregnancy-related information.

In the compassion and sympathy theme, participants highlighted their tendency to share information not only to support their partner but also when their friends face difficulties or seek advice related to pregnancy problems. The desire to assist others in navigating the challenges of pregnancy was evident, with participants sharing information with friends. In addition, participants found value in sharing personal experiences based on information obtained from the internet, aiming to provide insights and preventive actions for those facing similar issues.

In the information enhancement, participants mentioned sharing information either with their partners or others to complement or complete information they may have missed. Participants sought to enrich their understanding by incorporating the perspectives and insights of others.

The Reasons: Why Is Information Shared With Their Partner Only?

The exploration into why most first-time fathers share pregnancy information with their partners only resulted in thematic clusters, as outlined in Table 4. These findings encompass 5 key themes: asking over sharing (12/40, 30%), no relevant audience (5/40, 12%), self-situation awareness (5/40, 12%), privacy and intimacy (3/40, 8%), and physician-specific constraints (11/40, 28%).

Table 4. Reasons for sharing information about pregnancy only with their partner.

Theme	Participants, n (%)	Quotes
Asking over sharing	12 (30)	• “Mostly, I prefer to ask others and the doctors rather than share first (even though it continues with asking or validating). By asking, after I get the answers, then I can just privately compare them with my information.” • “During casual hangouts with friends, when we discuss pregnancy, I’d rather ask questions rather than share information. That is my preference, even though sometimes I already possess some of the information. I am afraid if I share incorrect information, they will judge me as an irresponsible expectant father.”
No relevant audience	5 (12)	• “I used to share everything with my close friends. But now, they live far away, so it is difficult to share pregnancy information with them. We are not comfortable sharing this kind of information with colleagues or neighbours. Therefore, I only share information about pregnancy with my partner.” • “We are the youngest couple in our circle both in friendship, in a work environment, and families. They already have children. No other couples with a similar situation. It’s unlikely for us to share pregnancy information.” • “I don’t know where and to whom I share the information. As far as I know, there is no online forum for me (and other fathers) to share information about pregnancy. Maybe, I can comment on social media posts. But the other commenters are mothers, so I am not very comfortable with it (joining the conversation).”
Self-situation awareness	5 (12)	• “I think I do not have relevant information to share. I feel that the others have more information than me. Thus, I don’t share any information with others.” • “I feel like I am not an expert in this field. I only have a little knowledge about pregnancy. So, I am afraid that I might give false information to others that might harm them.” • “This is the first time I have searched and obtained information about pregnancy. I am a first-time father. I don’t have any experience with this before. I need to have more experience before I can confidently share information with others.”
Privacy and intimacy	3 (8)	• “I think information related to pregnancy, particularly if it is related to our partner’s condition, I consider it as private and intimate information. Thus, I don’t share it with others, other than my partner.” • “Because we are not announcing pregnancy, I don’t share any pregnancy information with others. In my culture, it’s prohibited to announce pregnancy as it can heavily impact the family (particularly the mother) if there is something wrong with the baby. We will announce the baby’s birth, but not the pregnancy.”
Physician-specific constraints	11 (28)	• “The doctor is very busy. He has so many patients. Our antenatal care meeting is very short and concise. It’s already filled with procedures for health checking. So, there is no time to have a longer conversation.” • “My doctor is very famous but he is also a very strict guy. He doesn’t like to answer questions other than what is in the meeting session scope. We just do the antenatal care procedures and nothing else.” • “I feel that we go to the doctors to get examined by the experts. They have been studying pregnancy for years. So, I trust them to give the valid information. I just silently compared to information obtained by myself. Furthermore, they have a high social status in society. I won’t bother them with questions from a person with a lack of literacy in pregnancy matters (me).” • “The ob-gyn doctor already explains everything in detail (I think). Therefore, I rarely have further questions or need to validate any information obtained online.”

The first theme, “asking over sharing,” manifests as first-time fathers expressing a preference for asking others rather than actively sharing information. This behavior extends not only to interactions with physicians but also with friends or colleagues who have experienced pregnancy. First-time fathers articulated a preference for asking questions rather than potentially facing judgment by sharing information they obtained. In addition, first-time fathers stated that the feeling of being judged does not appear when sharing information with their partners.

The second theme, “no relevant audience,” emerges from first-time fathers living far away from the intended audience, particularly family and close friends, or perceiving their situation as unique. First-time fathers prefer face-to-face conversations for sharing information, and distance creates barriers in this regard. Some first-time fathers noted a lack of friends in similar pregnancy-related situations. This limits their willingness to share information with others.

The third theme, “self-situation awareness,” encapsulates first-time expectant fathers’ acknowledgment of their novice status in the field and lack of experience. This self-awareness influences their decision not to share information, reflecting thoughtful consideration of their knowledge and expertise. They recognize their status as beginners, feeling the need to gain more information, validate it, and accumulate personal experience before sharing. However, with their partners, first-time fathers are aware that their partners are also newcomers in this matter. Therefore, they can collaborate to improve their knowledge about pregnancy.

The fourth theme, "privacy and intimacy," underscores first-time fathers' perception of certain information as private. This emphasizes a desire to maintain confidentiality surrounding specific aspects of pregnancy. Furthermore, some cultural matters prevent them from announcing a pregnancy before certain weeks of pregnancy. This limits their opportunity to share pregnancy-related information with others. Therefore, first-time fathers keep the boundary by only sharing pregnancy-related information with their partners, especially related to their partner's health situation.

Finally, "physician-specific constraints" form a distinctive theme encompassing various constraints related to physician-patient communications that are different from their communication constraints with others (ie, friends, colleagues, and extended family members). Factors such as limited meeting time, feeling unwelcome or encountering unresponsiveness, respecting physicians' roles, and perceiving a communication gap influence fathers' decisions not to share information in the medical context. These constraints create situations where fathers find themselves unable to share their findings on pregnancy information, leading to a passive role in discussions with health care experts. However, while addressing communication situations with their partners, first-time fathers did not encounter any of these limitations.

Non–Information-Sharing Activities of First-Time Fathers

A small number of participants, specifically 10% (4/40) of the participants, did not share pregnancy-related information with anyone (Table 5). In total, 2 themes emerged; these themes were partners' health qualifications (2/40, 5%) and work environment (2/40, 5%). Under the partner health qualification theme, the reason for not sharing information was because of the partner's professional qualifications in the health care field (eg, physician or midwife). This led first-time fathers to perceive their partners as possessing superior knowledge about pregnancy. Consequently, they deemed it unnecessary to gain information about pregnancy intensively, including sharing any pregnancy-related information. Another factor influencing nonsharing was the demanding work environment of the respondent, such as military service, which was perceived as a hindrance to engaging in discussions about pregnancy. Furthermore, they lived apart from their partners daily, so they were not involved in their partners' pregnancies. Despite not sharing information, these fathers still searched for pregnancy-related information, mainly driven by personal curiosity and preparation for the baby's delivery.

Table 5. Reasons for not sharing information with anyone.

Theme	Participants, n (%)	Quotes
Partners' health qualification	2 (5)	"My partner holds a degree in health/medicine. Therefore, I think I don't need to find information intensively or share pregnancy-related information obtained as she knows better. I sometimes still search for information about pregnancy just in case, and also to prepare for the baby's delivery and becoming a new parent."
Work environment	2 (5)	"I work in the army and live afar with my pregnant partner and family. Both in my work and casual conversation environment, we rarely talk about our personal matters. Even though we talk about our personal topics, pregnancy is not included. However, in some break time, I occasionally search for information about pregnancy and parenting."

Discussion

Summary of Key Findings

This study reveals that most (36/40, 90%) first-time Southeast Asian fathers share information with others. Most (22/40, 55%) first-time fathers share information only with their partners, while the remaining (14/40, 35%) extend this to a small circle, including physicians, extended family, and friends. The most popular communication method for sharing information is face-to-face (36/40, 90%), followed by online messaging apps (26/40, 65%). Social media sharing is less common, with 35% (14/40) of the participants engaging in private sharing and only 5% (2/40) sharing information publicly. First-time fathers' motivations for sharing information include validating information (14/40, 35%) and compassion for others (13/40, 32%), with a smaller group aiming to enhance their understanding by adding others' perspectives (9/40, 22%).

Among those who did not share information beyond their partners, the reasons included a preference for asking questions rather than sharing information (12/40, 30%), self-situation awareness (5/40, 12%), lack of relevant audiences (5/40, 12%), concerns about privacy (3/40, 8%), and physician-specific constraints (11/40, 28%). A small group of first-time fathers (4/40, 10%) did not share information with anyone, mostly due to their partner's professional health qualification (2/40, 5%) or demanding work environments (2/40, 5%). However, these first-time fathers remained engaged in information seeking, driven by personal curiosity and preparation for the baby's arrival.

Sharing Approaches Depending on Audience

Overview

First-time fathers demonstrate various approaches to sharing information depending on the audience. This is influenced by the relational dynamic of the relationship with their audience [17,65]. In contrast to high-income countries where first-time fathers actively share pregnancy-related information on the internet publicly [11,23,26], in the Indonesian context, only a small number (2/40, 5%) of fathers post information about pregnancy on the internet publicly. This behavior stems from first-time fathers' inclination to share pregnancy-related information predominantly with people they have formed close relationships with, such as their partners, close friends, or immediate family members [27].

Several factors may contribute to this observed difference in information-sharing behavior among first-time Southeast Asian fathers, particularly related to sharing information about pregnancy publicly. Cultural nuances, societal norms, and privacy concerns could be influential in shaping the information-sharing landscape in Indonesia [45]. The cultural context in Southeast Asia often places a high value on privacy, especially regarding personal matters, such as pregnancy [66]. This cultural emphasis on privacy may lead fathers to be more cautious about sharing such intimate details publicly, in contrast to the more open sharing practices observed in high-income countries. Moreover, the level of digital literacy and familiarity with online platforms may play a role. While there are many online sharing platforms in Southeast Asia, 10% (4/40) participants highlighted the lack of appropriate forums on social media for posting and engaging with other fathers to discuss pregnancy-related matters, leading to limited activity in social media environments concerning pregnancy. The findings also suggest a preference for face-to-face communication. Fathers in Indonesia may place a higher value on personal interactions and traditional modes of communication [41]. The findings suggest that first-time fathers feel more comfortable sharing information about pregnancy in more intimate and private situations and featuring 2-way communication. It reflects the importance of personal connections and the cultural context, where sharing sensitive information is often reserved for close-knit relationships in Southeast Asian societies [16].

Within this close-knit relationship, results of this study show that first-time fathers prioritize their partners as the primary audience for information sharing, with a substantial 90% (36/40) choosing to share pregnancy-related details. The strong inclination to share information with their partners reflects a foundational trust that underpins their communication, as first-time fathers feel secure when sharing sensitive information with their partners [17,18]. In addition, in this context, perceived rewards, such as increased emotional connection, mutual understanding, and the opportunity for shared decision-making, also encourage first-time fathers to share information [17]. This inclination also emphasizes the central role of the partner in the first-time expectant father's information-sharing network [67]. The partner is considered a crucial and central figure in the information-sharing process. The partner's role as the one carrying the child makes her a primary stakeholder in the pregnancy journey. First-time fathers might recognize that the well-being of the child and the success of the pregnancy are directly linked to the mother's experiences and knowledge [65]. Sharing information with the partner may also contribute to her knowledge discovery. This information enhancement collaboration could help parents make better-informed decisions that might positively impact both the mother's well-being and the neonatal development of the child [3]. The collaborative effort in seeking and sharing information may enhance the overall experience of pregnancy for both partners.

First-time fathers use various communication channels to share information about pregnancy with their partners. The importance of the information, types of information, and source of information may influence the choice of communication channel used [68]. Certain details or important information may be deemed more urgent or critical. Therefore, fathers might choose to use faster channels, such as online messaging. In addition, the nature of the information itself could dictate the preferred method of sharing. For instance, if there is a need to convey information with informative images, online methods might be favored. However, if first-time fathers need to share sensitive information, they may opt for face-to-face communication. In addition, first-time fathers may share information directly using social media features, as most of the information about pregnancy is found on social media. Thus, it might be more convenient for first-time fathers. However, in this reciprocity and validation of information, it remains unclear whether partners feel overwhelmed or have preferences regarding specific channels. Further investigation into partner preferences and perceptions of information-sharing methods would be valuable in understanding the dynamics of this communication process. This includes the frequency of receiving new information about pregnancy and the types of information.

While communicating with friends, fathers still assess the dynamics of the situation and the level of closeness with friends before sharing the information [20]. This assessment considers not only the potential benefits and risks for the first-time fathers but also the well-being and comfort of the friends as recipients of the information. Consequently, some first-time fathers express a preference for sharing sensitive pregnancy-related details in face-to-face interactions rather than through group communication channels. This inclination highlights the significance of trust in the sharing process, indicating that fathers feel the need to establish a level of trust with their friends before sharing or exchanging intimate information about the pregnancy [17,18]. This suggests that the nature of the information and the level of personal relationships play crucial roles in shaping first-time fathers' choices of communication channels when sharing with friends.

With colleagues, most first-time fathers rarely share pregnancy-related information with them. This could be due to the desire to maintain a professional connection at work. However, first-time fathers express an intention to share information with their close colleagues, driven by a need for feedback from experienced fathers regarding pregnancy information they have acquired. Therefore, fathers emphasize that they are inclined to share pregnancy-related information primarily through face-to-face interactions, mostly during their lunch breaks. This practice may be influenced by the limited communication time fathers have with colleagues from the workplace. Moreover, first-time fathers choose to share information about pregnancy privately, specifically with their closest colleagues or those who are experiencing similar situations [17]. This result is consistent with the findings of the study by Widén and Hansen [27], emphasizing the importance of the interpersonal relationship with the audience, which often occurs through private conversations in sharing certain types of information.

Extended family also plays a role in the information-sharing network, with some participants relying on familial connections for sharing information about pregnancy. Most of these interactions occur in online group chat, and some of them use phone calls as they live separately with the other extended family members. Notably, first-time fathers express a willingness to share pregnancy-related information within the family, driven by the perceived expertise, experience, and credibility of certain members [17]. This willingness is particularly evident when family members possess relevant experiences in pregnancy or backgrounds in health sciences. First-time fathers aim to obtain responses and feedback when sharing pregnancy information to enhance the information they possess. Moreover, this tendency to share information to seek advice from older people resonates with findings in cultural studies conducted in Southeast Asia, as highlighted by Ford and Lyons [41]. This cultural aspect highlights the value placed on seeking guidance from more experienced individuals in the community. In addition, extended family members may recommend traditional methods or practices related to pregnancy that align with cultural and social norms in Southeast Asia [69]. Sharing pregnancy information with extended family in Southeast Asia goes beyond seeking advice; it is rooted in cultural and social norms that emphasize communal bonds and the importance of intergenerational wisdom [70].

Health care professionals, particularly physicians or midwives, were identified as pivotal figures in the information-sharing process, with 35% (14/40) of the participants expressing a preference for consulting medical experts. This choice could be motivated by the specialized knowledge and expertise that health care professionals bring to discussions [71]. Notably, it also reflects a cultural norm within Southeast Asian societies, where a high value is placed on the authority of medical professionals in matters related to health and childbirth [71]. The nature of information sharing with physicians or midwives occurred in the formal setting of one-on-one antenatal care meetings. In these limited-time interactions, first-time fathers engaged in sharing information with the implicit intention of initiating first-time further discussion or seeking validation of the information they have gathered [17]. However, the cultural context might play a pivotal role here, as the hierarchical structure in Southeast Asian societies underscores respectful communication with authority figures, particularly health care professionals. This could restrict physician-father communication, which aligns with the findings of the study by Claramita et al [72], suggesting that these interactions are confined within the formal boundaries of antenatal care settings. This nuanced approach reflects the broader cultural context in Southeast Asia, where respect for authority figures, particularly in the medical field, is ingrained in societal norms. This hierarchical gap might influence first-time fathers' decisions to not share pregnancy-related information obtained with the physicians outside the antenatal care settings [72]. The study by Claramita et al [72] illuminates how patients face limitations in discussing or sharing any health information with their physicians due to various reasons, such as limited time, differences in social status, and communication gaps. Similar situations arise during antenatal care, providing fathers with a restricted opportunity to share the information obtained with health care professionals. When first-time fathers have an opportunity to interact with physicians, they tend to prefer asking questions rather than actively sharing information, a behavior often accompanied by seeking validation or clarification. This emphasizes the challenges and constraints within the health care setting that influence first-time fathers' information-sharing practices.

On the basis of the various approaches discussed, technology, particularly online text messaging and social media platforms, plays an important role in shaping the information-sharing behaviors of first-time expectant fathers in Southeast Asia. These platforms offer accessible and convenient avenues for fathers to easily share the information found online [10]. First-time fathers use online messaging apps, such as WhatsApp, to share information obtained from website search results. In this case, the messaging platforms allow for direct, quick, and personal communication with their immediate circle. In addition to messaging platforms, first-time fathers optimize the use of social media's sharing features when sharing information obtained with others. This feature allows first-time fathers to share posts, videos, and expert advice more efficiently [9]. However, when using this feature, most first-time fathers in Southeast Asia tend to opt for private sharing with others over public sharing on social media [30]. This may also explain why first-time fathers prefer Instagram and Facebook over Twitter (subsequently rebranded X), as Twitter is primarily used for public sharing rather than private sharing, which raises concerns about privacy [30]. This suggests that first-time fathers are leveraging these features for their convenience and efficiency rather than the capabilities to amplify and disseminate information to wider audiences. Consequently, first-time fathers might limit the opportunities to receive feedback, advice, or validation from others, potentially hindering their ability to enrich their information-seeking and sharing experience in an online environment [67].

Reasons Behind Information-Sharing Decisions

First-time fathers who actively share pregnancy-related information emphasize the reasons they share pregnancy information are to validate the information, be compassionate to others, and enhance the overall quality and completeness of pregnancy-related information. By participating in information-sharing activities, first-time fathers aim to initiate discussions, seek advice, exchange information for validation, and compare notes to enhance the comprehensiveness of the information they acquire. This finding aligns with the findings of studies by Savolainen [15] and Tangaraja et al [16], which underscores that individuals share information as a way to gather information through collaborative engagement. This reciprocity and validation of information among first-time fathers as new parents highlight the social nature of their information-sharing practices during the journey [73]. In addition, by sharing valuable and valid information and offering personal experiences for guidance, these fathers aim to contribute to the improvement of their relationship with other fathers [17]. The observed practices resonate with the broader social and cultural norms that emphasize the value of communal support and shared experiences in navigating significant life events [74]. This collaborative aspect of information sharing might have broader implications for paternal involvement in the pregnancy journey, as it fosters a sense of community and mutual support among fathers. Moreover, information enhancement motives highlight fathers’ active efforts to ensure the quality and completeness of shared knowledge. This underscores the importance of validation and cross-checking information before making decisions, which resonates with the results of a study by Fletcher and StGeorge [26], demonstrating that first-time fathers share information with the aim of bolstering their confidence. This study suggests that by receiving feedback and comments on shared information, first-time fathers might aim to enhance their understanding of pregnancy. Thus, it is expected to boost their confidence during the pregnancy journey. These findings suggest that the information-sharing practices of first-time fathers play a crucial role in fostering a supportive community and enhancing paternal involvement during the pregnancy journey.

Conversely, instances, where first-time fathers did not share information beyond their partners, reveal nuanced themes, including a preference for “asking” over “sharing,” a lack of intended audiences, self-situation awareness, privacy and intimacy, and physician-specific constraints. Most of the reasons for not sharing pregnancy information, as uncovered in this study, mirror the findings of a study by Onyeze-Joe and Godin [29], which was conducted in low- and middle-income countries. For instance, participants in both studies expressed reluctance to share pregnancy information due to their perceived self-awareness of unfamiliarity with the topics and a lack of experience. The cultural context emphasizing the privacy and intimacy of pregnancy information that leads first-time fathers to rarely share such experiences is also evident in the results of both studies. In addition, both studies highlight the impact of local cultural norms dictating that fathers keep pregnancy matters a secret and refrain from discussing them with others. Another concurrence is that first-time fathers do not share pregnancy matters due to concerns about being judged by other men [20]. Both studies revealed that first-time fathers, in light of potential judgment, prefer to ask questions rather than share information with others, particularly regarding new knowledge or experience. This suggests a shared cultural inclination influencing fathers’ information-sharing behaviors across multiple studies in low- and middle-income countries. These studies suggest that first-time fathers are reluctant to share pregnancy-related information beyond their partner due to cultural influence, situational constraints, and low capabilities.

These findings also indicate that support networks play an essential role in promoting information sharing and exchange during pregnancy [75,76]. Results of this study highlight that the primary themes behind the decision to share information—whether with others or with their partners only—heavily depend on the audiences who often act as support networks. For example, first-time fathers cite reasons for sharing information with others, such as reciprocity and validation of information, which underscores the importance of feedback from others as they seek affirmation to enhance their understanding. Furthermore, the most common reason for sharing with their partner only is “asking over sharing.” This means that first-time fathers need direct support from their partners in terms of obtaining pregnancy-related information. By enhancing support networks for first-time fathers, they can increase their confidence and improve their knowledge, which can lead to more involvement during pregnancy [75,76]. Furthermore, by creating intervention programs that encourage open discussions not only with partners but also within broader circles, including health care professionals and experienced extended family members, first-time fathers’ involvement in the pregnancy journey can be improved.

Limitations and Future Directions

Several limitations should be acknowledged while interpreting the findings of this study. First, the study primarily relies on self-reported data from an interview, which introduces the possibility of social desirability bias and recall inaccuracies. In addition, the nature of the research design restricts the ability to capture the dynamic nature of information-sharing behaviors over time. Furthermore, the study’s focus on Southeast Asian cultural contexts may limit the applicability of the findings to other cultural settings.

Despite efforts to ensure diversity, the study’s geographical concentration in Indonesia might not fully capture the regional variations within the country. Finally, the rapidly evolving digital landscape introduces a temporal dimension to the study, and the information-sharing behaviors observed may evolve with technological advancements. These limitations should be considered when interpreting the findings, and they underscore the need for future research to address these constraints and further refine our understanding of first-time expectant fathers’ information-sharing practices.

A potential avenue for further exploration related to this topic is delving into the impact of cultural variations within low- and middle-income countries on fathers’ information-sharing behaviors during pregnancy. This could involve comparative studies across different regions or cultural subgroups within Southeast Asian countries, offering nuanced insights into how cultural diversity influences communication patterns. In addition, future research could investigate the role of digital literacy and access in shaping information-sharing practices among expectant fathers. Understanding how varying levels of digital literacy impact the use of online platforms for sharing pregnancy-related information could provide valuable insights for designing targeted interventions or support systems. Furthermore, longitudinal studies tracking fathers’ information-sharing behaviors throughout different phases of pregnancy and early parenthood could uncover how these practices evolve over time. Exploring how fathers’ roles and information-sharing dynamics shift from pregnancy to post partum could also contribute to a more comprehensive understanding of their evolving roles within the extended family unit. Finally, as demographic factors were not included in the analysis for this research study, exploring the relationship between sociodemographic aspects and information-sharing behavior could provide deeper insights into the dynamics of paternal involvement during pregnancy.

Conclusions

In conclusion, the results of this study provide an understanding of the intricate interplay of factors that influence information-sharing practices among first-time expectant fathers in low- and middle-income countries. The existing gap in research on this subject prompted this study’s exploration, recognizing the unique cultural, digital, and contextual nuances within Indonesia. The country’s diversity in cultural norms and varying degrees of digital literacy serve as a rich backdrop for comprehending how fathers engage in the sharing of pregnancy-related information. By focusing specifically on Indonesia, with its diverse cultural landscape and regional commonalities, this study contributes essential insights that might be extrapolated to other Southeast Asian countries. In doing so, it addresses the existing research gap and enriches the global understanding of fathers’ roles in the intricate journey of pregnancy. This not only increases our knowledge of paternal engagement but also emphasizes the importance of nuanced approaches that take cultural variation into account in future theoretical discussions.

On a practical level, this study offers valuable insights with implications for policy makers, health care providers, and support organizations. On the basis of this study’s findings, physicians and midwives in Indonesia might need to allocate additional time and diversify communication channels during antenatal care to enhance paternal involvement. Developers can leverage these insights to create dedicated online forums tailored for fathers. For governmental intervention programs, the study suggests initiating awareness campaigns, workshops, and support groups to encourage fathers’ active participation in pregnancy discussions. In the workplace, employers can foster an inclusive environment through programs addressing the unique needs of expectant fathers, creating designated spaces for open discussions, and implementing awareness campaigns to destigmatize pregnancy conversations. These contributions aim to promote paternal involvement, enhance support networks, and foster a collaborative sharing environment. The extrapolation of findings to other Southeast Asian countries provides actionable knowledge for those working in the region that guides the development of culturally tailored strategies to promote paternal involvement during pregnancy. Overall, the study bridges the gap between theoretical advancements and practical applications in the context of paternal involvement in low- and middle-income countries.

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Authors' Contributions

KA was involved in conceptualization, data curation, formal analysis, investigation, methodology, project administration, validation, visualization, writing the original draft, and reviewing and editing the manuscript. AI was involved in conceptualization, formal analysis, methodology, supervision, validation, visualization, writing the original draft, and reviewing and editing the manuscript.

Conflicts of Interest

None declared.

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Original Paper

A Risk Assessment and Planning Tool to Prevent Sudden Unexpected Death in Infancy: Development and Evaluation of The Baby Sleep Planner

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Abstract

Background: Successful national safer sleep campaigns in the United Kingdom have lowered the death rates from sudden unexpected death in infancy (SUDI) over the past 3 decades, but deaths persist in socioeconomically deprived families. The circumstances of current deaths suggest that improvements in support for some families to follow safer sleep advice more consistently could save lives.

Objective: This study aimed to develop and evaluate a risk assessment and planning tool designed to improve the uptake of safer sleep advice in families with infants at increased risk of SUDI.

Methods: A co-design approach was used to develop the prototype interface of a web-based tool with 2 parts: an individual SUDI risk assessment at birth and a downloadable plan for safety during times of disruption. The advice contained within the tool is concordant with national guidance from the Lullaby Trust, the United Nations International Children's Emergency Fund (UNICEF), and the National Institute for Health and Care Excellence. User testing of the prototype tool was conducted by inviting health visitors, midwives, and family nurses to use it with families eligible for additional support. Qualitative interviews with health professionals and families allowed for iterative changes to the tool and for insights into its function and influence on parental behavior.

Results: A total of 22 health professionals were enrolled in the study, of whom 20 (91%) were interviewed. They reported appreciating the functionality of the tool, which allowed them to identify at-risk families for further support. They felt that the tool improved how they communicated about risks with families. They suggested expanding its use to include relevance in the antenatal period and having versions available in languages other than English. They reported using the tool with 58 families; 20 parents gave consent to be interviewed by the research team about their experiences with the tool. Families were positive about the tool, appreciated the trustworthy information, and felt that it was useful and appropriate and that the plans for specific infant sleeps would be of benefit to them and other family members.

Conclusions: Our tool combines risk assessment and safety planning, both of which have the potential to improve the uptake of lifesaving advice. Refinements to the tool based on these findings have ensured that the tool is ready for further evaluation in a larger study before being rolled out to families with infants at increased risk.

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KEYWORDS

safer sleep; parent education; co-design; process evaluation; sudden infant death syndrome; SIDS; sleep; baby; babies; infant; infants; prototype; interface; develop; development; sleeping; pattern; tool; parent; infant mortality; risk; risks; assessment; death; mortality; parents; parenting; risk assessment; sudden unexpected death in infancy; SUDI; approach; antenatal; postnatal; user testing; user experience; web-based; experience; experiences; attitude; attitudes; opinion; perception; perceptions; perspective; perspectives

Introduction

Background

Recent data from the National Child Mortality Database show a strong link between known risks in the sleep environment (eg, infant prone sleeping and hazardous cosleeping) and sudden unexpected death in infancy (SUDI) in 2020, with at least 1 known factor present in 75% of the deaths [1]. These data also show the scale of inequalities, with a significantly larger proportion of unexplained deaths of infants living in the most deprived neighborhoods (42%) than of those in the least deprived neighborhoods (8%), a 5-fold increase. In 2017, a consensus process (based on the James Lind Alliance Priority Setting model) in identifying research priorities to reduce SUDI rated “developing and evaluating new ways to make safe sleep interventions more effective” as the top priority in the United Kingdom [2]. More recently, the Child Safeguarding Practice Review Panel has called for further efforts to increase the uptake of safer sleep advice in families in which the risks of SUDI are much higher than in the general population [3]. The Baby Sleep Planner was designed in response to recommendations to target support and resources to those families with infants most at risk, provide tailored and personalized risk information, and facilitate planning for infant safety during times when the normal routine is disrupted [3]. Risk assessment calculators for SUDI at the time of birth have not been widely used before in the United Kingdom, but the shift to increased prevalence among families living in the most deprived neighborhoods makes this more viable. The tool comprises 2 parts: a risk assessment at birth showing infant risk based on background and neonatal characteristics and a sleep environment planning section that provides an individualized plan for safety that can be downloaded as an image and shared with family and friends. Currently, most safer sleep advice and guidance in the United Kingdom is given by midwives, health visitors, and specialist nurses. Message delivery is often compounded by limited time and conflicting advice from multiple sources [4]. Health professional resources aim to increase parental knowledge of SUDI risks, and recent qualitative interviews with them suggest that they would welcome a targeted approach for families with infants at the greatest risk using parental input to come up with realistic strategies during disrupted routines [3,5]. A recent review of interventions to increase the uptake of safer sleep advice in families of infants at increased risk concluded that approaches moving away from “information giving” toward “information exchange” may be more effective for this group [6]. Using the detailed evidence we collected in Bristol and working closely with families whose infants are at higher risk to understand parental decision-making, we had a unique opportunity to derive a targeted intervention [4,7].

Objectives

This paper describes the development and evaluation of a web-based tool that aimed to improve the uptake of safer sleep advice in families with infants at increased risk of SUDI. The Baby Sleep Planner was designed together with health professionals, families, other academics, and a team of software developers. The objectives of this study were as follows:

1. To use a co-design approach to develop a prototype web-based interface that the target group can use
2. To conduct user testing of the tool, including training and data capture of tool answers
3. To conduct qualitative interviews with health professionals and family members who have used the tool to understand how the tool works in real-world conditions and refine it for testing in a future study

Theory-Based Approach

The Medical Research Council’s guidance on the development and evaluation of complex interventions puts developing and testing theory as a core concept [8]. By using previous research on the influences on behavior of our priority group, we hope to provide a transparent theoretical underpinning that can be tested in a future study.

The risk assessment and planning tool is based on a Capability, Opportunity, and Motivation–Behavior (COM-B; behavior change) model that considers the sources of behavior along with the behavior change techniques likely to work on the target behaviors [9]. The COM-B model proposes that capability, opportunity, and motivation interact to predict behavior and that intervention designers should consider how to influence these constructs. Our previous studies have provided the basis for identifying the behavioral targets for intervention and their corresponding behavior change techniques [4,5,10,11]. The goal of our intervention is to enable parents with infants at most risk of SUDI to consistently provide a safe sleep environment for their infants, especially during disrupted routines. We chose techniques that focus on increasing *capability* by providing information about their baby’s risk; *opportunity* by using their environmental context and resources to develop realistic strategies for providing a safe sleeping environment; and *motivation* through planning, goal setting, and increasing confidence (Table 1).

Table 1. Model of the intervention showing the Capability, Opportunity, and Motivation–Behavior (COM-B) model using Theoretical Domains Framework (TDF) domains and corresponding behavior change techniques.

COM-B construct and subconstruct	TDF domain	Finding or problem	Corresponding behavior change technique	Proposed mechanism of action of the Baby Sleep Planner
Capability				
Physical capability	• Physical skills	• Advice interpreted differently or misunderstood	• Instruction on how to perform the behavior	• Increased confidence to provide a safer sleep environment
Psychological capability	• Knowledge • Cognitive and interpersonal skills; memory, attention, and decision processes • Behavioral regulation	• Safer sleep advice too generic and not individualized • Disruption to the routine can create unplanned risky situations	• Information about health consequences • Behavior substitution	• Increased understanding of their own infant's risk status • Prioritizes safety over convenience
Opportunity				
Physical opportunity	• Environmental context and resources	• Poor-quality accommodation makes following advice harder	• Restructure the physical environment • Reduce exposure to cues for the behavior	• Increased confidence to maintain safety in nonstandard situations
Social opportunity	• Social influences	• Burden of following advice loaded on primary carer or mother	• Social support	• Sharing the plans with wider family and friends reduces burden and increases safety when the infant is cared for by others
Motivation				
Reflective motivation	• Social or professional role and identity • Beliefs about capabilities; optimism • Beliefs about consequences; intentions • Goals	• Trusted sources provide impactful information • "Just this once" mentality puts infants at increased risk during times of disruption	• Credible source • Goal setting • Behavioral contract	• Health professionals become trusted, and advice increases in credibility • Increased confidence to follow a personalized plan for safety
Automatic motivation	• Reinforcement • Emotion	• Fear of SUDI[a] can be stressful and overwhelming	• Reduce negative emotions	• Increased confidence that the plan is achievable and realistic

[a] SUDI: sudden unexpected death in infancy.

Methods

Ethical Considerations

The full study protocol was reviewed and given a favorable ethical opinion by the London – Chelsea Research Ethics Committee and granted Health Research Authority approval on June 21, 2022 (reference 22/PR/0445). Interview participants were compensated for their time with shopping vouchers.

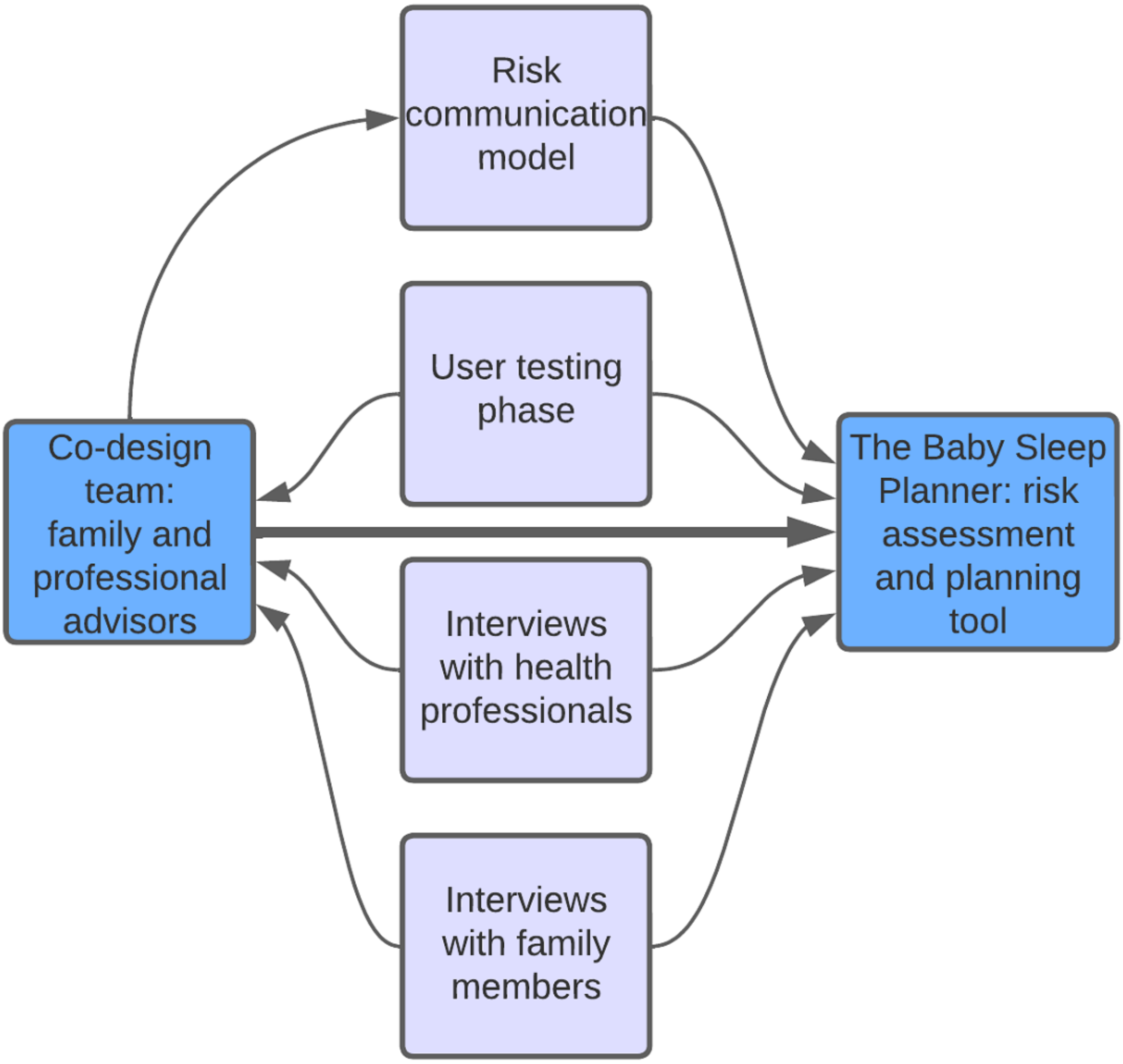
Professional Advisory Group

A group of experts was consulted to make sure that the content and advice within the tool supported the national advice for safer sleep. These experts comprised a professor of neonatology; a professor of midwifery and nursing; a professor of anthropology; a chief executive of a national SUDI charity; and a specialist health visitor for Gypsy, Roma, and Traveler families. Their input was sought during the development of the tool in conjunction with our co-design meetings.

Co-Design Meetings

Before developing the tool, we engaged a family advisory group made up of 15 families with infants at risk of SUDI or who were affected by SUDI. The group met regularly both before and during the evaluation phase to influence the concept and design of the tool. Members of this group were invited to join via local health visitors, family nurses, and our study website and social media accounts as well as through Little Lullaby, a branch of the Lullaby Trust specifically for young parents. Figure 1 shows the overall process of tool design, including the influence of the co-design team and evaluation activities.

Figure 1. Co-design process showing data sources used to design the risk assessment and planning tool.



Health Professional Recruitment

A total of 3 health professional roles were included in our process evaluation of the tool: midwives, health visitors, and Family Nurse Partnership (FNP) nurses. The midwives were all from a single community-based team for vulnerable and high-risk families. FNP nurses work solely with mothers aged ≤19 years, and 1 team from Bristol was invited to take part. Health visitors working with vulnerable families in 3 local areas (Bristol, North Somerset, and South Gloucestershire) were asked to volunteer to take part in the study by their managers. Study information sheets detailed all aspects of the research and included information on data security. Written consent to use the tool and take part in an interview was collected before participating in the study. All data collection for the evaluation followed the UK policy framework for health and social care research [12], including adhering to strict data protection guidance. Data were stored on secure university servers only accessible to members of the study team.

Health Professional Training

A training package comprising a handbook, video presentation, Microsoft PowerPoint (Microsoft Corp) slide show, and 30-minute session with a member of the study team was provided to each health professional. The handbook included information on the background of the tool, the evidence base, how it was developed, the structure of the tool, and details about how to use it with families. The video presentation covered both the structure and use of the tool and was presented at a 30-minute training session attended by every health professional. Completion of the training was a prerequisite for being sent the link to the tool. Health professionals were supported throughout the study with dedicated email and phone contact.

Health Professional Interviews

Semistructured interviews with health professionals provided insights at each stage into the conditions of delivery, including *adoption* of the tool (how it was used, which resources were used, how families were chosen, and which family members engaged), *appropriateness and acceptability* (response from professionals and ease of use), and *fidelity* (the details of implementation into practice vs what we envisaged). Health professionals were also asked about scope for widening the tool beyond safer sleep, for their suggestions for how to do this, and which other infant health or well-being topics would be relevant to their work with families experiencing poverty. The interview topic guide was developed with input from our professional advisors, and iterations were made as the interviews progressed.

Family Interview Recruitment

Consent to be shown the tool was given verbally to the health professionals during initial conversations on safe sleep. Separate consent was also embedded into the tool to allow researchers to view the responses. Thus, it was possible to consent to be shown the tool without collecting any data or participating in an interview. Consent to be contacted regarding a possible interview about their experience using the tool was passed on to the research team via the health professional for follow-up. A member of the research team contacted each family member with a study information sheet and consent form. Recruitment took place via telephone, email, or SMS text message depending on participant preference.

User Testing (Health Professionals Using the Tool With Families)

The link to the Baby Sleep Planner was provided for a period of 12 weeks to allow enough time for each health professional to use the tool with 5 to 6 families. Once health professionals had recruited enough families, they took part in a qualitative interview. At the end of the user testing phase, the data were downloaded. Where consent was given, the tool collected data on each answer to the risk assessment and planning sections and which plan options were chosen. All questions were multiple choice, no personal details could be entered into the tool, and no responses were stored locally on any device to prevent accidental data breaches or identification of any participants.

Family Interviews

Qualitative telephone interviews used a topic guide with families focused on *acceptability* (engagement with the tool and ease of use), *appropriateness* (language and literacy access and perceived targeting by professionals), and evidence of *influence on behavior* (experiences with using the plan and spreading awareness to other parents or carers). The interview topic guide was developed with input from our family advisory group, with iterations as the interviews progressed. Individuals aged <16 years, anyone who lacked the cognitive capacity to consent, and anyone unable to complete an interview in English were not eligible to take part in the study.

Interview Analysis

The interviews took place via telephone or face-to-face. The audio recordings were transcribed, anonymized, coded, and investigated using a framework analysis allowing for a systematic approach to generating themes [13]. An initial analytical framework of codes was developed inductively using the first 5 transcripts, agreed upon by 3 team members, and then applied consistently (deductively) across the remaining transcripts. Separate frameworks were developed for family and health professional interviews. Team members coded transcripts using double coding across 50%, and discrepancies were resolved through team discussion.

Results

Objective 1: Co-Design of the Tool Interface

Overview

Our family advisory group, together with the research team, developed a model for delivering risk information (Figure 2) to caregivers of infants involving five stages: (1) being honest about the risks, (2) giving reasons for the risks and feedback on reducing them, (3) showing options for reducing the risks (using other families' real experiences), (4) asking what would work and support planning, and (5) making it shareable for other caregivers. Using this input, we worked together with the software development team and a graphic designer to make the tool meet each of those 5 stages. We adapted the planning option wording and images based on the recommendations of the family advisory group and included advice specific to a wider range of families thanks to their focus on the realities of infant care, such as nonstandard housing and looking after more than 1 baby at a time.

Following the co-design meetings, we produced a flowchart of tool functions showing the questions and functions for each stage. This flowchart was refined through further family advisory group meetings and with feedback from our professional advisory group members. Decisions were made based on the complexity of the tool, the costs of the design, and how well it enabled each of the behavior change techniques.

During this process, we kept the risk assessment and sleep environment planning sections separate, with an option to complete them together if suitable. Feedback from professionals in our advisory group suggested that the separate risk assessment could be a useful stand-alone tool for professionals working with families to know who to target with additional support for safer sleep and to complete before using the tool with a family. The risk assessment is based on nonmodifiable family background and birth characteristics, whereas the sleep environment section is based on modifiable behavior.

An initial prototype of the tool interface was available for feedback from our professional advisors, after which any final refinements were made. Table 2 shows example changes made throughout the co-design process. The family and professional advisory groups also reviewed the training materials.

Figure 2. Risk communication model designed by the co-design team.

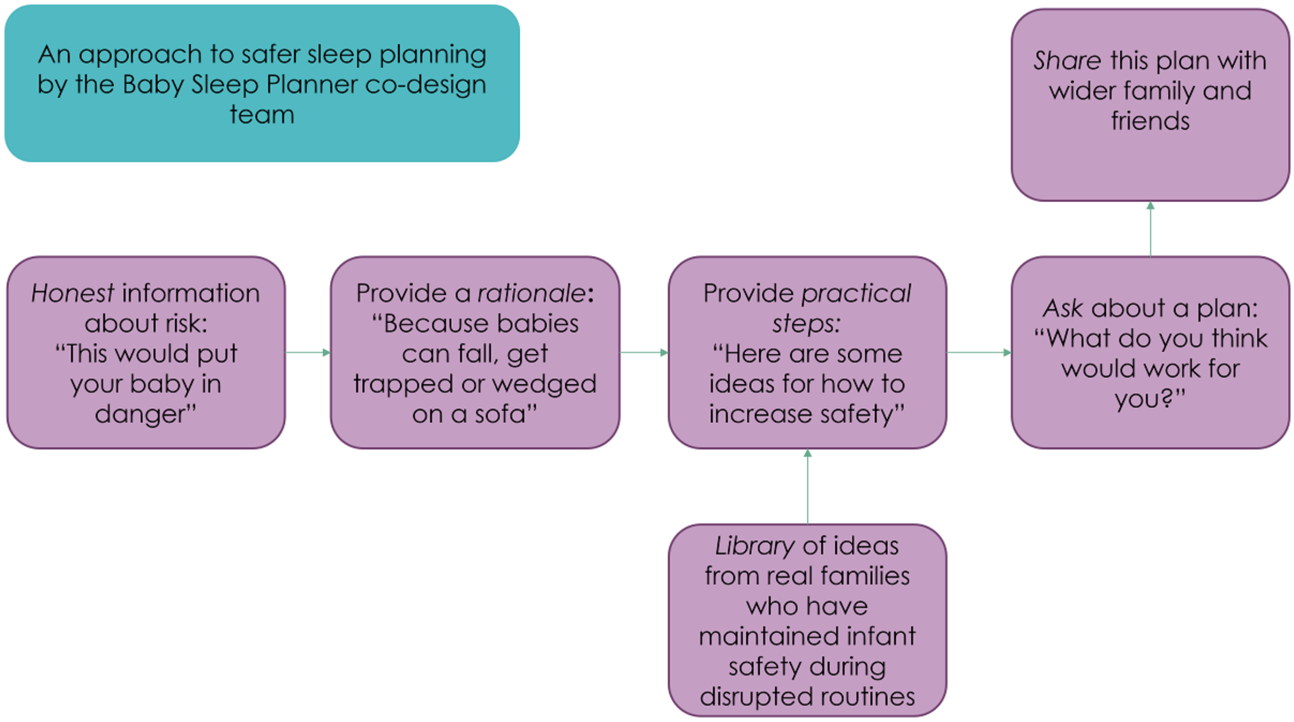


Table 2. Example changes from the co-design process and professional advisory groups.

Feedback, question, or wording in tool	Change	Reason and example
"Which one best describes your relationship to the baby?"	Add in an answer option for "both parents or caregivers"	Feedback from health professional advisor—if they are talking to both parents at the same time (eg, in midwifery clinic)
"Babies in larger families, especially if the mother is young, are nearly three times more at risk of SIDS."	Change to the following: "Babies in families with 2 or more children, especially if the mother is young, are nearly three times more at risk of SIDS."	Feedback from professionals and family advisors that 2 children is not really a "large" family
Feedback that the nonmodifiable nature of the risks feels unfair	Add in the following: "Your baby's background risk is fixed and often not something you can control. You can have control over your baby's sleep environment and reduce their risk greatly by following the advice."	Feedback from family members; this change may help give families a feeling of acknowledgment that their baby's risk status is not within their control and empower them to reduce risks by following safer sleep advice
Things to think about if answered "sheets or blankets": "Make sure sheets and blankets can't cover the baby's face. Putting the baby at the bottom of the space can stop them wriggling under blankets."	Change to the following: "Make sure sheets and blankets can't cover the baby's face. If baby is in a cot, putting their feet at the bottom of the cot can stop them wriggling under blankets."	Feedback from family advisors so that people do not interpret "bottom of the space" as the bottom of an adult bed
Question: what will be covering the baby?	Add in options for "nothing." If "nothing" is selected, add the following text: "If it is very hot in the room where the baby will sleep, it may be best not to use any bedding. You can also try to cool the room, please visit this site for more advice: [link to relevant Lullaby Trust web page]"	Feedback from health professionals and families during a heat wave to accommodate hot weather scenarios
Add in more detail when "blankets" is chosen: "Make sure sheets and blankets can't cover the baby's face. If baby is in a cot, putting their feet at the bottom of the cot can stop them wriggling under blankets."	Change to the following: "Make sure sheets and blankets can't cover the baby's face. If baby is in a cot, putting their feet at the bottom of the cot can stop them wriggling under blankets. Make sure sheets and blankets don't make the baby too hot—for advice about temperature please visit: [link to relevant Lullaby Trust web page]"	Feedback from health professional advisors to add information about thermal regulation and room temperature
Details about the risks of smoking	Added in a link to relevant Lullaby Trust web page.	Requested by professionals to support conversations about smoking cessation

The Baby Sleep Planner Intervention

The Baby Sleep Planner (Figure 3) is a web-based risk assessment and planning tool with 2 sections that can be completed together or separately. The risk assessment tool includes 8 questions about the background characteristics of the infant, usually delivered shortly after birth, and assigns a score based on an algorithm [14]. These questions include maternal age, number of children, smoking during pregnancy, partner support, partner smoking, infant sex, birth weight, and neonatal unit admission. A total of 7 other nonmandatory questions are asked to inform the research, including infant age, gestation, multiple births, ethnicity, relationship to the baby, whether this is the first time using the tool, and whether there is a health professional present. Each question is categorical, with 3 levels of risk assigned: lower, slightly higher, and higher risk. The information in the results is tailored to the risks present in each infant. The results are presented with information about research evidence and a key message that risks can be substantially lowered by following safer sleep advice.

Figure 3. Final design of the Baby Sleep Planner.

The planning tool includes 6 questions about the infant's sleep environment, including room sharing, sleep location (eg, cot or adult bed), sleeping position, items in the sleep space, coverings (eg, blankets or sleeping bag), and feeding method. The results of these questions comprise 3 categories: things going well, things to think about, and things to change. Feedback includes links to further information from a national advice charity, the Lullaby Trust. Users are then given 14 "plan options" comprising images with safety messages and asked to pick between 2 and 4 to create their own baby's plan. The plan can be downloaded to a device (eg, mobile phone) as an image that can be shared with wider family and friends.

The intervention includes training for health professionals, a 30-minute web-based session with a member of the research team to explain the background, theory, and use. For this evaluation, the tool was only available for use as part of a conversation with a health professional, and the link to the website was not shared directly with families. Although the tool is under development, we wanted to make sure that the content and interpretations were as intended.

Objective 2: User Testing, Including Tool Use Database Development

The tool and associated training were completed by 22 health professionals: 9 (41%) midwives, 8 (36%) health visitors, and 5 (23%) family nurses. In total, health professionals reported using the tool with 58 families, and the tool database recorded 55 uses of the tool. Of these responses, 48 (87%) were for the combined risk assessment and planning tool, 5% (3/55) were for the risk assessment tool only, and 7% (4/55) were for the sleep planner only. It was not possible to match tool use to a particular user because of data security, so we do not know whether the database responses are from real conversations with families or health professionals trying out the tool. We also do not know whether the tool was completed more than once per participant, although the reports from the health professionals suggest that it was not completed more than once. Health professionals reported that all the families they spoke to consented to seeing the tool, and the majority also consented to the research team seeing their answers. However, as we were unable to match the database responses, we could not quantify how many refused to provide information to the researchers, although it is thought to be a small number.

Objective 3: Qualitative Interviews

Health Professional Interviews

A total of 22 health professionals volunteered to take part in the process evaluation (Table 3), were recruited for the study, and attended either over the web or face-to-face training. In total, 9% (2/22) of the health professionals subsequently withdrew, both going on long-term sick leave. In total, 20 health professionals, comprising 9 midwives, 8 health visitors, and 3 family nurses, were interviewed.

Table 3. Description of health professionals recruited for the process evaluation.

ID	Role (n=22)	Training in person or over the web (n=11 in person and n=11 over the web)	Families shown the tool (n=58), n (%)	Took part in an interview? (n=20)
MW1	Midwife	In person	2 (3)	Yes
MW2	Midwife	In person	5 (9)	Yes
HV1	Health visitor	Over the web	4 (7)	Yes
HV2	Health visitor	Over the web	3 (5)	Yes
HV3	Health visitor	Over the web	1 (2)	Yes
HV4	Health visitor	Over the web	4 (7)	Yes
HV5	Health visitor	Over the web	5 (9)	Yes
FNP1	Family nurse	In person	1 (2)	Yes
FNP2	Family nurse	In person	0 (0)	No—off sick
FNP3	Family nurse	In person	0 (0)	No—off sick
FNP4	Family nurse	In person	2 (3)	Yes
MW3	Midwife	In person	0 (0)	Yes
MW4	Midwife	In person	5 (9)	Yes
HV6	Health visitor	Over the web	5 (9)	Yes
HV7	Health visitor	Over the web	5 (9)	Yes
HV8	Health visitor	Over the web	6 (10)	Yes
MW5	Midwife	In person	1 (2)	Yes
MW6	Midwife	In person	4 (7)	Yes
MW7	Midwife	Over the web	1 (2)	Yes
MW8	Midwife	In person	0 (0)	Yes
MW9	Midwife	Over the web	3 (5)	Yes
FNP5	Family nurse	Over the web	1 (2)	Yes

Practical Use and Engagement

Health professionals found the tool easy to use and appreciated its ability to engage parents in conversations regarding the risk of SUDI. They commented on its simplicity, plain language, and visual design. Some commented that it took a little bit of time to get used to using it, and some had difficulties accessing the internet while with the families:

> *...it was really good, and parents really engaged with it, because it was very much tailored to them, and so compared to other sleep conversations they were much more engaged and interested in it.* [HV7]
>
> *With anything it takes a little bit of getting used to, but it was easy enough once you have done it once with a family. You were both learning at the same time really with the first family I did it with.* [HV1]

Communicating About Risk

Health professionals appreciated the balance between being honest and up-front with families while being careful to avoid making parents feel anxious or judged. They described using the tool to support conversations that empower parents with knowledge about their individual infants, which then supports the need for the safer sleep messages:

> *What I liked about the tool is that directness about it...it gave me support, because often I feel like as a practitioner I was saying this stuff and can come across a little bit naggy...Whereas this was a really helpful tool to back up what we're asking of families.* [FNP5]
>
> *...you need to understand a certain level of risk, but it wasn't making people feel worse going through the questions, and going through the outcomes, it didn't*

> *make parents feel more anxious about the situation.* [HV6]

Beyond the Messages

Advice given to families is often didactic, and health professionals commented that the tool allowed them to go further than just giving out the safer sleep messages. They liked that it supported a conversation rather than just telling families what to do. They described being able to get more information across, feeling that parents were more involved in the conversation, and being able to delve into specific messages that parents wanted to discuss:

> *...she has some learning difficulties as well, so I was quite surprised she could focus throughout the whole thing really. It felt like that they were being involved, rather than just being told, and also I think what it did was it meant we talked about it for longer.* [FNP1]

> *...she could then ask questions just about little other areas, just talking about when can they have a pillow, what age? And it facilitated a little bit more of a wider discussion around safe sleep really.* [FNP5]

> *So engaging with people, listening to what they have to say, and then maybe just bringing it up more in conversation than this is what I'm telling you to do.* [MW9]

Wider Family Support

Advice about safer sleep is often given solely to the primary carer of the infant, and some health professionals described how they used the tool to encourage mothers to share their plans with their wider friends and family. Some found it difficult to send the image to the mother's device and would have preferred a printed option; however, there was a consensus that supporting how mothers communicate about safer sleep with their families is important:

> *We used it to help her communicate what was important to her with the paternal family, so that she could ensure her baby was safe, and those steps that she was taking at home could be continued in a different environment.* [FNP5]

> *We find this with a lot of our clients' parents in that they're giving a lot of advice themselves, so it's important that they are given the up to date advice so they can support the mum in making decisions.* [FNP1]

Barriers to Use and Changes Suggested

Health professionals cited time as a limiting factor in tool use as well as internet access problems and battery issues with work laptops. The timing of use was also raised, with some seeing value in repeating the process and starting sleep planning conversations during the antenatal period. They described seeing the value of the tool for all parents, not just those with infants at increased risk. Some suggested a variety of options for sharing the sleep plan image with the family, including printing it off for those without mobile devices. Changes suggested included versions in languages other than English, more information on the risks associated with smoking, rethinking our description of larger families, information on ideal room temperature, and more details on blanket use:

> *For some people having a visual maybe on the fridge printed off, that's what I intended to do but it got lost in the ether when I downloaded it on my phone and I couldn't find where it had downloaded to. For others, their phones break every week, and getting new numbers, something printed like that would be ideal.* [MW1]

> *More about smoking around the baby or smoking in the same room as baby?* [HV2]

> *Would you need a different tool for antenatals to look at the risk factors, and you could discuss those risk factors then with them?* [HV4]

> *The girl had only had two children, but it came up with a message at that point from babies from larger families are more at risk, and I wouldn't class two children as a larger family.* [MW3]

Scope for Future Work

Health professionals were asked about other topics they thought would be of benefit to the families they worked with, and they raised a variety of issues. The limited capacity for home visits and relationship building owing to heavy workloads was a constant problem. Some had ideas for widening the scope of the Baby Sleep Planner to be able to use it during pregnancy and with non-English speakers, and 1 health visitor suggested adding reminders that could be sent via email to parents to support the changing needs of infants over the first year, for example, at 6 months, when babies can potentially be moved into a room of their own. Several suggested including more detail in the existing tool focusing on use of substances, both prescribed and illicit, to increase awareness of the risks associated with cosleeping when parental responses may be impaired. Another health professional suggested incorporating a planning aspect into stressful parenting situations, for example, planning activities to reduce stress and potential injury to the infant, similar to ICON (a program to reduce abusive head trauma in infants). Finally, 1 family nurse suggested an intervention focused on domestic abuse, in particular on the effects of coercive control on parenting capacity:

> *Something about domestic abuse? Domestic abuse like to care and control, and neglect, of them not being able to focus and care for their babies, because of stuff going on in their relationship.* [FNP1]

> *More information about smoking or strong painkilling medication that might make someone sleepy.* [MW3]

> *In the future would it send parents reminders and things at all if they signed up for this planner and things? I think that would be good. As health professionals we don't see them as often as we can do, but just if they signed up they could get a text or whatever about sleeping, or if it was an app you would get a notification wouldn't you about remember these things, it's really important, your baby is 6 months, they can move into their own room, but they*

> *still can't have a pillow or duvet, that kind of thing.* [HV1]

Family Member Interviews

Health professionals sent contact details for 32 family members who had agreed to be contacted about a research interview. All were invited to take part in an interview except for 1, whose contact details were sent to the research team after data collection had been completed and recruitment was closed. A total of 20 families gave consent to be interviewed and completed a telephone interview (Table 4). In total, 4 interviews included both the mother and the mother's partner. Joint interviews were analyzed together, and 1 mother was still pregnant at the time of the interview. Risk scores (using the algorithm for interview participants' infants) ranged from 0 to 153 (mean 58.7, SD 49.5). A total of 3 of the infants had risk scores of >115, indicating increased risk of sudden infant death syndrome using our recently developed algorithm.

Table 4. Families interviewed, with corresponding infant risk status.

ID	Relationship to baby	Maternal age (y)	Infant sex	Birth weight (g)	NICU[a] admission	Parity	Smoking during pregnancy	Partner support	Partner smoking	Infant risk assessment score
01	Mother	<21	Male	≥2500	No	1	No	Yes	No	79
02	Mother	21-24	Female	≥2500	No	1	No	Yes	Yes	65
03	Mother	≥25	Male	≥2500	No	1	No	Yes	No	15
04	Mother	≥25	Female	≥2500	No	1	No	No	N/A[b]	18
05	Mother and partner	21-24	Male	≥2500	No	1	No	Yes	No	46
06	Mother	≥25	Male	≥2500	No	1	No	Yes	No	15
07	Mother	<21	Female	≥2500	No	1	Yes	Yes	Yes	146
08	Mother and partner	≥25	Male	≥2500	No	1	No	Yes	No	15
09	Mother and partner	≥25	Male	≥2500	No	1	No	Yes	No	15
10	Mother	<21	Male	≥2500	No	2	No	Yes	No	111
11	Mother and partner	≥25	Male	Pregnant	Pregnant	1	No	Yes	No	15
12	Mother	≥25	Male	≥2500	No	1	No	No	N/A	33
13	Mother	<21	Male	≥2500	No	1	No	Yes	No	79
14	Mother	≥25	Male	≥2500	No	1	No	Yes	No	15
15	Mother	≥25	Female	≥2500	Yes	2	Yes	No	N/A	114
16	Mother	≥25	Female	≥2500	No	1	No	Yes	No	0
17	Mother	≥25	Female	≥2500	No	2	No	Yes	No	32
18	Mother	<21	Female	1749-2499	No	1	Yes	Yes	Yes	153
19	Mother	<21	Male	≥2500	No	1	No	Yes	No	79
20	Mother	21-24	Female	≥2500	No	2	Yes	No	N/A	129

[a] NICU: neonatal intensive care unit.

[b] N/A: not applicable.

Tool as a Trusted Source

Parents commented on how they felt that they could trust the information they received from the tool and that this was supported by its delivery from a health professional and alignment with national advice. They appreciated the wording as "factual" and not judgmental. Some liked that it was interactive and tailored to their baby, whereas others felt that they knew the information already and this was just a useful reminder:

> *I thought it was presented very simply, but not in a patronising way. It just the imagery and the just having a few words around it just made sense, and made it a bit more engaging.* [ID04]

> *...it's not judgemental but straight down the middle factual, but not trying to ward people off. I think the wording was fine for me.* [ID03]

> *...as a first time mum it was very useful, because I wouldn't have...people tell me stuff, but to hear it from somebody professional who actually knows was a lot more helpful.* [ID02]

> *The hospital went over it when I was discharged, and my community midwife, but that was about it...They*

> *were the same but they weren't in as much detail as your survey.* [ID07]

> *I think it's good when they come across the whole planner about it, because I think a lot of people would like to go through it just so that they've got all the information they need as well.* [ID20]

Risk Assessment Process

Lower-risk parents reported feeling reassured by the results of the risk assessment, whereas higher-risk parents described it as unsurprising and supportive in that it encouraged them to follow the advice. Some described difficult feelings regarding the algorithm risks being unchangeable or related to things that they did not have any control over:

> *So yeah it was reassuring to know that as far as anyone can predict we are at lower risk. So that I found quite helpful.* [ID04]

> *I believe it came out that I was high risk, that it was high risk, but with doing everything that I'm doing she said it was okay, do you know what I mean?* [ID15]

> *The difficult one about with the single parent is unsupported partner. That's the one thing that was difficult for me was you're three times higher risk with SIDS, what can I really do about that? That was difficult. Tilted cot, fine I can change that, but I can't change a supportive partner thing.* [ID12]

> *Yeah, and I think at the end when you get your risk as well and it's like you're at this much of a higher risk, it opens your eyes and you're like wow and you're like okay, do you know like...yeah.* [ID20]

Sleep Planning Process

Parents had mostly positive things to say about the sleep planning process, commenting that it included all the information they would need and appreciating that it explained the reasons for the advice without just telling them what to do. Most of the parents had answered the sleep environment questions remembering a real sleep that had taken place recently or with what they normally did. Changes to this part of the tool may be required to encourage parents and caregivers to use the sleep planning process to imagine what might happen in times when the normal routine is disrupted, for example, when staying away from home overnight. Several of the parents commented that they did not receive their plan image from their health professional:

> *Because as well the idea is that it doesn't just tell you what to do or what you should do, it tries to explain why.* [ID15]

> *I think we've been quite realistic with our plan, so I think we could stick to it most nights, depending on how things go with the baby, things could change in terms of feeding patterns and that kind of thing. But I generally it would be quite straightforward to stick to.* [ID03]

One mother shared how she had used the sleep planning tool and downloaded the plan as a picture to share with her family members who were responsible for her baby's overnight care once a week:

> *This is what we done, we took a picture so then we could send it to them, because I thought it would be more helpful to them, whereas if they don't have him as much, so they're not...they don't know him as well in his sleep than what I would do. So I thought it would help them a lot more.* [ID01]

Changes Since Using the Tool: Potential Impact

Several parents described things that had changed as a result of using the tool with their health professionals. These changes included, taking items out of the Moses basket, tucking blankets in, using age-appropriate sleeping bags, and keeping unsupervised pets away from sleeping babies. Others felt that they were doing everything they could but still appreciated the reassurance that this gave them:

> *...it was nice that there was something on there that I hadn't considered. I felt a little bit nervous about the fact that he's been sleeping with a slant, but it was only for seven to ten days, and I've rectified that now.* [ID12]

> *I didn't know that you didn't have to...you weren't allowed anything in the Moses basket.* [ID07]

> *...a lot of things we were doing already, and it was good to get the advice about tucking the blanket under the mattress, because that bit we had been like oh how do we keep it secure so it doesn't go over his face? So yeah, no it was useful.* [ID09]

Barriers to Use and Changes Suggested

Some of the barriers included not being able to access the plan images and preferring to go through the tool on their own without their health professional present. Some suggested having more links to click through for more in-depth explanations of how the messages protect infants. Several parents felt that the way in which the risks were explained could be better, using pictures or comparators that were known to them. One parent commented that there could be more emphasis on the ways in which they can lower the risks and less on things that they cannot change:

> *...perhaps being able to click on something and go through to a bit more information. So as you were saying about the feet to foot of the bed, so if you want to know more about it you can click on the icon and go through and have a bit more information about why that's the recommended sleeping position and those sorts of things.* [ID04]

> *I suppose the only thing that would be easier to use would be something digitally, like an app, or something that could be sent through to you to do rather than being shown two you on another laptop.* [ID11]

> *...having this baby here that I need to look after on my own all night with no support from his dad, and then to look at that statistic it was like oh no, and what can I do about that apart from bring down all*

> *the other risks? That's the only feedback I would have in terms of there was no okay well what can I do to make sure that I'm lowering that risk in that way.* [ID12]

Discussion

Principal Findings

This study developed a risk assessment and planning tool that is pragmatic for use in a real-world setting. It has the potential to be used in clinical practice for the identification and support of high-risk infants and for families to use to reduce proven risk factors in the infant sleep environment. Interviews with users demonstrated how the tool could enable enhanced support to reach those most at risk while also reducing the burden of work for health professionals. Health professionals reported that they found the tool more conversational and less didactic, and families reported that they appreciated this approach.

Comparisons With Existing Literature

Our findings align with those of other research into behavior change for this group, including a recent COM-B analysis of interventions to improve the uptake of safer sleep that found that, although increasing capability by passing on information about risks was common, more effective interventions incorporated motivational factors such as goal setting and making plans [11]. The risk assessment and planning tool incorporates motivational factors within the planning part of the tool, asking about where and how the baby will sleep, providing feedback on a variety of answers, and inviting users to prioritize their goals for safety in an individualized safety plan. In our study, families appreciated the approach to bed sharing taken in the tool, aligning with recently updated advice from the National Health Service in England to acknowledge that bed sharing occurs in planned and unplanned ways and offering advice to reduce the risks in bed-sharing situations [15]. In a 2016 review of behavioral interventions, Moon et al [16] suggested that interventions should be multilevel, incorporating contextual factors into the design, as we have attempted to do in this study. They also recommended formal process evaluations and future studies that can measure effectiveness as needed to support wider implementation [16]. Other reviews have found similar issues with measuring effectiveness and concluded that creative methods may be needed, as well as interventions that include the wider family and peers [17].

Strengths and Limitations

The inclusion of a theory-based approach incorporating co-design elements, along with the evidence for behavioral influences that work for this group, gives this intervention a solid basis for effectiveness. Findings from the interviews support the theory that sharing individual risk status information (ie, "information about health consequences") may increase parental understanding of their own infant's safety needs. Sharing achievable and realistic plans may increase social support for following safer sleep advice, and having personalized conversations about safer sleep with health professionals as credible and trusted sources may enhance parental confidence and decision-making, especially during times of disruption to the normal routine. Integrating feedback from both health professionals and family members into the design and function of the tool meant that we were able to align the needs of both groups by ensuring that the tool provides evidence-based information in a way that supports the individual needs of each family. Testing the prototype intervention under real-world conditions provided insights into implementation and highlighted necessary changes. Issues with accessing the downloaded plan image meant that some families were not able to use this aspect of the tool, and this needs further consideration, with options for printing where possible. There were promising signals from the evaluation that understanding the risks to their baby and planning for safety during times of disruption may influence decision-making regarding the sleep environment, prioritizing safety at all times. The finding that some families found the unchangeable risks difficult to hear prompted further work to investigate how the risk assessment results can be presented as honest but not hopeless, providing more emphasis on how safer sleep planning can reduce the risks as much as possible even for an already higher-risk infant. It may be that the decision to describe infants as "higher risk" is unhelpful, and this should be explored in future work. This wording is currently used based on advice from our family advisors that being honest about the risk status of infants is important, as shown in the model in Figure 2. Most of the suggestions for changes to the tool were mainly minor, and we were able to incorporate them fairly quickly (see Table 2 for examples). Other changes, such as non–English language versions, will take longer. This was a small evaluation study using a prototype intervention. Our original aim included the development of a stand-alone tool that families could use independently, but studies that can collect more data on the safety and appropriateness of the tool to be used in this way will be required first. The risk status of the infants referred to the research team was also lower than we had expected; only 15% (3/20) of the families had infants at increased risk of SUDI, although every family except 1 had at least 1 risk factor present. We were also only able to include English-speaking families in this study, and future work to translate the tool for use in other languages should be included as part of future evaluations. Challenges with health professional recruitment because of current National Health Service pressures led to delays in data collection, resulting in health professionals using the tool with any families they thought suitable rather than those with higher-risk infants only. We were also unable to analyze the background tool data in this study as we were not able to discern "real" conversations with families from health professionals practicing with the tool. Improvements to tool background data collection have been made to make it possible to use these data to understand the characteristics of the families using the tool in future studies. We have also changed the wording of our "data usage" question to prevent this problem in future studies. To test the tool in "real-world" conditions, we did not restrict health professionals in terms of who they used the tool with, and some of them reported that they appreciated being trusted to use the tool with whom they thought best, including anxious parents with low-risk infants who would be reassured by the results. The implications of tool use for this population should be included in future evaluations without undermining the focus on families with infants at increased risk.

Conclusions

The Baby Sleep Planner was designed with involvement from families and key stakeholders and shows promise as a useful tool for health professionals having conversations about safer sleep with caregivers of infants. The web-based tool was acceptable to family members, midwives, health visitors, and FNP nurses. Further work should investigate whether the uptake of this intervention will significantly reduce known risk factors in the infant sleeping environment associated with sudden infant deaths and whether this algorithm can identify families with infants at risk of other causes of death.

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Data Availability

The data sets generated during and analyzed during this study are available at the University of Bristol data repository, data.bris [18].

Conflicts of Interest

AP is the chair of the Lullaby Trust Scientific Advisory Group and a member of the grants committee.

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Abbreviations

COM-B: Capability, Opportunity, and Motivation–Behavior
FNP: Family Nurse Partnership
SUDI: sudden unexpected death in infancy
UNICEF: United Nations International Children’s Emergency Fund

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Original Paper

Implementation of a Parent Training Program During Community-Based Dissemination (From In-Person to Hybrid): Mixed Methods Evaluation

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Abstract

Background: Parent training interventions support and strengthen parenting practices and parent-child relationships and improve child behavior. Between March 2018 and February 2020, a community-based parenting program conducted 38 in-person Chicago Parent Program (CPP) groups. In response to the COVID-19 pandemic, we modified the delivery of the in-person CPP to hybrid delivery using the self-administered, web-based version of the CPP (*ez*Parent) paired with web-based, videoconferenced group sessions.

Objective: This study aims to describe the delivery transition and implementation outcomes of the hybrid delivery of the CPP (ezParent+group) during community-based dissemination.

Methods: This single-group, mixed methods retrospective evaluation examined the implementation outcomes using the RE-AIM (Reach, Efficacy, Adoption, Implementation, and Maintenance) framework. We report on data from hybrid *ez*Parent delivery between September 2020 and August 2022. Parents completed pre- and postprogram surveys that included motivation to participate and perceived changes in parent-child behavior. Digital analytics captured *ez*Parent completion. Facilitators completed fidelity assessments and participated in postintervention interviews.

Results: In total, 24 hybrid *ez*Parent groups (n=240 parents) were delivered by 13 CPP-trained facilitators. Parents reported high levels of satisfaction with the program and improvements in their feelings of parenting self-efficacy and their child’s behavior following their participation in hybrid *ez*Parent. On average, parents completed 4.58 (SD 2.43) 6 *ez*Parent modules. The average group attendance across the 4 sessions was 71.2%. Facilitators found the hybrid delivery easy to implement and reported high parent engagement and understanding of CPP strategies.

Conclusions: Using the hybrid *ez*Parent intervention is a feasible and effective way to engage parents. Lessons learned included the importance of academic and community-based organization partnerships for delivering and evaluating robust programs. Implementation facilitators and barriers and future research recommendations are discussed.

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KEYWORDS

COVID-19; implementation; internet-based intervention; parenting; community dissemination; hybrid delivery

Introduction

Background

Behavior parent training (PT) is considered the gold standard for supporting and strengthening parenting practices and parent-child relationships and for the prevention and treatment of child behavior problems [1,2]. Positive parenting practices are a protective factor in buffering the negative effects of childhood trauma or early adverse experiences [3,4]. Parenting practices are often informed by family of origin, community, and social connections, and parents often look to their community for parenting support and guidance and many community-based agencies offer evidence-based PT [3].

Unfortunately, community organizations delivering PT experienced major disruptions in the provision of services with an abrupt ending of all in-person services due to the onset of the COVID-19 pandemic and shelter-in-place orders. These disruptions exacerbated an existing access gap for many communities, particularly those who were providing in-person individual or group-based PT. In addition, while parents lost access to parenting supports and child activities (eg, group activities, child care, school, and playgrounds), they experienced a substantial burden of shelter-in-place requiring a balance of work and parenting responsibilities [5,6]. Partially due to social isolation, balancing of responsibilities, and limited access to information and resources, data suggest a surge in negative mental, emotional, and physical health outcomes for parents and children [5,7,8]. Therefore, resources and support to mitigate the effects of the pandemic were crucial during this time.

Many community organizations shifted delivery of in-person PT and other parent supportive services using technology (eg, using videoconferencing for groups and web-based programming) [9-12]. The purpose of this paper is to describe the transition of a group-based PT program (ie, the Chicago Parent Program [CPP]) to a hybrid delivery model using the web-based PT of the CPP (*ez*Parent) paired with videoconferenced group sessions and implementation in a community-based parent support program. This study is the result of a community-academic partnership in which representatives from each coled the design, implementation, and interpretation of the data.

The Chicago Parent Program

The CPP is for parents of children aged 2 to 8 years and designed as a strength-based approach to promote positive parenting skills (ie, warmth, positive engagement, and support), support optimal child social and emotional development, and enhance parent-child interactions [13-16]. The CPP is a 12-session, group-based program that was developed with input from an advisory board of Black and Hispanic parents in low-income neighborhoods and aims to be contextually and culturally relevant for families from diverse racial, ethnic, and income backgrounds. Currently, the third edition of the CPP is broadly used in community agencies, pediatric primary care, early childhood care and education centers, and schools [17].

*ez*Parent is the web-based version of the CPP and was designed to deliver the core parenting skills and strategies in the CPP via 6 self-directed modules. Similar to the group-based delivery, *ez*Parent content and delivery was informed by an advisory group of Black and Hispanic parents and designed to help parents develop positive and effective parenting skills and decrease physical punishment through the use of behavioral strategies (eg, routines and labeled praise), brief videos of parents using the strategies, activities, quizzes, and practice assignments [18]. The web-based delivery of the CPP was developed to increase access by addressing challenges for parents and providers related to in-person delivery, including logistic barriers (eg, work demands, scheduling, childcare, and transportation), access to in-person groups, and potential for stigma [18,19].

Rochester Area Parenting Program

The Rochester Area Parenting Program (RAPP), a program initiative at the Children's Institute Inc in Rochester, New York, began implementing the group-based CPP in 2018. From March 2018 through March 2020, RAPP supported 35 CPP groups in collaboration with 6 partnering community programs across 14 sites (eg, churches, Head Start, childcare centers, and a large urban school district). During this time, 396 parents participated in CPP groups led by 23 CPP-trained group leaders. A key community engagement parent empowerment and leadership initiative of RAPP is to identify parents who completed CPP groups and subsequently support these parents in completing CPP training to become group leaders; thus, 25% of CPP-trained group leaders were parent graduates of CPP groups. At the onset of the COVID-19 pandemic shelter-in-place orders (ie, March 2020), RAPP suspended 3 in-person CPP groups and canceled 2 groups that were scheduled to start and began exploring options for alternative delivery methods of CPP to assure continued service provision and support for the families they serve. The RAPP coordinators engaged the CPP developers to determine options for delivery. During this time, many in-person CPP groups nationally moved to web-based delivery using videoconferencing platforms and adapted aspects of group delivery (eg, role-play, group activities, and discussion format). This option was presented to the RAPP leadership team, a group that provides strategic leadership and input on RAPP programming. The RAPP leadership team is a community collaboration with RAPP administrators and agency directors, staff, parent graduates of RAPP programming, trained facilitators, and faculty experts from partnering community agencies, schools, and universities. The RAPP leadership team reached consensus that 2-hour videoconferenced groups over 12 weeks would be challenging for the parents they serve due to logistics and competing demands on parents' time. In addition, the RAPP leadership team considered parent feedback from the group-based CPP indicating that parents highly valued peer and facilitator interaction and support. Therefore, RAPP worked closely with the CPP developers to develop a hybrid model of delivery where parents would complete *ez*Parent modules independently and participate in four 1-hour videoconferenced group sessions led by 1 CPP-trained facilitator.

The purpose of this paper is to describe the implementation outcomes of the hybrid delivery model of self-administered, web-based PT (ie, ezParent) and group sessions during community-based dissemination. Specifically, we seek to evaluate the implementation outcomes, using the RE-AIM (Reach, Efficacy, Adoption, Implementation, and Maintenance) model, of delivering the *ez*Parent program, and identify facilitators and barriers to implementation delivery to support the sustainability of program implementation.

RE-AIM Framework

The RE-AIM framework was designed to provide a model to enhance the quality, speed, and public health impact of efforts to translate research into practice using 5 dimensions: *reach* the intended target population; *efficacy* of the intervention and implementation strategies; *adoption* by trained facilitators and settings (agencies); *implementation*, including fidelity and consistency of delivery; and *maintenance* of intervention effects in individuals and implementation in settings over time [20,21]. In this evaluation, we will report on the reach, efficacy, adoption, and implementation components and present maintenance as part of the discussion.

Methods

Study Design

This single-group, mixed methods evaluation examined the implementation outcomes using RE-AIM of 24 hybrid *ez*Parent groups (n=240 parents) delivered by 13 CPP-trained facilitators in the northeastern United States. We report on survey and interview data from hybrid *ez*Parent delivery between September 1, 2020, and August 1, 2022.

Ethical Considerations

Exempt approval for this project was granted by the Ohio State University Institutional Review Board (number 2022E0128).

ezParent Hybrid Delivery

Although the change in delivery was reactive to the COVID-19 pandemic shutdown, the delivery modification was a thoughtful and engaged process occurring between April and August 2020. Modifications occurred as part of a collaborative effort between CPP and *ez*Parent developers, RAPP coordinators, and the RAPP leadership team to assure congruence with underlying CPP theory and content and RAPP family needs with the goal of maximizing intervention fit and implementation success. Refer to Textbox 1 for a description of key team members involved in the implementation of hybrid *ez*Parent. We describe the adaptation process in Table 1 using the last 4 of 8 categories of the Framework for Reporting Adaptations and Modifications–Expanded (FRAME) outline [22]. The FRAME provides a structure for reporting the delivery adaptation. The FRAME categories include what is changed or modified, at what level of delivery the modification is made, type or nature of context or content-level modifications, extent to which the modification is fidelity consistent, and the reasons for the modification (ie, the intent or goal of the change and contextual factors that influenced the decision). What did not change as part of the adaptation was the *ez*Parent program and core CPP skills and strategies, participation incentives provided for parents from RAPP, and groups facilitated by trained CPP group leaders.

The hybrid *ez*Parent program began with an introductory videoconferenced group session with the facilitator and parents. The purpose of this session was to introduce parents to the purpose of the *ez*Parent program and the groups sessions (eg, to review content parents were learning, review key strategies, and discuss parents’ successes and challenges in using the strategies) and to prepare them for the next session. The purpose of subsequent group sessions was to clarify the content, promote social connection and engagement, and help keep parents engaged in using *ez*Parent. At the introductory session, parents were instructed to complete module 1 and 2 over the next 2 weeks before the next group session. This schedule is repeated for modules 3 to 4 and 5 to 6, each followed by a group session (Figure 1).

Textbox 1. Key team members implementing hybrid ezParent.

Title and role in hybrid *ez*Parent implementation

- **Chicago Parent Program (CPP) and *ez*Parent developers**: authors of CPP and ezParent
- **Facilitators**: CPP-trained *ez*Parent group facilitators
- **Parents**: hybrid *ez*Parent participants
- **Rochester Area Parenting Program (RAPP) coordinators**: administrative support and coordination of Hybrid *ez*Parent
- **RAPP evaluator**: RAPP data manager and evaluator
- **RAPP leadership team**: community collaborative board providing leadership and input to RAPP programming
- **RAPP site**: community partner or organization providing *ez*Parent to families

Table 1. Description of parent program adaptations using FRAME[a].

Modification	Goal of modification	Who was involved in the decision and modification?	Level of delivery[b]	Nature and goal of modification
Contextual format (delivery modifications [eg, format, setting, personnel, and population])				
Videoconferenced group sessions	Intervention engagement and social connection	CPP[c] or *ez*Parent, developers, RAPP[d] coordinators, RAPP leadership, and team	Parent participants and facilitators	Parents complete the *ez*Parent independently and participate in 4 videoconferenced group sessions to promote *ez*Parent program completion and review of parenting strategies
Groups facilitated by 1 CPP-trained group leader	Feasibility and cost	RAPP coordinators, RAPP leadership, and team	Facilitators	Smaller groups and less administrative burden for the group leader than in-person groups
In-between group texts	Intervention engagement and social connection	CPP or *ez*Parent, developers, RAPP coordinators, and facilitators	Parent, participants, and facilitators	Text groups managed by the facilitators for weekly encouragement for program completion
Provided tablets and hotspots to parents	Reach, engagement, and equitable access to all program components	RAPP coordinators, RAPP leadership, and team	Parent and participants	Parents receive tablets and short-term internet access to access *ez*Parent and participate in videoconferenced groups
Training and evaluation (how staff are trained and how the intervention is evaluated)				
Facilitator training	Assure competency in *ez*Parent delivery and review virtual facilitator guide	CPP or *ez*Parent, developers, and RAPP coordinators	Facilitators	2-hour training to review *ez*Parent and the virtual session facilitator guide
Fidelity assessment	Evaluate facilitator adherence to group session protocol and parent engagement	CPP or *ez*Parent, developers, and RAPP coordinators	CPP or *ez*Parent developers, RAPP coordinators, and facilitators	Developed a facilitator self-report fidelity assessment tool (adaptation of CPP fidelity checklist [23] to evaluate adherence to the session components)
Implementation and scale up activities (strategies used to implement or spread the intervention)				
Administrative dashboard	Track *ez*Parent completion for stipend remittance to parents.	RAPP coordinators and CPP or *ez*Parent developers	RAPP coordinators, facilitators, CPP or *ez*Parent, and developers	A web-based administrative dashboard was created for RAPP coordinators and facilitators to track parent completion of ezParent modules
Tech support	Support program delivery	RAPP coordinators, CPP or *ez*Parent, and developers	RAPP coordinators, CPP or *ez*Parent, and developers	Tech support link provided to parents for support with *ez*Parent program

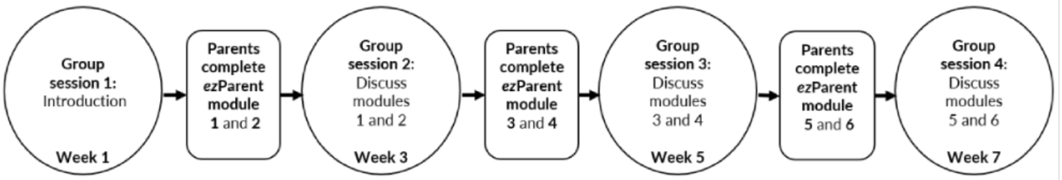
[a] FRAME: Framework for Reporting Adaptations and Modifications–Expanded.

[b] Level of delivery=for whom or what is the modification made.

[c] CPP: Chicago Parent Program.

[d] RAPP: Rochester Area Parenting Program.

Figure 1. Hybrid *ez*Parent schedule of delivery.



Setting and Sample

The RAPP partnered with 6 community organizations (hereafter referred to as RAPP sites). These sites included a large Head Start and Early Head Start program serving over 1000 families; a child care center serving families of children aged 0 to 5 years; a community organization providing childcare, free education and comprehensive services to support Latino/a families; a community organization with the goal of optimizing an nurturing and supportive environment to empower women; a child care network providing early care and education services, including universal PreK; and the Rochester City School District Early Childhood Education Department, serving over 2800 children (aged 3-4 years) and their families.

Parent Recruitment and Enrollment

The RAPP site managed parent recruitment to participate in the hybrid *ez*Parent and used successful recruitment techniques used for other programming for the parents they serve. Promotional flyers were provided by RAPP coordinators and emails were sent to parents to provide information about the *ez*Parent, provision of an android tablet, monetary incentives, and details on how to sign up. If there was in-person contact at the agency or school (eg, child drop-off or pickup), parents were provided with information regarding the program. All sites had a capacity of 10 parents per group. If more than 10 parents expressed interest, the sites kept a waiting list. In subsequent groups at the RAPP site, parents on the waitlist were invited first to participate.

Once the parents enrolled, they were invited to complete presurveys (refer to the Measures section) and received an android tablet computer that had been preloaded with the *ez*Parent program, zoom access, and internet access for the duration of program participation. Parents kept their android tablet at the end of the program for their personal use. Parents were instructed that all surveys throughout the course of the intervention were voluntary. A waiver of consent was obtained for these data as the parent data were anonymous and aggregated. In addition, parents were given instructions related to their first videoconferenced introductory group and paper copies of the curriculum handouts. Parents received US $20 for each group session and US $20 for completion of each module of *ez*Parent (ie, total possible US $200). These conditional cash incentives were provided using a debit card registered in the parents’ name. Conditional cash incentives have been shown to be an effective method for supporting engagement in programming [24,25]. The debit card was either sent to their address or hand delivered. Of note, using debit cards was selected by parents and the RAPP leadership team as the best and most effective way to compensate parents.

Measures

RE-AIM Components

Table 2 provides a description of the RE-AIM components and corresponding variable and measure and data source for the implementation evaluation [21]. Study results will be presented by RE-AIM component and include facilitators and barriers to implementation.

Table 2. Variables and measures aligned with the RE-AIM[a] component.

RE-AIM component and variable	Measure or data source
Reach	
Number of groups that could be supported by agencies and parent participation	Administrative data[b]
Reasons why parents choose to participate in the program	Presurvey
Characteristics of the parent	Presurvey
Parent program completion	*ez*Parent digital analytics and group attendance logs
Efficacy	
Change in parent behavior	End-of-program survey
Change in child behavior	End-of-program survey
Parents’ satisfaction with the program	End-of-program survey
Adoption	
Proportion of trained CPP[c] group leaders adopting *ez*Parent hybrid	Administrative data
Facilitators’ characteristics	CPP pretraining survey
Implementation	
Facilitators’ adherence to group session protocol	*ez*Parent fidelity checklists
Length of groups	*ez*Parent fidelity checklists and facilitator interviews
Facilitators’ perception of group delivery	Facilitator interviews
Implementation adaptations	Administrative data and facilitator interviews
Implementation technical issues	Administrative data

[a] RE-AIM: Reach, Efficacy, Adoption, Implementation, and Maintenance.

[b] Administrative data are information collected by RAPP coordinators as part of ongoing management of program implementation.

[c] CPP: Chicago Parent Program.

Presurvey

Parents completed the presurvey before the first group session. The presurvey includes general parent demographics (ie, race and ethnicity, parent education level, and relationship with child) and an 11-item list of reasons for participating in the parenting program [26]. Parents selected all that applied to the list of reasons for participating with *no, yes,* and *most important*. Sample items include “I would like the chance to talk with other parents with young children,” “I would like help disciplining my child,” “I’m always looking for ways to be a better parent,” “I would like extra money for participating in the program,” and “I am required/have been asked to take a parenting class.”

Parent Program Completion

Digital tracking of use of the *ez*Parent program provides a measure of module completion. At the end of each *ez*Parent module, parents are awarded a module completion badge. Module completion is determined by parent receipt of the module completion badge. Facilitators and RAPP coordinators can view module completion in the administrative dashboard (Table 1) in real time. Group attendance logs are completed by the facilitators and submitted to RAPP coordinators for attendance tracking.

End-of-Program Survey

Parents were invited to complete an end-of-program survey after the last group session (approximately 7 weeks after baseline). This survey is an adaptation of the CPP and *ez*Parent end-of-program surveys [23,27]. The survey included items related to parent perception of the usefulness of the program in managing child’s behavior (2 items), perceived program impact on participant as a parent (2 items), overall program satisfaction (2 items), and acceptability of intervention delivery format procedures (3 items). In addition, parents responded to 3 open-ended prompts: What would you tell other parents who are interested in joining *ez*Parent? What did you find the most helpful or useful about the *ez*Parent Program for changing child behavior? What did you find the least helpful or useful in the *ez*Parent Program for changing child behavior?

Characteristics of Facilitators

Facilitators participated in a 2-day CPP group leader training between 2018 and 2021. At the time of training, trainees completed a demographic survey that included their report of race, ethnicity, education, employment status, current position, and experience working with families of young children and leading groups with families. Either facilitators were paid a stipend or they facilitated the *ez*Parent groups as part of their work responsibilities.

Hybrid ezParent Fidelity Checklists

After each videoconferenced group session, facilitators were invited to assess their adherence to the session protocol using a 7-item (session dependent) measure adapted from the CPP fidelity checklist [28]. Facilitators were not required to complete fidelity forms as the RAPP leadership team were concerned about burden on facilitators. Facilitators indicated *yes* or *no,* depending on whether they performed the expected action during the group session. Examples of adherence items include review of group ground rules, review of module summary of important points, and discussion of the *ez*Parent module practice assignment. In addition, facilitators self-reported the length of time of the group (in minutes), rated parents level of engagement (eg, the overall groups interest and active involvement in the discussion) during the group session on a 3-point scale (ie, *high*, *mixed*, *and low*), and assessed the extent parents seemed to understand the program strategies (ie, *high*, *moderate*, *and low*). Finally, facilitators could provide additional comments or feedback as an open-ended response.

Administrative Data

As part of program implementation, the RAPP coordinators monitored the number of groups that could be supported by RAPP sites and parent participation. This was driven by funding constraints, and coordinators balanced program costs to increase the number of groups available to reach the maximum number of parents. Parents using the *ez*Parent program could report technical issues related to *ez*Parent through a link in the program or contact coordinators for other technical support needs. Data logs of technical issues were maintained by the coordinators. Finally, coordinators met with the facilitators on an as needed basis to meet specific training and implementation needs. Coordinators kept a log of any implementation adaptations reported during these meetings.

RAPP Facilitator Interviews

In spring 2022, 8 facilitators who were currently involved with RAPP and hybrid *ez*Parent delivery at the time of the evaluation were invited to participate in a brief (<30 minutes) postprogram interview. The goal of the interview was to assess facilitators opinions regarding the hybrid delivery methods (ie, implementation in RE-AIM framework), use of the discussion guide to support the conduct of the group session, and evaluate the strengths and weaknesses of the implementation model. An interview guide was developed (Multimedia Appendix 1) and interviews were conducted by 2 of the authors (RP and SMB) who were independent of the RAPP. Interviews were not recorded; detailed notes were taken during the interview. In total, 6 participants (response rate: 6/8, 75%) completed the informed consent process and the phone interview. Participants received a US $25 gift card as a thank you for their time and input.

Data Analysis

All statistical analyses were conducted using SPSS (version 29; IBM Corp) [29]. Descriptive statistics were used to describe the sample and the reach, adoption, and implementation components of the RE-AIM model.

A thematic analysis focused on identifying implementation outcomes aligned with the implementation component of the RE-AIM model. Specific implementation categories were identified a priori (ie, facilitator adherence to group session protocol, length of group sessions, and facilitator perception of group delivery and parent engagement). Two authors (RP and SMB) reviewed the data independently, then met to review quotes for consensus and alignment with the implementation variables. Data from the interviews were used in a convergent design [30] to corroborate and provide examples of the quantitative data.

Results

Reach

Number of Groups and Parent Motivation for Participation

From September 1, 2020, to August 1, 2022, a total of 24 hybrid *ez*Parent groups were conducted by 13 facilitators. The goal for each group was 10 parents per group and the average group size was 10 (SD 0.42). All enrolled parents (n=240) were invited but not required to complete the pre- and postsurveys. In total, 77.9% (187/240) of eligible parents responded to the presurvey and 61.3% (147/240) of the eligible parents responded to the postsurvey. Of the 187 parents responding to the presurvey, 180 (96.3%) endorsed at least 1 motivation for participating in the program. Parents could endorse multiple motivations as *most important*. As shown in Table 3, the top-rated items endorsed as a motivator by over 94% of the respondents included “I would like to learn better ways to communicate with my child,” “I’m always looking for ways to be a better parent,” and “I would like to learn better ways of managing my child’s behavior.” The top items not endorsed as *most important* included “I am required/have been asked to take a parenting class” and “Another parent recommended I take this program.”

Table 3. Reasons parents (n=180) endorsed motivating their participation in the program[a].

Motivation	Most important, n (%)	Yes, n (%)	No, n (%)
I’m always looking for ways to be a better parent[b].	101 (56.4)	73 (40.8)	5 (2.8)
I would like to learn better ways to communicate with my child.	91 (50.6)	85 (47.2)	4 (2.2)
I would like to learn better ways of managing my child’s behavior.	82 (45.6)	88 (48.9)	10 (5.6)
I would like the chance to talk with other parents with young children.	33 (18.3)	128 (71.1)	19 (10.6)
I would like help disciplining my child[b].	30 (16.8)	84 (46.9)	65 (36.3)
I was motivated by the recruiter to take this program[b].	18 (10.1)	88 (49.2)	73 (40.8)
I would like the extra money for using the new parenting skills with my child.	15 (8.3)	104 (57.8)	61 (33.9)
I would like the extra money for attending the parent group.	8 (4.4)	109 (60.6)	63 (35)
I am required/have been asked to take a parenting class.	6 (3.3)	12 (6.7)	162 (90)
My child’s teacher recommended that I participate in this program.	3 (1.7)	55 (30.6)	122 (67.8)
Another parent recommended I take this program[b].	3 (1.7)	43 (24.0)	133 (74.3)

[a] Parents could select multiple items as most important.

[b] One respondent picked multiple conflicting responses (eg, “no” and “most important”); therefore, these were not included in the summary.

Parent Characteristics

Of the 187 parents responding to the presurvey, 112 (59.9%) identified as Black or African American, 46 (24.6%) as White, and 42 (22.5%) identified as Hispanic. Of the 103 parents who reported their relationship with their child, 90 (87.4%) were mothers, 8 (7.8%) were fathers or stepfathers, and 5 (4.9%) were foster parents or grandmothers. Finally, parents (n=180) reported their highest level of education being less than high school (n=16, 8.9%), high school (n=59, 32.8%), some college (no degree; n=46, 25.6%), associate degree (n=29, 16.1%), bachelor’s degree (n=15, 8.3%), and graduate degree (n=15, 8.3%).

Parent Program Completion

On average, parents (n=240) completed 4.58 (SD 2.43) of the 6 *ez*Parent modules and 72.1% (173/240) of the parents completed all 6 modules. A total of 47 (19.6%) parents did not complete a single module. Average group attendance across all participants (N=240) was 71.2% across the 4 sessions. Of those who attended at least 1 group session (219/240, 91.3%), average attendance was 77.7% across the 4 sessions.

Parent Satisfaction and Parent and Child Behavior

Parents reported high levels of satisfaction with the program and improvements in their feelings of self-efficacy and their child’s behavior following their participation in *ez*Parent hybrid. Specifically, 81.5% (110/135) reported that the concerns they had about their child’s behavior were *better* or *much better* and 82.6% (109/132) felt their child’s behavior was *better* or *much better* following their participation in hybrid *ez*Parent. Before participating in hybrid *ez*Parent, 42.5% (57/134) of the parents indicated that they were *not at all* (n=13) or *a little* (n=44) confident about managing their child’s behavior and 57.5% (77/134) reported feeling *confident* (n=45) or *very confident* (n=32) managing their child’s behavior. After participating in hybrid *ez*Parent, 92% (126/137) of these same parents reported they were *confident* (51/137, 37.2%) or *very confident* (75/137, 54.7%) about managing their child’s behavior, while 8% (11/137) remained *not at all* or *a little* confident about managing their child’s behavior.

Parent Satisfaction

Parents (n=137) responded to a program satisfaction question and 89% reported they were very satisfied (n=90, 65.7%) or satisfied (n=32, 23.4%) and 10.9% (n=15) of parents reported they were either dissatisfied (n=10, 7%) or very dissatisfied (n=6, 4%) with the program. When asked if they would recommend hybrid *ez*Parent to another parent, responding parents (n=117) reported they would highly recommend (n=94, 80.3%) or recommend (n=21, 17.9%) the program.

Most parents (104/117, 88.9%) said it was not at all hard to use the *ez*Parent program and 83.7% (98/117) felt the time spent using the program was "just right." Similarly, 88% (103/117) of the parents found the *ez*Parent program very helpful and 91.2% (107/117) found completing the module practice assignments was "not at all hard." Although these group sessions were conducted remotely, 71.8% (84/117) of the parents indicated their intention to remain in contact with other members of their group.

Adoption

Of the 23 facilitators who conducted in-person CPP groups sessions, 11 (48%) facilitated *ez*Parent group sessions. Two additional trained facilitators ran *ez*Parent sessions who had not previously conducted in-person groups. Overall, this was a diverse group of facilitators with 69% (9/13) identifying as Black, 17% (2/12) identifying as White, and 17% (2/12) identifying as American Indian (individuals could select all that apply). In addition, 17% (2/12) of the facilitators identified as Hispanic ethnicity. Of the 13 *ez*Parent facilitators, 2 (15%) reported having a high school degree, 5 (39%) having an associate degree or some college, with the remaining of the sample having a bachelor's degree (n=2, 15%) or a graduate degree (n=4, 31%). Facilitator (N=13) experience at the time of training varied with greater experience working with individual families (*a lot*: n=6, 46%; *quite a bit/some*: n=7, 54%) and less experience leading groups of families *a lot*; n=2, 15%; *quite a bit/some*; n=10, 77%; *a little*; n=1, 8%).

Implementation

In total, 38% (n=5) of the 13 facilitators completed end of session adherence self-reports, representing 31 of the 96 group sessions (32.3%). In addition, 6 of the 8 current facilitators participated in the facilitator interviews. Refer to Table 4 for facilitator quantitative and qualitative themes for implementation from adherence self-reports and facilitator interviews. Overall, facilitators found the hybrid delivery easy to implement and reported high parent engagement and understanding of CPP strategies. Implementation technical issues were infrequent and related to issues with the parent tablet which were administratively resolved. Only 1 technical issue was reported for the *ez*Parent program and was related to logging in. RAPP coordinators experienced technical issues related to the *ez*Parent administrative dashboard that was developed for this project. Because of these technical issues, *ez*Parent prepared monthly parent use reports for the RAPP coordinators to assure accurate use data for parent incentives.

Times of the group meetings were determined based on parent polls, most groups occurred on weekday evenings (ie, Monday through Thursday) between 5 PM and 7 PM, 1 group was held at lunch time (ie, noon to 1 PM) and 1 group was held on a Friday evening from 6 PM to 7 PM. No parents indicated wanting a weekend meeting time. Facilitators reported several adaptations to address challenges to hybrid delivery.

Three main challenges were identified by facilitators, including completing a group session in 1 hour, fostering parent engagement in the program, and building connection in the virtual environment. As 1 facilitator noted, "for in-person groups we had more bonding time, it was hard to build relationships virtually." To address these challenges, several facilitators would stay on the videoconference an extra 30 minutes to provide time for the parents to continue sharing. A facilitator reported, "I would say I'm here to stay on and many would stay on to discuss, talk it out, vent, I let them. They need that. In person they would have the time they needed." In addition, facilitators created text groups and provided text reminders for group sessions and to engage parents in completing the practice assignment with their children. As 1 facilitator noted "one thing I liked was the text messaging—once I started doing that—parents would thank me for reminding them—they liked that."

Although the facilitators felt positive about the group session delivery, they reported needing to tailor facilitation methods for videoconferenced groups. This included creating strategies to keep parents' attention and promoting group sharing, as one facilitator noted, "I had to get creative to keep everyone's attention." Strategies included, asking parents to keep videos on, calling parents by name, and responding to nonverbal behaviors. One facilitator reported "For the last session I did a round robin and asked each parent what their take was away from completing the modules. I also asked if they were practicing. Each parent shared what really stood out for them and what helped them the most."

Despite the challenges, facilitators found the hybrid delivery convenient for them and for parents. Facilitators reported that the hybrid delivery was logistically easier for them compared with in-person groups. In addition, although many reported that there was some loss in group connection compared with in-person groups, facilitators agreed that the convenience and ability for parents to participate in the "comfort of their own homes" might outweigh the challenges. Additional benefits of delivering the hybrid program included managing childcare (for both parents and facilitators), not having to spend time in gathering food and beverages for in-person group meetings, and not needing to spend time driving to and from the group. In addition, facilitators reported that parents were highly engaged and would readily report what they were learning from the program and changing in their own lives and the group session helped parents learn from each other's experiences.

Table 4. Implementation outcomes.

Implementation variable	Quantitative (RAPP[a] facilitator self-report; n=31 group sessions)	Qualitative (RAPP facilitator interviews; n=6)[b]

Facilitator adherence to group sessions	• 92% facilitator adherence to the group protocols[b]
	• 57% (17/30) *agree*[c] *or strongly agree* that the guide was helpful in running group sessions
		• Facilitators reported high consistency in delivery and the group session guide was helpful.
		  • "Every time I start a new class—go back to the group book—and I get how to facilitate the session"
		  • "Followed the facilitator guide closely; it was really helpful"
		  • "Used the script as a guide—but not so stringent. Always feel like room for flexibility..."

Length of groups	• Mean 60.5 (SD 14.7; range 34-90) minute
	• 73% (22/30) reported *about the right amount of time* and 27% (8/30) reported *not enough time for group discussion*.
		• Facilitators reported parents wanted to talk more and sessions often would run over time.
		  • "...a little more time is always needed. One hour is not enough time to cover and allow everyone to be able to express what they are feeling, experiencing and get the feedback needed to help motivate and encourage."
		  • "I felt like I am rushing the parents through the conversations"
		  • "One and half hour would be ideal. There were plenty of times that conversation could continue"
		  • "I think if we stay virtual, not a bad thing—need to add more time or do weekly"

Facilitator perception of group delivery and parent engagement	• Parent engagement was *high* (23/31, 74%) and *mixed* (8/31, 26%).
	• Parent understanding of program strategies was *high* (18/22, 82%) and *moderate* (4/22, 18%).
	• Affective tone of the group was *positive* (30/31, 97%) and *neutral* (1/31, 3%).
		• Parents came to the groups consistently and web-based delivery was convenient for them.
		  • "Felt like got better attendance in virtual than in person"
		  • "I think it is a very safe method—families feel comfortable"
		  • "Parents in the group reviewed everything so they would know what was coming"
		• Parents were overall engaged but often multitasked during the sessions.
		  • "I could tell they were engaged because of the conversation—it would be consistent"
		  • "Would often see parents nodding, paying attention, a matter of everyone joining in and they would share"
		  • "See them cooking dinner, feeding children"
		  • "They have the kids in and out—trying to do the session and getting interrupted"
		• The group discussions reflected grasp of material learned from the ezParent module and parents discussed putting the parent strategies learned in the modules into practice in their household.
		  • "Several parents would say we tried this, most of them had an example of what worked"
		  • "One father even shared that he now dances with his son—something that he never did before."
		  • "There was one parent who said that all of them helped her because she is learning how to take care of herself so that she can take better care of her children."
		  • "One parent told the group that the child now has a schedule that she even follows on the weekend."
		  • "I was skeptical, but the program does work."

[a] RAPP: Rochester Area Parenting Program.

[b] Adherence frequency is based on a sum the adherence items (session-dependent) across the 31 fidelity reports received from the group leaders.

[c] Italicized words represent survey response choices.

Discussion

Principal Findings

The purpose of this paper was to describe the implementation outcomes of the hybrid delivery model of *ez*Parent during community-based dissemination in response to the COVID-19 pandemic lockdown causing in-person intervention to be unavailable. Using the RE-AIM framework, we found that the *ez*Parent program was successful in reaching a diverse sample from the city of Rochester, New York, resulting in high levels of parent satisfaction and improvements in confidence in managing their child's behaviors. Our findings for parent satisfaction are consistent with prior research investigating general parent satisfaction with *ez*Parent [31]. The improvements in parental confidence in managing their child's behaviors within hybrid *ez*Parent is consistent with prior research conducted with CPP [13].

Overall, the trained facilitators easily adopted the new delivery format and implemented the sessions with minimal difficulties. As the aim of launching hybrid *ez*Parent was not to conduct research but support the community during the COVID-19 pandemic, we were unable to determine potential sustainability (ie, *M*aintenance) as proposed by the RE-AIM framework. While we were able to demonstrate success within the implementation of *ez*Parent, it is imperative to identify facilitators and barriers to implementation delivery to support the sustainability of the implementation of the program using the hybrid delivery model.

Facilitators and Barriers to Implementation

Factors that eased *ez*Parent implementation included the support and strength of the RAPP leadership team relating to decisive actions in implementing the new modality, the use of community-based facilitators who were familiar with the community which was represented in the group and in CPP delivery, flexibility of timing of the group sessions including the length of the meeting (60-90 minutes), parental preference in day and time of meetings, and ability to participate from anywhere. Group day and times were parent driven, not chosen by the facilitator or the community partner. One facilitator polled parents for the best time to meet and was overwhelmed and challenged by the variety of responses. We recommend community organizations provide parents with a few meeting times to lessen variability while providing an opportunity for parents to choose. Most groups were held between 5 PM and 7 PM on weekday evenings as parents identified this as the best timeframe. However, there were competing priorities during synchronous group sessions, including childcare or preparing dinner that may affect parent engagement. However, many parents were able to creatively address these competing priorities. For example, some parents arranged their meal break at work for the group session. We believe this flexibility contributed to the proportion of parents who attended at least one session (91.3%) and of those who engaged in all 4 group sessions (77.7%). Attendance in this sample was slightly below parent attendance rates recently reported for videoconferenced delivery of 12-session CPP (82.3% of the enrolled parents attended at least 1 group session) [32]. We calculated our engagement metrics (ezParent use and group attendance) for all parents who enrolled in the program regardless of attending group to assess program adoption.

In addition to providing access and flexibility for parent engagement, the RAPP facilitators enjoyed the flexibility in the internet-based groups and conserving efforts and resources to manage in-person meetings. However, increased flexibility seemed to come with a loss of the reported social connection that came with in-person groups. Therefore, facilitators used other tools, such as group text messaging to stay in contact with parents between group sessions and to help build and maintain a sense of community. Social connection and building community are vital components to successful group interventions and the pandemic gave rise to challenges in maintaining social connectedness. The facilitators' use of digital tools to create, maintain, and enhance a sense of community within their groups were found to be useful ways to engage parents and create community. These results are consistent with Plesko et al [32], highlighting the challenges with moving from in-person CPP to web-based group meetings.

We recommend using a variety of communication means to engage parents in-between sessions to support completion of the *ez*Parent module, support parent enactment and practice of parenting skills, and to remind parents of the next scheduled group sessions. Although not included in our hybrid delivery model, we suggest including a booster session 6 to 8 weeks after the last live session to determine if parents have any questions or barriers to practicing and implementing new behaviors to support their children. This will also aid in obtaining data for the Maintenance component of the RE-AIM framework.

Limitations and Strengths of the Project

Evaluation Metrics

When developing the hybrid delivery model, priorities were focused on the community needs during the height of a global pandemic and not on the project's evaluation. Upon analysis of the outcomes, we determined that our measures were not set up in a way that supported investigating parent changes over time or evaluating baseline data relationship with program engagement. For example, using unique identifiers for the baseline and follow-up questionnaires is planned for RAPP delivery of hybrid *ez*Parent starting August 2024. In our evaluation, the lack of paired surveys allowed only for independent and unrelated group analyses; however, in conducting the evaluation, we were able to identify this need highlighting the importance of academic and community-based organization relationships. The strengths that each partner brings to hybrid *ez*Parent will allow for continued support in reaching the most underserved populations in the Rochester area and an opportunity for more formal and robust outcome evaluations in the future. An additional strength includes the inclusion of facilitator interviews to examine perceptions of implementation outcomes. This provides a first-hand account of the benefits and drawbacks of the videoconferenced group sessions and examples of problem-solving that facilitators implemented to best support parents' needs.

Parental Motivation in Participating

Parent motivation is an important factor in PT delivery; thus, a question was asked about the parent's motivation in participating in hybrid *ez*Parent. However, respondents could select all that apply for motivational reasoning, and we could not determine each parent's primary motivation to participate. Given the nature of the responses, it was difficult to determine the most salient reason for participating; however, our results showing parents endorsing, "I'm always looking for ways to be a better parent" as a motivator is consistent with prior research [25]. In addition, most selected items for motivation related to strengthening parenting skills and supporting their child. For evaluation purposes, we recommend implementing a primary motivation question and then a way to assess other motivations to see if results differ by motivation factor.

Although approximately 8% (15/180) of the parents identified the financial incentive as a *most important* motivator for participating, 57.8% (104/180) to 60.6% (109/180) endorsed incentives as *a* motivator to attend sessions and complete practice. This finding is consistent with previous work related to incentive-based attendance as motivators for behavioral change interventions [24,25]. In a previous study of CPP and financial incentives, 71% of parents identified receiving extra money as a motivator and this was a predictor of program attendance [25]. In this study, the *ez*Parent dissemination was part of a community-led initiative through RAPP and funded through these programs, representing a sustainable method for maintaining implementation and supporting program engagement. Although providing financial incentives and a tablet for program access increases the overall cost of program delivery, these barrier reduction strategies may be important to support program access and parent engagement.

Lessons Learned

While reflecting on the implementation and evaluation of hybrid *ez*Parent, there are several lessons learned for future community-based dissemination. During year 1 of implementation, parents were sent a web-based link for the presurvey and anecdotal comments, which indicated that this was seen as impersonal and not particularly relevant for parents to complete. In year 2, we changed this to a paper survey being administered at the time of disbursement of the tablet. This change resulted in a more robust completion of the presurvey by parents. In addition, parents were not incentivized to complete the presurvey and postsurvey; therefore, we suggest that parent participants receive an incentive to complete surveys. This may improve response rates and allow for more rigorous evaluation of the program outcomes.

An *ez*Parent administrative dashboard was developed for this project; however, RAPP coordinators reported multiple technical issues. On the basis of these concerns, revisions have been made to the dashboard and we anticipate more autonomy for RAPP coordinators to process desired reports accurately and efficiently. In addition, further refinements of the *ez*Parent dashboard have been implemented based on these findings and others [33] to assure relevance to community organizations implementing *ez*Parent. For example, the ezParent dashboard now allows lists of users to be created based on cohort as well as the main page having a summary of users. If the user needs more detailed information on a participant, they can easily access the information from the main page.

Our results indicate that using the hybrid *ez*Parent is a feasible and effective way to engage parents. We also found that facilitators and parents enjoyed the flexibility that a web-based group session provides. Future research should comprise of more rigorous evaluation processes so that changes in the outcomes of hybrid *ez*Parent participants can be explored more precisely. In addition, more research needs to be conducted on the processes surrounding implementation of the *ez*Parent program and its dissemination.

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Conflicts of Interest

Under an agreement between Rush University and author DG, author DG is entitled to remuneration from sales of the Chicago Parent Program, which was described in the study discussed in this publication. This arrangement has been reviewed and approved by the Johns Hopkins University in accordance with its conflict-of-interest policies. All other authors declare no other conflicts of interest.

Multimedia Appendix 1
Interview script.
[DOCX File , 16 KB - pediatrics_v7i1e55280_app1.docx]

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Abbreviations

CPP: Chicago Parent Program
FRAME: Framework for Reporting Adaptations and Modifications–Extended
PT: parent training
RAPP: Rochester Area Parenting Program
RE-AIM: Reach, Efficacy, Adoption, Implementation, and Maintenance

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Original Paper

Indigenous Parents’ Perspectives of Factors That Facilitate or Impede Engagement in Internet-Based Parenting Support Programs: Interpretive Description Study

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Abstract

Background: Parenting support programs enhance parents’ health and their child’s development. The COVID-19 pandemic necessitated the delivery of these programs over the internet. After the pandemic, internet-based programs are still preferred by some.

Objective: We aimed to understand Indigenous parents’ experiences engaging in internet-based parenting support programs; thus, an interpretive description study was conducted.

Methods: A total of 20 Indigenous (female, male, and Two-Spirit) parents of children aged <5 years participated in semistructured interviews; data underwent collaborative thematic analysis with Indigenous community partners informed by the Two-Eyed Seeing framework and ethical space.

Results: Parents’ experiences were classified into five themes: (1) Purpose: Program Delivery and Content, (2) Belonging: Building Relationships and Connections, (3) Hope: Cultural Connection, (4) Meaning: New or Improved Parenting Skills and Mental Wellness, and (5) Recommendations for Organizations.

Conclusions: The study findings can inform internet-based parenting program delivery to enhance engagement for Indigenous families.

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KEYWORDS

child; parenting; qualitative; Indigenous health; support programs

Introduction

Background

Parenting programs provide critical support to individuals parenting a child. Research indicates that these programs have numerous positive outcomes for parent and child health and wellness, such as improved parent mental health and positive child development outcomes [1,2]. Parenting programs are especially important for parents of young children (aged <5 years) as this stage in life is a critical time for learning and child development [3]. Early childhood experiences impact brain development, and healthy relationships with adults are pivotal to that development [3]. Problems or delays not addressed in early childhood could potentially have long-term implications for health and wellness [4].

Parenting programs typically target specific populations, such as parents of children aged <5 years, parents of children with unique needs (eg, autism spectrum disorder), or parents belonging to groups or communities who are marginalized by mainstream society. Indigenous-specific parenting programs incorporate cultural teachings and traditions, including the presence of elders, ceremonies, and crafts [5]. These programs are congruent with Indigenous parenting approaches that draw from traditional roles and a community-oriented approach with family kinship models and nonnuclear families and are distinct from Western parenting approaches [6].

Parenting programs in Ontario, Canada, include the generic and Indigenous-specific Healthy Babies Healthy Children, Head Start, and EarlyON programs, which offer education and activities by licensed early childhood educators to promote healthy parenting and early childhood development [7-10]. Aboriginal Health Centres and Indigenous-led community centers such as the Indigenous Friendship Centres in Ontario also offer a wide array of programs and services, including parenting programs with a culturally grounded approach [11,12]. Indigenous parents can choose to access any of these programs according to their needs and availability.

Parenting programs can be offered in various formats: in person; internet based (self-guided); or facilitated and supported by a service provider over the internet, which may include early childhood educators or those otherwise trained to provide parent and child programs. During the peak of the COVID-19 pandemic, many parenting programs were exclusively offered over the internet and have continued with that mode of delivery. The efficacy of internet-based parenting programs on child and parent health has been previously well documented in the literature [1,2,13]. A meta-analysis of the effectiveness of internet-based parenting programs, for example, found that the programs increase positive parenting, parent confidence, parent satisfaction, and positive child behaviors and were effective in reducing negative parent-child interactions, parent stress, child behavior problems, and child anxiety [1].

Despite the benefits of parenting programs, parent attendance and engagement are not consistent across all parenting programs. The opportunity to meet other parents and exchange ideas, the ability to learn new skills, and trust in the person delivering the program [14] facilitate engagement in parenting programs. However, barriers such as limited resources; feeling judged or discriminated against; inadequate program funding; programs that are not culturally relevant; and program-specific factors such as delivery, content, and support impact attendance and participation in these programs for some families [15,16]. Typically, attendance and engagement by parents who need the services the most is low [15].

In view of the positive impacts of parenting programs on the parent and child, parental attendance and engagement in programs is important. With an increase in internet-based parenting programs since the COVID-19 pandemic, an understanding of how to effectively engage parents in parenting programs over the internet is needed. This need was also identified by the Hamilton Regional Indian Centre (HRIC), a nonprofit organization sitting on the traditional territories of the Haudenosaunee and Mississauga Nations that provides culturally relevant Indigenous programs and services, including programs aimed at supporting urban-residing Indigenous parents of young children and their families. These programs address topics such as prenatal guidance, parent-infant bonding, building communication skills, emotional regulation, and nutritional education, to name a few. Service providers follow a curriculum provided by the HRIC and adjust content to meet their clients' needs, including integrating teachings that align with the specific cultures of the program's attendees. During the COVID-19 pandemic, parenting programs at the HRIC switched from in-person to internet-based delivery, facilitated and supported by service providers in real time with varying success. Service providers at the HRIC have shared their challenges with internet-based program delivery, including initiating and maintaining parental engagement.

Given the importance of Indigenous parents receiving culturally relevant parenting support, especially for parents of young children, it is important to members of leadership and staff at the HRIC to understand the experiences of Indigenous parents who attend internet-based parenting programs—what is helpful for their engagement and what poses challenges. However, no studies were located that explored the experiences of Indigenous parents engaging in parenting programs over the internet. Thus, examining the perspectives of parents who have attended internet-based programs in a study will help identify the barriers to and facilitators of engagement in internet-based parenting programs, contribute to the existing gap in the literature concerning the experiences of Indigenous parents, and provide the HRIC with information to optimize delivery and improve parental engagement in their internet-based parenting programs.

The Indigenous Wellness Framework as an Organizing Structure

Fostering the wellness of parents is a key objective of Indigenous parenting support programs; thus, the Indigenous Wellness Framework [17] was selected for structuring this study and organizing the study findings described in this paper as it reflects the HRIC's holistic understanding of health and wellness. The Indigenous Wellness Framework was developed through a partnership between the Assembly of First Nations and the First Nations and Inuit Health Branch of Health Canada, along with Indigenous mental health leaders, as a shared vision for mental wellness and services for First Nations [17]. The framework was designed to strengthen mental wellness programs and support but has also been used to provide guidance for communities who wish to adapt or optimize their mental wellness programs and services to address their own priorities. At the core of the Indigenous Wellness Framework are 4 *directions* or main wellness outcomes: *purpose*, *belonging*, *hope*, and *meaning*. Within the framework, *purpose* is described as the sense of purpose that people gain through their education, employment, caregiving activities, or cultural ways of being and doing. *Belonging* is the sense of connectedness with their families, community, and culture. *Hope* is described as hope for the future and that of their families, grounded in a "sense of identity, unique values and a belief in spirit" [17]. Finally, *meaning* is an understanding of how their lives and that of their families is part of Creation and a rich history.

Study Purpose and Research Questions

The purpose of this study was to understand Indigenous parents' experiences engaging in internet-based parenting support programs. Specifically, the research questions were as follows: (1) What do parents identify as factors that facilitate or impede engagement in internet-based parenting support programs? and (2) What strategies do parents recommend for enhancing the experience of engaging in internet-based parenting programs?

For this study, internet-based parenting support programs were defined as programs that provide parents with information or support for their role as parents. These internet-based programs had to be offered via a platform whereby content was delivered and supported by an individual from an organization in real time. As the HRIC provides programs and services to clients representing many First Nations, Inuit, and Métis communities and cultures, the term *Indigenous* in this paper is used to refer to parents or parenting programs that reflect more than one cultural group.

Methods

Steering Committee and Positionality of the Researchers

A steering committee was established to oversee the development of the research plan and conduct of the research in collaboration with the HRIC. The steering committee comprised authors VM, BJ, MLB, and ALW; members VM and BJ from the HRIC led the committee. All steering committee members had previously collaborated on research, most notably members VM, BJ, and ALW, who have a long-standing relationship of >10 years working collaboratively on research projects aimed at understanding the needs of Indigenous parents to better service the community though programs. In addition to the steering committee oversight, research and administrative support for the study was provided by authors YJW and EMF.

When conducting research with Indigenous Peoples, a relational and community-led approach to research is ethically imperative and morally necessary [18,19]. As such, it is important that we situate ourselves by providing the positionality of the research team. First, the first author, MLB, is a non-Indigenous nurse researcher with clinical expertise in neonatal nursing and healthy parenting and a parent of 2 children. She has worked alongside the HRIC on projects for 4 years. YJW is a Mi'kmaw and settler woman from the Acadia First Nation, Squlj Clan, living and working in the S pekne'katik district within the traditional territory of Mi'kma'ki of what is now known as Nova Scotia, Canada. She has an academic background in public health and strives to uplift the voices of Indigenous Peoples in her work. VM and BJ are First Nations from Six Nations of the Grand River in Ontario, Canada. VM is of the Cayuga Nation, Turtle Clan, and BJ is from the Mohawk Nation, Bear Clan, and a Knowledge Holder. Both act as managers at the HRIC overseeing portfolios consisting of cultural safety training for local non-Indigenous organizations, programming and staffing at the HRIC, and child protection advocacy. They are both mothers and have close relationships with clients at the HRIC. EMF is a non-Indigenous nurse and mother of 3. Finally, ALW is a non-Indigenous nurse researcher and clinician with European settler ancestry and lives with her husband and children in the traditional territories of the Haudenosaunee and Mississauga First Nations in Southern Ontario, Canada. She strives to use her unearned privilege as a White scholar and academic to support the research needs of the Indigenous communities and organizations with whom she collaborates in a community-led approach to research. Together, the team worked collaboratively, deferring to those with Indigenous lived experience and integrating the perspectives of other staff members and parents at the HRIC throughout the project.

Guiding Principles for the Research

The Two-Eyed Seeing framework [20] and the principles of the ethical space of engagement [21] guided the research. First, the Two-Eyed Seeing framework guided the steering committee in valuing seeing the world with one eye grounded in an Indigenous worldview and the other eye with a Western worldview [20]. In particular, the Two-Eyed Seeing framework guided our collaborative approach to the study. The focus of this research was identified through cooperative dialogue with service providers from the HRIC and Indigenous parents in Hamilton, Ontario, to discuss community strengths and challenges related to the availability and delivery of parenting programs. This study, including the development of the research questions and data collection procedures, was designed in collaboration with First Nations staff from the HRIC to ensure that they were culturally appropriate and safe. The steering committee oversaw the project, including assisting with recruitment, data analysis, and conceptualization of modalities of knowledge dissemination outputs that best suit the needs of the community.

Second, the principles of the ethical space offered guidance on cooperative dialogue and engagement between 2 diverse groups with differing worldviews—First Nations community members, including a Knowledge Holder (BJ), and non-Indigenous researchers originating from and trained within a Westernized worldview [21]. The ethical space was a safe space for engagement for both groups, with a valuing of the concept of equality and a recognition and respect for the diversity created by philosophical and cultural differences [21]. Throughout this collaboration, the research team deferred to First Nations partners and their understandings of the local context, cultures, traditions, and protocols. Their understanding was especially important during analysis as this informed the findings.

Research Design

Interpretive description methodology was selected to address the study aims to understand what facilitated and impeded parents' ability to engage in parenting programs that were offered in an internet-based format and what strategies parents identified to improve parental engagement in internet-based parenting programs [22]. Interpretive description is a qualitative research approach that transcends the description of a phenomenon [22]. The approach not only allows for an understanding of the characteristics, themes, and patterns within subjective perceptions of a phenomenon but provides an interpretive account that can guide and inform practice [22]. Interpretive description emphasizes the integration of expert knowledge, including the perspectives of those participants who have lived experience of the phenomenon. As such, our use of this methodology facilitated the cocreation of knowledge with HRIC service providers, who have a deep understanding of the contextual forces impacting parents' experiences of internet-based programs. Along with parents' experiences, this collective understanding can inform change at the program delivery level, promoting more effective and engaging internet-based program delivery for Indigenous parents and young children.

Setting and Sample

A purposive sample of 20 parents who had used an internet-based parenting support program was recruited. Parents met the following inclusion criteria: (1) self-identification as Indigenous or being members of a family who self-identified as Indigenous, (2) engagement in an internet-based offering of a program related to parenting in southern Ontario, and (3) having been expecting or parenting a child aged <5 years when they participated in the parenting program. Parents who had only engaged with in-person parenting programs were excluded.

Purposeful, maximum variation sampling allowed for the selection of a diverse group of parents [23] who had used internet-based parenting programs. Specifically, we sought parents of varying ages, support (partner involved or not), socioeconomic statuses, previous parenting experiences, previous use (or not) of in-person, non–internet-based parenting programs, and experiences of parenting a child with or without health or developmental challenges. To complement the purposive sampling, snowball sampling was also used to increase the sample size and offer access to potential participants that otherwise may not have been reached. A sample size of 15 to 20 was considered a reasonable target to capture the diversity of parents who attended the programs. The sample size was ultimately determined when information power and conceptual redundancy were achieved [24].

Recruitment

Parents were recruited using two primary methods: (1) via parenting program staff at the HRIC and (2) through social media. A research flyer identifying the study purpose, eligibility criteria, and contact information for the research coordinator was distributed by HRIC staff via email to their program attendees, or printed copies were physically shared with parents attending parenting programs, as well as posting it on the information board at the center. The flyer was also made available on social media platforms, including one research team member's professional Twitter (subsequently rebranded X) account and on HRIC social media platforms. Participants were encouraged to share the flyer with other parents they knew had experience participating in internet-based parenting programs.

Data Collection

Parents providing informed consent participated in individual, in-depth, one-on-one semistructured interviews via Zoom (Zoom Video Communications) or telephone at a mutually agreeable time. Author YJW, a research team member with experience in qualitative study interviewing, conducted the interviews. Before commencement of the interview, YJW first prioritized establishing rapport with the participant, taking a relational approach to research and as a way to facilitate reciprocity through promoting a positive experience for the participant [18,19]. YJW then reviewed the consent form and reminded the study participant that they may choose not to answer some or all the questions. A semistructured interview guide was used to elicit parents' perspectives on their engagement in internet-based parenting programs. The interview guide was developed based on the study purpose and literature on internet-based parenting support. The interview guide was pilot-tested with 2 First Nations community members and modified accordingly to make certain that the questions adequately explored the topic of focus and were clear and culturally appropriate. The interviewer also verbally administered a short demographic questionnaire at the beginning of the interview. The demographic questionnaire included questions such as the age of the parent, self-identified gender, educational level completed, number of children they were parenting at home, relationship with a partner, number of people living in the home, and cultural background. Each interview was 30 to 80 minutes in length depending on how expressive the participant was and was video or audio recorded.

Data Management

All digital recordings of the participant interviews were transcribed using an automated transcription service. Transcripts were reviewed by a research assistant for accuracy, and identifying information such as names or places was removed. The NVivo software (version 12.0; QSR International) [25], a computer-assisted qualitative data management program, was used to organize, analyze, and store the data during analysis.

Data Analysis

In keeping with the interpretive description research design, data collection and analysis occurred concurrently in an iterative process [26]. Data collection continued until conceptual redundancy and information power occurred [24]. Inductive thematic data analysis was used guided by the Two-Eyed Seeing framework [20]. Coding strategies as described by Saldana [27] were used to conduct several iterations of coding until final themes were identified. The themes were the patterns of meaning identified and derived from the data. Demographic data from the semi-structured interviews were entered into SPSS (version 26; IBM Corp) and summarized using descriptive statistics.

Using a Two-Eyed Seeing approach, data analysis was a collaborative process with all members of the steering committee, and authors VM and BJ guided the analysis to ensure that local Indigenous ways of knowing and service providers' expertise were incorporated and accounted for in the results. Non-Indigenous researchers deferred to Indigenous ways of knowing throughout the analysis.

Rigor

Strategies were used in the research to promote the rigor or trustworthiness of the study findings, including approaches to promote credibility, transferability, dependability, and confirmability [28]. Credibility or the truth value of the study findings was promoted through investigator triangulation, whereby more than one member of the research team conducted the data analysis and the findings were validated with the entire steering committee to confirm the interpretation of the findings. Transferability was promoted through documentation of a thick description of the research context and study participants. Strategies to enhance dependability included memos to describe the process of analyzing and interpreting the data as part of an audit trail. Reflexivity (journaling) of the team members helped enhance the confirmability of the data collection and interpretation of the study findings [28].

Ethical Considerations

Research ethics approval was obtained from the University of Toronto Research Ethics Board (#43372), and the study was reviewed by the Hamilton Integrated Research Ethics Board (#15047). Researchers adhered to the principles of the Tri-Council Policy Statement 2 [29] and the 4 Rs of research (respect, relevance, reciprocity, and responsibility) [18]. All eligible participants were informed of their right to end the interview at any time or refuse to answer any question they were uncomfortable answering. All participants gave written and oral consent to the research coordinator or interviewer before beginning the interview. Throughout the study, measures were instituted to maintain the confidentiality of the data and the privacy of the study participants. Participants were assigned a code number, and several privacy and safety features of Zoom were enabled during internet-based interviews. The First Nations principles of ownership, control, access, and possession (OCAP) [30] governed the ownership, protection, and storage of the research data, which will be held locally at the Six Nations Polytechnic knowledge institute for access and use by community members to meet community-identified needs at study completion. In addition, findings from the community gathering have been translated into graphic form and made available in paper and electronic formats, including on a public-facing website [31], for the HRIC to distribute to their clientele and use to further inform their programs and services. All study participants were provided with a CAD $50 (US $35.80) gift card as a thank you for their participation.

Results

Participants

A total of 20 parents participated in individual interviews; 19 (95%) were Indigenous (First Nations: 15/20, 75%; Métis: 4/20, 20%), and 1 (5%) was non-Indigenous but their household family members were Indigenous. Those who identified as First Nations represented the Cree, Ojibwe (including the Anishinaabe and Chippewa Peoples), Oji-cree, Mohawk, Oneida, Onondaga, Seneca, Algonquin, and Mississauga Nations. Most parents (16/20, 80%) identified as women, whereas the remainder identified as men (2/20, 10%) or Two-Spirit (2/10, 10%). Parents had a mean age of 34.7 (SD 10.33; range 20-67) years. More than half (11/20, 55%) of the participants had completed college, had some university education, or had completed a university undergraduate or graduate degree; approximately one-third (6/20, 30%) had some college education, whereas the highest level of education of a small portion of the parents (3/20, 15%) was the completion of high school. Participants were primarily residents of 1 of 2 large cities in southern Ontario, Canada—Hamilton (10/20, 50%) or Toronto (6/20, 30%)—with other parents residing in the surrounding Greater Toronto Area or Niagara region. None of the participants lived in on-reserve communities. The household size of participants ranged from 2 to 7 individuals. Approximately one-third (7/20, 35%) of the parent participants were caring for only 1 child, whereas the remainder had 2 (6/20, 30%), 3 (5/20, 25%), or 5 (2/20, 10%) children.

Participants shared experiences of using a range of internet-based programs, including Indigenous-specific programs and non-Indigenous programs. Indigenous-specific programs included government-run early childhood programs, known as EarlyON in Ontario, Canada, and programs run by Indigenous-led organizations, including Aboriginal Health Centres and Indigenous Friendship Centres. Non-Indigenous programs encompassed those run by the Boys and Girls Clubs of Canada, non-Indigenous EarlyON programs, prenatal programs, and a young parent–focused program. Most participants (13/20, 65%) drew on experiences from at least 2 parenting programs, whereas 35% (7/20) had used only 1 parenting program.

Thematic Summary

Overview

Study participants identified numerous factors that facilitated or impeded their engagement in internet-based parenting support programs. These factors encompassed many facets of the program and its delivery—from the point in time when parents learned that the program was being offered to the effect of program engagement on them as individuals and parents. Parents also provided many suggestions for organizations to enhance programs and encourage other parents to engage in the internet-based parenting support programs more actively.

The steering committee, as noted previously in this paper, selected core elements from the Indigenous Wellness Framework [17] as a structure for sharing the study findings. Specifically, the 4 main outcomes of the framework are the structure under which the themes are presented. Collectively, the findings of the analysis of the individual interviews are classified into four main themes and organized under the Indigenous Wellness Framework: (1) *Program Delivery and Content (Purpose)*, (2) *Building Relationships and Connections (Belonging)*, (3) *Cultural Connection (Hope)*, and (4) *New or Improved Parenting Skills and Mental Wellness (Meaning)*. A fifth and final theme, *Recommendations for Organizations*, was also identified in addition to those presented under the Indigenous Wellness Framework. Each theme and its respective subthemes are presented in the following sections, including exemplars from study participants.

Purpose: Program Delivery and Content

Effective parenting program delivery that purposefully met parents' informational needs through providing their desired program content was a major theme among study participants. Parents identified their need to be aware of programs being offered, the importance of accessible delivery, and the program content they valued.

Awareness of the Program

Before parenting program delivery, organizations advertised their program offering to parents. Parents in this study noted the importance of being aware of programs that would be of benefit to them. Most parents in the study did not voice concerns about *how* they became aware of available programs, but rather, a few parents found it difficult to learn about *what* programs were being offered. One parent, for example, noted the difficulty they had in finding a parenting program:

> *...you have to really do your researching and find them kind. It seems...they were all given through certain providers and stuff like that throughout the community. So unless it's like, how do you say, marketed type thing through them, it's very hard to find them.*

Many parents learned about the programs offered through social media. Despite the efficiency and reach of that medium, other parents felt that sharing through physical flyers would also have benefits, as noted by a participant:

> *...I dunno, maybe there's lots of people out there who it's just easier when you're walking, you see a flyer, it's like, oh, I didn't know. And then you just take it and go, or you see it and you take a photo and just, yeah.*

Accessible Delivery

Accessible program delivery was important for parents and facilitated their engagement in programs. Parents identified two areas that were needed to optimize the accessibility of the parenting program for them: (1) equipment plus internet connectivity and (2) skills and support to use technology.

Equipment Plus Internet Connectivity

Access to a laptop or other electronic device was essential for a parent to engage in internet-based programs. Participants emphasized the importance of having a device and that the lack thereof impeded engagement with the program. In addition, parents needed internet access to be able to participate in internet-based parenting programs, and access to this service was a potential barrier perceived by some parents. This participant compared her experience to that of her family member's, who did not have access to a laptop to participate in the internet-based program:

> *I guess if you don't have a laptop or a computer, that could be an issue. Cause I think I remember telling my cousin about it because she had kids young too. She has kids my younger son's age. And I was like, oh, why don't you do this? You could sign up...but she's like, oh, my laptop, the kid's actually broken her laptop. So she was like, I don't know. I'm like, oh. She said, can I go on my phone and do it? I'm like, maybe if your camera's working, I guess. But then I think she did. She complained about it saying like, oh, on the phone, it's so small, the screen. And was, that was an issue. So I think back to your question, I think it's definitely no issue signing up and accessing it if you have a laptop that's working, that's good connection. But if you don't, then yeah, there could be some barriers there because your phone wouldn't be the best and it wouldn't really keep the kids' attention cause it's so small, you can't really stationary it so that they can just sit down or something. They have to hold it and their kids are always moving around. So it's just kind of chaotic.*

Another parent noted the following:

> *It would be nice to ensure everybody has this kind of access. I don't know how feasible that is. I know there were parents struggling when school went online and scrambling to get their children tablets and not everybody has internet. And that was a big struggle...I don't think we're doing anybody any good by not having that accessibility.*

A lack of the appropriate equipment or electronic connectivity meant that some participants had to travel outside their home to obtain the needed equipment and resources to participate, as described by one parent:

> *And I know for a fact there are people that go to the library just to be able to have access to the basics that you and I probably take for granted. And maybe people are going to the library and engaging in programs that way, but it sucks that you have to, in the middle of minus 30-degree weather, have to trek down to your local library to be able to access that.*

Skills and Support to Use Technology

The ability to use technology to connect with the internet-based parenting program was a new skill for some participants and created an immense learning curve. One parent verbalized how this learning curve was a stressor:

> *The one thing that really got in the way of it being able to be really helpful is the virtualness, it's hard to deal with, it's just learning how to use the different programs and stuff online seeing if my phone can actually run certain programs. That was definitely something that came in the way of me being able to completely throw myself in.*

This limited experience or challenges with using technology was felt by some participants as a barrier to actively engaging with the program, as one parent noted:

> *It really all just had to do with the technology. I think it was just because with...in-person groups and everything, it's really different cause you, you're have something in your hand and you're focusing on something else and try to read this and trying to read that. You're really more focused when you're in person. But then online it was really just for lack of a better explanation, it was just all the technology and trying to get used to one program and then go to a different program to do something else. And then it was just very, very confusing.*

Despite the challenges experienced by parents due to limited skills in the use of technology, parents were pleased to obtain support from individuals conducting or supporting the delivery of the parenting program. The ability to connect with a program facilitator or staff member via telephone to troubleshoot problems was felt by parents to be important in facilitating their participation in programs.

Content Valued by Parents

Overview

The parenting support programs provided education for parents on caring for and parenting their children. Parents valued several specific content areas of the parenting support programs that prompted their engagement. These were (1) prenatal care and infant health and development and (2) parenting strategies.

Prenatal Care and Infant Health and Development

Parents felt that it was important to learn about what to expect during labor and understand how to prepare for this event. This information was valued not only by expectant mothers but also by their partners who would be providing support. Parents valued the opportunity to learn about infant health, including breastfeeding, nutrition, and infant safety related to sleep and water. Parents also felt it important to have a cardiopulmonary resuscitation (CPR) training and certification course. Parents valued the prenatal and infant education thoroughly and enjoyed learning this information as it helped prepare them for their new role as parents.

Another content area that parents valued was learning about infant and child development and developmental milestones. Parents appreciated knowing what to keep an eye out for as their children grew to ensure that they were healthy and on track for their age.

Parenting Strategies

Parents valued parenting support program content that provided various strategies related to parenting effectively. This included strategies to promote engagement with their child, how to address frustrations encountered during parenting, and coping mechanisms to use. For example, one parent described their learning related to strategies to promote engagement with their child:

> *I know this is about parent engagement, so just from a child and parenting standpoint...I've learned more about just how to better engage with your children and appreciate the time you have and to take time.*

Parents also expressed the positive impact of strategies learned through parenting:

> *They warned us about crying and how frustrating it can get and just that if they're okay and they just keep crying to take a minute to yourself, go take 30 seconds a minute, take a few breaths, come back. That has really helped me work on my patience with my daughter.*

Belonging: Building Relationships and Connections

The second major theme noted in the data was that the relationships developed with other parents and the parenting program facilitator aided participants' engagement in the programs. In general, it was important for parents to develop connections and build relationships, particularly during the pandemic as the social distancing measures dramatically changed how parents received services and connected with other parents or supports before, during, and after the birth of their child.

Other Parents

Parents wanted to develop relationships with other parents in the programs. New mothers or parents most notably felt that developing these relationships was extremely critical. These new parents were particularly postnatally isolated during the pandemic with limited opportunity to interact with other parents.

Although parents sought interpersonal relationships with other parents in the program, this might not be feasible with or desired by all parents attending a support program. However, it was still deemed important by parenting program participants to generally know the other parents in the program. Even if parents did not seek friendship with other parents, they felt that they had to get to know them as they were sharing personal information about themselves and their families during the program.

Program Facilitators

Parents sought and felt that it was important to have a relationship with parenting program facilitators and other workers supporting the parenting program. One parent described why they felt that this relationship was so important:

> *I think it was important to have that relationship because when you're talking about child development and parenting, that's a spectrum and there is so much unknown to that. It's good to have people in your corner that can support you and have that, that knowledge.*

The need for a good interpersonal relationship with program staff and facilitators was largely attributed to the desire to be close with those surrounding and supporting their families—those who knew personal, intimate information about them. Parents described that workers with whom they had a good relationship were almost like friends—people they could go to in a time of need and not feel fear or judgment, as one parent explained:

> *The relationship that I think we built was a solid one...So she was kind...all the way around. So it didn't just become a therapeutic relationship, it was also kind of a confidant...Somebody you could turn to if you needed help or advice.*

A Sense of Belonging and Shared Experience

Developing a sense of belonging to a community and having a sense of shared experiences was a subtheme that was repeatedly discussed by almost all parents who participated in the study. Parents valued the opportunity to have a sense of community during a time when in-person interactions and social connections were limited. They also appreciated the ability to share individual experiences with others, to know that they were not alone in some of the situations they encountered and the subsequent emotions that ensued during that time. One parent spoke about how participating in the parenting support programs made them feel:

> *I think it felt really good, especially with the pandemic of not having anyone and not just being secluded to your family. So I feel like it gave you a sense of community, a sense of belonging, just kind of like, okay, something to look forward to, something to pencil into your days.*

Another parent expressed how the ability to have a sense of community was especially important when others whom they typically relied on were not available due to the restrictions of the pandemic:

> *Also just still being able to connect with people in a time where we weren't able to, and especially with our families even...It was the same way with the Indigenous perspective and lines. Traditionally, you have your community there, you have your aunties, your uncles, your brothers and sisters, and we didn't have that in that time. So it was good to connect with people and still be able to talk and ask questions in a judgment free space, which is something that you would get from your family or could expect, hopefully expect from your family. I mean...mentally it made me feel better in ways too, just to be able to socialize and laugh and joke with people about things and to share feelings. And over time you built a relationship.*

This value of a sense of community and connectedness with other parents was also echoed by another parent:

> *So I think that that sense of community and not feeling alone is probably the most important thing. You can take all the parenting classes, they can give you all the advice that's important, but you need to give parents an opportunity to connect and talk just [to] them, whether that's a focus group where you get together and you talk about different topics every week, or a book club where you read different, it can be parenting books, it can be self-help books, it can be whatever. And then you get together and you talk about it. As much as those may not be formally parent related, I do believe that a happy parent is a good parent. And to have that, I feel like you do need to feel like you're not alone.*

This sense of belonging was extremely important as parents noted that they were more likely to share and participate more if they felt connected with other parents and workers.

Hope: Cultural Connection

Parents felt that participating in parenting programs provided them with an important opportunity to connect more deeply with their culture and traditions; having this cultural connection was the third major theme in the study data. Parents wanted cultural elements such as traditional teachings, crafts, or cooking included in the programs they accessed. They placed a higher value on programs that integrated cultural components than programs that did not:

> *I think this is fairly obvious is the cultural connections that you're able to attain through online. I'm a busy lady and I can't necessarily commit to evenings a week...to take language courses. So, I'd see another benefit is just being able to connect culturally on a different platform...It's another connection...I think especially with our agencies...that cultural component. And even in our food, the food that they try and bring that culturally relevancy to their programs, and I really appreciate that. So, I think there's a good balance of just fun and engaging and cultural. I think there's a big balance there.*

Parents felt that the parenting support programs offered information that served as a reminder of culture that they could share with their children:

> *There's things in my childhood that I'm grateful for culturally that I want my child to have that same, to be that fortunate, to have that privilege. And those are words that shouldn't really be used when you were talking about culture, but when we're talking specific to First Nations, to Indigenous people, it's scarce now. So that's something I want to have instilled in our child. And I just reflect back on different sessions and it's like I said, those reminders. So it, it's weird because I think there's not maybe a week that goes by that I don't think about these programs in some ways, something that they've offered.*

The cultural elements of the programs also helped address gaps that parents felt they had in their own knowledge that they could teach their children:

> *A lot of things I've learned that my mother couldn't teach me...I'm teaching my children that well; I'd like to say my partner is fully native and he doesn't know anything about his background really. So it has to be my job. So that's why I need [Program Name]. This is why I need [Parenting Program Name]. This is why I need the HRIC to show them because I don't know myself.*

The cultural elements desired among study participants varied. Participants wanted programs that included crafts and art, such as medicine bags, beading, ribbon skirts, moccasins, and dreamcatchers. Participants wanted to learn more about traditional foods and recipes, such as bannock and Three Sisters soup. Parents wanted programs to be land based if possible and have opportunities to learn their Indigenous languages. Parents desired opportunities to learn more about traditional teaching and ceremonies, such as the Seven Grandfather Teaching, moon ceremonies, powwows, and drumming. They also wanted to learn more about traditional medicines. Learning about how to raise children through a cultural lens was also deemed important.

Meaning: New or Improved Parenting Skills and Mental Wellness

Overview

Parenting support programs helped create meaning in parents' lives through the development of new parenting skills or enhancing their current repertoire of skills. The programs also helped create meaning through supporting parents' mental wellness. This was the fourth and final major theme in the study data.

New or Improved Parenting Skills

Nearly half of the parents interviewed reported that engaging in internet-based parenting programs improved their parenting skills and strategies. This included response strategies that were more appropriate than the ones they had either previously used or grown up with. Some parents also described how their newfound skills and abilities—such as cooking—inspired them to be more involved with their children and come from a place of love and patience rather than aggression:

> *The whole point of that was to learn different methods that my child's going through to learn different techniques, to not be the type of parent that my father was. So, I've definitely sat back and watched my son go out into the world and come back and check in and then go back out into the world and come back and check in. Just like we learned all about in* [Parenting Program Name]

These new skills being learned had a positive impact on individuals' ability to parent:

> *I feel that I'm a better parent now learning new things, how to not go at it aggressively, but to go at it at different approaches.*

Mental Wellness

During the pandemic, parents also reported that they enrolled and participated in internet-based programs when components of health and wellness were included or focused on self-growth. As mental health was a prominent issue during the pandemic, parents appreciated and valued programs that included components of self-care, mental wellness, and strategies for coping with stress. The positive impact of focusing on well-being in the programs was explained by one parent:

> *It was a really good space to just express...to talk about experiences in the past and really go into...there were some sessions there where we...focused on wellbeing and so we'd sort of look back and talk about things that happened in the past and why, how they maybe have been carried over the years and impact things that, how we think what we do, the way we do things in the present. So, it was really nice to have those opportunities for inner reflection and building that self-awareness and how that can impact your relationships with others, including your kids.*

Recommendations for Organizations

Overview

Throughout the study, parent participants discussed program elements that facilitated their engagement. Recommendations for organizations to help promote parental engagement in parenting support programs included improved accessibility, delivery that is interactive and engaging and has inclusive support, and incorporation of family-oriented activities. In addition, parents wanted to ensure that food and mental wellness were incorporated as components of the programs. Each of these recommended parenting program elements are discussed in more detail in the sections that follow.

Accessibility

Overview

Parenting programs had to be accessible for parents to engage with them and reap their benefits. Parents recommended more scheduling options for programs, alternate ways to access programs, and strategies to optimize accessibility of the programs. Sign-up for programs had to be straightforward, and the internet-based parenting program platform had to be uncomplicated and easy to navigate.

Scheduling

Challenges were experienced by parents in relation to the scheduling of programs, with few options available that fit parents' schedules. This challenge was also applicable to the times offered for parents to pick up or for the program team to deliver material or food kits to be used in the program. Thus, parents recommended that more program timeslots be available. However, parents recognized that funding and resources might limit the ability of staff to provide additional program offerings and, therefore, suggested archived recordings (where appropriate) as an alternate way for parents to access the program and relevant information; this would address scheduling challenges.

Parents provided other recommendations to facilitate program accessibility and scheduling. This included posting monthly calendars of all programs available rather than distributing individual flyers for each program to make it easier for parents to plan and choose the program that would work best for their needs, interests, and availability. Another suggestion by parents was for program managers and facilitators to administer a poll to all parents enrolled (or interested) in a program to determine their availability. A unique time that works (mostly) for everyone could then be offered rather than having a prescheduled offering of the program.

Sign-Up, Log-In, and Navigation

Parents were less likely to participate or continue in a parenting support program if the sign-up and log-in processes were difficult or overcomplicated. The sign-up for programs had to be straightforward to reduce the potential for parents to choose not to participate due to challenges experienced in enrolling in the program. For example, navigating websites to sign up for programs was sometimes difficult, and some parents preferred the option of calling in to register for programs. Parents recommended that the internet-based parenting program platform have an uncomplicated log-in process and that the program needed to be easy to navigate on the internet. Keeping track of log-in emails and passwords or using several websites, apps, or platforms during the program was difficult for parents. Several parents felt that they were not "tech savvy" and, therefore, a lot of the programs offered were particularly difficult to navigate. These factors should be considered by organizations when setting up future programs to make sign-up, log-in, and navigation as simple and streamlined as possible.

Delivery

Overview

Parents mostly preferred in-person over internet-based programs for a number of reasons, including improved supports, services, and activities; fostering deeper and more meaningful connections with other parents and workers; better instruction; and the ability for their children to play or interact with other children to develop their social skills. However, parents recognized the value of internet-based programs and thoroughly appreciated the accommodation provided during the pandemic. Parents provided recommendations for enhancing internet-based program delivery, including interactive and engaging programs, inclusive support, and activities.

Interactive and Engaging Programs

Parents repeatedly expressed the importance of having programs (and facilitators) that were interactive and engaging. This included not only programs specifically for parents or those who were expecting a child but also family-oriented programs that involved children. Activities that parents viewed as *interactive* or *engaging* included tactile activities, drumming and singing, arts and crafts (with children), cooking, and activities that incorporated opportunities to talk to other program attendees.

Inclusive Supports

Parents desired supports and services that were more inclusive. Some explained that they would like programs to be inclusive of a wider children’s age range (ie, beyond 12 months). Other parents wanted to see more Two-Spirit and lesbian, gay, bisexual, transgender, and queer support for children; specific activities for children with attention-deficit/hyperactivity disorder and autism spectrum disorder; and multigenerational programs that included elders and other family member roles rather than only the parent and child. Several parents identified the need to increase the number of current supports and programs available to teenage and young moms, as well as individuals who are expecting to be parents for the first time or are new mothers.

Activities

Parents sought programs that were activity based and family oriented so that they could spend quality time with their children. Programs that were hands-on and interactive, such as drumming and singing circles or cooking classes, were often chosen to maintain engagement and excitement and avoid feelings of boredom or repetition. Parents appreciated it when there was an educational component (ie, traditions, healthy recipes, and infant care) included in these activities.

Program Components

Parents wanted food to be a part of the program components and content included that addressed health and wellness.

Food

Parents described the value of having food incorporated into internet-based programs. Some programs included a weekly food delivery kit as a cooking class to provide recipes and offer a fun activity to do with children. Others taught how to make traditional teas and medicines, such as elderberry juice. Although some organizations offered food delivery services during the pandemic to support food security, the inclusion of food in the programs was viewed by parents as an important consideration for future internet-based programs.

Health and Wellness

Parents expressed the need to include more content on self-care (particularly after delivery and in the early stages of parenthood) and mental wellness tips in parenting support programs. Parents wanted to see the incorporation of emotional support and sharing groups into programs—as a means of support and social interaction. Parents also identified healthy eating and the importance of proper nutrition in supporting the body, mind, and spirit as an area for inclusion in parenting programs.

Discussion

Principal Findings

This study provides important insights into parents’ perspectives on what facilitates or impedes their participation in Indigenous parenting support programs that are delivered over the internet. While some of the findings of this study echo those in the literature on mainstream internet-based programs, many are novel as this is the first study to consider the unique perspectives of *Indigenous* parents using internet-based parenting programs. In particular, parents’ priorities to use internet-based programs to build relationships and a sense of community with other new parents; the importance of cultural connections to families; and specific ways in which programs can be more inclusive of families impacted by attention-deficit/hyperactivity disorder and autism spectrum disorder and those who are multigenerational, as well as Two-Spirit and lesbian, gay, bisexual, transgender, and queer parents, are important additions to the literature.

One of the major findings of this study was the importance of program delivery, which included accessibility to programs. The need to have the appropriate equipment and internet access was critical. This is not unlike the challenges that many, such as the educational sector, experienced when they had to pivot to internet-based delivery in the early weeks and months of the COVID-19 pandemic; many families did not have computers at home for their children’s schooling [32]. Organizations delivering programs need to consider the need for these technology resources when planning programs and have the resources necessary to provide to parents through a strategy, such as a loan program for devices with internet access. Given the limited resources that many service sector organizations have, working with public libraries to facilitate clients’ access to computers and the internet would be another potential strategy to facilitate internet access. However, this strategy may create another barrier if parents planning to participate are geographically not located close to a library or have limited resources available for transportation to a public library. For example, many Indigenous communities in Canada face high internet costs and slow, unreliable speeds or a lack of internet access entirely [33]. Parents may need to modify screen use to accommodate slow speeds and resort to less ideal formats, such as direct messaging rather than video calls [33]. Organizations need to consider their local context to design strategies to improve access to their programs.

Another component revealed in this study related to accessibility was parents' steep learning curve in setting up and using the technology or the platform for delivery of the program. Given that parents felt that support from staff via telephone helped them navigate these technological challenges, organizations should consider dedicating a staff person to online support when initially commencing an internet-based program. This will help facilitate program access for parents who have limited experience with technology.

Content that parents valued was another study finding that was identified by parents as facilitating engagement. Not surprisingly, expectant parents valued learning about prenatal care, whereas parents in general valued learning about infant health and child development, in particular elements such as child safety and sleep. These are important areas that are typically included in many programs to support expectant or new parents, such as a public health offering of *Healthy Babies Healthy Children* [7]. However, the difference in this study is that parents emphasized the importance of Indigenous culture and an Indigenous lens when presenting content. Thus, an Indigenous parenting support program would provide this valued lens when delivering content, which parents would not receive in other generic parenting programs.

Parents also valued learning about Indigenous culture and saw this knowledge as a facilitating factor to their program engagement. This is not surprising considering the devastating impacts that colonialism has had on Indigenous Peoples and the resulting loss of cultures, language, and identity [34]. Indigenous parents living in urban areas may not have as strong a connection with their culture as those living on a reserve and may be seeking to reconnect with and learn about their history, culture, and traditional ways [5,35-37]. A study exploring family engagement and well-being in the Aboriginal Head Start programs in British Columbia, Canada, suggests that engagement was most active when families established relationships with elders, facilitating the sharing of Indigenous ways of knowing [5]. This sharing of knowledge and teachings that celebrates culture created a sense of belonging for families and helped programs be culturally inclusive [5]. Access to culturally inclusive parenting programs can increase family wellness and provide support and healing from the harms of colonization [16]. These studies emphasize the need to continue offering programs that integrate culture throughout their educational content. In addition, incorporating activities that create the opportunity for parents to learn about or revisit cultural teachings is extremely important. However, to avoid a pan-Indigenous approach to programs that results in cultural erosion, service providers should reach out to elders or Knowledge Holders from their clients' home communities and Nations and incorporate information and activities that reflect their unique cultures into their programs.

Relationships with other parents and program facilitators were important to participant parents. Throughout the COVID-19 pandemic, interpersonal relationships were limited to household contacts and some internet-based connections with family and friends for those who had technology. This restriction on interpersonal interactions created a stressor for many individuals and the need for a connection with others. This connection is important, most notably in times when support is more likely to be needed, such as during the transition to parenthood or even when engaging in the day-to-day challenges that many individuals encounter as they parent their children [38]. Thus, the delivery of programs over the internet during the COVID-19 pandemic was very important. It provided individuals with an opportunity to build relationships that became key sources of support when encountering the challenges of parenting or enduring the isolation that the pandemic created. Given this, organizations should consider having opportunities within their programs for individuals to build relationships with other parents attending the program and with program facilitators and staff. Having contact information for the facilitator, if feasible, would also be helpful so that parents can have contact with an individual to support them or refer them to resources as needed.

The parenting support programs provided many benefits or positive outcomes for attendees. It is not surprising that the programs created a sense of belonging and improved mental wellness, especially due to the limited interpersonal interaction posed by the pandemic. Given that mental wellness is important and some parents—such as those in the early postpartum period—are at risk of depression [39], these programs provide a key source of support to help optimize positive mental health.

Despite the overall positive experience and beneficial outcomes that parents had from engaging in parenting support programs, parents did offer recommendations for enhancing programs. Parents verbalized that they wanted interactive, engaging programs that were family oriented. They felt that incorporating food into programs was important. In addition, health and wellness should be considered when developing future programs. These recommendations are important for organizations to consider as they engage in budgeting and planning for future program delivery. Eliciting the help of a few parents in an advisory capacity might be beneficial for exploring how to implement these recommendations cost-effectively and in a way that is responsive to parents' needs.

Strengths and Limitations

This interpretive description study incorporated rigorous design elements that contribute to the strength of the research and the credibility of the study findings. Our community-engaged approach ensured that the study met the needs of the local community, including helping improve programs at the HRIC, and that it was guided by leaders and parents at the HRIC. Our purposive sampling approach allowed us to understand the diverse experiences of Indigenous parents, although most participants identified as First Nations. Inuit and Métis parents' experiences were not adequately captured in this study, and therefore, their experiences with internet-based programs may differ from those in the findings presented here. In addition, we recognize the diversity of First Nations Peoples, and as such, the experiences of the parents in this study may not reflect those of other Nations and communities. Similarly, the experiences of men were not well represented, with only 10% (2/20) of the participants identifying as men. This represents a gap in understanding that should be further explored. Next, we were able to achieve information power and redundancy of concepts [24] and themes during our concurrent approach to data collection and analysis. We engaged in triangulation throughout our collaborative approach to data analysis, which included all members of the steering committee and other First Nations parents. Finally, parents provided their experiences of participating in several different programs that offer support to Indigenous parents, which was a study strength. However, how many programs parents participated in and their frequency of use was not consistently discussed with all participants and could have helped provide further insight into the context of parents' experiences with specific internet-based parenting support programs.

Conclusions

Collectively, parents engaging in internet-based, available, Indigenous parenting support programs had positive experiences. The programs facilitated parents' engagement, providing them with opportunities to develop new parenting skills, develop relationships with other parents and program staff, create a sense of belonging, and deepen their connection with their culture. Organizations offering internet-based Indigenous parenting support programs should consider integrating these recommendations into their programs to better engage parents and children in services.

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Conflicts of Interest

None declared.

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Abbreviations

CPR: cardiopulmonary resuscitation

HRIC: Hamilton Regional Indian Centre
OCAP: ownership, control, access, and possession

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Photos Shared on Facebook in the Context of Safe Sleep Recommendations: Content Analysis of Images

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Abstract

Background: Sudden unexpected infant death (SUID) remains a leading cause of infant mortality; therefore, understanding parental practices of infant sleep at home is essential. Since social media analyses yield invaluable patient perspectives, understanding sleep practices in the context of safe sleep recommendations via a Facebook mothers' group is instrumental for policy makers, health care providers, and researchers.

Objective: This study aimed to identify photos shared by mothers discussing SUID and safe sleep online and assess their consistency with infant sleep guidelines per the American Academy of Pediatrics (AAP). We hypothesized the photos would not be consistent with guidelines based on prior research and increasing rates of accidental suffocation and strangulation in bed.

Methods: Data were extracted from a Facebook mothers' group in May 2019. After trialing various search terms, searching for the term "SIDS" on the selected Facebook group resulted in the most relevant discussions on SUID and safe sleep. The resulting data, including 20 posts and 912 comments among 512 mothers, were extracted and underwent qualitative descriptive content analysis. In completing the extraction and subsequent analysis, 24 shared personal photos were identified among the discussions. Of the photos, 14 pertained to the infant sleep environment. Photos of the infant sleep environment were then assessed for consistency with safe sleep guidelines per the AAP standards by 2 separate reviewers.

Results: Of the shared photos relating to the infant sleep environment, 86% (12/14) were not consistent with AAP safe sleep guidelines. Specific inconsistencies included prone sleeping, foreign objects in the sleeping environment, and use of infant sleeping devices. Use of infant monitoring devices was also identified.

Conclusions: This study is unique because the photos originated from the home setting, were in the context of SUID and safe sleep, and were obtained without researcher interference. Despite study limitations, the commonality of prone sleeping, foreign objects, and the use of both infant sleep and monitoring devices (ie, overall inconsistency regarding AAP safe sleep guidelines) sets the stage for future investigation regarding parental barriers to practicing safe infant sleep and has implications for policy makers, clinicians, and researchers.

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KEYWORDS

SUID; SIDS; parenting; safe sleep; photo analysis; pediatric; pediatrics; paediatric; paediatrics; infant; infants; infancy; baby; babies; neonate; neonates; neonatal; newborn; newborns; sleep; safety; death; mortality; social media; picture; pictures; photo; photos; photographs; image; images; Facebook; mother; mothers; parent; co-sleeping; sudden infant death; sudden unexpected infant death; adherence; parent education; parents' education; awareness

Introduction

In the United States, approximately 3500 infant deaths are attributed to the category of sudden unexpected infant death (SUID) on a yearly basis [1]. SUID includes death due to sudden infant death syndrome (SIDS), accidental suffocation and strangulation in bed, and ill-defined deaths [1]. SUID is the leading cause of unintentional, injury-related infant death in the United States [2] and is often related to unsafe infant sleep environments, including, but not limited to, prone sleeping, bed sharing, use of soft bedding, or unsafe sleep surfaces [3,4]. Recent characteristics of identified SUID deaths included that almost 60% of infants were sharing a sleep surface when they died and at least 76% had multiple unsafe sleep factors present [5].

The medical community has faced challenges in terminology associated with SUID [6], and the US Centers for Disease Control and Prevention recently updated reporting forms [7] to code such deaths more accurately. Confusion regarding SUID terminology also exists among parental groups [8]; for instance, parents often use the term "SIDS" when discussing SUID-related deaths. Progress related to the prevention of SUID has stalled since the Back to Sleep campaign in the 1990s [6,9]; therefore, further investigation into barriers to parental practices of safe sleep is warranted.

Social media is widely used among parenting groups and for health communication [10-12]. Mothers especially seek community and informational support—often found in online environments [8,13]. Given the breadth of information shared on social media, analyzing data from this source can identify concerns and practices of specific populations. Due to the stagnation in the prevention of SUID [1,2], we believed it would be helpful to complete a qualitative content analysis on Facebook and assess how mothers discuss SUID and safe sleep. In completing this analysis, we noted shared photos posted throughout the forum. Assessing infant sleep environments in the home setting is challenging [14]; thus, analyzing photos shared in an online community in the context of SUID and safe sleep discussions can yield invaluable insight into the reality of infant sleep environments. Understanding actual infant sleep environments in the home setting can also help in the development of research and prevention efforts regarding SUID.

This study therefore aimed to analyze photos shared among mothers engaged in discussions about SUID and safe sleep on a Facebook mothers' group. Specifically, we were interested in the following question: If applicable, are the shared photos consistent with safe sleep guidelines as defined by the American Academy of Pediatrics (AAP) [1]?

Methods

Overview

Details regarding the extraction process and qualitative content analysis of the data have been published, and findings shared [8]; however, this will be briefly discussed here. Data were extracted from a Facebook mothers' group in May 2019. This specific Facebook group was for women only, based in the southern United States, and had approximately 17,500 members. After trialing various options, "SIDS" was selected as the most effective term resulting in the most relevant conversations surrounding SUID and safe sleep. Thus, "SIDS" was entered in the search toolbar without additional filters applied. This search resulted in 20 posts and 912 comments from 512 mothers, all relevant to the topic of SUID and safe sleep. Once the data were identified, the posts and related conversations were transferred to an extraction spreadsheet and later analyzed via qualitative descriptive content analysis, as described by Sandelowski [15]. The descriptive analysis process was completed as per Miles et al [16] via Atlas.TI (ATLAS.ti Scientific Software Development GmbH) and was guided by the socioecological model of human development [17] and the uses and gratifications approach [18]. Inductive coding was completed so that codes emerged progressively, and all data were analyzed by 2 reviewers to ensure trustworthy findings and increase reliability [16].

During data extraction, photos shared among mothers were noted on the extraction spreadsheet. Two reviewers analyzed the photos to identify those related to the infant sleep environment. The identified photos related to the infant sleep environment were then assessed for consistency with safe sleep guidelines. The photos were analyzed based on 5 criteria derived from the AAP safe sleep guidelines (including risk factors and protective factors) that were current at the time of the analysis. These included (1) a supine sleep position, (2) no bed sharing, (3) the absence of soft bedding (crib bumpers, positioners), (4) a safe sleep surface, and (5) pacifier use [3]. If there was a discrepancy in assessing the safety of the environment, this was discussed among the members until a consensus was reached.

Ethical Considerations

This study was submitted for review by the institutional review board (IRB) at the University of Texas at Austin and deemed exempt as the study did not meet the criteria for human subjects research. IRB review and oversight was not required because the activities involved obtaining information from publicly available data sets. Despite the exempt status, any personal or identifying information was removed from the data set to maintain confidentiality. Thus, privacy and confidentiality were maintained throughout the data collection and analysis process. Additionally, in discussing the findings, we have chosen to share minimal details regarding specific posts and will not share the actual photos included in this analysis.

Results

Sleep Environment Assessment

Among the data extracted from the Facebook group, 24 personal photos were identified. Of these photos, 14 were related to the infant sleep environment, 10 of which included sleeping infants. The remaining photos, which were not included, depicted infants and toddlers that were awake, personal photos of infant monitoring devices, and screenshots of personal monitoring device results via applications originating from monitoring devices.

After review, 8 of the 10 photos of infants sleeping were classified as being inconsistent with AAP safe sleep guidelines. Reasons for being deemed inconsistent included prone sleeping, the use of sleeping devices, and foreign objects in the sleeping environment (blankets, stuffed animals, crib bumpers). Four of the photos depicted infant sleeping environments but did not have the infant present. Despite the absence of the actual infant, the shared photos depicting sleeping environments were all classified as being inconsistent with AAP safe sleep guidelines after review. Examples of these environments included foreign objects in the sleeping environment (blankets, stuffed animals, diapers, wipes). In evaluating the photos shared among this specific Facebook group, it is important to consider the context in which the photos were initially shared.

Context of Shared Photos

To better understand the mothers' intentions in sharing photos, some of the scenarios will be discussed in more detail. However, it is worth noting that significant effort was made to maintain the anonymity of the Facebook members and actual photos are not available for viewing.

Most of the photos shared among members were "for attention" or to discuss infant sleeping habits rather than to clarify whether the sleeping environment was safe. For example, a mother was considering using crib bumpers and asked the group for advice since her infant slept with his head touching the side of the crib. In posting her question, she shared a photo of her infant in the crib, in which there were multiple foreign objects present and the infant was sleeping prone. This resulted in other shared photos among the mothers. For instance, a mother commented, "This is how my son sleeps! We have used crib bumpers with all 3 of my kids" and included a photo of her infant sleeping prone in the crib with crib bumpers present. She also added there were "cute" crib bumpers available via Amazon. A different mother stated, "I've used a bumper with every one of mine" and shared a photo of her infant, supine with a stuffed animal and crib bumpers present in the crib.

When another mother asked how many parents went against pediatrician recommendations for infants sleeping on their backs, she posted a photo of her infant sleeping prone on a blanket with the caption "Picture of my LO for attention!!" In response to this post, another mother shared a photo of her infant sleeping prone in their crib from that morning and commented "Do what works for you!" Within the same concept of prone sleeping, another post inquired about mothers who have infants that "tummy" sleep and shared a photo of her infant in her lap, "just because."

One mother asked the group for advice for "any product similar" to the Owlet baby monitor (Owlet Baby Care Inc), as she was looking for a solution to "always getting up to check that they're still breathing." In response to this question, a different mother commented, "DO IT!!" Along with this comment, this mother shared a photo of her infant, aged 4 months, sleeping in a Rock n Play (Fisher-Price Inc) with a neck bandana and an Owlet.

The selected Facebook group also discussed transitioning infants to different sleep settings, such as from a bassinet to a crib. This topic resulted in shared personal photos of various sleeping environments. For example, one mother demonstrated her transition to a crib via a pack and play pictured with netting cut out and multiple foreign objects present. Another shared photo depicted a bassinet in which the mother emphasized the importance of keeping her essentials, "diapers and stuff," in the bassinet in order to be successful with nighttime diaper changes.

It is worth noting that one of the personal photos of an infant sleeping (classified as being consistent with AAP safe sleep guidelines) was an infant lying on their back, with the glow of a baby monitoring device clearly visible through their onesie. Another photo of an infant that was awake (also classified as consistent with safe sleep guidelines based on the visualized sleep environment) included text referencing that the infant slept in a bassinet, "in the middle of our bed," thus implying an unsafe sleep environment in actuality.

Only one photo in this analysis was posted with the mother's intent to ensure a safe sleep environment. This mother sought confirmation that her infant was sleeping "appropriately" and shared a personal photo. This was one of the few environments consistent with safe sleep guidelines among the sample, as there were no foreign objects in the crib. In summary, among the main posts and associated comments, 14 personally shared photos were related to the infant sleep environment, and 86% (12/14) were inconsistent with AAP safe sleep guidelines.

Discussion

Unsafe Infant Sleep Practices

These specific data are unique in that the users openly shared their photos in a forum, a Facebook mothers' group, without researcher interference. The photos were also shared within the context of discussing SUID and safe sleep. It is therefore interesting that most of the shared photos demonstrated sleep environments inconsistent with AAP safe sleep guidelines.

Our findings are concordant with prior analyses of actual infant sleep practices [14], although our analysis involved photos and assessed the home setting rather than an artificial environment. Prior research on this topic has identified unsafe sleep environments depicted on Instagram [19], in stock photographs [20], in magazines [21], in crib marketing [22], and among websites resulting from a Google search [23].

At the time of the study, AAP guidelines were clear regarding use of a firm sleep surface and restriction of objects in the crib, yet guidelines were not clear regarding infant monitoring devices. Thus, repeating this study after device recalls [24-27] and subsequent federal regulations on the use of infant sleep devices [28] might be worthwhile.

Limitations

This study is not without limitations. The number of photos analyzed is small and does not necessarily represent the general population. Furthermore, the photos analyzed represent snapshots and may not fully capture typical sleeping conditions. Additionally, there is concern for potential bias in what photos were shared among the members and in what context. For example, a member may have shared a photo if they were unsure about the safety of the environment; therefore, this study might overestimate environments inconsistent with AAP safe sleep guidelines. However, when assessing the context of the shared photos, only one photo was shared with the mother's intention of inquiring about the safety of the sleep environment.

Results from this photo analysis do not necessarily represent all parents, especially those who do not use Facebook or engage in groups on Facebook. Demographic information regarding the mothers was also not obtained, further limiting generalizability of the findings and resulting in an inability to verify the accuracy of the information shared by mothers.

Despite such limitations, visualizing the actual sleep environment in a naturalistic setting provides helpful insight into true parental practices of infant sleep and has implications for future research and practice.

Conclusions

The commonality of sleep environments inconsistent with AAP safe sleep guidelines should be considered by policy makers, health care professionals, and researchers when aiming to prevent the occurrence of SUID. The practice of infant sleep is complex [8], and despite the known risks of bed-sharing, parents are often motivated to use infant sleep practices inconsistent with AAP guidelines [29]. Additionally, infant sleep is a controversial parenting topic, and while bed-sharing is discouraged in the United States, this practice is commonplace worldwide [30]. While much research focuses on knowledge-based interventions regarding infant sleep practices, we suggest a shift to focus on supporting parents so they can create a sleep environment consistent with AAP guidelines.

This shift involves broad policy changes, such as paid parental leave and financial assistance so families can afford to live in a home with a sufficient number of bedrooms or can purchase safe environments for their infant to sleep (eg, a pack and play or crib). Other suggested policy changes include extending health care coverage for the birthing person up to a year postpartum to ensure adequate care and social services for the mother-infant dyad. Additionally, continued federal regulations are needed to safeguard families. Research has identified widespread use [8] and popularity of infant sleep and monitoring devices among families [31]; however, despite deaths attributed to the use of these devices, their regulation [24-27] has lagged. For instance, the Safe Sleep for Babies Act of 2021 [28], which bans inclined sleepers and crib bumpers, only passed in 2022 despite documentation that such devices have contributed to infant deaths since the 1990s [32].

Health care organizations and personnel should aim to emulate a comfortable environment where parents can engage in open discussions about their infant sleeping practices. Parents seek support from social media [8,11] because it is often a place of acceptance; health care professionals should aspire to be another source of support while providing anticipatory guidance regarding infant sleep. Additionally, health care providers should approach this conversation with the intent to empower parents to create safe sleep environments while having honest conversations about barriers to these practices. Health care personnel should also aim to address infant sleep environments when counseling parents—beginning at pregnancy and throughout the infant's first year of life.

Lastly, since SUID remains the leading cause of unintentional, injury-related infant death in the United States [2], future research should prioritize investigating parental barriers to creating sleep environments consistent with AAP guidelines. Efforts should be made to find new ways to support parents, rather than focusing on knowledge-based interventions. In conclusion, this study highlights the critical need for policy makers, health care professionals, and researchers to engage in the prevention of deaths attributed to SUID by supporting families at the interpersonal, community, and system levels.

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Authors' Contributions

KP conceived the idea and designed the study, extracted the data, raised funds, and wrote the manuscript. SK and EC assisted in data analysis and proofread the manuscript.

We acknowledge that not all birthing persons identify as women or mothers; however, our analysis included a group of individuals who self-identified as "mothers."

Conflicts of Interest

None declared.

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Abbreviations

AAP: American Academy of Pediatrics
IRB: institutional review board
SIDS: sudden infant death syndrome
SUID: sudden unexpected infant death

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Parenting-Related Social Networking Site Use and Psychological Distress in Parents of Infants: Cross-sectional Study Exploring the Moderating Effects of Loneliness and Parenting Anxiety

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Abstract

Background: In the digital age, social networking sites (SNSs) have revolutionized the approach to parenting. These platforms, widely used to access parenting information and support, affect parents both positively and negatively, with negative effects potentially increasing for those experiencing loneliness or anxiety.

Objective: This study examined the relationship between SNS use and psychological distress among parents of young children, controlling for the moderating effects of loneliness and parenting anxiety. We hypothesized that higher SNS use correlates to greater psychological distress, particularly among parents with elevated levels of loneliness or parenting anxiety.

Methods: A cross-sectional survey design using a closed web-based questionnaire was employed. Participants included 429 parents (205 mothers and 224 fathers) of children aged 0 - 3 years recruited through a web-based survey company in Japan. The majority of the participants were couples, with some living with extended family members. The sample also encompassed individuals in cohabiting partnerships and single parents. The survey included measures of psychological distress, loneliness, parenting anxiety, frequency of SNS use for parenting, and covariates. Analytical models to explain psychological distress included interactions between loneliness or parenting anxiety and SNS use, individually for both fathers and mothers.

Results: For mothers, a significant interaction effect was determined only between parenting anxiety and SNS use (b=0.247, SE 0.091; P=.008). Meanwhile, for fathers, significant interaction effects were observed for both loneliness (b=0.324, SE 0.127; P=.012) and parenting anxiety (b=0.144, SE 0.069; P=.038) with SNS use. A simple slope analysis for mothers indicated that SNS use was related to psychological distress only at higher levels of parenting anxiety (b=0.304, SE 0.090, β=.317; P<.001). Among fathers, SNS use was associated with psychological distress at higher levels of either parenting anxiety (b=0.330, SE 0.069, β=.346; P<.001) or loneliness (b=0.390, SE 0.098, β=.409; P<.001).

Conclusions: The study concluded that the relationship between SNS use and psychological distress among parents of young children is moderated by loneliness and parenting anxiety. The findings highlight the need for tailored approaches to help parents manage SNS use, particularly focusing on those with higher levels of loneliness and parenting anxiety. It is imperative that health professionals provide nuanced guidance to parents on SNS use, considering individual psychological factors and potential gender differences in the impact of SNSs on mental well-being.

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KEYWORDS

social networking sites; social media; psychological distress; loneliness; anxiety; social support; mother; father; infant; psychological; distress; children; web-based questionnaire; parent

Introduction

In the wake of rapid digitalization, social networking sites (SNSs) such as Facebook, X (formerly Twitter), and Instagram have changed the landscape of parenting. Parenting-related SNS use is increasingly common, with parents employing these platforms to obtain parenting information and support [1,2]. This specific use of SNSs in parenting has both positive and negative implications. Parenting-related SNS use provides access to a wide range of information that may be unavailable offline [3,4] and offers solutions related to parenting, particularly by expanding maternal social networks [5,6]. However, parenting-related SNS use tends to disseminate idealized images of parenting, posing a risk of loss of confidence due to unrealistic expectations and pressures [7]. The idealized parenting images prevalent on SNSs may prompt parents to compare their parenting methods with others’, potentially triggering depressive symptoms and negative emotions [8,9]. Given the dual nature of parenting-related SNS use, it is critical to determine methods of use that minimize drawbacks while maximizing benefits.

Among the negative impacts of social media use is psychological distress, which is generally characterized by emotional experience marked by symptoms of depression and anxiety [10]. It has been theoretically demonstrated that psychological distress can impair parenting practices [11], and understanding its mechanisms is crucial for supporting effective parenting functions. The impact of social media use on mental health varies widely [12], highlighting the need to focus on the differences in effects based on users' backgrounds when exploring the relationship between psychological distress and social media.

Psychological distress associated with SNS use may be driven by the loneliness experienced by parents. Loneliness can be defined as a "negative psychological state in which there is a discrepancy between one's actual and desired social relationships" [13]. Parental loneliness raises the risk of child maltreatment and may be associated with potential maladjustment in children [14,15]. Lonely people tend to prefer social interactions on the web, reducing the time spent undertaking offline interactions [16]. Although they use social media to compensate for the lack of offline interpersonal relationships, they may not always realize satisfying web-based social relationships [17,18]. Consequently, parents with higher levels of loneliness may rely on limited social relationships through SNSs and experience greater psychological distress owing to unsatisfactory connections. Moreover, the correlation between mothers' high levels of loneliness and the negative emotions experienced through social comparisons on SNSs [19] suggests that the degree of loneliness may influence psychological distress on SNSs.

In addition to loneliness, parenting anxiety may influence parents' psychological distress driven by SNS use. Parenting anxiety, characterized by confusion and fear regarding a child's health, development, and parenting methods, could increase the risk of child maltreatment and child anxiety disorders [20,21]. Parents with high levels of parenting anxiety reportedly use social media more frequently and consider it useful in alleviating anxiety [22]. However, in general, people tend to share information focusing on the successful aspects of their lives on SNSs, facilitating upward comparisons with others who appear to have achieved their goals [23]. Numerous studies have reported that such upward comparisons on SNSs could have negative effects on mental health [24-26]. Given the prevalence of idealized images of parenting on SNSs [7], parents with high parenting anxiety may be increasingly vulnerable to psychological distress from upward comparisons. In addition, elevated parenting anxiety often correlates with lower parenting self-efficacy and self-esteem [27]. Lack of parenting self-efficacy may attenuate the comforting and anxiety-reducing effects of addressing concerns through smart devices [28].

Systematic reviews of the relationship between SNSs, loneliness, and social anxiety indicate that individuals who are lonely or experience social anxiety are more likely to engage in problematic social media use [29], suggesting that such individuals may be increasingly vulnerable to psychological distress from SNSs. Despite the accumulation of knowledge on the relationship between social media, SNSs, loneliness, anxiety, and depression, research in the context of parenting remains limited [30]. Knowledge regarding SNS use among parents of young children is particularly limited, and studies concerning social media use in parenting have predominantly focused on mothers. Exploring the relationship between SNS use and psychological distress in parenting, taking into account levels of loneliness and parenting anxiety for both fathers and mothers, may provide nuanced evidence for SNS use in parenting and professional support.

The usage of SNSs exhibits cultural differences [31], and Japan has its own unique cultural characteristics. In Japan, the widely known international platforms, such as X (formerly Twitter), Instagram, and Facebook, are used alongside LINE, which is popular in some parts of Asia [32]. Compared with other countries, Japanese users tend to employ SNSs more for browsing than for sharing information [33]. SNS use comprises 2 aspects: active and passive use [34], with a tendency for passive use to be more prevalent in Japan. Passive use of SNSs is often linked to negative impacts on mental health [35]. As Japanese users are predicted to be a group potentially at risk of psychological stress due to SNS use, it is significant to focus on this issue.

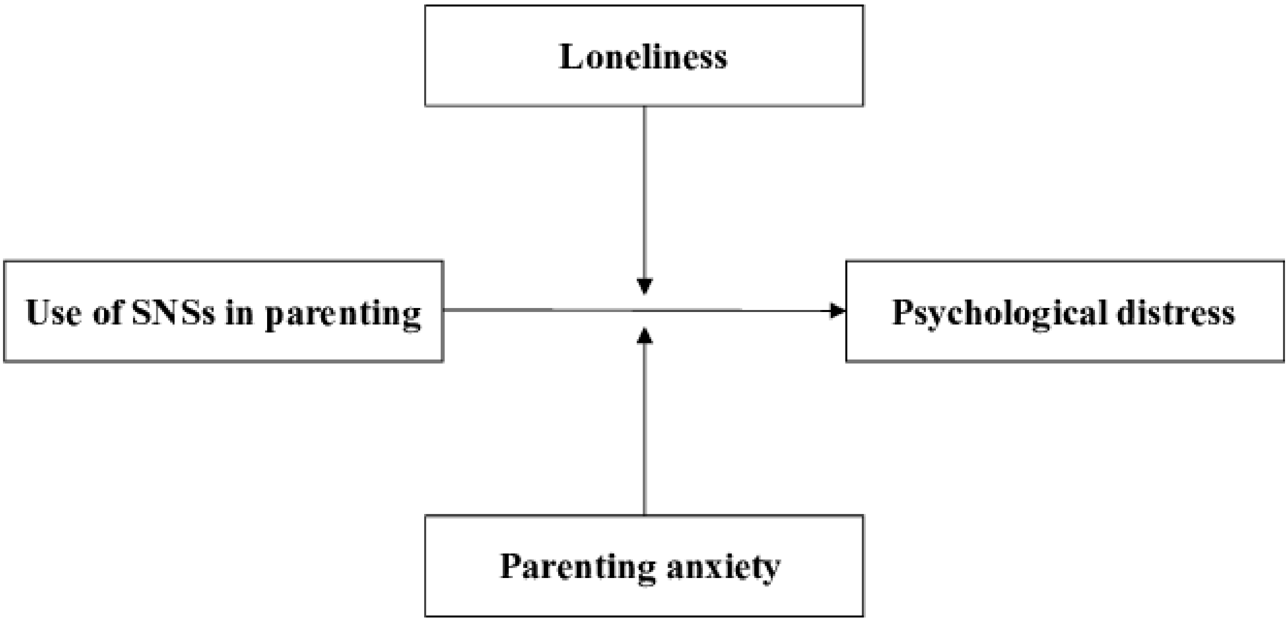
This study elucidates the moderating effects of loneliness and parenting anxiety on the relationship between SNS use and psychological distress among mothers and fathers of young children. This study focuses on the individual experiences of fathers and mothers, as it is predicted that their parenting roles differ qualitatively owing to sociocultural and biological factors, despite sharing commonalities as parents. In Japan, there is a strong gender role division where fathers are seen as responsible for work outside the home, while mothers are responsible for household chores and child-rearing duties [36]. As of 2021, surveys on parenting time in Japan reveal a significant disparity in the time spent on child rearing, with wives contributing substantially more time than husbands [37].

In addition, it is generally observed that women engage in the exchange of support on social media more frequently than men [38]. While it is widely recognized that mothers use social media to share information and support regarding child-rearing [5], social media platforms specifically targeting fathers are limited [39], indicating a gender disparity in web-based parenting resources. Therefore, it is crucial to conduct analyses that consider gender differences. Moreover, lonely individuals may lack a sense of fulfillment from social relationships on social media [17,18]. Upward comparisons, which are more likely to occur on these platforms, may particularly harm the mental health of individuals with parenting anxieties [24-26]. These risks can affect both fathers and mothers. Accordingly, we constructed a hypothetical conceptual model (Figure 1), and the following hypotheses were formulated:

- Hypothesis 1: Mothers use SNSs for parenting more frequently than fathers.
- Hypothesis 2: Only when mothers and fathers have high levels of parenting anxiety, frequent SNS use for parenting is associated with high psychological distress.

- Hypothesis 3: Only when mothers and fathers have high levels of loneliness, frequent SNS use for parenting is associated with high psychological distress.

Figure 1. Hypothetical conceptual model. SNS: social networking site.



Methods

Study Design

This study used a cross-sectional design with a closed web-based questionnaire. To ensure the quality and transparency of research, the work employed the Survey Reporting Checklist (CROSS) developed by Sharma et al [40] and the CHERRIES (Checklist for Reporting Results of Internet E-Surveys) developed by Eysenbach [41]. This study reports a subset of data from the “Information Behavior on Social Networking Services Among Parents Raising Infants” survey.

Operational Definitions

In this study, SNSs were defined as communication platforms where participants can consume, produce, and interact with a stream of content generated by connections on the site [42]. Specific SNSs considered were X (formerly Twitter), Instagram, Facebook, and YouTube, taking into account the context of Japan. LINE, which is widely known in Japan, was excluded from this category owing to its limited use of the feed function characteristic of SNSs and its primary use as a tool for routine communication with acquaintances. The use of SNSs for parenting was operationally defined as usage to gather information related to parenting, monitoring other families, and building social relationships.

Participants

This study included 429 parents of 0- to 3-year-old children. The eligibility criteria required that the participants were actively parenting at least 1 child aged between 0 months and 3 years and 11 months at the time of the survey. There were no restrictions based on the health status of the parents or children or on family structure. The exclusion criterion was the absence of any experience using SNSs for parenting-related activities.

Sampling was conducted using convenience sampling from the national panel managed by Cross Marketing, Inc, a web-based survey company in Japan, which manages more than 5 million active web users and provides academic web-based survey services to a wide range of demographic groups. The company’s active panel comprises a wide variety of web users, creating a large-scale monitor that is not biased by influx from specific sites or advertisements. The recruitment process began with a one-time survey invitation sent by the survey company to a randomly selected group of approximately 2000 individuals deemed eligible for this study. Those who received the invitation first answered a question regarding their child’s age; inconsistent responses were excluded. Subsequently, individuals who agreed to participate in the study were directed to the web-based questionnaire link via a click of an “agree” button after reading the research request document prepared by the authors. The study aimed to include 200 fathers and 200 mothers, and distribution continued randomly until this goal was reached, at which point the survey distribution was halted.

Data Collection

Data were collected in August 2023 using a web-based survey. The questionnaire was developed and administered by the authors using the Qualtrics web-based survey system [43]. Qualtrics ensures data management through encryption, redundancy, continuous monitoring, and single sign-on, and is FedRAMP-authorized as well as ISO27001-certified. The questionnaire was designed by the authors to be user-friendly and was pretested to avoid design issues. Participants who completed the questionnaire received a web-based reward based on Cross Marketing, Inc standards.

Measures

The survey included sections on SNS use, SNS use for parenting, psychosocial characteristics, and basic demographics. The questionnaire was developed through the following process.

First, the content validity of the questionnaire was reviewed by a researcher (RO) with extensive experience in public health nursing practice and research, who also has experience in child-rearing support. Potential common errors in the questionnaire (eg, double-barreled questions, confusion, and leading questions) were checked by a representative from Cross Marketing Inc, who has extensive experience in designing web-based surveys, and appropriate revisions were made. In addition, face validity for all survey items was ensured through pretesting with 4 university students and 5 mothers with infants and older children. Owing to the limitations of the pretest sample size, the factor structure and internal consistency were confirmed in the main survey. Details of the survey items are shown in Multimedia Appendix 1.

SNS Use

Data were collected with regard to the possession of digital devices (smartphones, tablets), currently used SNSs (X, Instagram, Facebook, YouTube, LinkedIn, etc), and overall frequency of SNS usage by participants. The frequency of SNS usage, based on previous research [34], considered both active and passive usage aspects. Active usage was mainly related to information production (eg, posting updates on SNSs, sending private messages), while passive usage concerned information consumption (eg, scrolling through news feeds and viewing other users' profiles). The frequency of active and passive SNS usage over the past week was assessed, with response options ranging from 1 (not at all) to 8 (more than 10 times a day).

SNS Use for Parenting

Considering the lack of a specific scale to measure SNS use for parenting, original measurement items were created. Based on previous studies [44] and interview data from mothers in the parenting phase, 3 categories were formulated for SNS use in parenting: "information gathering," "monitoring," and "connecting." Each category consisted of 2 items, with "information gathering" including items related to gathering information on parenting and children. "Monitoring" included tracking other families' parenting and their children's conditions, while "connection" included making friends in parenting and communicating with peers in parenting. Items were measured on a 5-point scale (1=never use to 5=always use), with the mean value calculated within a range of 1‐5, and higher scores indicating greater subjective frequency of use.

An exploratory factor analysis using maximum likelihood promax rotation was conducted to determine the handling of the scale for SNS use in parenting. The applicability of factor analysis was confirmed by ensuring that the Kaiser-Meyer-Olkin measure was greater than 0.8, and Barlett's test of sphericity was significant. The number of factors was determined by examining the scree plot and using eigenvalues greater than 1. A factor loading of 4.0 or higher was employed as the criterion for item selection. Reliability was assessed by calculating Cronbach α.

Table 1 shows the results of the exploratory factor analysis. Bartlett's sphericity test for the 6 items measuring SNS use in parenting was significant (χ^2_{15}=2319.43; *P*<.001), and Kaiser-Meyer-Olkin values were above 0.8, confirming the suitability of the data for exploratory factor analysis. Exploratory factor analysis with maximum likelihood promax rotation revealed a 1-factor structure for the 6 items (Table 1). An attempt was made to confirm a 3-factor structure considering the 3 categories, but eigenvalues for the factors after the first were lower than 1, indicating that the model was not suitable. Therefore, the study measured SNS use for parenting by employing the total score of all items, with a Cronbach α value of 0.92.

Table . Exploratory factor analysis (N=429).

Statements	Factor loading	Communality
Parenting insights browsing	0.93	0.86
Observing childhood moments	0.91	0.82
Gathering parenting-related information	0.80	0.65
Gathering child-related information	0.78	0.61
Building a parenting community	0.72	0.52
Communication among parenting peers	0.72	0.52

Psychosocial Factor

Psychological Distress

The Japanese version of the K10 scale developed by Kessler et al [45,46], a globally recognized gold standard screening tool for mood and anxiety disorders in the general population, was used to measure the level of psychological distress but not in screening for mental disorders; therefore, no cutoff value was applied. Higher scores indicated greater levels of psychological distress. Sample items were rated on a 5-point Likert scale (1=not at all to 5=all the time), and the mean was calculated within a range of 1‐5. Cronbach α value for this study was 0.95.

Parenting Anxiety

A subscale of the Parenting Emotions Scale developed in Japan [47] was employed to measure parenting anxiety. The parenting anxiety subscale, one of the negative emotion subscales, includes aspects of anxiety about the child's development and parenting methods, with established reliability and validity [47]. For example, items such as "Feeling unsure about how to parent" were rated on a 4-point Likert scale (1=not at all to 4=often), with the mean value calculated within a range of 1‐4, and higher scores indicating greater parenting anxiety. Cronbach α value for this study was 0.86.

Loneliness

The Japanese version of the 10-item short form of the UCLA Loneliness Scale (Version 3) [48,49], validated among mothers of infants, was employed. Items were rated on a 4-point Likert scale (1=not at all to 4=always), with the mean value calculated within a range of 1 - 4, and higher scores indicating greater feelings of loneliness. Cronbach α value for this study was 0.79.

Social Support

A subscale related to support from significant others from the Japanese version of the Multidimensional Scale of Perceived Social Support [50-53] was also used. It includes 4 items rated on a 7-point Likert scale (1=very strongly disagree to 7=very strongly agree), with higher scores indicating higher perceived social support. Example items include “I have someone with whom I can share joys and sorrows.” The average score for each subscale was calculated on a scale of 1 - 7. The reliability and validity of this scale have been previously established [50]. Cronbach α value for this study was 0.91.

Participant Characteristics

Data were collected on participants’ age, number of children, age of youngest child, cohabiting family members, occupation, level of education, subjective economic status, and division of childcare and housework.

Statistics

Initially, descriptive statistics were first applied for all variables in the study, stratified by fathers and mothers. To identify differences between variables for fathers and mothers, *t* tests or chi-square tests were performed. Thereafter, separate multiple regression models were constructed for mothers and fathers, with psychological distress as the outcome variable and SNS use for parenting, parenting anxiety, and loneliness as predictor variables. Interaction terms between SNS use for parenting and parenting anxiety and loneliness were included in the model to examine their interactions. Covariates included parental age, which influences affinity for digital devices; number of children and age of youngest child, which influence childcare realities; subjective economic status, which was found to be related in univariate analyses; and active or passive use, reflecting the impact of SNS use in contexts other than parenting. Comprehensive checks were undertaken to ensure that the necessary assumptions for the use of multiple regression analysis were met. First, the skewness and kurtosis of the dependent variable were evaluated to ensure that the analysis was not affected by nonnormality. Second, the linear relationship between the dependent and independent variables was visually assessed using scatter plots. Third, the Durbin-Watson ratio was confirmed to be around 2 to ensure the independence of the observations. Fourth, normality and homoscedasticity of errors were visually assessed using normal Q-Q plots of residuals and studentized residuals. Fifth, multicollinearity was assessed by ensuring that the variance inflation factor for independent variables was lower than 10. Moreover, for significant interaction terms, a simple slope analysis [54] was conducted by plotting psychological distress scores at low (−1 SD) and high (+1 SD) levels of loneliness or parenting anxiety at low and high levels of SNS use for parenting.

Statistical analyses were performed using JMP Pro 16.0 (SAS Institute) with a significance level of 5%. Sample size was calculated using G-power, assuming an effect size (f_2) of 0.15 (medium), α error probability of .05, power of 0.8, and a number of predictors of 24, confirming that a sample size of 124 or more was required. In addition, in the analysis, when missing values for psychological distress, loneliness, parenting anxiety, and perceived social support were less than half of the items, missing values were imputed by predicting values based on the least squares method using the nonmissing parts of each scale. If more than half the items were missing, they were treated as missing data. Participants with missing values in nonpsychological scale items were also treated as having missing data. While participants with missing values were included in the analysis because of research ethics, they were excluded from the creation of multiple regression models. During this process, the usage of parenting-related SNSs and other psychological scale scores was compared between participants with missing data and those with no missing data, ensuring that there were no significant differences.

Ethical Considerations

Informed consent and opt-out procedures were implemented as follows. First, individuals referred by the web survey company were provided with written information detailing the study's purpose, the voluntary nature of participation, the absence of any penalties for nonparticipation, the right to refuse to answer, the maintenance of anonymity, the use of data solely for research purposes, and the strict management of personal information. Second, participants were given the choice to either agree or decline participation in the survey; only those who clicked the consent button were considered to have consented to participate, thereby ensuring the opportunity to opt out. In addition, all survey questions included an option to decline to answer. Respondents’ personal information was not disclosed to the researchers, and the data remained fully anonymized, ensuring that researchers had no means of identifying individuals. Participants received digital reward points as compensation for their effort in completing the survey, in accordance with the web survey company’s guidelines. This study was conducted with the approval of the ethics committee for research involving human subjects at Toyama Prefectural University (approval number: R5-16, dated August 10, 2023).

Results

Descriptive Statistics

Among those who returned the survey, responses from 429 individuals with experience using SNSs for parenting and no missing data on SNS use were analyzed. Table 2 illustrates the descriptive statistics and differences between mothers (205 individuals; 205/429, 47.8%) and fathers (224 individuals; 224/429, 52.2%). The differences were related to parental age, age of the youngest child, employment status, educational level, and division of childcare and housework. No differences in psychosocial factors were determined between fathers and mothers.

Table . Descriptive statistics and gender differences (N=429).

	Mothers (n=205)		Fathers (n=224)		*t* test (*df*)	Chi-square (*df*)	*P* value
	n (%)	Mean (SD)	n (%)	Mean (SD)			
Demographics							
Parent’s age (years)[a]	—[b]	34.5 (4.83)	—	39.8 (6.76)	8.85 (394)	—	<.001
Number of children					1.72 (427)	—	.09
1	94 (46)	—	91 (41)	—			
2	87 (42)	—	92 (41)	—			
≥3	24 (12)	—	41 (18)	—			
Youngest child’s age					2.31 (427)	—	.02
Infant	71 (35)	—	53 (24)	—			
1 year	61 (30)	—	72 (32)	—			
2 years	44 (21)	—	59 (26)	—			
3 years	29 (14)	—	40 (18)	—			
Cohabiting family members							
Partner	196 (96)	—	220 (98)	—	—	2.47 (2)	.12
Own family members	12 (6)	—	13 (6)	—	—	0.48 (2)	.79
Partner’s family members	9 (4)	—	4 (2)	—	—	2.47 (2)	.12
Occupational status					—	227.06 (3)	<.001
Full-time worker	59 (29)	—	220 (98)	—			
Part-time worker	23 (11)	—	1 (0)	—			
Homemaker	76 (37)	—	1 (0)	—			
On maternity or childcare leave	47 (23)	—	2 (1)	—			
Educational level (highest educational qualifications) [c]					—	33.91 (3)	<.001
Junior high school/high school graduate	24 (12)	—	28 (13)	—			

	Mothers (n=205)		Fathers (n=224)		*t* test (*df*)	Chi-square (*df*)	*P* value
	n (%)	Mean (SD)	n (%)	Mean (SD)			
Junior college/vocational school graduate	63 (31)	—	23 (10)	—			
University/graduate school graduate	117 (57)	—	172 (77)	—			
Subjective economic status					–0.95 (427)	—	.34
Very concerned	23 (11)	—	35 (15)	—			
Somewhat concerned	90 (43)	—	89 (39)	—			
Slightly concerned	82 (39)	—	97 (42)	—			
Not concerned at all	14 (7)	—	9 (4)	—			
Division of household and childcare responsibilities	—	74.8 (18.46)	—	34.4 (17.86)	–23.06 (427)	—	<.001
Psychosocial factor							
Psychological distress[d]	—	2.12 (0.96)	—	2.09 (1.03)	–0.30 (423)	—	.77
Loneliness[e]	—	2.31 (0.49)	—	2.35 (0.51)	0.80 (424)	—	.43
Parenting anxiety[f]	—	2.44 (0.70)	—	2.37 (0.71)	–1.09 (424)	—	.28
Perceived social support[g]	—	4.98 (1.48)	—	4.90 (1.29)	–0.62 (426)	—	.53

[a] Missing values: n=35 (mother: n=13; father: n=22).

[b] Not applicable.

[c] Missing values: n=2 (mother: n=1; father: n=1).

[d] Missing values: n=4 (mother: n=2; father: n=2).

[e] Missing values: n=5 (mother: n=1; father: n=2).

[f] Missing values: n=3 (mother: n=1; father: n=2).

[g] Missing value: n=1 (mother: n=1).

Gender Differences in SNS Use

Table 3 presents the descriptive statistics and differences in SNS use between fathers and mothers. As regards digital device ownership, a significantly greater proportion of fathers owned a computer than mothers ($\chi^2_1=25.12$; $P<.001$). In terms of SNS usage, a significantly higher percentage of mothers used Instagram than fathers ($\chi^2_1=41.87$; $P<.001$). The frequency of SNS use showed that mothers were significantly more passive than fathers ($t_{427}=-2.45$; $P=.006$).

Table . Gender differences in social networking sites use (N=429).

	Mothers (n=205)		Fathers (n=224)		*t* test (*df*)	Chi-square (*df*)	*P* value
	n (%)	Mean (SD)	n (%)	Mean (SD)			
Having digital devices [a]							
Having smartphones	203 (99)	—[b]	218 (97)	—	—	1.70 (2)	.19
Having tablets	45 (22)	—	72 (32)	—	—	5.61 (2)	.02
Having computers	86 (42)	—	148 (66)	—	—	25.12 (2)	<.001
SNS[c] use [a]							
X (Twitter)	96 (47)	—	106 (47)	—	—	0.01 (2)	.92
Instagram	147 (72)	—	91 (41)	—	—	41.87 (2)	<.001
Facebook	65 (32)	—	79 (35)	—	—	0.61 (2)	.44
Youtube	130 (63)	—	153 (68)	—	—	1.14 (2)	.29
TikTok	30 (15)	—	29 (13)	—	—	0.26 (2)	.61
Nonuse	26 (13)	—	35 (16)	—	—	0.76 (2)	.38
Frequency of SNS use							
Active use	—	3.37 (2.5)	—	3.24 (2.49)	–0.53 (427)	—	.59
Passive use	—	5.47 (2.4)	—	4.82 (2.45)	–2.78 (427)	—	.006
SNSs for parenting							
Gathering parenting-related information	—	2.89 (1.25)	—	2.33 (1.25)	–4.62 (427)	—	<.001
Gathering child-related information	—	2.79 (1.21)	—	2.29 (1.23)	–4.24 (427)	—	<.001
Parenting insights browsing	—	2.49 (1.27)	—	2.18 (1.23)	–2.61 (427)	—	.01
Observing into childhood moments	—	2.56 (1.25)	—	2.16 (1.24)	–3.33 (427)	—	.001
Building a parenting community	—	2.02 (1.33)	—	1.96 (1.22)	–0.49 (427)	—	.63

	Mothers (n=205)		Fathers (n=224)		*t* test (*df*)	Chi-square (*df*)	*P* value
	n (%)	Mean (SD)	n (%)	Mean (SD)			
Communication among parenting peers	—	2.02 (1.33)	—	1.96 (1.22)	–0.27 (427)	—	.79
Total scale	—	2.46 (1.02)	—	2.15 (1.08)	–03.04 (427)	—	.003

[a] Multiple selection.

[b] Not applicable

[c] SNS: social networking site.

Regarding the frequency of SNS use for parenting, mothers were significantly more likely than fathers to gather parenting (t_{427}=−4.62; *P*<.001) and child-related information (t_{427}=−4.24; *P*<.001), browse parenting insights (t_{427}=−2.61; *P*=.01), and observe childhood moments (t_{427}=−3.33; *P*=.001). The mean scores for the frequency of SNS use for parenting, divided by the number of items, were 2.15 (SD 1.08) for fathers and 2.46 (SD 1.02) for mothers. An independent *t* test indicated that mothers had significantly higher scores than fathers (t_{427}=−3.04; *P*=.003).

The Effect of SNS Use for Parenting on Psychological Distress

Multiple regression models were created for both mothers and fathers to explain psychological distress with SNS use for parenting, loneliness, parenting anxiety, and covariates (Table 4). The model was constructed for mothers ($F_{12, 177}$=11.78; *P*<.001; R^2=0.44) and fathers ($F_{12, 189}$=15.43; *P*<.001; R^2=49.5). In the mothers model, a significant interaction effect was found only between parenting anxiety and SNS use for parenting (*b*=0.247, SE 0.091; *P*=.008). Meanwhile, in the fathers model, significant interaction effects were found between loneliness (*b*=0.324, SE 0.127; *P*=.01) and parenting anxiety (*b*=0.144, SE 0.069; *P*=.04) following SNS use for parenting.

Table . The effect of social networking sites use for parenting on psychological distress (N=392).

	Mothers (n=190)[a]						Fathers (n=202)[b]					
	b[c]	SE	95% CL[d]		β[e]	*P* value	*b*	SE	95% CL		β	*P* value
			LL[f]	UL[g]					LL	UL		
Main effect												
Loneliness	0.49	0.14	0.21	0.77	0.25	.001	0.40	0.16	0.07	0.72	0.20	.02
Parenting anxiety	0.51	0.09	0.33	0.68	0.37	<.001	0.42	0.10	0.23	0.60	0.29	<.001
SNS[h] use for parenting	0.13	0.06	0.00	0.26	0.14	.04	0.23	0.07	0.09	0.36	0.24	.001
Moderation effect												
SNS use for parenting × loneliness	−0.17	0.12	−0.41	0.08	−0.09	.18	0.32	0.13	0.07	0.58	0.16	.01
SNS use for parenting × parenting anxiety	0.25	0.09	0.07	0.43	0.19	.008	0.14	0.07	0.01	0.28	0.13	.04
Covariates												
Parent’s age	−0.01	0.01	−0.03	0.02	−0.04	.54	0.00	0.01	−0.02	0.01	−0.02	.70
Number of children	−0.01	0.09	−0.18	0.16	−0.01	.89	0.07	0.08	−0.08	0.23	0.05	.33
Youngest child’s age	−0.04	0.06	−0.15	0.08	−0.04	.53	0.03	0.05	−0.07	0.14	0.03	.53
Subjective economic status	−0.16	0.07	−0.30	−0.01	−0.13	.03	−0.30	0.08	−0.45	−0.16	−0.23	<.001
Frequency of passive use of SNS	0.06	0.03	0.00	0.11	0.14	.03	0.00	0.03	−0.05	0.06	0.01	.90
Frequency of active use of SNS	−0.02	0.02	−0.07	0.03	−0.05	.42	0.00	0.03	−0.06	0.05	0.00	.96
Perceived social support	−0.05	0.05	−0.14	0.04	−0.08	.28	−0.15	0.06	−0.27	−0.04	−0.19	.009
Intercept	2.97	0.46	2.05	3.88	0.00	<.001	3.44	0.44	2.59	4.30	0.00	<.001

[a] Model fit: *F*=111.78; model *P* value <.001; R^2=0.44; adjusted R^2=0.41.

[b] Model fit: *F*=15.43; model *P* value <.001; R^2=0.49; adjusted R^2=0.46.

[c] *b*: estimate.

[d] CL: confidence limit.

[e] β: standardized estimate.

[f] LL: lower limit.

[g] UL: upper limit.

[h] SNS: social networking site.

Moderation Effects of Loneliness and Parenting Anxiety

The results of the simple slope analysis are illustrated in Figures 2 and 3. The mothers model showed that, at higher levels of parenting anxiety, SNS use for parenting was related to psychological distress (*b*=0.304, SE 0.090, β=.317; *P*<.001) but not at lower levels (*b*=−0.044, SE 0.090, β=−.046; *P*=.63). In the fathers model, SNS use for parenting was related to psychological distress at higher levels of parenting anxiety (*b*=0.330, SE 0.069, β=.346; *P*<.001) but not at lower levels (*b*=0.127, SE 0.097, β=.133; *P*=.19). In addition, SNS use for parenting was associated with psychological distress in fathers at higher levels of loneliness (*b*=0.390, SE 0.098, β=.409; *P*<.001) but not at lower levels (*b*=0.067, SE 0.089, β=.070; *P*=.45).

Figure 2. Simple slope analysis: interaction of parenting anxiety and use of SNSs in parenting predicting psychological distress. SNS: social networking site.

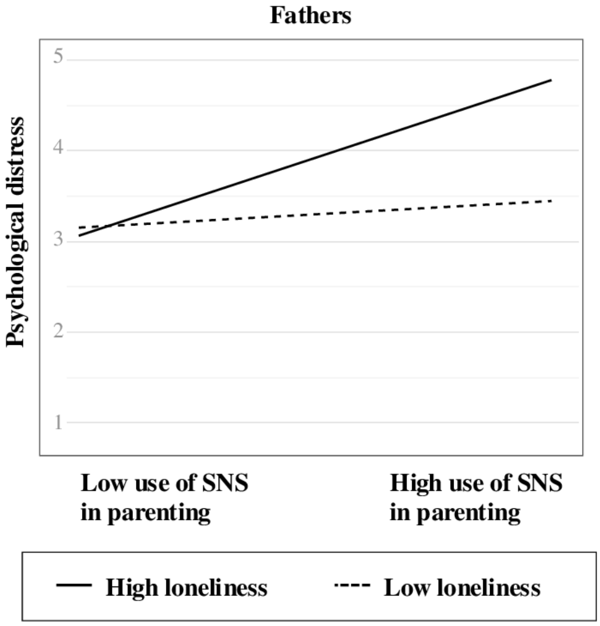
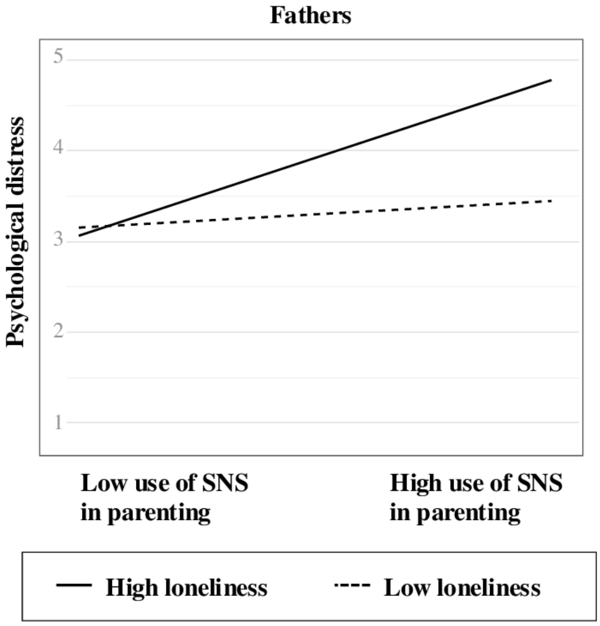


Figure 3. Simple slope analysis: interaction of loneliness and use of SNSs in parenting predicting psychological distress. SNS: social networking site.



Discussion

Major Findings

This study examined the moderating influence of loneliness and parenting anxiety on the relationship between SNS use for parenting and psychological distress among mothers and fathers of young children. We observed that mothers used parenting-related SNSs more frequently than fathers, primarily for gathering parenting information and monitoring others' parenting activities. In addition, parenting anxiety moderated the relationship between SNS use for parenting and psychological distress in both genders, whereas the effect of loneliness was discernible only in fathers. Therefore, hypotheses 1 and 2 were fully supported and hypothesis 3 was partially supported. This novelty in our findings suggests the presence of both common and divergent elements in dynamics through which SNS use in parenting precipitates psychological distress in fathers and mothers. Previous research on SNS use and mental health has shown that the quality of interactions on SNSs (positive or negative) [55] and the attitude toward their use (passive or active) [56] can result in either positive or negative impacts on mental health. A systematic review of the relationship between SNS use, loneliness, and social anxiety [29] found that high levels of loneliness and social anxiety are correlated with problematic SNS use. However, it also highlighted the need for studies that simultaneously address these factors to explore their complex interrelationships. Most studies focusing on SNS use, loneliness, and anxiety have concentrated on adolescents, where SNS research is prevalent, leaving limited insights into both fathers and mothers in the context of early childhood parenting. This study extends previous findings by specifically examining SNS use in parenting and simultaneously addressing loneliness and anxiety to explore their moderating effects.

First, the moderating role of parenting anxiety was substantiated for both fathers and mothers regarding the association between SNS use in parenting and psychological distress. This suggests that parents struggling with heightened parenting anxiety may inadvertently exacerbate their psychological distress when using SNSs to cope with parenting challenges. An earlier study demonstrated that using information from smart devices to alleviate parenting concerns can paradoxically amplify anxiety when those concerns are severe [44]. Our findings align with previous research, hinting at the limited benefit for highly anxious parents in seeking comfort through SNSs. The background of psychological distress experienced by fathers and mothers with high parenting anxiety owing to SNS use may be related to low parenting self-efficacy and self-esteem, which are correlated with anxiety [27]. It is conceivable that parents burdened with acute parenting anxiety lack buffers such as self-efficacy and self-esteem against negative web-based influences, making them more vulnerable to psychological distress. In addition, parents prone to parenting anxiety inherently possess neurotic traits, which may foster upward social comparisons on SNSs and lead to increased psychological distress [57].

Second, the moderating effect of loneliness was observed solely among fathers, indicating that only those with significant levels of loneliness showed a strong correlation between intensive SNS use for parenting and high psychological distress. In general, higher levels of loneliness correlate with lower socioeconomic status [58]. In Japan, a persistent belief in gender roles assigns work responsibilities to men and domestic and child-rearing responsibilities to women [36]. Fathers of young children may identify strongly with the role of breadwinner and feel a deep sense of duty and pride. For fathers who feel isolated owing to socioeconomic constraints, SNS platforms that facilitate peer comparison [23] may exacerbate feelings of inadequacy regarding their family parenting practices, thus fostering psychological distress. Similarly, fathers who experience loneliness following strained partner relationships may face psychological distress from upward comparisons to seemingly idyllic families on SNSs. Furthermore, the lack of SNS platforms that naturally facilitate information sharing and camaraderie among fathers in the parenting domain may have also contributed to the distress experienced by lonely fathers. While social media and platforms for pregnant women and mothers are prevalent, there is a dearth of resources for fathers, including face-to-face peer support [39]. On more open platforms such as Instagram, X, and Facebook, fathers may find opportunities to connect with their peers, but in environments in Japan with strong gender-role divisions [36], they are likely to encounter more mother-centered information exchange. The use of SNSs in the context of fathers seeking connections and information sharing in parenting may have exacerbated psychological distress by creating a sense of alienation among them.

It is worth noting that no moderating effect of loneliness among mothers could be determined. This suggests that, regardless of loneliness, increasing SNS use for parenting among mothers is indicative of psychological distress. Previous studies have suggested that women experience significantly higher levels of depression owing to social comparisons on social media than men [59]. Mothers, as opposed to fathers, may be more susceptible to the mental health detriments of SNS use, regardless of whether or not they experience loneliness. In addition, the literature presents conflicting views on whether SNSs contribute positively by fostering desired social relationships [60,61] or negatively by forming unsatisfactory social connections for lonely individuals [18]. Previous research demonstrated that, for mothers in the parenting phase, the extent of their social networks on SNSs is inversely related to feelings of loneliness [62], suggesting that SNSs may not necessarily accentuate negative effects for lonely mothers.

Furthermore, given that this study is cross-sectional, there is the possibility of a reverse causal relationship, where parents with high levels of loneliness and parenting anxiety may engage more actively in SNS use for parenting because of their high psychological distress. Previous research reported that individuals with neurotic tendencies, which precede psychological distress, tend to use social media excessively or compulsively [63]. It is possible that parents experiencing high psychological distress, along with loneliness and parenting anxiety, may inherently possess neurotic tendencies and, consequently, may frequently use SNSs for parenting.

Implications

This study highlights the differences in the moderating effects of loneliness and parenting anxiety on the relationship between SNS use and psychological distress among parents. It was observed that both fathers and mothers experiencing heightened levels of loneliness or parenting anxiety reported that SNS use in parenting activities was associated with increased psychological distress. This observation suggests that SNS use may not always be beneficial for parents experiencing loneliness or parenting anxiety, and it might be useful for professionals to discuss the potential drawbacks of relying heavily on SNSs for parenting support. Conversely, it is also suggested that parents experiencing high psychological distress, along with loneliness and parenting anxiety, may use SNSs frequently for parenting. As SNSs might serve as necessary support for parents in distress, it is crucial for professionals to support its moderate use while considering the limitations of its benefits. Given that SNS use for parenting is more common among mothers, it is important for professionals to recognize mothers as a group potentially more susceptible to both the positive and negative impacts of SNS use. Finally, enhancing SNS platforms specifically for lonely fathers as a parenting resource may be beneficial.

Limitations

This study has several limitations. First, owing to its cross-sectional design, causality cannot be established. Second, the study relies on self-reported questionnaires, which does not eliminate the possibility of information bias. Third, the use of convenience sampling by a specific survey company in Japan may have introduced selection bias. Specifically, the sample may have been biased toward those with a high affinity for web-based information and high information literacy, thus limiting the generalizability of the results. Fourth, the study did not use a validated scale to measure SNS use for parenting, and although it considered real-life parenting situations through interview data, it lacks clear conceptualization and validation of construct validity, limiting the accuracy of the phenomenon measured. Fifth, the study did not consider the information literacy of the participants. Future research should use scales that more accurately measure the concept of SNS use in parenting. In addition, because a bidirectional causal relationship between SNS use and mental health is assumed, longitudinal studies that test for causality could provide higher-resolution insights into SNS use and parenting mental health.

Conclusions

This study examined the moderating effects of loneliness and parenting anxiety on the relationship between SNS use and psychological distress among parents of young children. The moderating effect of parenting anxiety on this relationship was confirmed for both fathers and mothers, but the moderating effect of loneliness was established only for fathers. Given that different mechanisms underlie the loneliness experienced by fathers and mothers, the impact of SNS use on mental health may differ. Health and medical professionals might well need to tailor guidelines for SNS use in parental support taking into account gender. For fathers, a cautious approach to SNS use when feeling lonely is recommended, while for mothers, guidance on how to effectively balance SNS use with other support resources based on the level of parenting concerns may be needed.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Questionnaire.
[DOCX File, 50 KB - pediatrics_v7i1e59029_app1.docx]

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Abbreviations

SNS: social networking site

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Original Paper

Chinese Women’s Concept of Childbirth Based on the Social Media Topic “What Does Childbirth Mean to a Woman”: Content and Thematic Analysis

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Abstract

Background: In recent years, women’s fertility desire has attracted increasing attention in China.

Objective: This study aims to detect attitudes toward giving birth among young female users on Douban, a very popular Chinese social media platform.

Methods: A total of 2634 valid posts from 2489 users discussing the topic “What does childbirth mean to a woman” on Douban were crawled and retained for analysis. We utilized content and thematic analysis methods to capture users’ concepts of childbirth.

Results: The findings reveal that a significant majority of users conveyed generally neutral (1060/2634, 40.24%) or negative (1051/2634, 39.90%) attitudes toward childbirth, while only about one-fifth of users expressed positive (523/2634, 19.86%) sentiments. Notably, posts with negative attitudes garnered more replies and likes, and the proportion of posts expressing negativity exhibited fluctuations over time. Health risk (339/2634, 12.87%) emerged as the most frequently cited aspect of childbirth cost, with subjective happiness and the fulfillment of mental needs identified as primary benefits. Surprisingly, only a minimal number of posts (10/2634, 0.38%) touched upon the traditional objective benefits of raising children for old-age care. Thematic analysis results suggest that discussions about fertility on social media platforms might contribute to an exaggerated perception of health risks among women. Additionally, a lack of knowledge about childbirth was observed, partially attributable to longstanding neglect and avoidance of communication on these matters, likely influenced by traditional cultural biases. Moreover, there is a prevailing assumption that women should naturally sacrifice themselves for childbirth and childcare, influenced by the idealization of the female figure. Consequently, women may harbor hesitations about having a baby, fearing the potential loss of their own identity in the process.

Conclusions: The results indicate a shift in the perception of childbirth among modern Chinese women over time, influenced by their increasing social status and the pursuit of self-realization. Implementing strategies such as public education on the health risks associated with pregnancy and delivery, safeguarding women’s rights, and creating a supportive environment for mothers may enhance women’s willingness to undergo childbirth.

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KEYWORDS

childbirth willingness; social media; risk perception; childbirth cost; childbirth benefit

Introduction

The academic community in demographics has centered its attention on fertility issues, and China is currently grappling with a significant challenge in population development due to its low fertility rate. In August 2020, the National Health Commission of the People's Republic of China issued a document highlighting that the low fertility rate has emerged as a major risk impacting the balanced development of the country's population. To mitigate the consequences of population aging and the decline in demographic dividends resulting from the low fertility rate, China introduced the "Universal Two-Child Policy" in January 2016, followed by the "Three-Child Policy" in May 2021. The implementation of these policies has elevated individual childbirth willingness as a crucial factor influencing the childbirth rate [1]. The determinants of childbirth are multifaceted and intricate; past research indicates that cultural norms and values play a substantial role in shaping both the concept and behavior associated with childbirth [2,3]. Research on the willingness to have a second child among Chinese women has indicated that cultural concepts play a pivotal role in influencing the decision to pursue a second child [4]. In the context of a highly "mediatized" modern societal culture, where the media not only exerts influence but also, to some extent, shapes cultural attitudes [5], it appears that women's fertility desires are more significantly impacted by media exposure compared with men [6].

In contemporary society, the internet has emerged as one of the foremost cultural media. As of June 2022, the number of internet users in China had surpassed 1.051 billion, with an adoption rate of 74.4% [7]. Serving as a crucial platform for individuals to articulate their perspectives, the internet fosters cultural diversity and the expression of values. This, in turn, influences personal attitudes toward marriage, inspiring individuals to seek independence, personal happiness, and a heightened awareness of emotional connection and respect for individuality [8]. The evolution of the internet is concurrently driving a shift in the concept of gender roles among rural residents, transitioning from traditional to modern perspectives. This influence is evident in both men and women, with a notably more pronounced effect on women compared with men [9]. Social media, as a novel form of online communication, provides users with an extensive platform for active participation. It embodies features such as engagement, openness, real-time communication, community-building, and connectivity [10]. Social interaction serves as a crucial mechanism by which media can shape fertility behaviors and concepts [11]. Consequently, the utilization of social media can influence people's perceptions of fertility and their intentions regarding it. Examining discussions about fertility on social media becomes valuable in gaining insights into the collective understanding of fertility among the populace.

In recent years, a growing number of women have been actively sharing comments on childbirth-related topics, including discussions about the "2-child" and "3-child" policies, expressing their personal insights and thoughts on the matter. A notable distinction is that the majority of discussions on foreign social media platforms exhibit a predominantly positive attitude toward childbirth [12,13]. Nevertheless, the discourse on fertility in China's social media landscape is characterized by a prevalence of antifertility sentiments [14]. On the one hand, the textual information available on the internet partially mirrors the childbirth concepts held by contemporary women. On the other hand, public opinion expressed on social media platforms may exert an influence on women's perceptions of childbirth, potentially diminishing their willingness to pursue childbirth [15,16]. In this study, content analysis was used to delineate the predominant attitudes evident in posts within a social media topic focused on childbirth. Additionally, the analysis aimed to identify the costs and benefits associated with childbirth that garnered attention and concern among the participants. Furthermore, thematic analysis was utilized to reveal the underlying childbirth themes embedded in the posts under this particular topic.

Methods

Sample

Selection of Research Platform

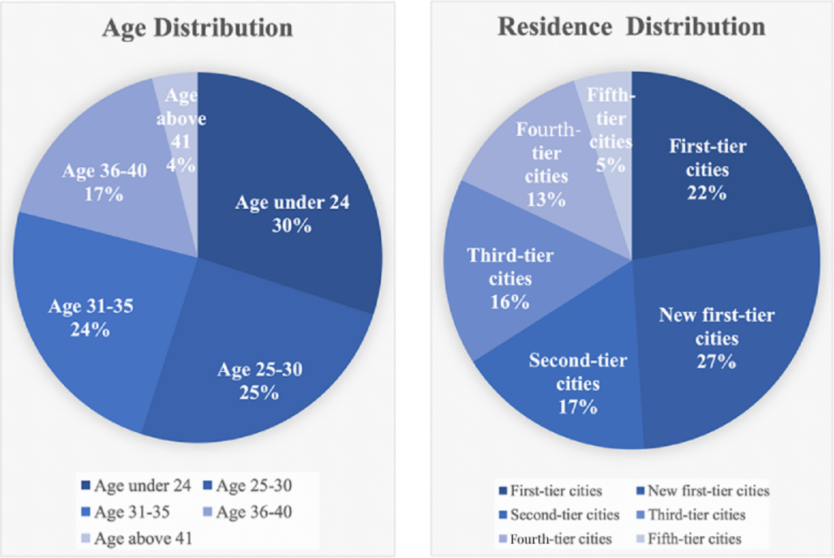
This paper selected Douban (Beijing Douwang Technology Co. Ltd.) as the source platform for data collection based on the considerations outlined in Textbox 1.

Textbox 1. Considerations for data collection.

1. To identify suitable social media data for the study, the research team conducted a screening of childbirth topics across various popular platforms in China, such as Weibo (Weibo Corporation), WeChat (Tencent Holdings Limited), TikTok (ByteDance), Bilibili (Bilibili Inc.), and Douban. It was observed that the feature settings of Douban and Weibo rendered them more conducive to text analysis. However, on Weibo, no topics closely aligned with our research objective were found, and the word count and content quality of Weibo posts were found to be inferior to those on Douban.

2. Douban stands out as a popular social media platform, particularly among young women of childbearing age. As per data from the "Qianfan" query platform, which serves as a digital economy market information and data terminal, Douban boasts a monthly active user base of 10.51 million. Notably, within this user demographic, women constitute a significant majority at 63.3%. In comparison to other social media platforms such as Weibo and WeChat, Douban exhibits a higher proportion of female users. The bulk of Douban's user demographic falls within the childbearing age range, with 30.07% aged under 24 years, 24.83% aged 24-30 years, and 24.25% aged 30-35 years. Additionally, 49.14% of users originate from first-tier or new first-tier cities. This demographic profile underscores that a significant proportion of Douban users are urban women of childbearing age. Consequently, their discussions on childbirth have the potential to reflect the attitudes and concerns toward childbirth among Chinese women to a considerable extent. It is noteworthy that many studies focusing on Chinese women have selected Douban as their research platform (Figure 1, [17-20]).

Figure 1. User groups in May 2022 according to the “Qianfan” query platform.



Selection of Research Topic

Among the numerous childbirth-related topics on Douban, this paper selected the one most pertinent to women’s concept of childbirth and with the highest number of posts. Specifically, the chosen topic is “What does childbirth mean to a woman.” Initiated in June 2020, this discussion has garnered significant engagement, accumulating 3655 posts as of August 5, 2022. Notably, the most popular post on this topic received 5596 likes. The substantial quantity and the evident quality of the posts led us to conclude that they met our inclusion standards.

Selection of Posts Under the Research Topic

This study focused on analyzing the discussions within the topic “What does childbirth mean to a woman,” and data were collected by crawling posts from June 10, 2020, to July 16, 2022. A total of 3403 raw posts from 2838 users were gathered, encompassing information such as post time, content, and likes. Additionally, permanent residence details were obtained for 2128 users. Recognizing the contextual nature of replies below the posts and the challenges associated with their identification and categorization, we opted to solely crawl the original posts. Replies beneath the posts were not included in the data collection process, acknowledging the potential complexity in comprehending their content without the necessary context from the original posts.

The crawled posts underwent a standardized screening and cleaning process, which unfolded in 2 steps. Initially, 2 categories of invalid data were systematically removed. The first category encompassed elements such as emojis, symbols, pictures, and blanks, which were deemed unsuitable for text analysis. The second category included irrelevant posts or those with an ambiguous attitude toward childbirth, such as advertisements, personal life records, ambiguous sentences, questions, and posts from men, among others. Following these criteria, a total of 460 posts were eliminated in the first step of the cleaning process. In the second step, for users who posted more than once, we analyzed their attitude toward childbirth. If all posts from the same user exhibited a consistent attitude, the post with the highest number of likes was retained. In cases where posts had the same number of likes, the one with the greater word count was preserved, and any remaining posts were eliminated. This approach aimed to distill the most representative content from users with multiple posts on the same topic. If a user’s attitude toward childbirth changed, the post with the highest number of likes under each different attitude was retained. For instance, if a user’s attitude shifted from positive to neutral and then to negative, 3 posts would be retained. Adhering to this criterion, a total of 309 posts were sequentially eliminated. Importantly, to maintain the focus on women’s concepts of childbirth, all posts where the posters identified as male were removed. While the data did not explicitly specify the gender of the posters, given the topic’s nature, the predominant female user base on Douban, and the thorough data cleaning process, it is argued that most of the retained posts after elimination originated from women. In the end, 2634 valid posts from 2489 users were retained for analysis.

Ethics Approval

To safeguard user privacy, this study used the practice of using the first letter of each word in the username to replace the full name. For English usernames, the first 3 letters were utilized. Additionally, the post time was appended after each post. The study adheres to ethics code H15009 and obtained approval from the Institutional Review Board at the Institute of Psychology at the Chinese Academy of Sciences.

Content Analysis Procedure

Content analysis aims to describe the prevailing attitudes of people toward childbirth and their concerns about the costs and benefits associated with childbirth. We referenced the methods from MacPherson et al [21] and Liu et al [22]. Two investigators (TY and YHW), with an in-depth understanding of Douban’s cultural environment, conducted the content analysis. Initially, the 2 researchers read 10% (340/3403) of the posts and then engaged in discussions to generate coding criteria for attitudes toward childbirth, the costs of childbirth, and the benefits of childbirth (Tables 1, 2 and 3). Subsequently, they randomly selected 50 posts to verify the saturation of the coding criteria.

Following that, both researchers independently coded all the data based on the coding criteria. During this process, they conducted regular cross-checks to ensure the consistency of their coding results, and any disagreements were adjudicated by the third researcher (NH). After that, quantitative descriptive results concerning childbirth attitudes, childbirth costs, and childbirth benefits were obtained.

Table 1. Coding criterion for attitudes toward childbirth.

Category and definition	Example
Negative	
• Willingness not to give birth or regret to give birth	• If I had known that childbirth would deprive the freedom to live an unconstraint life, to cook, to attend an exhibition, and to sleep late at weekends, to improve myself and play at night, I truly would not have a baby. [Poster and Time: CC, June 23, 2020, 16:21:08]
• Negative effects of childbirth	• It means my belly not going back to how it was before I was pregnant, anterior pelvic tilt, fat saddlebags, diastasis recti abdominis, sagging breasts and no freedom. [Poster and Time: LTGZ, October 12, 2020, 15:02:29]
• Sharing of personal experiences or stories that makes researchers feel subjective negative attitudes toward childbirth	• Today, a colleague returned to work after maternity leave. Her office cubicle was no longer available in the department. I asked if there was a need to register in new financial software for her, while the manager said he didn’t know. Then, the leader said to seal her employment separation certificate. What a sad story! [Poster and Time: PSH, April 27, 2021, 21:12:27]
Neutral	
• A view that agrees with both giving and not giving birth	• It means freedom and rights. As a woman, getting married or having children is only one of the choices. Whether to get married or not, whether to have children or not is our own choice. [Poster and Time: WZHYLDN, June 11, 2020, 15:07:05]
• Positive or negative effects of childbirth with no indication of personal willingness	• Having a baby means the loss of your own life. Isn’t taking care of children a part of your life? There is no accounting for tastes. Opportunities and costs are everywhere and need to be chosen. [Poster and Time: MISS, October 15, 2020, 08:43:17]
• Sharing of personal experiences or stories does not make researchers feel subjective attitudes toward childbirth	• I don’t have a child, but I have a friend who already has a baby. I see her state, there are gains and losses. What childbirth means to women may depend on their own state of mind/family attitudes. [Poster and Time: QHCD, November 28, 2020, 23:44:33]
Positive	
• Willingness to give birth	• Most likely, because my own family is incomplete, I personally want to get married and have children to start a new family. [Poster and Time: NKWKBKN, June 13, 2020, 04:31:45]
• Positive effects of childbirth	• For me, I am very happy, I have a sense of responsibility, one more person I care about, more maturity and stability. It is like a seed, growing with my care, and I have a sense of achievement and pride. [Poster and Time: XYCDXWB, June 11, 2020, 12:18:34]
• Sharing of personal experiences or stories makes researchers feel subjective positive attitudes toward childbirth	• I chatted with my friend last night, who was the same age as me. Her daughter is five years old, and I thought she would become complaining, grumpy and anxious like other mothers, but she doesn’t. She has a strong ability of introspection and awareness to change and adjust her state of mind. [Poster and Time: YYSH, June 17, 2020, 10:12:49]

Table 2. Coding criterion for the costs of childbirth.

Category	Posts (N=2634), n (%)	Definition	Example
Health risks	339 (12.87)	Severe reactions during pregnancy, physical pain of childbirth, sequelae of childbirth, and postpartum depression	*After giving birth, I still feel pains in some part of my body. The arms, knees and heels feel cold even in summer, so that I have to wear socks to sleep every day. As the mother of two daughters, I hope that they will choose not to marry and be infertile in the future.* [Poster and Time: QQWDBB, June 18, 2020, 10:14:30]
Constraint on freedom	232 (8.81)	Constraint on freedom and the lack of self-personality caused by childbirth	*It means losing freedom and self within an uncertain period.* [Poster and Time: LSSJL, July 17, 2020, 22:08:34]
Energy investment	162 (6.15)	Energy investment during pregnancy and parenting, such as the inability to sleep due to breastfeeding	*After being a mother, 24 hours a day is not enough. I don't want to sleep more, just want to fight for more time of my own.* [Poster and Time: CXMY, July 19, 2020, 08:50:38]
Influence on occupation	159 (6.04)	Workplace discrimination and the impact of childbirth on occupation	*Having a baby means your career will be forced to stagnate for 3 to 5 years. The tiredness and concern for children are really a major cost for women in the workforce.* [Poster and Time: BBQDJXK, April 18, 2021, 02:02:55]
Parenting responsibility	84 (3.19)	Responsibility for childbirth and education of children	*I don't know why. But when I see the topic, the first thought coming into my mind is responsibility, being responsible for myself and for my baby. If I can't do it well, I will not give birth. I don't yearn for giving birth. And I will not regret if I don't have any children.* [Poster and Time: CSG, June 11, 2020, 19:31:50]
Influence on appearance	84 (3.19)	Influence of appearance, figure, scar, etc	*After giving birth, it is easy to welcome the coming of a new baby but is difficult to face with the linea nigra, stretch marks on the thighs and flabby belly.* [Poster and Time: LKNT, May 1, 2021, 02:53:04]
Family relationship	69 (2.62)	Negative effects of family relationships caused by childbirth	*Many spouses will engage in emotional abuse. I have seen numerous examples around me, where after the wife gave birth, the husband became particularly distant and cold towards her.* [Poster and Time: DY, November 20, 2020, 01:38:22]
Financial investment	33 (1.25)	Financial investment due to childbirth	*My baby is 16 weeks old. I need to have the Down syndrome screening, Mediterranean anemia test, and an ultrasound. These tests will cost 953 yuan, which is really expensive......* [Poster and Time: PTR, December 30, 2021, 09:31:21]

Table 3. Coding criterion for the benefits of childbirth.

Category	Posts (N=2634), n (%)	Definition	Example
Parenting experience	196 (7.44)	Well-being, love, and happiness felt in the parenting process	*It is lucky for a woman to be able to deliver a baby, because only by giving birth can you know how happy it is to be a mother. A little baby who is as small as a meat ball can grow up after your care. And every progress he achieved will let you feel happy. I think companion is the best moment in the world.* [Poster and Time: HL, June 13, 2020, 17:37:32]
Self-growth	115 (4.37)	Growth of knowledge, the reconstruction of world outlook and values, and the maturity of self-character	*I think giving birth is an opportunity for a woman and a man to grow up. The deeper life goes, the greater the difference and the resistance to seeking common ground. Because of children, we have the desire to seek common ground, so the creativity to overcome resistance is stronger and the vitality is also stronger.* [Poster and Time: KGZDM, June 30, 2020, 17:09:09]
Continuation of life	38 (1.44)	The social value of propagation of the race and the significance of the personal continuation of life	*I chose to have children just because I think child is still a continuation of our blood in this world when my husband and I died, which can prove that we have been here. It is beautiful to think about it, isn't it?* [Poster and Time: NL, June 16, 2020, 08:14:36]
Children's company and psychological support	23 (0.87)	Children's daily company, psychological sustenance, etc	*Parents accompany you in the first half of your life, and children do the same in the second half of your life. People will feel reassured when there is always a person accompanying you in your life.* [Poster and Time: TK, June 23, 2020, 12:18:10]
Complete life	22 (0.84)	The integrity of personal values and life experiences	*I think childbirth has completed a transformation from being a woman to a mother for me. It lets me realize the greatness and selflessness of my mother. It also makes my life as a woman more complete.* [Poster and Time: HX, June 15, 2020, 21:01:44]

Thematic Analysis Procedure

Thematic analysis aims to explore more intricate childbirth concepts, providing an exploratory theoretical explanation for the results of content analysis. More specifically, the results of the thematic analysis can provide explanations and insights into why there is a widespread prevalence of negative childbirth attitudes, why some childbirth costs are of particular concern, and what kind of support individuals require from the government and society. While content analysis helps identify themes based on frequency, thematic analysis reveals potential themes within the data that can present a more nuanced perspective [23]. This study utilized the thematic analysis approach with the 5 phases outlined by Braun and Clarke [23]. In the first phase, the authors immersed themselves in the data through repeated readings and viewing, critically contemplating the meanings within the content of the posts. In the second phase, the research team identified initial codes. Moving into the third phase, the authors shifted from identifying codes to identifying themes, interconnecting the codes logically to form themes. The fourth phase involved reviewing each theme's relation to the data overall and to the other themes to determine the boundaries of each theme. In the fifth phase, the research team defined, named, and elaborated on each theme and extracted illustrative examples of the final themes [24].

Results

Content Analysis

Basic Attitude

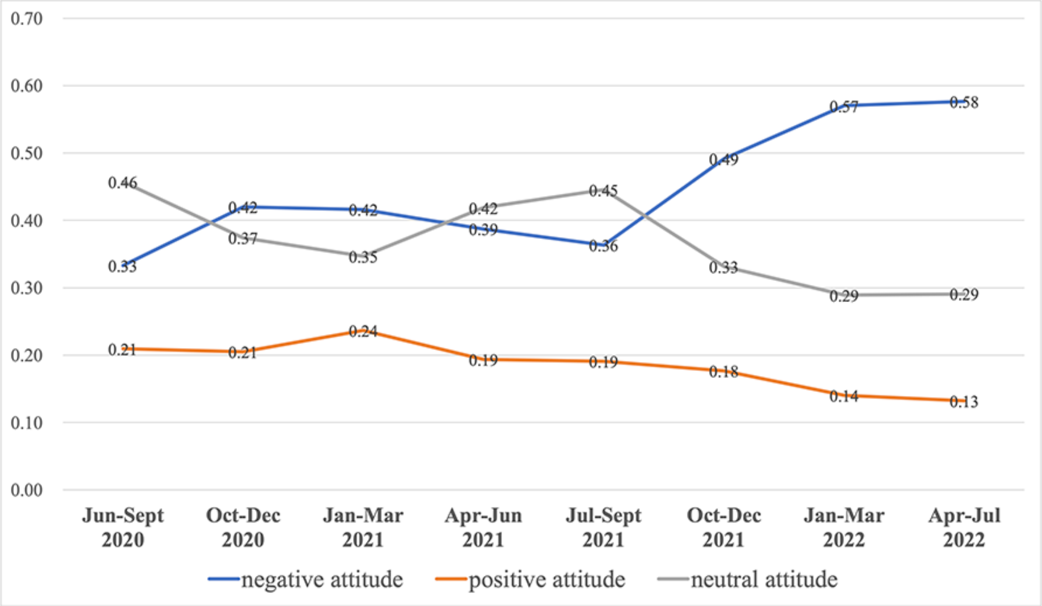
In the content analysis, we identified coding criteria related to attitudes toward childbirth, and Table 1 illustrates specific criteria and examples. The basic classification of the attitude toward childbirth showed that 1051/2634 (39.90%) posts had a negative attitude, 523/2634 (19.86%) posts had a positive attitude, and 1060/2634 (40.24%) posts had a neutral attitude. This indicates that the public attitude toward childbirth is generally neutral or negative, with fewer instances of a positive outlook. By extracting and classifying the top 10 most-liked posts, we found that there were 5 posts with a negative attitude (50%), 2 posts with a positive attitude (20%), and 3 posts with a neutral attitude (30%). The negative ratio was higher, but it was basically consistent with the whole distribution. From the word count, the posts with a positive attitude are the longest, but the number of likes is the lowest. By contrast, the posts with a negative attitude are the shortest, but the number of likes is the highest (Table 4).

If the factor of time is taken into account and the changes in the proportion of childbirth attitudes in different periods are analyzed, it can be found that the proportion of posts with a negative attitude fluctuates to rise, the proportion of posts with a neutral attitude fluctuates to decline, and the proportion of posts with a positive attitude has small fluctuations and shows a downward trend (Figure 2).

Table 4. Distribution of childbirth attitude of posts.

Category	Posts (N=2634), n (%)	Top 10 most-liked posts, n (%)	The average number of words in 1 post	The median number of words in 1 post	The average number of likes in 1 post	The median number of likes in 1 post
Negative	1051 (39.90)	5 (50)	277.64	103	41.27	4
Neutral	1060 (40.24)	3 (30)	352.87	101	28.48	3
Positive	523 (19.86)	2 (20)	415.86	158	26.26	3

Figure 2. Changes in the proportion of three childbirth attitudes with time.



Childbirth Costs and Childbirth Benefits

In the content analysis, we identified coding criteria for the costs and benefits of childbirth, and the proportions in Tables 2 and 3 refer to the proportion of posts mentioning this category in the total number of posts. It should be noted that the content of posts under research topics varies in length. Some posts involve multiple categories, while others only indicate attitudes without involving any categories. Therefore, the total proportion of categories related to childbirth benefits and costs does not equal 100%.

Among all the categories related to childbirth cost, health risk is the most common category, including severe reactions during pregnancy, physiological pain during childbirth, sequelae of childbirth, and postpartum depression. In addition, limited freedom, energy input, negative influence on the workplace, parenting responsibility, and appearance change are the childbirth costs that people are more concerned about.

Among all the posts, the parenting experience is generally recognized as the greatest childbirth benefit, which includes happiness and love felt in the process of parenting. Compared with childbirth costs, childbirth benefits are mostly subjective feelings and spiritual needs, such as parenting experience, the continuation of life, companionship of children, and the integrity of life. There were only 10/2634 posts (0.38%) that mentioned the objective benefits of bringing up children for the purpose of being looked after in old age.

Thematic Analysis

Overview

Results of thematic analysis generated 4 childbirth concepts from all posts: (1) amplified perception of childbirth risk; (2) hidden childbirth experience and childbirth knowledge spread through informal channels; (3) gender equality and childbirth trap; and (4) the deification of the mother figure. Each theme is presented with detailed descriptions and illustrative examples from the posts.

Amplified Perception of Childbirth Risk

In the discussion under the topic, the frequency of mentioning childbirth costs is much higher than that of childbirth benefits, and the explanation of the former makes it easier to attract the attention of the audience and get more likes. Taking the cost of health risks as an example, many users share their personal childbirth experiences, and the real delivery process highlights the physiological pain of childbirth.

> *I felt regular contractions at two o'clock in the morning when I gave birth to my daughter. When my cervix dilated to about 2cm, I was extremely painful. When it dilated to about 3cm, I couldn't bear it, so I asked for painless childbirth. After the injection of epidural, I felt tired and breathless without any*

> *energy. My head went blank and I couldn’t help to trembling. There was no way but call an anesthesiologist to stop the epidural. Then, I couldn’t feel anything but the pain of contractions. On the second day after I was discharged from the hospital, my lateral incision broke along the suture and became inflamed, so it had to be sutured twice. It was my second time in the delivery room. But this time, I had to have a suture without anesthetic. It was so painful that I even wanted to die and would never forget that feeling in my life.* [Poster and Time: XXXXAX, November 1, 2020, 13:42:03]

These negative posts may make many unmarried and childless women fear giving birth and then show resistance to childbirth. In addition to the pain and discomfort of pregnancy and childbirth, the complications of pregnancy strengthen the negative perceptions of netizens about childbirth.

> *Some worries include severe morning sickness during pregnancy, frequent urination at night, a sense of breathlessness as the stomach gets bigger, overwhelming back pain after sitting or standing for a long time in class, too much or too little fetal movement...* [Poster and Time: LLL, September 29, 2020, 20:09:01]

> *Pregnancy makes pelvic floor muscles loosen and natural labor will cause bladder prolapse, which takes a long time to heal.* [Poster and Time: QSXX, June 24, 2022, 14:02:12]

Pregnancy discomfort reactions and recovery processes after childbirth are common experiences for pregnant women, and these symptoms vary in different pregnancy periods and for different individuals. However, many posts emphasize that childbirth will inevitably bring significant health effects and attribute some individuals’ postpartum health changes to childbirth.

> *Childbirth is a gamble, and it is common to make you get out of shape and have urinary incontinence. Apart from that, you may suffer from some lifelong diseases such as diabetes and eclampsia. Two of my relatives and friends have systemic lupus erythematosus (SLE) after delivery.* [Poster and Time: MDAY, October 29, 2020, 00:46:09]

> *Childbirth is a gambling which risks a mother’s life to deliver a baby. Even if it is a successful delivery process, the harm to women is irreversible. My mother used to be a long-distance runner, who is even stronger and healthier than most men. But now this 50-year-old woman still feels cold in winter even when we use many ways to get her warm by opening air conditioner and underfloor heating.* [Poster and Time: PER, June 21, 2020, 09:46:47]

By browsing so many negative posts listed under this topic, viewers are inclined to think that “childbirth must be painful and will bring negative effects to the body.” In addition to physical health, limited freedom and influence on occupation are important childbirth risks. Without correct guidance, these posts will increase viewers’ perception of childbirth risk to a certain extent and then prevent their willingness from giving birth. Of all the posts, 34/2634 (1.29%) posts mentioned the negative impact of browsing this discussion.

> *I feel very scared when I view this topic by accident. It seems that I fear marriage and childbirth. I suddenly want to withdraw my couple seeking post. Well, it’s fine to just live alone.* [Poster and Time: JDXJ, February 7, 2021, 21:21:59]

> *Whenever I have doubts and shake my faith in marriage and childbirth, I will find this topic to see the advice of my predecessors, and I think I will be safe without marriage and childbirth.* [Poster and Time: WAQDZ, April 15, 2022, 18:38:57]

Hidden Childbirth Experience and Childbirth Knowledge Spread Through Informal Channels

On the one hand, the deviation in viewers’ perception of childbirth risks, especially health risks, comes from the influence of the spread of network information, and on the other hand, it is due to the lack of systematic, complete, and scientific childbirth knowledge. In the posts, many users expressed their lack of relevant knowledge, suggesting that the popularization of childbirth knowledge in schools and society, especially women’s childbirth health, is still insufficient.

> *There are countless books on the market that teach people how to have a healthy and intelligent child from conception, but few books tell people what damage childbirth will cause to women’s bodies and how to minimize this damage as much as possible. China’s policymakers attach great importance to prenatal and postnatal care. There are all-around and multilevel support means from card establishment during pregnancy, and prenatal care check-ups to breastfeeding and pediatric health care after delivery. But there is almost no means of support for the physical and mental health of mothers. I think this is a result caused by the whole society, paying too much attention to children and neglecting mothers.* [Poster and Time: OYSS, July 17, 2020, 11:43:46]

Childbirth is an important event that most women in China will experience, and its specific process and health risks rarely appeared in the public field in the past. From the perspective of older females in traditional society, they were ashamed to discuss the childbirth process and its sequelae. Moreover, because every woman in society has to experience this kind of pain, there is no need to emphasize it. Therefore, women are less likely to get relevant experience from relatives and older individuals.

> *Until the moment I give birth, I never know what it means to my body. Before this, no relatives and friends who become mothers around me have talked about this topic with me. I remembered that in college, I asked my cousin-in-law who gave birth to a child this question and she replied: I feel like I have grown up all of a sudden. When I was a graduate student, I asked my cousin, and she replied: You will know the answer when you deliver a baby—maybe she is shy*

> *or maybe she doesn't know where to start to answer my question.* [Poster and Time: PAS, December 5, 2020, 04:14:16]

There are various reasons why women lack knowledge about health risks during pregnancy and delivery. For a long time, the whole society has had an insufficient understanding of women's childbirth, as pointed out by some posts.

> *For a long time, we have not been allowed to talk about our bodies in public, and some details and experiences including the physiological period, pregnancy and childbirth, are regarded as taboo. But, if we don't talk about it, we can't communicate with each other, let alone attract a public concern in society. And if we don't pay attention to our own body and mind, no one will.* [Poster and Time: MMJJ, December 13, 2020, 17:16:08]

Gender Equality and Childbirth Trap

With the progress of modernization, a growing number of women have gained access to education, actively participated in employment, and started to seek fair labor remuneration and equalized social status. All these factors combined have led to the rise of feminism. Feminism strives to attain gender equality and promote equal rights, opportunities, social recognition, and space for development for all family members, irrespective of gender. The most significant biological difference between men and women lies in the distinct reproductive function of women. Women's reproductive behavior is a key factor contributing to inequality between men and women, manifesting in various aspects such as access to educational resources, career opportunities, and labor remuneration. Consequently, in the online public opinion environment, discussions related to feminism are often sparked by the topic of childbirth.

Under the research topic, 172/2634 (6.53%) posts mentioned content related to feminism, covering aspects such as unequal reproductive responsibilities between men and women, protection of women's rights, gender discrimination, abortion rights, and reproductive rights. Among these, 115 posts expressed a negative attitude toward reproduction. In these posts, the reproductive function was no longer perceived as a biological advantage or a gift to women but rather as a negative factor hindering women from pursuing personal development and achieving self-fulfillment. The reason is that the career development of many professional women often comes to a standstill during childbirth, especially during the postpartum period. After giving birth, their incomes suffer as well because a significant portion of their energy has to be invested in caregiving. This has a notable negative impact on those who seek freedom, equality, and socioeconomic status as modern, independent females.

> *Childbirth has made me a complete feminism and understand the plight of women who can only fight back by not having children. At least at this stage, feminism and childbirth are still at odds with each other. The enormous amount of energy and time required to bear and raise a child is an exponentially increasing workload that has been placed on women for a long time as a 'punishment for motherhood'. Women are tied to unrecognized labor, and their status is naturally inferior. In addition, there is no security. Now the only option for women to achieve equal economic status is not to have children, not to take on this unrecognized part of the work, but to fight for rightful social status.* [Poster and Time: TTZ, October 15, 2021, 17:53:04]

In addition to the reality of career stagnation and the unrecognized value of domestic work, the collected posts argued that childbirth can have other negative spiritual effects. These include the identity shift after reproduction, which can confuse women's self-perception and a lack of self-subjectivity. Moreover, in some cases, childbirth even becomes a tool for society to discipline women.

> *Marriage and childbirth mean disciplining and reshaping women. The gender concept tends to be traditional, and what once believed, insisted on, and pursued may be annihilated in the trivialities of life and other people's demands. I fear that kind of change is irresistible, and the fear of losing a part of myself makes me resistant to marriage and childbearing.* [Poster and Time: YSBG, July 13, 2020, 00:36:04]

Some posts even expressed the belief that childbirth has become a kind of original sin for women, and it does not bring any benefits to them.

> *Having children is a life choice. In a male-dominated society, childbearing is a disaster for women.* [Poster and Time: WT, October 7, 2020, 21:10:08]
>
> *A pair of bulging breasts and a uterus is the sole source of modern female woe, in a society marinated in misogynistic thinking.* [Poster and Time: PLPLB, June 27, 2022, 14:22:05]

Admittedly, many of the posts were, to some extent, radical. However, it is essential to consider that the subject of female fertility discourse has been historically obscured for so long that, once people gain the right to free speech, they may resort to language for a thorough emotional release. While women are expressing their repressed feelings, the court of public opinion can influence women who are not married or pregnant, leading to negative evaluations of marriage and fertility.

These feminism-related posts intensively conflict with traditional concepts. In agricultural societies, reproduction and fertility are among the most important values attributed to women in the family. Although modern women are gradually finding new sources of value from education, careers, and society, and to some extent, detaching their self-worth from reproduction, traditional cultural evaluations are slow to change. Many posts also indicated that fertility behavior is subject to social and family pressure.

> *For a woman who is about to enter her 30 s, the real feeling is that no one (especially the elders) cares about what you want to do in the future, whether you are happy with your life or what your career plan is, but only when you are going to prepare for pregnancy? When are you going to have a baby? It*

> *seems that only having a child is the most important thing in your life, and your life is not complete without it!* [Poster and Time: BLZ, December 31, 2021, 03:45:34]

> *My mother's classic quotes are 'A woman is not complete without a child; bearing no child is a waste of womb; at least have one child, otherwise there is no point in living; a woman will definitely be miserable if she does not have a child......' In the eyes of traditional women like my mother, the major prerequisite for a woman to have value is that she must have children, otherwise she will not be happy in any way.* [Poster and Time: SAN, October 4, 2020, 19:39:56]

The Deification of the Mother Figure

The image of motherhood is often perceived by society as great, loving, and sacrificial. Becoming a mother is also a process of self-growth for many women. Self-growth is one of the most frequently cited childbirth benefits under the topic, and it includes the maturation of character, usually embodied in the shift from self-centeredness to child-centeredness. However, this shift can sometimes be overdone and give rise to a lack of self.

> *Childbearing means that henceforth she will literally become a so-called attachment to the family in the eyes of the world; it means that henceforth she is better off realizing her value as a virtuous wife and mother than as an independent human being in the eyes of the world.* [Poster and Time: HEL, November 21, 2020, 23:23:08]

> *In a life of constant reinforcement, people take the phenomenon that a mother gives 100% of her love and care her children for granted. However, the truth is that the independence of the woman herself has been overlooked. Imagine you are going to visit a friend who recently gave birth to a baby, will you prepare a gift for the baby?* [Poster and Time: DHAXX, November 22, 2020, 10:39:39]

It is not difficult to see that this neglect of the mother's subjectivity is socially structured, with all the attention from the mother herself to family relatives and even society revolving around the child. The lack of maternal subjectivity is based on the cultural notion that it is obligatory and common for mothers to sacrifice for their children. When a family accommodates a child, the child becomes the most important being in the family. When a woman becomes a mother, society expects her to become a great mother. Being shackled by such an expectation, the woman's sacrifices become deserved and her feelings become secondary.

> *A woman who is married and has children is taken away from the immunity of making mistakes and is by default an indestructible file. She is supposed to understand everything and bear all the hardships. Those who have experienced it know that it is anguished, but she is not allowed to cry out in pain.* [Poster and Time: LHQ, February 21, 2021, 20:17:02]

The deification of the mother figure is also reflected in society's belief that women should do their best in all aspects of the childbirth process for the good of their children and that it is common to sacrifice a mother's time, energy, and even health to do so.

> *I think society has a very strong tendency towards perfectionism in the mother-infant relationship. Anytime you see contents like mom's hands make the best supplements (what about dad's or grandparents' hands?) Even if it's just bottle-feeding, it's believed that mom ought to do it herself (does it truly have that much of a negative impact if someone else does it?) As a woman, I think we need to realize that these requirements may not actually be very scientific. Most people grew up with a handful of 100 in examinations, so how is possible that when you get to raise a child you suddenly become perfect at everything?* [Poster and Time: AHJM, August 15, 2021, 19:32:23]

The high expectations of society for mothers may be internalized and transformed into high standards for themselves. Admittedly, it has a positive impact from this aspect, as mothers would actively seek to grow if they want to take better care of their children or use themselves as role models.

> *I myself do not truly like little kids, but after becoming a mother, I always want to set an example so that my baby feels that his mother is also an awesome person.* [Poster and Time: DAR, June 23, 2020, 22:17:02]

> *After you lost your temper and lashed out at your child, you are likely to think you are not a competent mom after calming down, and cringe at not being able to control yourself. Then, you will naturally want to be better in order to be a role model for your child. As a mother of a three-and-a-half-year-old kid, childbirth for me was something I needed to become stronger, better, and more mature.* [Poster and Time: Sayly, August 1, 2020, 14:17:49]

While such high standards can promote women's self-growth to some extent, these standards may bring about negative emotions, such as anxiety, if they are too high to meet. For example, some posters indicated that they would feel guilty for not loving their children enough or for not prioritizing them above all else.

> *I was recently reading The House on the Slope, and I clearly remembered that the main character, Risako, faced the challenge of not having enough breast milk after becoming a new mother. The idea of exclusive breastfeeding instilled in her by people around her made her feel less confident, doubt, and deny herself. There was even one time she became tired of parenting and only wanted to escape. Is it true that if you cannot breastfeed exclusively, you are not a good mother and therefore not worthy of being a human being?* [Poster and Time: XRK, September 29, 2021, 12:28:33]

> *I don't want to be a mother anymore. It's too hard. I always unintentionally hurt my child, such as underdressing her, overcovering her, holding her*

> *incorrectly, accidentally bumping her, and not being able to give her a comfortable living environment. She cries, and in many cases, I don't even know why.* [Poster and Time: TJDSXJ, December 8, 2020, 21:03:02]

The unreasonably high standards dissuade women who are not married or pregnant. Many of the users posting are not afraid of bearing children but are apprehensive about not being able to be a "perfect" mother and not being able to take responsibility for their children's upbringing and education.

> *I don't have confidence that I can provide a good enough life for him, that I have enough patience to educate him, and that I can give up something for him without regret.* [Poster and Time: YKDGJ, May 5, 2021, 23:56:59]

Discussion

Principal Findings

Based on the representative topic of childbirth, this study analyzed the ecology of online public opinion on childbirth using a mixed method of content and thematic analyses. It has been found that women's attitudes toward childbirth were generally neutral (1060/2634, 40.24%) or negative (1051/2634, 39.90%), with only a few showing a positive stance (523/2634, 19.86%). Messages with negative attitudes received more follows and likes. This finding is consistent with existing Chinese literature analyzing childbirth willingness from online texts [25,26]. Previous studies showed that there are often more negative posts on fertility-related topics on Weibo [14], TikTok [27], WeChat [28], and other social media platforms in China. By analyzing the trend of women's attitudes toward childbirth, we found that the proportion of posts expressing a negative attitude fluctuates and rises over time. According to previous reports [26,29,30] and the analysis of this study, we believe that both environmental factors and personal subjective factors interact to affect women's attitudes toward childbirth. On the one hand, environmental factors, including rising housing and living costs, intense competition in child education, and the job market, as well as increased work pressure, lead young people to choose to have fewer children. On the other hand, from the perspective of subjective factors, the need for self-realization has motivated women to pursue higher education and success in their careers, leading to a delay in the age of marriage and childbirth, and a choice to have fewer children [31].

Childbirth costs and benefits are common concerns for women. In this study, health risk, restricted freedom, and energy input were the most frequently mentioned aspects in the broad topic of childbirth costs. This finding differs from Gao [25], who used textual analysis on childbirth-related content crawled from other social media. In our study, health risks were discussed more frequently and received more attention, whereas Gao [25] found that economic impacts such as financial investment were more important. The difference may be attributed to the fact that different social media have different audiences and public opinion climates. Compared with other social media such as Weibo and WeChat, Douban's users have a higher proportion of female users. Currently, Chinese families generally have more financial responsibilities borne by men, while most of the users posting under the topic of childbirth are women. Therefore, the collected posts were mostly generated from women's perspectives, which naturally include health risks, restricted freedom, and energy input. Turning our attention to childbirth benefits, we found that posters focused on spiritual needs and subjective feelings, such as parenting experience, self-growth, and the continuation of life. However, only 10/2634 posts (0.38%) mentioned the objective benefits of bringing up children for the purpose of being looked after in old age. It shows that the childbirth concept of urban women has gradually changed from the traditional ones of "passing on the family line" and "bringing up children for the purpose of being looked after in old age" to the modern ones of "emotional experience," "spiritual needs," and "the pledge of love." This finding is consistent with the findings of previous studies investigating childbirth motivation and childbirth willingness [4].

Concept of Childbirth

Childbirth was described as a painful process in social media. Some women have pregnancy complications. Physical pain during childbirth is a major source of fertility fear for young women [32]. Some social media users vividly describe their childbirth experience in detail. It makes viewers feel like they went through the same situation personally. Negative events could be widely spread on the internet and attract public attention [33]. This negativity can affect social media users through emotional contagion [34]. In line with previous findings on the relationship between social media and risk perceptions [28], this paper concludes that social media indeed increase women's childbirth risk perceptions. Taking a step further, this paper also provides specific examples for the expansion of women's risk perception.

This study also finds that many women lack comprehensive and scientific knowledge about the health risks of pregnancy and delivery. Without systematic and scientific health knowledge, many women are not only unable to properly cope with potential health risks but also have a misleading perception or wrong expectations of childbirth risks, thereby increasing their anxiety about childbirth due to the information received through informal channels. At present, the internet has become an essential means for women to gather knowledge about childbirth health [35,36]. However, most of them did not discuss the information they retrieved from the internet with their health care professionals [37,38]. Social media such as Twitter, Reddit, and Facebook provide forums for private citizens to freely express their views, including those about medicine and health care. Yet, the content disseminated through websites and online communities is largely unregulated [39]. This situation highlights that the internet, as an informal communication channel, may unfavorably bias women's fertility perceptions. Currently, network information has become a crucial means for people to acquire knowledge about childbirth, with some blogs focused on the popularization of childbirth knowledge and sharing childbirth experiences gaining widespread attention on the internet. Under this topic, among the top 20 posts, 3 (15%) are about personal health changes and sharing information about breast milk. This reflects the prevalence of personal blogs discussing childbirth health knowledge and also underscores the demand for this type of information among the audience.

The discussions on the topic of childbirth illustrate that modern women are influenced by both traditional and modern fertility concepts. On the one hand, women seeking independence and equality are easily swayed by internet trends, believing that childbirth contributes to gender inequality and impedes personal self-fulfillment, leading to resistance to marriage and childbirth. On the other hand, they face significant pressure from traditional family values, as mentioned earlier. The collected posts reflect that the value of childbirth to women has become ambiguous and contradictory as the approaches to women's self-worth have broadened. Zhang et al [27] also pointed out the ambivalent mindset of the new generation of women regarding childbirth and self-evaluation. This shift in gender concepts often has a negative impact on fertility [40].

In addition, the shift in women's family identity brought about by childbirth leads many of them to feel a lack of subjectivity. The image of motherhood is often perceived by society as great, loving, and sacrificial. Most women believe that motherhood is a rite of passage for women, characterized by the transition from a selfish child to a selfless adult [41]. The maternal norms constructed by society embody characteristics of self-sacrifice. All mothers are expected to adhere to the moral standards of being a "good" mother. These norms make some mothers feel uncomfortable and distressed [42,43]. This kind of sacrifice has also faced criticism from some feminists because sacrifices made for children and partners might perpetuate oppressive gender norms, burdening women and further relinquishing their freedom [44,45].

This article reveals that the elevated social expectations imposed on mothers can be internalized, leading to the establishment of high standards for themselves. While this motivation drives them to pursue self-growth, it simultaneously triggers anxiety about parenting. These heightened social expectations have the potential to not only induce anxiety in mothers who have experienced childbirth but also instill fear among those who have not given birth.

Strengths and Limitations

To our knowledge, only a limited number of previous studies have explored the influence of social media on women's perceptions of childbirth. Among them, even fewer have delved into the analysis of user-generated text on social media platforms. Instead, some studies opted to assess the sentiments of their study participants through questionnaires and interviews. In this study, we conducted a thorough analysis of the posts and discussions shared by users on Douban, a social media platform known for attracting a large population of highly educated young individuals. This user base contributes to the clarity, completeness, and rationality of the points expressed in the discussions. The chosen research method enables us to gain new insights, particularly highlighting how the deification of the mother figure may result in elevated public expectations, pressuring women to sacrifice themselves to attain the ideal of a perfect mother. Women may be hesitant to become mothers as they fear losing their sense of self. Another noteworthy insight is that longstanding social and cultural biases in China may have hindered open discussions on the childbirth process and its health implications, consequently contributing to a lack of comprehensive childbirth knowledge among young women.

The findings of this study should be considered in light of certain limitations. The majority of Douban users reside in urban areas, limiting the generalizability of the results to rural women who may have different perspectives on childbirth. Future research on the attitudes and concepts of childbirth among rural women is warranted. However, previous studies have indicated that the internet's development also influences the gender role concepts of rural residents, transitioning from traditional to modern, with women being significantly more affected than men [9]. The suggestion is made that the influence of cultural concepts via the internet is present in both urban and rural areas, and analyzing urban women's concepts is valuable for understanding those of rural women. Additionally, the gender of all users in this study could not be determined. However, based on the content of the topic and the detailed study of part of the selected sample, it is considered that the majority of the sample consisted of females. While it cannot be ruled out that a few users might be male, it is considered that this would not significantly alter the analysis results and findings.

Conclusion and Suggestions

This study discovered that users generally held neutral or negative attitudes toward childbirth, with fewer expressing a positive stance. Additionally, posts with a negative attitude garnered more attention and likes. Moreover, there was an observed increase in posts with negative attitudes in recent years compared with earlier years. A significant number of young women lack comprehensive and scientific knowledge about the health risks associated with pregnancy and delivery. They tend to rely on the internet to gather relevant information. However, the internet, functioning as an informal communication channel, may inadvertently skew women's perceptions of fertility. As women's socioeconomic status has elevated, there is a redefinition of the value attached to childbirth. In Chinese society, women often encounter greater restrictions on their freedom and are required to invest more energy in childcare compared with men, leading them to hesitate or even resist childbirth [46,47]. Moreover, the structural neglect of mothers' needs and desires in Chinese society creates a perception among women that they might lose themselves due to childbirth and child-rearing, contributing to their hesitation or resistance to giving birth.

The study findings highlight the importance of monitoring public expressions on the internet, offering guidance to women seeking information on pregnancy and delivery, and assisting them in developing a scientific understanding of childbirth. Furthermore, enhancing the public childcare system, safeguarding women's rights, and creating a supportive societal environment for mothers could potentially contribute to an increase in women's fertility desires.

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Authors' Contributions

TY and TL participated in the study design, data collection, and qualitative analysis, as well as the drafting and editing of the manuscript. YW and NH participated in the study design, drafting, and critical revision of the manuscript.

Conflicts of Interest

None declared.

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Review

Parenting Information on Social Media: Systematic Literature Review

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Abstract

Background: Social media has become extremely popular among parents to seek parenting information. Despite the increasing academic attention to the topic, studies are scattered across various disciplines. Therefore, this study broadens the scope of the existing reviews by transcending narrow academic subdomains and including all relevant research insights related to parents' information seeking on social media and its consequent effects.

Objective: The aims of this systematic literature review were to (1) identify influential journals and scholars in the field; (2) examine the thematic evolution of research on parenting and social media; and (3) pinpoint research gaps, providing recommendations for future exploration.

Methods: On the basis of a criteria for identifying scholarly publications, we selected 338 studies for this systematic literature review. We adopted a bibliometric analysis combined with a content thematic analysis to obtain data-driven insights with a profound understanding of the predominant themes in the realm of parenting and social media.

Results: The analysis revealed a significant increase in research on parenting and social media since 2015, especially in the medical domain. The studies in our review spanned 232 different research fields, and the most prolific journal was *JMIR Pediatrics and Parenting*. The thematic analysis identified 4 emerging research themes in the studies: parenting motivations to seek information, nature of parenting content on social media, impact of parenting content, and interventions for parents on social media.

Conclusions: This study provides critical insights into the current research landscape of parenting and social media. The identified themes, research gaps, and future research recommendations provide a foundation for future studies, guiding researchers toward valuable areas for exploration.

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KEYWORDS

parenting; social media; parenting information; systematic literature review; bibliometric literature review; thematic analysis

Introduction

Background

The experience of transitioning into parenthood often elicits a feeling of being overwhelmed [1], through which parents may encounter an intricate transformation of their identity [2]. Achieving a balance among their parental obligations, roles as partners, and individual identities presents a difficult challenge [3]. In addition, they are confronted with social pressures and societal norms surrounding parenthood [3]. In today's digital era, social media plays an important role in how parents manage everyday issues and decisions [4,5]. This comes as no surprise given the massive popularity of social media, with 4.89 billion users worldwide in 2023 [6]. The largest group of users is aged

25 to 34 years [7], which corresponds to the age group of many young parents [8]. Research has demonstrated that parents actively seek online social support and parenting information [5,9,10]. Previous generations have often relied on family and close friends for parenting information, whereas today's parents depend heavily on social media, where they share information and experiences with like-minded others [10]. Obtaining this informational and emotional support empowers parents to feel prepared and confident in their new roles, easing their transition into parenthood [11].

The impact of social media on parents has been studied across various fields, such as health sciences, communication, and pedagogic research [12,13]. For example, within the field of persuasive communication, *momfluencers* (a portmanteau of the words "mom" and "influencer") have been demonstrated to generate feelings of support and understanding among parents but can also cause stress, lower parental efficacy, and anxiety [8,14,15]. Within the health information domain, Chan and Chen [16] found that social media represents an effective source for improving maternal health, mental health, and pregnancy knowledge. Hence, various individual studies from different research domains have made significant contributions by examining parents' information seeking on social media and its consequent impact on their lives and decision-making [13,17,18].

While considerable research exists at the intersection of parenthood and social media, comprehensive review papers that summarize collective insights in this domain are extremely limited. Within the overall field, we identified 6 review papers that addressed subtopics related to that of this study. In total, 2 papers evaluated specific social media interventions for parents [16,19], 2 focused on health information for parents [10,20], and 2 addressed subdomains such as a target group (eg, military families [21]) or a specific variable (eg, family connectedness [22]). Moreover, it is crucial to highlight that a significant proportion of studies that have explored the impact of social media on contemporary parenting are predominantly situated within the realm of medical research [10,19]. However, despite the notable interest of media and communication scholars in this subject [15,22], their research remains fragmented. Consequently, a comprehensive systematic review of parenting information disseminated through social media from a media and communication perspective can significantly enhance our understanding of this field.

To address this gap, this study broadens the scope of existing reviews by transcending narrow academic subdomains and including all relevant research insights related to parents' information seeking on social media and its effects. Using both bibliometric and content thematic analyses, our approach combined objectivity and data-driven insights with an understanding of key themes in the realm of parenting and social media [23,24]. This allowed us to provide an overview of the research, detect patterns, delineate topics, and identify knowledge gaps [24]. The main objectives of this study were to (1) identify the journals and scholars who are actively involved in, contribute significantly to, and exert the most influence in the field; (2) examine the themes explored in existing research on parenting and social media and how they have evolved over time; and (3) highlight current research gaps and provide recommendations for further exploration in this domain.

Literature Review

Several review papers in the field of parental information seeking on social media are pertinent to our study. Among them, 6 were found to align with our focus on social media, whereas 1 fell outside due to its focus on the internet in general. Nevertheless, the findings of the aforementioned systematic literature review were deemed relevant and, therefore, are briefly discussed as follows. Plantin and Daneback [25] consolidated research on how parents use the internet to access child-, health-, and family-related support and information, as well as how professionals use it to offer support and information to parents. They concluded that parents' tendency to seek online information is explained by the desire to seek support and information. They argued that this is mostly driven by the anonymous nature of online information seeking and its round-the-clock accessibility. For professionals, key benefits include cost-efficiency and reaching a large audience. However, the study was published 14 years ago, and the studies in the authors' sample were mostly conducted during the Web 1.0 era, when the internet predominantly consisted of static, informational websites. Since then, parents' online experiences have significantly evolved with increased interactivity and the widespread use of social media. Therefore, we considered it important to reassess and synthesize the research on how parents engage with the wealth of real-time information on social media, which often includes personalized, user-generated advice, creating collaborative, global communities of parents.

The aforementioned 6 review studies that focused on social media had specific thematic focuses on interventions [19]; particular subdomains of parenting information, such as health information [10]; specific target groups, such as military families [21]; or demarcated variables, such as family connectedness [22]. The following paragraphs discuss these 6 reviews on social media and parenting.

Of the reviews, 2 evaluated the effectiveness of social media interventions for parents. First, Hamm et al [19] conducted a systematic review in 2014 analyzing 25 studies on the use and effectiveness of social media in child health interventions. Their review provided insights into how social media is used in interventions promoting child health, such as encouraging healthy eating and exercise among children and adolescents [19]. The authors highlighted that social media interventions that aim to improve children's health predominantly focus on adolescents rather than on children and parents [19]. In addition, they evaluated the effectiveness of these interventions and the factors driving their success [19]. Despite reported benefits from interventions using discussion forums, no studies using such forums achieved significant health outcomes [19]. Second, Chan and Chen [16] conducted a meta-analysis of 16 papers on the effectiveness of social media and mobile apps in pregnancy care. In contrast to the study by Hamm et al [19], their review found that interventions using mobile apps and social media in the context of pregnancy care were effective, with moderate to large effect sizes in maternal health, mental health, and pregnancy knowledge [16].

Furthermore, 2 studies focused on specific target groups or variables [21,22]. Wood et al [21] conducted a scoping review of social media and internet-based communication use by military families. Their research included 11 papers, identified the most popular social media platforms, and highlighted the challenges and advantages of social media use during military deployment [21]. In another systematic review, Tariq et al [22] examined 14 quantitative studies exploring the link between social media use and family connectedness. They discussed how families are connected through social media and its impact on parent-child relationships and broader family connectedness [22].

Finally, 2 review papers examined parents' use of social media for health information [10,20]. First, Pretorius et al [20] conducted an integrative review of 12 studies on parents' motivations and use of social media to obtain information about their children's health, with attention to race, ethnicity, and region. Second, Frey et al [10] conducted a similar scoping review (N=42) on parents' motivations, understanding, and evaluation of health information on social media and its consequent impact. Both studies found that parents obtained valuable online health information and received support from like-minded others [10,20]. An important difference is that Pretorius et al [20] focused on differences in motivations and platform preferences by race and region, whereas Frey et al [10] focused more on parents' perceptions and sentiments toward health information on social media.

This systematic review built on but diverged from the previous reviews by adopting a multidisciplinary perspective, integrating various dimensions, and providing a comprehensive and holistic understanding of insights on social media and parenting. It offers a comprehensive overview of parents' motivations to seek information and the parenting information available on social media and its impacts.

Methods

Literature Search and Selection

To collect relevant papers for this systematic literature review, we adhered to the criteria by Kraus et al [23] for identifying scholarly publications. First, we determined relevant keywords and the search formula. All words related to parenting, such as "parent," "mother," "father," "maternal," "mom," "dad," "paternal," "pregnancy," "conception," "postnatal," "prenatal," "family," "kid," and "child," were identified, as well as words related to social media, such as "social media," "influencer," "Instagram," "YouTube," "vlog," "Facebook," "Twitter," and "TikTok." We combined these terms using Boolean operators (eg, AND and OR) to form the final search formula: *TITLE, ABSTRACT, KEY ([Parent* OR mother* OR father* OR maternal OR m?m* OR dad* OR paternal OR pregnancy OR conception OR postnatal OR prenatal OR family OR kid* OR child*] AND [*fluencer* OR Instagram OR youtube OR? log* OR facebook OR "social media" OR twitter OR TikTok]).*

Second, a literature search was conducted using the search formula on the Scopus database. Scopus was chosen for 2 main reasons. First, Scopus is the largest multidisciplinary database for science, technology, medicine, social science, and arts and humanities, which is useful for mapping a smaller and more multidisciplinary research field, such as parenting and social media research [26,27]. Second, the Scopus database provides various document data formats, allowing bibliometric software to process them conveniently. All relevant studies published before June 2023 were identified, resulting in 2600 articles in the initial search. The results were saved in RIS format, and information such as title, abstract, authors, keywords, and references was exported. Moreover, we refined the selected articles. The articles collected in the initial search included various document types written in a variety of languages. To guarantee the quality of the papers included in the data analysis, we only focused on full-length and peer-reviewed articles; therefore, other document types, such as conference proceedings and books, were excluded [23]. Furthermore, considering that English is the most common language of research, we only included papers written in English [23]. After this screening, of the 2600 articles, a total of 1540 (59.23%) remained.

Subsequently, we carefully reviewed the remaining papers' titles, abstracts, and main texts based on the inclusion and exclusion criteria. The inclusion criterion was papers on how parents search for and consume parenting information on social media. All research methodologies, whether empirical studies or reviews, were considered eligible for inclusion in this comprehensive review. Conversely, papers discussing parental mediation and influencers' motivations to share parenting content were excluded as they fell outside the scope of this review. This procedure left us with a total sample of 338 articles. To guarantee completeness, a snowball literature search was conducted by reviewing the references in each included study, but no new relevant studies emerged.

Data Analysis

To map the development of parenting and social media research, we conducted a bibliometric and thematic content analysis.

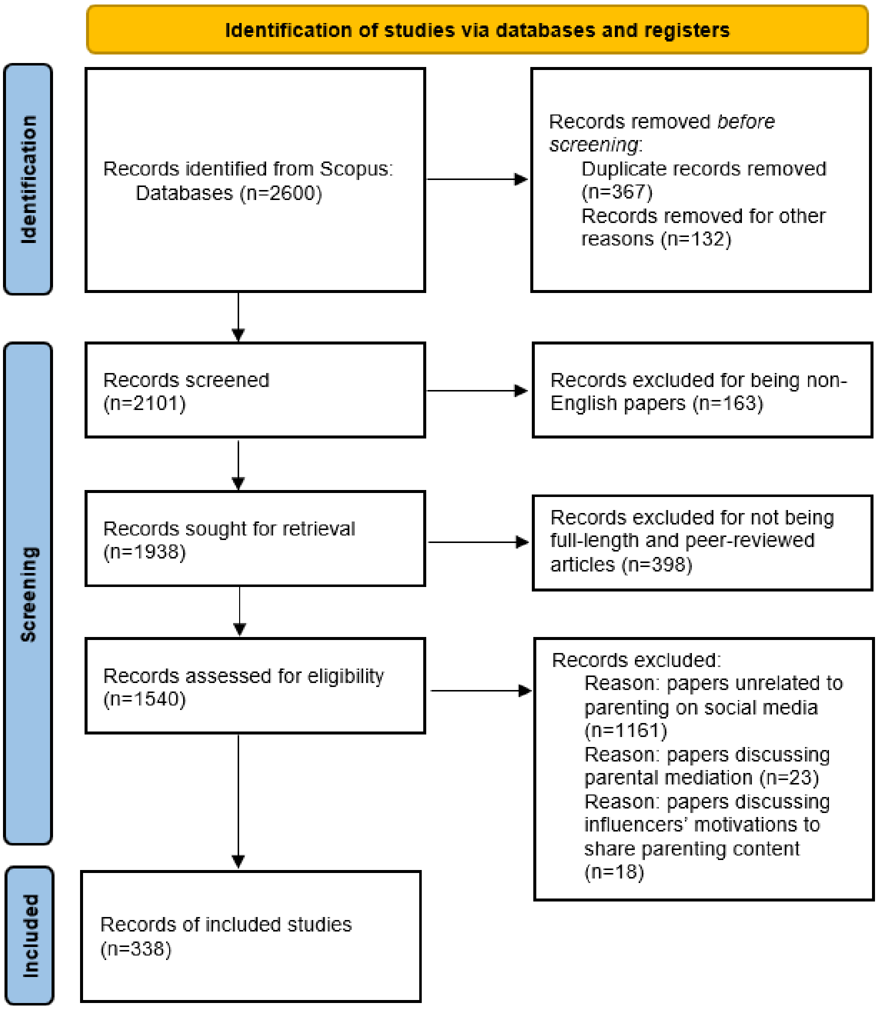
In the bibliometric analysis, we provided a descriptive overview of the research. On the basis of the authors, journal, reference, and publication time, we depicted the evolution of published studies throughout the years, identified the most prolific journals and authors, and detected the most influential articles and authors. BibExcel was used to extract relevant information and perform data analysis.

In the thematic content analysis, we further explored research developments and trends. A keyword analysis examined titles, keywords, and abstracts to identify frequently used words or phrases. A co-occurrence analysis using VOSviewer visually represented the relationships between keywords, creating a co-occurrence network. These analyses enabled us to pinpoint key research topics related to parenting and social media. On the basis of the identified research topics, we conducted a further in-depth investigation of the studies' contents to categorize them in relation to the research topics. Each study underwent a comprehensive qualitative analysis, which involved screening based on the scientific domain, primary focus, dependent and independent variables, methodology used, target audience, and social media platform used.

Results

Figure 1 presents a detailed overview of the literature search and refinement process.

Figure 1. Literature search and refinement criteria for the bibliometric analysis.



Bibliometric Analysis

Development of Parenting and Social Media Research

From the graph in Table 1, one can infer that parenting and social media is a relatively emerging research area. The first relevant study was published in 2009. From 2009 to 2014, only 4.4% (15/338) of the papers were published. Conversely, between 2015 and 2022, there was a remarkable surge in the number of publications on parenting and social media. This period encompasses 85.5% (289/338) of the papers analyzed in this study. Moreover, 10.1% (34/338) of the papers were published over the first 5 months of 2023, which indicates that the current general trend of parenting and social media research is rapid growth.

Table 1. Number of publications on parenting and social media over the years (n=338).

Year	Publications, n (%)
2009	1 (0.3)
2010	0 (0)
2011	3 (0.9)
2012	2 (0.6)
2013	3 (0.9)
2014	6 (1.8)
2015	10 (3)
2016	11 (3.2)
2017	19 (5.6)
2018	26 (7.7)
2019	33 (9.8)
2020	46 (13.6)
2021	68 (20.1)
2022	76 (22.4)
2023	34 (10.1)

Most Prolific Journals and Authors

The articles that we examined were published in 232 different journals, which underscores the broad scholarly attention to the topic of parenting and social media. Of the 232 journals, 13 (5.6%) contributed ≥4 articles, accounting for 20.7% (70/338) of all articles (Table 2). The journal with the most publications related to the topic of parenting and social media was *JMIR Pediatrics and Parenting*, which published 11 articles, followed by *the Journal of Medical Internet Research*, *New Media & Society*, *Feminist Media Studies*, *JMIR Research Protocols*, *Human Vaccines & Immunotherapeutics*, and the *International Journal of Environmental Research and Public Health*. Upon closer examination of the scholarly domains represented by the journals that have disseminated research on parenting and social media, it became apparent that they encompassed a wide spectrum of academic disciplines as classified by Scopus. These disciplines comprised communication, education, medicine, health science, social science, immunology, and allergy. This emphasized the multifaceted research interest in this subject matter.

Table 2. Journals that contributed ≥4 articles on parenting and social media research (N=70).

Journal name	Subject matter	Articles n (%)
JMIR Pediatrics and Parenting	Technologies, medical devices, apps, engineering, informatics applications for patient and parent education in pediatrics, training and counseling and behavioral interventions, and preventative interventions and clinical care for children and adolescent populations or child-parent dyads [28]	11 (16)
Journal of Medical Internet Research	Digital health, data science, health informatics and emerging technologies for health, medicine, and biomedical research [29]	9 (13)
New Media & Society	Communication; sociology and political science [30]	6 (9)
International Journal of Environmental Research and Public Health	Global health, health care sciences, behavioral and mental health, infectious diseases, chronic diseases and disease prevention, exercise and health-related quality of life, environmental health, and environmental sciences	5 (7)
Human Vaccines & Immunotherapeutics	Vaccinology and immunotherapy [31]	5 (7)
Feminist Media Studies	Feminist approaches to the field of media and communication studies, with attention to historical, philosophical, cultural, social, political, and economic dimensions and analysis [32]	5 (7)
JMIR Research Protocols	Medical and health-related research and technology innovations [33]	5 (7)
PLOS ONE	General biochemistry, genetics, and molecular biology [34]	4 (6)
BMC Public Health	Focus on the social determinants of health; the environmental, behavioral, and occupational correlates of health and disease; and the impact of health policies, practices, and interventions on the community [35]	4 (6)
BMC Pediatrics	Health care in neonates, children, and adolescents, as well as related molecular genetics, pathophysiology, and epidemiology [36]	4 (6)
Family Relations	Central focus on families within a wide range of topics of interest to both scholars and practitioners, such as child and parent relationships, cross-cultural and international issues that impact families, family health, family interventions, family life education, and much more [37]	4 (6)
Health Communication	Provider-patient (or family) interaction, health campaigns, health information, health promotion, interviewing, health public relations, and gerontological concerns [38]	4 (6)
Journal of Child and Family Studies	Behavioral health and well-being of children, adolescents, and their families [39]	4 (6)

Moreover, a total of 1447 different authors made contributions to the development of parenting and social media research. Of the 1447 authors, 1342 (92.74%) published only 1 study on parenting and social media, whereas the remaining 105 (7.26%) published at least 2 papers included in our sample. Scheibling (5 articles) published the most parenting and social media studies in the sample, followed by Cino, Moreno, and Evans, each with 4 publications (Table 3). All other authors in Table 3 published 3 of the studies each. These results indicate that there is no dominant author on the topic of parenting and social media. However, examining the academic collaborations among these authors revealed that many of them share strong academic relationships. For example, Klein and Gonzalez-Hernandez coauthored 4 studies. Buller, Walkosz, Berteletti, Pagoto, Bibeau, Baker, Hillhouse, and Henry worked together on all their published studies. Regarding authors' affiliations, we found that authors currently affiliated with the University of Toronto, Università Cattolica del Sacro Cuore, University of Wisconsin–Madison, University of Pennsylvania, and Cedars-Sinai Medical Center contributed the most to parenting and social media research.

Table 3. Authors who contributed ≥3 articles on parenting and social media research. This table only considers papers published before June 2023.

Author	Current affiliation	Publications, n (%)
C Scheibling	University of Toronto, Canada	5 (0.01)
D Cino	Università Cattolica del Sacro Cuore, Italy	4 (0.01)
MA Moreno[a]	University of Wisconsin–Madison, United States	4 (0.01)
YN Evans[a]	University of Washington, United States	4 (0.01)
MA Bryan[a]	University of Washington, United States	3 (0.01)
AZ Klein[b]	University of Pennsylvania, United States	3 (0.01)
G Gonzalez-Hernandez[b]	Cedars-Sinai Medical Center, United States	3 (0.01)
DB Buller[c]	Klein Buendel, United States	3 (0.01)
J Berteletti[c]	Klein Buendel, United States	3 (0.01)
BJ Walkosz[c]	Klein Buendel, United States	3 (0.01)
SL Pagoto[c]	University of Connecticut, United States	3 (0.01)
J Bibeau[c]	University of Connecticut, United States	3 (0.01)
K Baker[c]	East Tennessee State University, United States	3 (0.01)
J Hillhouse[c]	East Tennessee State University, United States	3 (0.01)
KL Henry[c]	Colorado State University, United States	3 (0.01)
A Lapointe[d]	Université Laval, Canada	3 (0.01)
V Provencher[d]	Université Laval, Canada	3 (0.01)
S Desroches[d]	Université Laval, Canada	3 (0.01)
A-A Dumas[d]	Université Laval, Canada	3 (0.01)
J Robitaille[d]	Université Laval, Canada	3 (0.01)
S Lemieux[d]	Université Laval, Canada	3 (0.01)
RS Gruver[e]	The Children’s Hospital of Philadelphia, United States	3 (0.01)
S Virudachalam[e]	University of Pennsylvania, United States	3 (0.01)
AG Fiks[e]	University of Pennsylvania, United States	3 (0.01)
CT Bishop-Gilyard[e]	University of Pennsylvania, United States	3 (0.01)
A Burke-Garcia[f]	NORC[g] at the University of Chicago, United States	3 (0.01)
KB Wright[f]	George Mason University, United States	3 (0.01)
JA Manganello	University at Albany School of Public Health, United States	3 (0.01)
HK Tabor	Stanford University, United States	3 (0.01)
JR Levi	Boston University, United States	3 (0.01)

[a] These authors have close academic cooperation.

[b] These authors have close academic cooperation.

[c] These authors have close academic cooperation.

[d] These authors have close academic cooperation.

[e] These authors have close academic cooperation.

[f] These authors have close academic cooperation.

[g] NORC: National Opinion Research Center.

Most Influential Authors and Publications

Next, we conducted a local and global citation analysis to identify the most influential authors (Table 4) and publications (Table 5) in our sample. The local citation times refer to the number of citations within the sample, whereas the global citation times refer to the number of citations in the Scopus database. Hence, the discrepancy between the global and local citation index refers to the impact that a paper or author has in domains other than parenting and social media research. In addition, the authors' local *h*-index was explored, which refers to an author's number of parenting and social media papers (*h*) that have each been cited at least *h* times by other parenting and social media studies. This index provides an insight into both the quantity (in terms of the number of studies in the domain) and quality (in terms of the impact on other scholars) of an author's parenting and social media publications. To measure the impact (in terms of shares, discussions, and likes) of parenting and social media research concerning society, we used the Altmetrics score. This score provides an insight into the number of mentions in online media, such as Facebook, Mendeley, Twitter (subsequently rebranded X), and Wikipedia.

Table 4. The 20 most cited authors in the parenting and social media area. This table only considers papers published before June 2023.

Author	Local citation times, n	Global citation times, n	Local *h*-index	Altmetrics score
AG Fiks[a]	27	84	3	34
RS Gruver[a]	27	84	3	34
S Virudachalam[a]	27	84	3	34
M Gerdes[a]	23	74	2	18
GK Kalra[a]	23	74	2	18
A Lieberman[a]	23	74	2	18
RI Berkowitz[a]	23	74	2	18
TJ Power[a]	23	74	2	18
J Shults[a]	23	74	2	18
AW Suh[a]	23	74	2	18
CT Bishop-Gilyard[a]	23	74	2	18
LK Lopez	20	139	1	10
JM Sullivan[b]	19	155	1	403
MK Bartholomew[b]	19	155	1	403
SJ Schoppe-Sullivan[b]	19	155	1	403
CM Kamp Dush[b]	19	155	1	403
M Glassman[b]	19	155	1	403
I Yang[c]	14	70	1	7
B Baker[c]	14	70	1	7
K Orton-Johnson	13	48	1	16

[a] These authors have close academic cooperation.

[b] These authors have close academic cooperation.

[c] These authors have close academic cooperation.

Table 5. The 10 most cited papers regarding parenting and social media. This table only considers papers published before June 2023.

Publication	Local citation times, mean	Local citation times, n	Global citation times, n	Altmetrics score	Research topic
Jorge et al [40]	7	7	13	6	Examining the self-presentations of mummy and family influencers on social media
Moon et al [5]	3	12	47	34	Parental perceptions of the advantages and disadvantages of the internet and social media as sources of parenting and health information regarding their infant
Baker and Yang [41]	2.8	14	70	7	Investigating the critical role of social media in providing social support for mothers' lives
Archer and Kao [42]	2.4	12	33	9	Discussing both the negative and positive aspects of social media use for new mothers
Orton-Johnson [43]	2.17	13	48	16	Discussing both the liberating and constraining roles of motherhood in the digital terrain
Haslam et al [44]	2	12	48	74	The status of parents' use of social media and the potential factors that motivate its use for parenting support
Fiks et al [45]	2	12	36	9	The effectiveness of a Facebook peer-group intervention for low-income mothers to foster behaviors that promote healthy infant growth
Pretorius et al [20]	2	8	16	1	The impacts of social media use on parenting
Ouvrein [46]	2	2	11	31	The impact of exposure to mommy influencer content on parental self-efficacy
Bartholomew et al [47]	1.73	19	155	403	The relationship between new parents' Facebook use and parenting satisfaction, parenting self-efficacy, and parenting stress

Fiks, Gruver, and Virudachalam obtained the highest number of citations within our sample, indicating that they are the most influential scholars in the parenting and social media domain (Table 4). Among the prolific authors identified in Table 4, they also had the highest local *h*-index, which denotes their substantial body of high-caliber publications. Noteworthily, we found that most of the prolific authors (eg, Scheibling, Cino, Moreno, Klein, and Gonzalez-Hernandez) were not yet highly cited authors. A likely explanation for this finding is that they have only become devoted to this research topic in recent years, and thus, their publications have had less time to accumulate citations. For instance, Scheibling, the most prolific author among them, published all of his studies in the past 3 years. Furthermore, the high deviation between local and global citations of Sullivan, Bartholomew, Schoppe-Sullivan, Kamp Dush, and Glassman indicates that their publications have been frequently cited not only within the area of parenting and social media but also by papers in other disciplines. In addition, their work garnered a high Altmetrics score, which indicates that their publications are frequently discussed and shared on the web.

Given that the citation frequency is closely related to the study's publication time, we compiled a list of the 10 most cited studies based on their average local citation count (Table 5). Among them, the most influential publication in our sample was by Jorge et al [40]. Their work revealed how mummy influencers reconcile motherhood and their career by examining the ways in which they portray parenting and family, work-life balance, and the boundaries for privacy and intimacy. In addition, the studies by Moon et al [5], Baker and Yang [41], Archer and Kao [42], Orton-Johnson [43], Haslam et al [44], and Pretorius et al [20] are also recognized as highly influential papers due to their substantial number of local and global citations. These papers cover a wide spectrum of topics, ranging from the impact of social media use on parental expectations and attitudes [46], the motivations to seek out parenting information on social media [44], and the effectiveness of social media peer-group interventions for promoting healthy infant growth [45]. Noteworthily, the study by Bartholomew et al [47] had the highest Altmetrics score, which indicates that it has received great attention on the web.

Thematic Analysis

Overview

An analysis of the title, keywords, and abstract fields revealed a total of 1599 title words that occurred 3620 times, a total of

894 keywords that occurred 1610 times, and a total of 5442 abstract words that occurred 42,620 times in our sample. All title words, keywords, and abstract words were then manually screened to group words with similar or identical meanings (eg, “blog” and “blogs”). On the basis of the results of the word segmentation, a keyword analysis and co-word analysis were conducted to identify the most prominent research themes in the area of parenting and social media.

Keyword Analysis

The keyword analysis aimed to assess the frequency of the words and phrases used within the titles, keywords, and abstracts of the research papers. A consistent pattern emerged in the use of specific words (Table 6). In particular, the terms “social,” “media,” and “social media” were found to be the most frequently used words or phrases. This prevalence was primarily attributed to their status as primary search keywords in our study. Similarly, terms referring to social media such as Facebook, YouTube, blogs, Instagram, Twitter, and the internet were also found to appear frequently.

Table 6. The 20 most frequently used words in paper titles, keywords, and abstracts[a].

Words or phrases	Frequency, n
Paper titles	
“Social”	186
“Media”	157
“Children”	61
“Facebook”	52
“Mothers”	45
“Parents”	43
“Information”	32
“Blogs”	31
“Pregnancy”	29
“Health”	27
“Support”	25
“Parenting”	23
“YouTube”	22
“Content”	21
“Instagram”	19
“Group”	18
“Family”	18
“Group”	18
“Parental”	18
“Covid-19”	16
Keywords	
“Social media”	167
“Pregnancy”	31
“Facebook”	27
“Parenting”	22
“Parents”	21
“Covid-19”	20
“Motherhood”	20
“Instagram”	18
“Internet”	18
“YouTube”	17
“Mothers”	16
“Blogs”	15
“Social support”	14
“Sharenting”	10
“Pediatrics”	9
“Twitter”	8
“Health information”	8
“Communication”	8
“Breastfeeding”	7
“Technology”	7

Words or phrases	Frequency, n
Abstract	
“Social”	928
“Media”	629
“Information”	388
“Parents”	330
“Health”	311
“Mothers”	282
“Posts”	239
“Facebook”	218
“Support”	215
“Children”	188
“Content”	183
“Online”	182
“Videos”	176
“Women”	171
“Group”	164
“Parenting”	149
“Pregnancy”	145
“Intervention”	113
“Family”	112
“Vaccine”	108

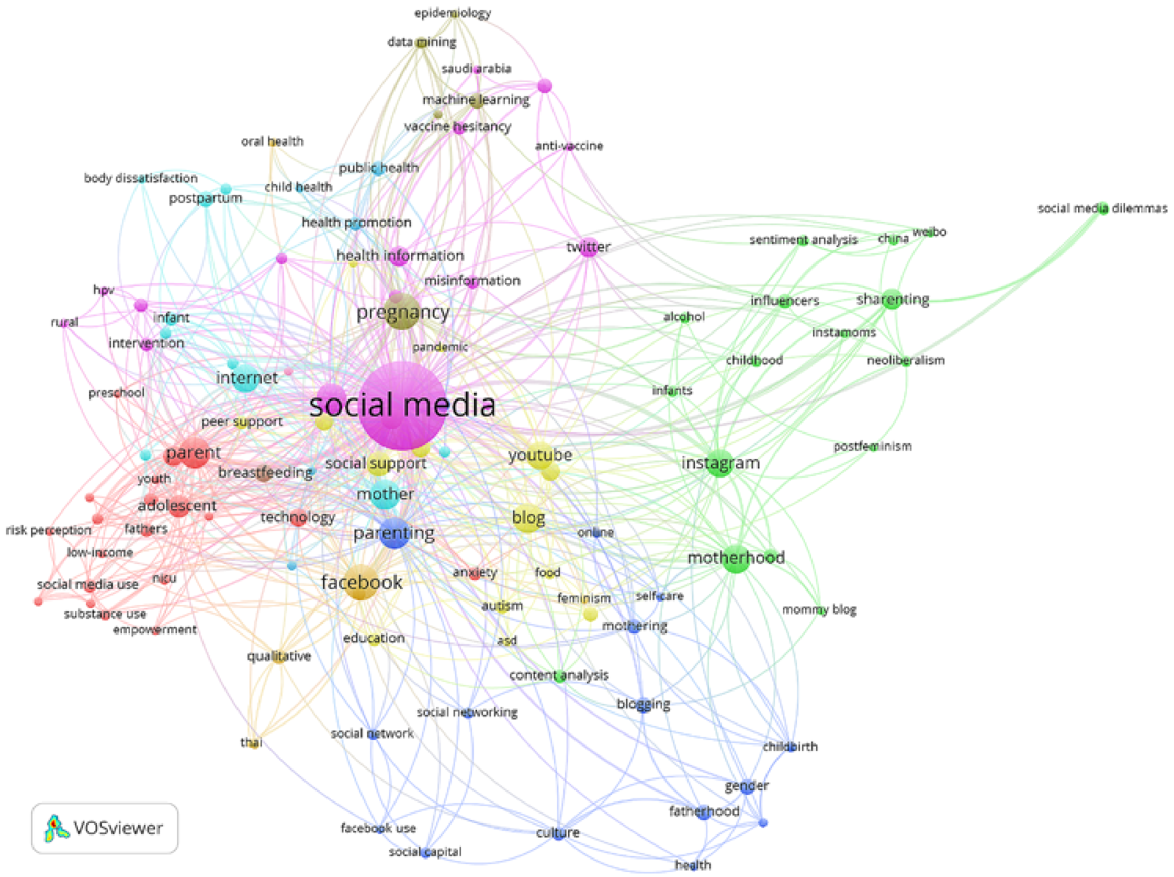
[a] Percentages corresponding to the frequencies of words in paper titles, keywords, and abstracts cannot be provided due to the unavailability of total word counts across the analyzed papers.

Furthermore, it was evident that words associated with familial relationships, including “mothers,” “parents,” “children,” “child,” and “family,” were frequently used, which aligns with their pivotal roles as stakeholders in the realm of parenting. In addition, terms such as “pregnancy,” “parenting,” “motherhood,” “pediatrics,” “Covid-19,” “vaccine,” and “breastfeeding” were found to appear frequently, which indicates that these topics are the core research concerns in the area of parenting and social media. Moreover, terms such as “support,” “health,” “information,” “health information,” and “social support” indicate the multifaceted purposes for which parents use social media. Finally, the prevalence of terms such as “group” and “intervention” within the abstracts highlights the substantial body of literature focused on interventions through social media.

The Co-Word Analysis

The co-word analysis aimed to map the co-occurrence of words that appear in different articles. A visualization of the keywords that often appear together was performed using VOSviewer, and it is depicted in Figure 2. Each node represents an independent keyword, and its size is proportional to the frequency with which the keyword appeared in the articles. The lines between the nodes indicate that the 2 connected keywords appear together in papers, and the thickness of the lines represents the frequency of their co-occurrence.

Figure 2. Visualization of the co-word analysis.



From Figure 2, one can infer that the nodes for “social media,” “Facebook,” “Instagram,” “YouTube,” “Internet,” “parent,” “parenting,” “mother,” “motherhood,” “pregnancy,” and “adolescent” are larger than those of other keywords, which indicates a strong focus on these topics. The analysis further revealed that all keywords could be grouped into 10 clusters (cf the 10 different node colors in Figure 2), which could be further grouped into 4 thematic research topics through a cluster labeling process.

The first research theme covered studies in clusters 3, 4, and 7. The keywords that reflect the theme were “health,” “health communication,” “health promotion,” “self-care,” “social support,” and “peer support.” Consequently, the first theme was inferred to involve research on parents’ motives to seek information on social media and the identification of variables that may predict the occurrence of this behavior. The second research theme covered studies in clusters 2, 8, 9, and 10, all of which were characterized by keywords closely tied to types of parent-related content on social media and text-mining methodologies—namely, “parenting forum,” “mommy blog,” “instamoms,” “feminism,” “neoliberalism,” “qualitative,” “data mining,” “machine learning,” “natural language processing,” and “sentiment analysis.” This research theme centered on the analysis of online parenting content, where the aim was to construct meaningful insights from such data. The third research theme covered studies in clusters 1 and 6, as indicated by keywords such as “mental health,” “postnatal depression,” “risk perception,” “depression,” “anxiety,” “body image,” and “body dissatisfaction.” These keywords suggest that researchers demonstrated interest in the impact of parenting information on social media. Finally, the fourth research theme covered studies in cluster 5, with keywords such as “intervention,” “obesity prevention,” “anti-vaccine,” “HPV,” and “vaccine hesitancy.” This research focused on parenting interventions with the use of social media.

Thematic Content Analysis

Overview

To obtain deeper insights into the research content of each of the 4 research themes identified through the co-occurrence analysis, we conducted a thematic content analysis. The first theme consolidated articles that pertained to the underlying motivations of parents to seek information on social media platforms, the second theme encompassed a significant number of articles that explored which parenting-related content can be found on social media, the third theme clustered all articles on the impact of parenting social media information on parents, and the fourth theme contained articles that evaluated interventions on social media. Given that some articles were related to topics across different research themes, we discuss those within the multiple clusters they belong. In the following subsections, we discuss the methodologies and specific social media platforms used in the selected studies. Subsequently, we provide more insights into the various research domains and emphasize the key findings within the extensively investigated research areas.

Theme 1: Parental Motivations to Seek Information on Social Media

A total of 14.8% (50/338) of the studies in our sample were found to examine parents' motivations to seek information on social media. While these studies used various methodologies, half (23/50, 46%) adopted a quantitative approach, primarily applying surveys to gather data. In contrast, the qualitative studies (22/50, 44%) mainly used focus groups, in-depth interviews, and qualitative content analyses to obtain insights into parents' motivations to use social media as platforms for seeking information. Only a small fraction of the studies (5/50, 10%) used mixed methods research approaches to explore the motivations of parents, mainly through combining surveys, content analysis, or interviews.

In terms of social media platforms, most of the studies within this scope (27/50, 54%) investigated parents' motivations for seeking information on social media in general rather than specifically focusing on 1 platform. These studies investigated the most popular social media platforms among parents and the motivations that drive them to seek information on social media [48]. Facebook emerged as the most popular platform for parents [48-50]. This is also in line with the keyword and co-occurrence analyses, where Facebook emerged as a big node. Unsurprisingly, studies that examined a specific platform primarily focused on Facebook (16/50, 32% [51,52]), whereas little attention was paid to exploring the motivations of parents on other social media platforms, such as blogs, Twitter, or forums (7/50, 14%).

Parents' motives to seek information on social media received the most attention in the domain of health information and medicine (34/50, 68%). These studies investigated parents' motivations for seeking information about general health issues (eg, physical activities), specific diseases (eg, cancer, cleft lip, and autism spectrum disorder), and health-related topics (eg, vaccinations). The 3 dominant motivations for parents to seek health information on social media were as follows: providing and obtaining support from peers, receiving advice and information about one's child's diagnosis to guide health decisions, and accessing a community with families who experience the same issues [5,10,50,52-56]. We observed a dominant focus on mothers in the other clusters, whereas the studies within cluster 1 predominantly focused on parents in general regardless of gender.

In addition, attention was paid to parents' information-seeking motivations within the domains of family science, pregnancy and childbirth, and child feeding (16/50, 32% [57-59]). Such studies did not solely focus on the broader category of parents as one homogeneous group (ie, encompassing both mothers and fathers) but also paid specific attention to mothers and pregnant women individually. Similarly, as in the health-related parenting studies, parents were found to seek informational and emotional support from peers and seek advice and information on various parenting topics, such as pregnancy, activities for their children, and motherhood [44,58,60-63]. However, community feeling was less prominently studied compared with studies in the health and medicine domain.

Across the multiple research subdomains, Moon et al [5] and Suminar et al [58] discovered that mothers attribute greater value to the information they obtain through social media compared with the information they acquire from their family and friends. One of the biggest advantages of social media compared with more traditional sources of parenting information is that information is always available and tailored to parents' interests and needs [5,20,63,64]. Consequently, young parents in particular exhibit a high level of trust in digital information and opinions provided by other parents on social media [5,44]. Given parents' great engagement with and active quest for parenting-related support and information on social media, it is evident that these platforms exert a profound impact on their lives and decision-making processes. These subjects are discussed in the following sections.

Theme 2: Type of Parenting-Related Content on Social Media

The studies in this cluster (174/338, 51.5%) focused on the types of parenting-related information available on social media. More than half (113/174, 64.9%) of the studies used a qualitative approach, primarily conducting qualitative content analyses to identify the various parent-related topics discussed on social media. Other qualitative methods, such as sentiment analysis, interviews, focus groups, and sociolinguistic analyses, were also applied but on a remarkably smaller scale. The quantitative studies within this cluster (49/174, 28.2%) mainly used quantitative content analysis, whereas a smaller number used surveys to obtain insights into the parenting information available on social media. Finally, some studies (10/174, 5.7%) used a mixed methods approach, mainly combining qualitative and quantitative content analyses to investigate the variety of parenting information. In total, 1.1% (2/174) of the studies were found to have not defined their methodology.

Moreover, to comprehensively analyze the diverse spectrum of parenting-related content on social media, researchers scraped data from various social media platforms. Most of the data in the studies within this cluster were gathered from blogs, YouTube, and Facebook (93/174, 53.4%). A smaller amount of studies (64/174, 36.8%) analyzed parenting content on Instagram or Twitter or examined content from multiple platforms. Other platforms, such as Weibo, online forums, Reddit, TikTok, and WhatsApp, were examined in a minority of studies (17/174, 9.8%). Noteworthily, some studies (11/174, 6.3%) did not explicitly mention or define the specific social media platform from which they gathered their data.

Furthermore, parenting information on social media was studied within a variety of research fields, including health information and medicine, pregnancy and childbirth, family science, nutrition, influencer marketing, and COVID-19. However, most research attention concerning parenting information on social media focused on the fields of health and medicine, followed by the fields of pregnancy and childbirth and family science. In the following paragraphs, we discuss these fields in detail.

First, in the domain of health information and medicine, 2 broad categories were identified—namely, parental health and child health. The studies that focused on parental health encompassed diverse topics, such as medication use, general health practices, alcohol consumption, and infertility [65-67]. The studies that focused on child health information for parents on social media covered a range of health-related topics, such as child vaccinations, autism, child diabetes, cancer, child obesity, sun protection for children, congenital anomalies, elbow fractures, rhizotomies, and mouth sores [68-73]. Across these 2 categories, some studies (14/174, 8%) also examined the quality of and level of trust that parents place in information obtained from social media platforms [72,74,75].

Second, considerable research was conducted in the domain of family science. Such studies primarily focused on the representation and narratives of motherhood and fatherhood on social media [76,77]. Various narratives surrounding the ideals of the "perfect mother" and the notion of a "bad mother" were identified. Other topics, such as the transition into fatherhood, genderfluid parenting, daily life of American families, and grief of parents were detected on social media.

Third, within the domain of pregnancy and childbirth, 3 prominent clusters of information were identified: childbirth (eg, birth stories, hypnobirthing videos, information about miscarriage, and maternal mortality), health and pregnancy (eg, vaccination, physical activities, alcohol, drugs, COVID-19, and anxiety), and representations of pregnancy on social media [78-80]. While research was also conducted in other research domains to map the information about parenting on social media (eg, influencer marketing and nutrition), the volume of such studies was relatively limited.

Theme 3: The Role of Parenting Information on Social Media in Parents' Lives

A total of 21.6% (73/338) of the studies were found to have investigated the relationship between parenting content on social media and parents' experiences. Most of these studies (41/73, 56%) adopted a quantitative approach, predominantly using surveys to explore the correlations between online parenting information and parents' daily experiences. Conversely, a smaller subset of studies (17/73, 23%) used qualitative methodologies to delve deeper into parents' experiences with parenting content on social media. The qualitative methodologies encompassed in-depth interviews, qualitative content analyses, and digital ethnographies. A total of 3% (2/73) of the studies conducted systematic reviews to consolidate existing findings. In addition, 14% (10/73) of the studies used mixed methods research combining various research approaches, such as ethnographies, interviews, focus groups, surveys, content analyses, discourse analyses, and social network analyses. A total of 4% (3/73) of the studies did not clearly specify their methodology.

Regarding the focus of the studies, a substantial portion (38/73, 52%) adopted a broader approach, concentrating on social media in general rather than choosing 1 specific platform. Most of these studies (24/38, 63%) conducted surveys to explore the correlations between parenting content on social media and various dependent variables. These variables include attitudes toward pregnancy and specific diseases, perceptions of social media information, parents' mental health, and child feeding practices [81]. Among the specific social media platforms, Facebook—particularly specific Facebook groups—was a popular platform to investigate (13/73, 18%). In addition, the studies examined other platforms, such as Instagram, Twitter, YouTube, blogs, or a combination of these (22/73, 30%).

The relationship between parenting content on social media and various variables (eg, parental self-efficacy) was studied within various research domains, such as family science, education, health information and medicine, nutrition, pregnancy and childbirth, advertising, and communication.

First, a notable portion (19/73, 26%) of the studies within this cluster were situated in the domain of family science. They explored a wide range of variables, such as well-being, anxiety, the role of humor in social media posts, the quality and credibility of information, family connectedness, perceived parental skills, and involuntary childlessness. Notably, a range of insights on different topics within the field of family science were identified. For instance, the experimental study by Germic et al [82] revealed that mothers who sought information from online sources had lower perceived self-efficacy than mothers who did not seek online information regardless of the content they were exposed to. Another qualitative study conducted a thematic content analysis and indicated that humor played an important and positive role in reducing parents' anxieties and distress during the pandemic [83].

Second, a smaller portion (12/73, 16%) of the studies on the role of parenting information in parents' everyday lives fell within the domain of communication. Most of these studies (9/12, 75%) were conducted in the field of influencer marketing, primarily focusing on "momfluencers." A momfluencer is a social media influencer (SMI) who has attracted a large number of followers on social media by actively sharing their everyday life of motherhood and who often participates in commercial collaborations [8,84]. More specifically, these studies revealed correlations between the idealized content of momfluencers on Instagram and lower well-being, more anxiety, and less parental self-efficacy among mothers [8,14,84,85]. However, Kirkpatrick and Lee [14] as well as Egmose et al [8] also suggested that momfluencers can have a positive influence by providing support and an online community. Moreover, Ouvrein [46] indicated that a positive relationship exists between regular exposure to momfluencer content and perceived parental self-efficacy for pregnant women. Other studies in the research area of influencer marketing focused more on the promotion of food products or the use and effects of disclosures and visual brand promotion [12,86]. Furthermore, a smaller subset of studies (3/12, 25%) delved into the role of social media in facilitating communication processes between families experiencing military separation or migration [21,87,88].

Finally, some studies (10/73, 14%) were conducted within the research area of pregnancy and childbirth. These examined the correlations between social media use and various aspects of pregnancy, including body satisfaction, childbirth, mental health, and eating disorders. Their findings suggest that social media content that addresses pregnancy-related subjects demonstrates associations with both positive and negative outcomes for pregnant women [89-91]. For instance, the experimental study by Tang et al [89] demonstrated that mothers exposed to body-focused social media posts exhibited higher levels of body dissatisfaction and poorer body image than mothers in the control group. Another study indicated that Facebook serves as a source of social support for new mothers, enabling them to interact with like-minded individuals and feel less isolated during maternity leave by staying in contact with their family and friends [42].

Theme 4: Professional Parenting Interventions on Social Media

Given that parents regularly consult social media platforms for parenting information [10], several studies developed professional interventions that targeted parents through various social media platforms. In particular, 12.1% (41/338) of the studies investigated various professional interventions on social media for parents and their children. These interventions were developed and implemented across multiple social media channels, and nearly half (20/41, 49%) were conducted within specific Facebook groups. In 20% (8/41) of the articles, the specific platform used for the intervention was not specified. Other platforms used for implementing the interventions included blogs (5/41, 12%), TikTok (1/41, 2%), WeChat (2/41, 5%), WhatsApp (1/41, 2%), or a combination of these (7/41, 17%).

The professional interventions can be categorized into 3 main research domains, namely, health (20/41, 49%), nutrition (11/41, 27%), and pregnancy (10/41, 24%). First, the interventions within the health domain focused on diverse health topics, such as vaccine concerns, parents of children with specific diseases, parents' mental health, breast cancer, and sleep in infants. A total of 10% (2/20) of the studies, which addressed parental vaccine concerns and hesitance, indicated that the interventions were effective in improving parents' attitudes toward vaccination [92,93]. In contrast, a human papillomavirus vaccine intervention by Chodick et al [93] was ineffective at improving the uptake of the vaccine among mothers' daughters. In addition, the interventions targeting children with specific diseases and their parents (5/20, 25%) were found effective [94]. The target audience of the health interventions varied, encompassing parents, caregivers, mothers, and children.

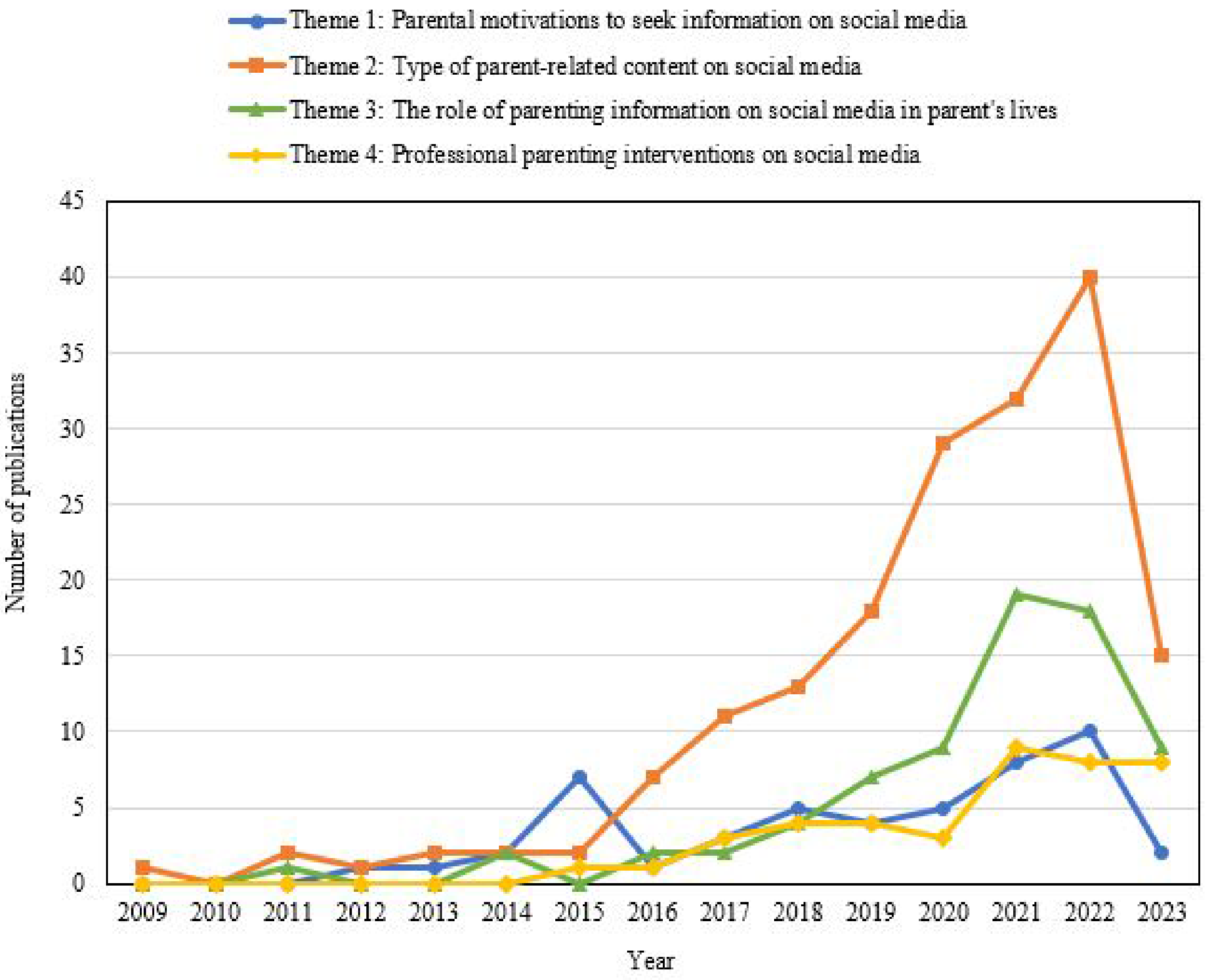
Second, the interventions in the nutrition domain aimed to enhance parents' food-related behaviors and decision-making processes. Noteworthily, all interventions that focused on nutrition were specifically tailored to parents, mothers, or caregivers, which is unsurprising given that parents—particularly mothers—are recognized as key influencers in shaping their children's eating habits [95]. Most of the interventions (30/41, 73%) were highly effective at improving the healthy food decisions that parents made for their children. For example, a peer-group intervention implemented through social media had a significant impact on specific feeding behaviors within families with infants at high risk of obesity [45].

Third, the interventions in the pregnancy domain were designed to improve various aspects, such as anxiety during pregnancy, knowledge about vaccines or pregnancy in general, prenatal stress, maternal mental health, and physical health. All interventions that pertained to pregnancy specifically targeted pregnant women and demonstrated positive outcomes. For instance, the self-help mindfulness intervention by Zhang et al [95] was effective at decreasing prenatal stress and negative affect as well as improving positive affect and mindfulness.

Thematic Evolution Analysis

Figure 3 illustrates the thematic evolution analysis that we conducted, offering insights into the progression of the identified themes over time in the realm of parenting and social media research. The analysis revealed notable trends in research focus across different periods. Theme 2, namely, the type of parent-related content on social media, emerged as the initial focal point in 2009 and consistently remained a central area of investigation with the exception of the year 2015. During this period, researchers redirected their attention to understanding the motivations that drive parents to seek information on social media platforms (theme 1). Subsequently, themes 3 and 4 gained prominence, with a growing emphasis on examining the effects of parenting information disseminated through social media channels and evaluating professional interventions.

Figure 3. Results of the thematic evolution analysis.



Discussion

Research Gaps and Future Research Recommendations

Overview

The area of parenting and social media has received growing academic attention since 2015, aligning with today's digital turn in information dissemination. In this section, we aim to provide a broader lens for understanding the overall domain of parenting information on social media. Therefore, we discuss the most crucial research gaps that we identified, followed by concrete recommendations for future research to help move our understanding forward of why and how parents consult and are influenced by social media. A summary of recommendations with research questions can be found in Multimedia Appendix 2. These research gaps and recommendations follow the structure of the communication model by Lasswell [96]—communicator, message, medium, audience, and effect—preceded by a brief discussion of the methodologies used in the included studies.

Methodologies

Few studies in our sample (28/338, 8.3%) adopted a mixed methods approach to conduct research on parenting information on social media. However, combining qualitative and quantitative research is highly valuable for addressing complex research problems in social sciences [97,98]. Quantitative data reveal the impact of parenting content, whereas qualitative data illuminate individual experiences. Mixed methods are increasingly used within various disciplines, including health sciences, nursing, sociology, psychology, and education [98]. Future research on parenting and social media should use more mixed methods to obtain a holistic understanding of parental interactions and behaviors on social media.

Communicator

Within the collected studies, we identified that little to no attention was paid to the sources of parenting content on social media. Crucial to note is that studies that examined the motivations of people to share information on social media were excluded from the sample as they did not align with our objectives. Nevertheless, little to no attention was devoted to answering the question of who is sharing parenting information (eg, everyday parents, medical experts, and parent influencers) on social media and which features characterize these individuals. Hence, numerous questions concerning the source characteristics of individuals sharing parenting information on social media remain unexplored and require further investigation.

Specifically, we noticed that only a fraction of the studies within our sample (13/338, 3.8%) focused on SMIs as sources of parenting information. However, scholars have consistently emphasized that the impact of SMIs on parents and society should not be underestimated [14,99,100]. Specifically, parent influencers provide support and establish a readily accessible and relatable community for parents who want to discuss various parenting topics [100]. Consequently, research has revealed that the content produced by parent influencers exerts a substantial influence on parents in various aspects, including the intention to initiate and sustain breastfeeding and the shaping of parenting ideologies [101-103]. In total, 2 types of momfluencers were distinguished: typical momfluencers who share their personal experiences and professional momfluencers who create content based on their education and professional background [8]. However, research on how parents judge and give meaning to the expertise of information sources on social media is lacking. In addition, while influencer marketing focuses on SMIs' commercial value, it lacks insights into their role in promoting prosocial behavior [104]. In the context of parent influencers, an important research gap exists in the lack of empirical insights on the effectivity of parent influencers as digital agents for promoting prosocial behavior [105].

Message

Studies related to the "message" construct by Lasswell [96] fell under theme 2 (ie, the "types of parenting-related content on social media"). These studies explored the nature of parenting content disseminated on social media, of which a substantial proportion was medical information. Notably, these studies primarily focused on the health information available on social media while often overlooking the assessment of its reliability. Scholars have raised concerns about disinformation on social media [106]. More specifically, one study has argued that there is an absence of gatekeepers for evaluating the information's veracity before its dissemination; moreover, peers share available information from both professionals and nonprofessionals at an unpredictable speed and pattern, making it difficult to distinguish reliable information [107]. Other research has similarly indicated that misinformation is frequently shared in parenting contexts [69].

When we examined the available parenting content more closely, we noticed that a variety of parenting topics were investigated, such as pregnancy, child vaccinations, nutrition, and specific diseases. This is also reflected in the fact that the studies examined within this scope were published in 232 journals. However, social media content related to parenting styles remained unexplored. Considering that mothers actively seek online parenting information [5,10], it is crucial to gain insights into the different parenting styles that are shared with peers on social media. Furthermore, little attention was paid to the commercial content targeting parents despite evidence showing their vulnerability in early parenthood [3] and the variety of sponsored content on the web [108]. Notably, and similar to the source cluster, little to no research exists on the type of parenting information shared by SMIs. However, momfluencers are extremely popular among pregnant women and first-time mothers, who regularly consult their profiles [8,14,84]. Given the influential voices of SMIs, it is crucial to study both influencer characteristics and the content they share with their large audiences.

Medium

This study identified some research gaps in the social media platforms studied. The co-word analysis highlighted "social media," "Facebook," and "YouTube" as prominent nodes, indicating a focus on Facebook groups and YouTube videos [109,110]. Instagram and TikTok are 2 increasingly important social media platforms that are currently overlooked. Instagram is highly popular among brand-new mothers, and the second largest group of Instagram users is aged 25 to 34 years [111]; thus, they represent the age demographic of a considerable number of young parents [8]. Similarly, TikTok's popularity extends beyond young demographics to encompass individuals aged 18 to 34 years, who account for 36% of the platform's users worldwide [112]. Given that parenting information on TikTok and Instagram remains largely uncharted in research, we recommend that future research endeavors encompass a diverse array of methodological approaches and cover all 4 thematic domains of this study (ie, motivations, content type, impact, and interventions). This multifaceted approach will enable a more comprehensive exploration of these social media platforms.

Audience

Most of the studies within this scope (326/338, 96.5%) focused on mothers or parents in general. Although mothers are identified as primary health information seekers and caregivers [113], it is crucial not to overlook the role of fathers. In the 21st century, there has been a discernible increase in fatherly involvement [114,115], as seen in the rise of dad bloggers [76,116]. Dad bloggers attempt to counterbalance the stereotypes and narratives of fatherhood that depict fathers as absent or incapable [116]. Given the scarcity of academic attention to dad bloggers, "dadfluencers," and fathers in general as a target audience, we recommend that future research explore modern family dynamics in an inclusive manner.

The results of our systematic literature review have already indicated that a substantial portion of research delved into parents' motivations to seek information on social media (cf cluster 1). Nevertheless, a notable research gap exists in the specific types of online information-seeking behaviors of parents. Furthermore, it would be interesting to investigate whether the types of information seeking are associated with parental consumer behavior as well as parents' decision-making processes. In addition, research could investigate whether certain types of information lead to more informed parenting decisions.

Effects

While there was a substantial number of studies on parenting content on social media (174/338, 51.5%), few examined its impact on parents' decision-making for their children. Thus, future research is necessary in several key areas. First, neoliberal parenting ideals, which emphasize the individual responsibility of parents and their focus on autonomy [117,118], are increasingly represented on social media [119], but their effects on parenting styles, decisions, norms, and practices remain understudied.

Second, parents devote a significant amount of time to social media seeking support and information [5,10] but face an overload of misinformation on the web [69]. Compounded by their non–"digital native" status, parents often grapple with limited digital knowledge, which necessitates further research on their media and advertising literacy [120]. While current studies predominantly focus on children and adolescents in this regard [121], obtaining insights into parents' media literacy is equally vital because they not only spend a lot of time on the web but also play a crucial role in their children's social media literacy [122]. In addition, the overload of health information available both on the web and offline was reported to overwhelm parents, leading to anxiety and confusion [123]. Future research should further investigate these negative effects of information overload on parents in the health domain as well as other domains, such as pregnancy and nutrition.

Third, a nuanced analysis of SMIs' influence is crucial. Current research mainly emphasizes the negative impact of momfluencers, particularly on mothers [85]. Nevertheless, studies have already indicated that SMIs could in general be interesting sources for promoting prosocial behavior [124,125]. Thus, leveraging momfluencers as allies to endorse prosocial behavior, such as advocating for healthy nutrition, is a highly interesting avenue for future research. However, it is imperative to exercise caution concerning the potential drawbacks associated with the commercial arrangements in which momfluencers engage. Richins and Chaplin [125] demonstrated that parents who seek to ensure their children's happiness through materialistic parenting inadvertently contribute to the development of materialistic adults in the future. Therefore, future research should scrutinize whether the commercial partnerships of momfluencers inadvertently promote materialistic parenting styles and propose strategies to mitigate such effects.

Conclusions

While parents easily find their way to social media for parenting information and questions, academic research in this area remains fragmented across diverse disciplines and is still in its infancy. This paper has presented the first study to use bibliometric and thematic content analyses to provide a systematic overview of parenting and social media research. This will enable researchers to have a general understanding of the current state of the art regarding research on parenting information on social media. Current research can be classified into the following 4 main categories: parents' motivations to seek parenting information, types of parenting-related content on social media, the role of parenting information on social media in parents' lives, and professional interventions for parents on social media. Insights from the thematic content analysis of these themes helped us identify research gaps and provide recommendations for future research.

However, this study has some limitations. One important limitation pertains to the keywords used to select relevant papers. While we included a comprehensive set of keywords related to parenting, such as "parent," "mother," "father," "maternal," "mom," "dad," "paternal," "pregnancy," "conception," "postnatal," "prenatal," "family," "kid," and "child," we did not initially include the terms "infant," "baby," or "foetus" in our search formula. Therefore, it is important to acknowledge that the absence of certain keywords in our search strategy may have impacted the inclusivity of our review. Another limitation pertains to the database's ability to scrape articles. In this study, we only searched for articles in 1 database, namely, Scopus. Even though it is the largest multidisciplinary database of science, technology, medicine, social science, and arts and humanities, we might have missed articles relevant to our topic.

Despite its limitations, this review has significant theoretical and practical implications. First, it highlights the broad interest among researchers from various disciplines, including vaccinations, dietary choices, and pregnancy, in understanding what information can be found for parents on social media and how it affects them. However, the dispersed nature of this research area poses a significant challenge, which could potentially lead researchers to overlook valuable insights from other domains. Therefore, this review serves as a clarion call for researchers to exert a concerted effort to synthesize knowledge across and within domains. Second, this review underscores the significant growth in research pertaining to parenting information disseminated through social media over the past 7 years. The rapid expansion in this field indicates its dynamic nature. As such, this review establishes a robust foundation on which researchers can build to further explore this emerging domain. In addition, we provided an extensive list of future research directions with concrete research questions. By providing this extensive list of research avenues, we aim to encourage future researchers to make substantial contributions and enrich the field's knowledge base. As for the practical implications, this review highlighted that there is an overload of information for parents on social media. The plethora of (often conflicting) information is often perceived as overwhelming for parents [126]. Therefore, it is crucial to equip parents with strategies for navigating the deluge of information effectively and empower them with the skills to discern and use information to their advantage.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist.

[PDF File (Adobe PDF File), 881 KB - pediatrics_v7i1e55372_app1.pdf]

Multimedia Appendix 2

Future research directions with concrete research questions.

[DOCX File , 19 KB - pediatrics_v7i1e55372_app2.docx]

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Abbreviations

SMI: social media influencer

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Original Paper

Parental Information-Use Strategies in a Digital Parenting Environment and Their Associations With Parental Social Support and Self-Efficacy: Cross-Sectional Study

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Abstract

Background: In today's digital society, the acquisition of parenting information through online platforms such as social networking sites (SNSs) has become widespread. Amid the mix of online and offline information sources, there is a need to discover effective information-seeking methods for solving parenting problems.

Objective: This study aimed to identify patterns of information use among parents of young children in the digital age and elucidate the characteristics of these patterns through a comparative analysis of parental social support and self-efficacy.

Methods: An internet-based survey was administered to fathers and mothers of children aged 0-3 years. Convenience sampling, facilitated by an internet-based survey company, was adopted, and data from 227 fathers and 206 mothers were analyzed. The survey included questions on personal characteristics, frequency of use of different sources of parenting information (websites, SNSs, parenting apps, family, friends, and professionals), availability of parental social support, and parental self-efficacy. The Partitioning Around Medoids (PAM) clustering algorithm was used to identify patterns in parenting information use.

Results: A total of 4 clusters were identified: multisource gatherers (n=161), offline-centric gatherers (n=105), online-centric gatherers (n=86), and minimal information gatherers (n=68). The availability of parental social support was perceived to be relatively higher among multisource and offline-centric gatherers compared with online-centric and minimal information gatherers. Parental self-efficacy was highest among multisource gatherers, followed by offline-centric and online-centric gatherers, and lowest among minimal information gatherers.

Conclusions: This study contributes to the evidence that online information can effectively complement offline information in addressing parenting challenges, although its ability to fully replace offline sources remains limited. Parenting support professionals are encouraged to understand parents' current information use strategies and actively foster their social relationships, helping them to adopt more diverse and comprehensive approaches to information use.

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KEYWORDS

parenting; information use; digital society; online information; social support; self-efficacy; parents; surveys; information seeking; information behaviors; resources; children; youth; pediatric

Introduction

In the current digital age, the proliferation of applications designed to make pregnancy and parenting more convenient is changing the landscape of parenting [1,2]. The space for sharing parenting information and support has expanded from offline to online, becoming a normalized aspect of daily life [3]. The expansion of the online information space has provided many benefits for parents. Parents now have immediate access to a wide range of parenting information, including insights that are not available offline [4,5], and barriers to professional advice have reduced owing to parenting applications and online platforms [4]. Furthermore, online peer support has become increasingly active through platforms such as social networking sites (SNSs) [4], helping parents solve problems and learn about and establish parenting styles.

Since the outbreak of the COVID-19 pandemic, online family support services have rapidly expanded [6]. These services include professional family support through video conferencing tools [7] and online parenting programs [8]. The effectiveness of online parenting support programs has been shown to be comparable to that of in-person support programs [9], indicating that the digital society has brought about innovative advancements in the methodology of professional parenting support.

However, the online information space also presents certain challenges. Internet use that results in an information overload can overwhelm parents, complicate decision-making, and potentially lead to suboptimal actions due to misinformation, with the risk of triggering inappropriate parenting behaviors [5]. Furthermore, idealized images of parenting that proliferate on social media can create unrealistic expectations and pressures that undermine trust [10]. In addition, the “filter bubble” effect, where individuals are exposed only to information that aligns with their preferences and values, can promote biased parenting styles and isolate them from diverse viewpoints [11]. These challenges within the online information space pose the risk of complicating problem-solving processes in real-life parenting scenarios. Thus, online information related to parenting may have both positive and negative effects on problem-solving and the establishment of parenting styles. There is a need to accumulate knowledge that can help parents overcome the disadvantages of online information while maximizing its benefits in the context of parenting.

To examine the effective use of online information in parenting, it is critical to examine the interplay between online and face-to-face information. One explanatory model for the relationship between digital device use and human activity and well-being is the displacement-interference-complementarity (DIC) framework [12]. This framework offers a comprehensive understanding of the impact of digital devices on parenting by identifying 3 potential effects: displacement, interference, and complementarity. The displacement hypothesis suggests that digital devices may replace other activities, explaining that online social relationships serving as sources of parenting information may sometimes substitute for those in face-to-face settings. The interference hypothesis posits that digital devices may disrupt ongoing activities, indicating that parents’ use of online information could hinder face-to-face information gathering and support. Both hypotheses suggest that digital devices may limit face-to-face interactions in parenting, potentially negatively affecting positive parenting outcomes. In contrast, the complementarity hypothesis suggests that digital devices may provide access to information not available through face-to-face social relations, allowing parents to comprehensively use both online and offline sources of information to support their parenting efforts. By using the DIC framework, evidence can be provided to demonstrate the contexts in which online information benefits parents, contributing to a better understanding of how parenting support can be enhanced in the digital age.

Academic knowledge focused on technological advances is lagging [13], and research focusing on the interactivity between online and offline parenting information remains limited. For parents in the digital age, referring to or using online information has become commonplace. However, the affinity for digital technology varies among individuals, even within the so-called digital native generation, indicating diverse preferences [14]. In parenting, the level of online information use may vary based on factors such as the gender of the parent and the age of the child (in months) [15]. In the context of health information, information-seeking behaviors are significantly influenced by personal subjective norms [16]. This suggests that parents may exhibit a variety of patterns in their use of parenting information, ranging from those who integrate both online and offline sources to those who prefer online information or have traditional values and, therefore, use online resources sparingly. Exploring patterns of parenting information use, considering both online and offline sources, can provide nuanced evidence about the efficacy and challenges of digital information in parenting in light of the DIC framework.

To understand which component of the DIC framework online information falls under, it is important to consider parents’ social relationships as a potential influencing factor. Isolated individuals may use online communities, such as SNSs, to compensate for limited face-to-face interactions [17], suggesting that parents with limited social relationships might use online information as a substitute for face-to-face support. In addition, strong social support is correlated with higher health literacy [18], which in turn is associated with an increased rate of online health information searches [19]. This suggests that parents with extensive social networks are likely to be more adept at using both online and offline information, with online resources supplementing face-to-face interactions.

One outcome of effectively using parenting information to address parenting challenges is improved parenting self-efficacy, which is defined as parents’ beliefs about their ability to influence their children in ways that promote health and success [20]. High parenting self-efficacy is associated with positive outcomes in the parent-child relationship, child development, and parental mental health, underscoring its clinical importance [21]. Identifying the patterns of online or offline parenting information use associated with high parenting self-efficacy could provide insights into information use that enhances parenting performance.

Accordingly, this study aimed to explore the various patterns of combined online and offline parenting information use among parents in the digital age, categorize these patterns, and examine their characteristics by comparing the levels of parental social support and self-efficacy. This study seeks to answer 3 questions in particular:

1. What are the distinct patterns of the combined use of online and offline parenting information?

2. What are the demographic characteristics of the identified information usage patterns?
3. Which of these patterns of combined information use are associated with higher levels of parental social support and parenting self-efficacy?

Methods

Design

This study used a cross-sectional design, and a close-ended internet-based questionnaire survey was administered. To ensure the quality and transparency of the research, the Checklist for Reporting of Survey Studies (CROSS) developed by Sharma et al [22] and the CHERRIES (Checklist for Reporting Results of Internet E-Surveys) developed by Eysenbach [23] were used. This paper reports a portion of the data from a survey titled "Information Behavior on Social Networking Services Among Parents of Infants and Toddlers."

Participants and Sampling

Convenience sampling was adopted for participant recruitment and was performed in collaboration with Cross Marketing Inc, an internet-based survey company that oversees nationwide sampling in Japan. With over 5 million active online users, Cross Marketing Inc provides academic survey services for diverse demographics. The panel managed by the company consists of a broad range of internet users, providing a large control group that is unbiased by specific sites or advertisements. In this study, 434 parents of children aged 0-3 years were recruited from the Cross Marketing Inc panel. As part of the recruitment process, a one-time survey invitation was sent by the research company to approximately 2000 randomly selected individuals deemed eligible for the study. Recipients who answered a preliminary question about their children's age that was inconsistent with the study criteria were excluded. Those who agreed to participate in the study clicked "agree" after reading the research request document, which directed them to the internet-based survey link. The target sample size was set at over 200 participants each for fathers and mothers. Recruitment concluded once this target was reached. However, some individuals submitted late responses after recruitment ended, resulting in a final number of respondents that exceeded the target.

Data Collection

In August 2023, data were collected through an internet-based survey involving those directed through the aforementioned process. The survey was created and administered by the authors using the Qualtrics online survey system, which ensures data security through mechanisms such as encryption, redundancy, continuous monitoring, and single sign-on, and is FedRAMP certified and ISO27001 accredited. The survey was user-friendly, designed by the authors, and pretested to avoid design problems. Participants who completed the survey received reward points or other rewards according to the protocols of Cross Marketing Inc.

Measures

The survey items used in the internet-based survey are presented in Multimedia Appendix 1.

Frequency of Use of Parenting Information Resources

In this study, the selection of parenting information resources used by parents in today's digital society was based on the concept of the information space surrounding parents of young children by Xie et al [3]. Parents' information space consists of offline and online communities defined by proximity and the broader public sphere—the lifeworld. Online communities include everyday online spaces such as web search platforms, SNSs, and online parenting communities. Offline communities represent more immediate everyday spaces that include family members, friends, and parenting peers. The lifeworld includes broader public institutions and services, both online and offline, including medical institutions and their websites. Accordingly, in this study, the categorization followed was "online resources" from online communities and lifeworlds and "offline resources" from offline equivalents. Online sources of parenting information were divided into websites, SNSs, and parenting-related applications. Websites included child- and parent-related websites, blogs, and hospital homepages. Given the Japanese context, SNSs included platforms such as X (formerly known as Twitter), Instagram, Facebook (Meta Platforms), and YouTube (Google), excluding LINE (LY Corporation) because of its primary use for personal communication and limited feed functionality. Parenting apps included those useful for pregnancy tracking, baby development updates, and immunization schedules. Offline resources were identified as family, friends, parenting peers, and professionals (including health and education professionals), who provided information from offline communities and lifeworlds. Participants rated their subjective frequency of use of 6 information sources on a 6-point scale from "1: Never use" to "6: Always use."

Parenting Self-Efficacy

The Parenting Self-efficacy Scale [24], which was developed and validated in the Japanese context, was used. It consists of 13 items rated on a 5-point Likert scale, with higher scores indicating greater parenting self-efficacy. The Cronbach alpha for this study was 0.85.

Parental Social Support

Drawing on the classification of social support proposed by previous research [25], I developed items based on another previous study in the context of parenting [26], focusing on informational and emotional support. It is assumed that the availability of support varies depending on the source; therefore, I established 4 categories of respondents: spouses (including partners), other family members, friends and parenting peers, and professionals. A total of 8 items were created to reflect both types of support. Respondents evaluated these items using a 4-point scale ranging from "1: Strongly disagree" to "4: Strongly agree." In cases where the designated respondent category did not apply (eg, if the participant was a single parent), respondents were instructed to select "0: Not applicable."

Participant Demographics

Data were collected on participants' age, number of children, age of the youngest child, occupational status, educational level, and subjective economic status.

Statistical Analysis

First, descriptive statistics for both fathers and mothers were conducted to examine differences in the frequency of information source usage and social support related to parenting. Next, the partitioning around medoids (PAM), a nonhierarchical clustering method applicable to ordinal scales, was used to identify patterns in gathering parental information. This approach addresses traditional challenges of hierarchical clustering, which may hinder finding optimal solutions because participants remain in specific clusters throughout all analysis steps. Unlike the k-means method, which relies on means, PAM uses actual data points (medoids) as cluster centers, maintaining rank information and providing robust clustering results in the presence of outliers or noise. Initial medoids are determined using a Greedy algorithm, which sequentially selects locally optimal solutions to minimize the total cost (the sum of distances from each data point to the nearest medoid), effectively reflecting the data's structure. The Manhattan distance was adopted as the distance metric, which, unlike Euclidean distance, represents movement along each dimension rather than straight-line distance, offering robustness against outliers and noise.

The number of clusters was determined based on theoretical and practical interpretability, along with results from the elbow method and gap statistic, both indicators of clustering appropriateness. The elbow method visualizes how the sum of squared errors (SSE) within clusters decreases as the number of clusters (k) increases, with the "elbow" point indicating the optimal number of clusters. In this study, SSE was plotted for values of k from 1 to 20 to locate the elbow. The gap statistic method compares the clustering results of observed data with those of randomly generated data to determine the optimal number of clusters, identifying the maximum gap statistic as optimal and indicating how much better the clustering results are compared with random data. A maximum of 500 bootstrap iterations was conducted for the observed data set from 1 to 20 clusters.

Initially, we conducted separate analyses for the father and mother, confirming similarities in their clustering. Given the observed similarities between both parents, the measures taken to reduce the sample size for each cluster, and the importance of integrating the clusters, we decided to consolidate all samples for cluster analysis. The Kruskal-Wallis test and the Steel-Dwass test were used for multiple comparisons to identify clusters based on the reference variables.

To investigate the association between the extracted clusters and demographic characteristics, as well as the availability of parental social support, we conducted the analysis using the Kruskal-Wallis test, Steel-Dwass test, or chi-square test. In addition, to compare parenting self-efficacy across clusters, 1-way ANOVA and Tukey honest significant difference (HSD) tests were performed for multiple comparisons. Statistical analyses were conducted using JMP Pro (version 17.0; SAS Institute) and R language (R Foundation for Statistical Computing), with a significance level set at 5%.

The required sample size for 1-way ANOVA was calculated using G-power, considering an effect size (f) of 0.25 (medium), α error probability of 0.05, power of 0.8, and 20 groups, resulting in a minimum required sample size of 360. The number of groups was based on the maximum expected in PAM for this study. Missing values in parenting self-efficacy were imputed using least squares prediction based on nonmissing values for each scale when less than half of the data were missing.

Ethical Considerations

Participants were provided written information about the following aspects related to the study and their participation: an overview of the study, voluntary participation, no penalty for nonparticipation, their right to refuse to answer, maintenance of anonymity, use of data only for research purposes, and strict management of personal information. Consent to participate was obtained when participants selected the consent button in the internet-based survey. All questions included the option for participants to refuse to answer if they preferred. This study was conducted following approval received from the Institutional Ethics Committee, the ethics committee for research involving human participants at Toyama Prefectural University (August 10, 2023, approval number: R5-16).

Results

Descriptive Statistics

Of the respondents who returned the questionnaire, data from 420 individuals—those without missing data on items related to the use of information sources in parenting—were included in the analysis. The basic demographic characteristics of the participants are presented in Table 1. The sample consisted of 201/420 mothers (47.9%) and 219/420 fathers (52.1%). The distribution of the Parenting Self-Efficacy Scale exhibited a skewness of –0.35 and a kurtosis of 0.14. None of the scales violated the thresholds (skewness: absolute value >2; kurtosis: absolute value >7) [27], which could potentially cause bias in parametric analyses.

Table 1. Demographics.

	Mothers (N=201)		Fathers (N=219)	
	n (%)	Mean (SD)	n (%)	Mean (SD)
Demographics				
Parent’s age (n=388)	—[a]	34.5 (4.89)	—	39.8 (6.57)
Number of children				
One	93 (0.46)	—	90 (0.41)	—
Two	83 (0.41)	—	91 (0.42)	—
Three or more	25 (0.12)	—	38 (0.17)	—
Youngest child’s age				
Infant	69 (0.34)	—	52 (0.24)	—
1 year old	62 (0.31)	—	73 (0.33)	—
2 years old	41 (0.2)	—	56 (0.26)	—
3 years old	29 (0.14)	—	38 (0.17)	—
Cohabiting family members				
Partner	192 (0.96)	—	214 (0.98)	—
Own family members	12 (0.06)	—	13 (0.94)	—
Partner's family members	9 (0.05)	—	4 (0.02)	—
Occupational status				
Full-time worker	58 (0.29)	—	215 (0.98)	—
Part-time worker	23 (0.11)	—	1 (0)	—
Homemaker	73 (0.36)	—	1 (0)	—
On maternity or childcare leave	47 (0.23)	—	2 (0.01)	—
Educational level (n=418)				
Junior high school or High school graduate	24 (0.12)	—	27 (0.12)	—
Junior college or Vocational school graduate	61 (0.31)	—	21 (0.1)	—
University or Graduate school graduate	115 (0.58)	—	170 (0.78)	—
Subjective economic status				
Very concerned	22 (0.11)	—	32 (0.15)	—
Somewhat concerned	83 (0.41)	—	86 (0.39)	—
Slightly concerned	82 (0.41)	—	93 (0.42)	—
Not concerned at all	14 (0.07)	—	8 (0.04)	—
Having digital devices				
Having smartphones	200 (1)	—	215 (0.98)	—
Having tablets	45 (0.22)	—	70 (0.32)	—
Having computers	85 (0.42)	—	146 (0.67)	—
Parenting efficacy (n=418)	—	3.48 (0.67)	—	3.50 (0.66)

[a] Not applicable.

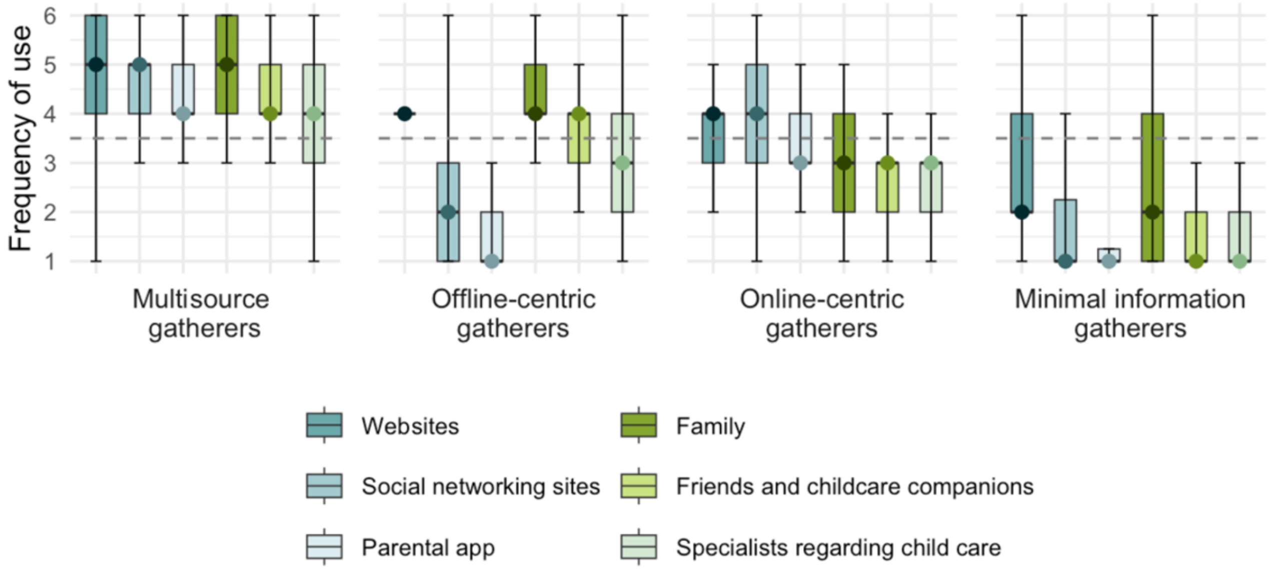
Gender Differences in Parental Information Use and Availability of Support

The frequency of using information sources in parenting and descriptive statistics for parental social support are presented in Multimedia Appendix 2. Among the parenting-related information sources, mothers more frequently used websites (*P*=.003), SNSs (*P*<.001), parenting apps (*P*<.001), and friends or parenting peers (*P*<.001) compared with fathers. Regarding parental social support, fathers perceived greater availability of informational support (*P*<.001) and emotional support (*P*=.02) from their partners compared with mothers. Conversely, mothers perceived greater availability of emotional support from friends than fathers (*P*=.01).

Cluster Analysis

Based on the clusters extracted by PAM, the elbow method was applied. Although a clear elbow point could not be definitively established, the reduction in the total within-cluster sum of squares became more gradual at k=4 (Multimedia Appendix 3). The gap statistic plot indicated that k=4 yielded the maximum value, followed by a slight decrease (Multimedia Appendix 4). Consequently, we decided to proceed with a cluster count of 4 (Figure 1 and Multimedia Appendix 5). The clusters were named based on the Kruskal-Wallis test and the Steel-Dwass test, as follows: Cluster 1, with a high frequency of use of all information sources, was named “Multisource gatherers (n=161).” Cluster 2, with a relatively higher frequency of use of offline sources compared with online sources, was named “Offline-centric gatherers (n=105).” Cluster 3, with a relatively higher frequency of use of online sources compared with offline sources, was named “Online-centric gatherers (n=86).” Cluster 4, with an extremely low frequency of use of all information sources, was named the “Minimal information gatherers (n=68).”

Figure 1. Clusters of use patterns of parenting information resources.



Differences of Demographics by Parent Information Use Patterns

The comparison results of the demographics of the 4 clusters are presented in Table 2. “Multisource gatherers” are relatively younger, have more mothers, fewer children aged 2, more often cohabitate with spouses, exhibit a higher prevalence of maternity and parental leave, and enjoy a better living situation. “Offline-centric gatherers” are relatively older, have more fathers, tend to have more families with two children rather than one, and predominantly work full-time with less maternity and parental leave; they also have a higher rate of university graduates. “Online-centric gatherers” tend to have more infants as their youngest children and fewer 3-year-olds, work more part-time, and have a higher proportion of junior college or vocational graduates, with fewer holding university degrees. “Minimal information gatherers” are relatively characterized by more fathers, a higher number of 2-year-olds, and a predominance of full-time employment.

Table 2. Demographic differences by parental information-use patterns.

	1. Multisource gatherers (n=161)		2. Offline-centric gatherers (n=105)		3. Online-centric gatherers (n=86)		4. Minimal information gatherers (n=68)		*F*[a] test (*df*)	Chi-square (*df*)[b]	*P* value	Multiple comparisons[c]
	n (%)	Mean (SD)	n (%)	Mean (SD)	n (%)	Mean (SD)	n (%)	Mean (SD)				
Parent’s age (n=388)	—[d]	35.51 (5.81)	—	39.7 (5.88)	—	36.2 (7.14)	—	38.7 (5.89)	11.20 (3,384)	—	<.001	2≧4≧3≧1
Gender									—	31.09 (3)	<.001	—
Mother	95 (0.59)[e]	—	36 (0.34)	—	51 (0.59)	—	19 (0.28)	—				
Father	66 (0.41)	—	69 (0.66)[e]	—	35 (0.41)	—	49 (0.72)[e]	—				
Number of children									—	16.36 (6)	.01	—
One	74 (0.46)	—	29 (0.28)[f]	—	45 (0.52)	—	35 (0.51)	—				
Two	62 (0.39)	—	55 (0.52)[e]	—	32 (0.37)	—	25 (0.37)	—				
Three or more	25 (0.16)	—	21 (0.2)	—	9 (0.10)	—	8 (0.12)	—				
Youngest child’s age									—	42.31 (9)	<.001	—
Infant	54 (0.34)	—	16 (0.15)	—	36 (0.42)[e]	—	15 (0.22)	—				
1 year old	58 (0.36)	—	39 (0.37)	—	22 (0.26)	—	16 (0.24)	—				
2 years old	20 (0.12)[f]	—	28 (0.27)	—	21 (0.24)	—	28 (0.41)[e]	—				
3 years old	29 (0.18)	—	22 (0.21)	—	7 (0.08)[f]	—	9 (0.13)	—				
Cohabitating family members									—	8.13 (3)	.04	—
Partner	159 (0.99)[e]	—	101 (0.96)	—	80 (0.93)	—	66 (0.97)	—				
Own family members	16 (0.10)	—	4 (0.04)	—	4 (0.05)	—	1 (0.01)	—				
Partner's family members	9 (0.06)	—	1 (0.01)	—	2 (0.02)	—	1 (0.01)	—				
Occupational status									—	34.66 (9)	<.001	—
Full-time worker	88 (0.55)[f]	—	80 (0.76)[e]	—	53 (0.62)	—	52 (0.76)[e]	—				
Part-time worker	8 (0.05)	—	4 (0.04)	—	10 (0.12)[e]	—	2 (0.03)	—				
Homemaker	34 (0.21)	—	19 (0.18)	—	11 (0.13)	—	10 (0.15)	—				
On maternity or childcare leave	31 (0.19)[e]	—	2 (0.02)[f]	—	12 (0.14)	—	4 (0.06)	—				
Educational level (n=418)									—	14.92 (6)	.02	—
Junior high school or High school graduate	21 (0.13)	—	7 (0.07)	—	11 (0.13)	—	12 (0.18)	—				
Junior college or Vocational school graduate	33 (0.20)	—	14 (0.13)	—	25 (0.29)[e]	—	10 (0.15)	—				
University or Graduate school graduate	107 (0.66)	—	83 (0.80)[e]	—	49 (0.58)[f]	—	46 (0.68)	—				

	1. Multisource gatherers (n=161)		2. Offline-centric gatherers (n=105)		3. Online-centric gatherers (n=86)		4. Minimal information gatherers (n=68)		*F*[a] test (*df*)	Chi-square (*df*)[b]	*P* value	Multiple comparisons[c]
	n (%)	Mean (SD)	n (%)	Mean (SD)	n (%)	Mean (SD)	n (%)	Mean (SD)				
Subjective economic status[g]									—	10.10 (3)	.02	1≧2=3=4
Very concerned	12 (0.07)	—	12 (0.11)	—	13 (0.15)	—	17 (0.25)	—				
Somewhat concerned	68 (0.42)	—	38 (0.36)	—	36 (0.42)	—	27 (0.40)	—				
Slightly concerned	69 (0.43)	—	52 (0.5)	—	33 (0.38)	—	21 (0.31)	—				
Not concerned at all	12 (0.07)	—	3 (0.03)	—	4 (0.05)	—	3 (0.04)	—				

[a] Results of 1-way ANOVA.

[b] Results of chi-square test or Kruskal-Wallis test.

[c] The result of Steel-Dwass test or Turkey HSD test.

[d] Not applicable.

[e] Indicates significant differences observed in the residual analysis and denotes a significantly higher proportion. +

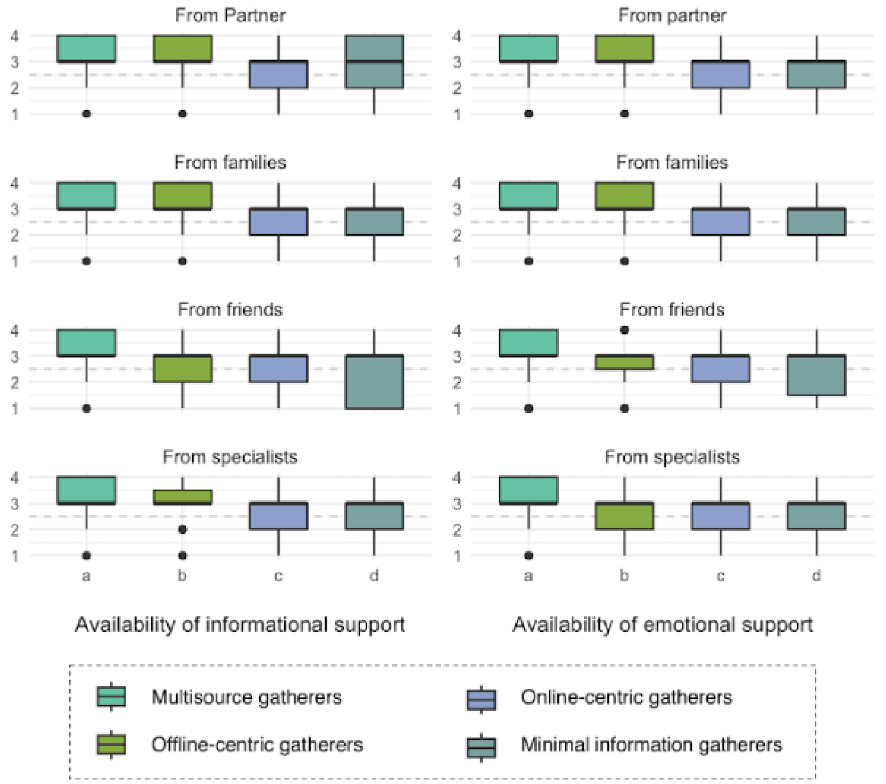
[f] Indicates significant differences observed in the residual analysis and denotes a significantly lower proportion. -

[g] The larger the value, the less concern there is about the economic situation.

Comparison of Parental Social Support Based on Parenting Information Use Patterns

The comparative results of the availability of social support in childcare across the 4 clusters are presented in Figure 2 and Multimedia Appendices 6 and 7. A significant relationship was confirmed between all types of available support and clusters. Regarding spousal support, both informational and emotional aspects were more available to “Multisource gatherers” compared with “Online-centric gatherers.” For family support, both informational and emotional aspects were more available to “Multisource gatherers” and “Offline-centric gatherers” compared with “Online-centric gatherers” and “Minimal information gatherers.” In terms of support from friends and parenting peers, both informational and emotional aspects were higher for “Multisource gatherers” compared with “Online-centric gatherers” and “Minimal information gatherers,” while “Offline-centric gatherers” also had more availability than “Minimal information gatherers.” Finally, support from professionals showed greater availability in both informational and emotional aspects for “Multisource gatherers” compared with “Online-centric gatherers” and “Minimal information gatherers.”

Figure 2. Comparison of parental social support based on parenting information use patterns.

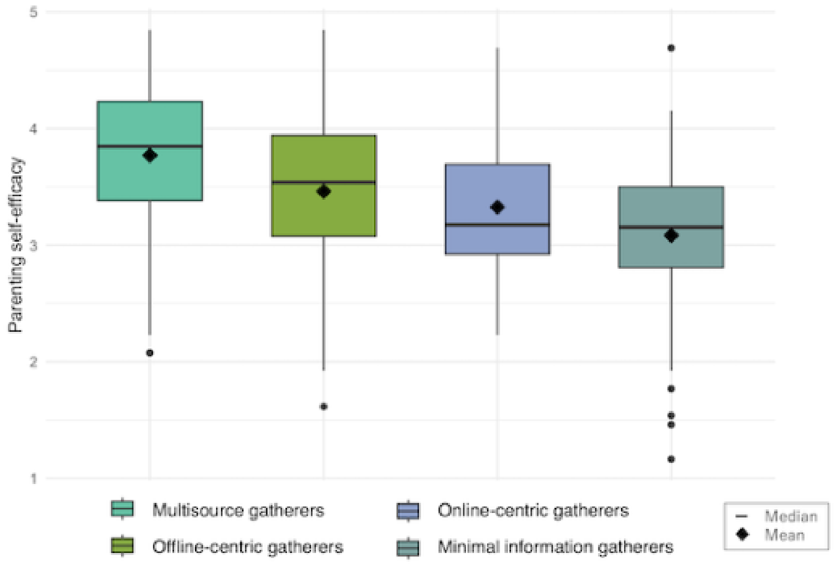


Note. The results of the Kruskal-Wallis test. The figure presents a box plot with median indicated by a bold line.

Comparison of Parenting Self-Efficacy Based on Parenting Information Use Patterns

The results comparing parenting self-efficacy based on parenting information usage patterns are presented in Figure 3 and Multimedia Appendix 8. The 1-way ANOVA revealed a significant relationship between parenting information usage patterns and parenting self-efficacy ($F_{3,414}$=22.86, P<.001). According to the Tukey HSD test, “Multisource gatherers” demonstrated significantly higher parenting self-efficacy compared with “Offline-centric gatherers,” “Online-centric gatherers,” and “Minimal information gatherers” (P<.001 for each). In addition, “Offline-centric gatherers” exhibited significantly higher self-efficacy than “Minimal information gatherers” (P<.001).

Figure 3. Comparison of parenting self-efficacy based on parenting information use patterns.



Note. The results of the one-way ANOVA. The figure presents a box plot with median indicated by a bold line and the mean represented by a diamond.

Discussion

Principal Findings

This study identified 4 types of parenting information use patterns among parents of infants and toddlers and elucidated their characteristics through comparisons of parental social support and parenting self-efficacy. The main findings of the study are discussed below.

Multisource Type

First, the “Multisource gatherers” tended to use both online and face-to-face information sources frequently. This suggests that online information resources may function as a complement for these groups, according to the DIC framework [12]. Parents of this type had higher levels of support from family, friends, and specialists related to parenting than did “Online-centric gatherers” and “Minimal information gatherers.” This suggests that they may have extensive social networks that allow them to access a wide range of information sources for parenting. In addition, individuals in this type had higher levels of parenting self-efficacy than those in the other types. Access to diverse information can contribute to problem-solving when information utilization skills are high; otherwise, it can lead to confusion owing to information overload [4]. These parents may effectively use diverse information from both offline and online sources to solve parenting challenges because of their information use and social relationship-building skills, which may contribute to higher parenting self-efficacy. However, given the cross-sectional design of this study, reverse causality is also possible. Parents with high parenting self-efficacy may experience a greater sense of reassurance when using smart devices to alleviate parenting anxiety, leading to reduced anxiety [28]. High parenting self-efficacy, which is associated with reduced psychological distress in parenting [29], may mitigate the negative aspects of online information, such as psychological distress from social comparisons on SNSs [30], enabling parents to use multichannel information effectively.

This type has a relatively high proportion of mothers and individuals on maternity or parental leave and a low proportion of full-time workers. In addition, this type, along with “Online-centric gatherers,” exhibits a high frequency of online information usage, which aligns with previous research indicating that women engage more frequently in internet use and the exchange of social support through SNSs [31,32]. Furthermore, working mothers are expected to have a broader social network due to their workplace connections compared with stay-at-home mothers. Mothers on maternity or parental leave are more likely to have more time to use their parenting networks than those currently used. As a result, it can be inferred that mothers on maternity or parental leave were leveraging both online and offline information to address parenting challenges.

Online Type

“Online-centric gatherers,” who exhibit a relatively higher frequency of use of online information sources centered around SNSs compared with offline sources, tend to show lower availability of informational and emotional social support in parenting compared to “Multisource gatherers” and “Offline-centric gatherers.” This type may be using online information to replace limited face-to-face social relationships, suggesting that online information acts as a substitute, according to the DIC framework [12]. The lower parenting self-efficacy observed in this type, compared to “Multisource gatherers,” suggests that substituting face-to-face information with online information may be limited to offer positive outcomes in parenting. Previous research has suggested that using digital resources as a substitute for family support in solving parenting challenges may lead to low parental role achievement [26]. The results of this study are consistent with previous research and strengthen the evidence regarding the effectiveness of online information as a complement to and its limitations as a substitute for offline information in resolving parenting challenges. Individuals struggling with social isolation or loneliness may have a high affinity for online information from SNSs [17], suggesting that parents of this type may have limited face-to-face social relations and may intentionally or unintentionally rely on online information to cope with these issues.

This type is characterized by a relatively high proportion of mothers with infants, part-time workers, and individuals with associate degrees. During the infant stage, the emphasis on caregiving is greater compared with the toddler stage, resulting in more restrictions in daily parenting life. This may have led to the use of online parenting networks, which are more easily accessible than in-person support. In addition, previous research [28] indicates that highly educated mothers tend to experience anxiety related to problem-solving in parenting when using smart devices. Parents of this type, owing to their higher educational status, may recognize concerns regarding online information, making them less likely to adopt an information use style that is heavily biased toward online sources.

Offline Type

“Offline-centric gatherers” preferred face-to-face to online sources of information. This type, likely a conventional type from the pre-SNS era, appeared to prioritize information obtained through face-to-face interactions for parenting. Despite the proliferation of digital technology and the tech-savvy population, there is a certain proportion of nonadopters who either intentionally or unintentionally choose not to use technology [33,34]. As such, those in the offline group may be similar to nonadopters of digital technology. Compared with the “Online-centric gatherers” and “Minimal information gatherers,” this type perceived greater availability of support from family and friends and appeared to rely on ample face-to-face resources for parenting without the need for online information. However, this type exhibited lower parenting self-efficacy compared with “Multisource gatherers.” This suggests that online information, as a complementary hypothesis, may contribute to higher levels of parenting self-efficacy. Using online information in this context may help further enhance the parenting self-efficacy of these parents.

This type is characterized by a relatively high proportion of fathers, parents with only one child, full-time workers, and individuals with university or graduate degrees. Compared with pregnant women and mothers, there are limited SNSs and peer support opportunities for fathers related to parenting [35], which may restrict their ability to expand online parenting networks and effectively use online information. In addition, the prevalence of highly educated individuals in this type is consistent with the aforementioned tendency for online use in problem-solving to evoke negative emotions [28].

Minimal Information Gatherers

“Minimal information gatherers” exhibited a generally low frequency of information use. This type recognized the availability of support from family, friends, and professionals to a lesser extent, and their self-efficacy in parenting was lower than that of all other types. This type may have limited access to all parenting information resources and an extremely narrow social network, both within and outside the family, indicating potential problems in social relations. Social isolation is a significant factor in worsening parental mental health [36] and a risk factor for maltreatment [37]. This type may represent a high-risk case that requires assistance from experts.

In this group, there was a high proportion of fathers and full-time workers among the samples. In Japanese society, owing to the influence of gender role division, mothers often take on the central role in child-rearing, while fathers’ involvement may be limited in some households [38]. Busy fathers, who may have less active involvement, might lack sufficient parenting experience, which could lead to lower self-efficacy in child-rearing. In addition, this group uniquely recognized the availability of informational support from partners as comparable with “Multisource gatherers” and “Offline-centric gatherers” while acknowledging the lower availability of emotional support from partners compared with the other two types. This implies that, despite problems in the emotional relationship between couples, the limited social networks they possess confine their sources of parenting information to their partners. Fathers may struggle more than mothers to distinguish negative emotions stemming from marital discord from those associated with parenting, which supports the “Fathering Vulnerability Hypothesis [39].” Considering this hypothesis, fathers in this category might experience complex negative emotions due to their reliance on partners for parenting information despite having emotional challenges in their relationships, thereby reinforcing negative experiences in parenting and leading to a decline in self-efficacy.

Implications

The results confirm that the DIC framework is generally applicable in the context of parenting information use. As those with the highest levels of parenting self-efficacy are “multisource gatherers,” it is recommended that parents use online information as a complement to face-to-face advice when seeking parenting information. On the other hand, it should not be used as a substitute for face-to-face information provision, as it is less likely to lead to favorable outcomes. However, parents who rely on online information may face potential issues, such as limited social networks. Therefore, simply reducing the use of online information does not guarantee an improvement in parenting outcomes.

Parenting support professionals are required to provide customized assistance based on the types of parenting information use identified in this study. “Multisource gatherers” are encouraged to enhance their ability to use diverse information sources, both online and offline. For “Online-centric gatherers,” there is a need to strengthen information literacy to assess the reliability and quality of online information, particularly given the variability in these factors in the short term. For example, reports indicate that interactive websites, parent-created sites, and sites originating from South America have significant room for improvement in ethical and content aspects [40]; therefore, parents should be cautious when using them. In the medium to long term, promoting enriched social relationships in parenting to facilitate a transition to “Multisource gatherers” would be effective. For “Offline-centric gatherers,” having robust offline social networks is crucial, and supporting the strengthening of these networks to obtain valuable informational support from family and community is beneficial. For “Minimal information gatherers,” identifying underlying issues, such as family discord or social isolation, and providing tailored professional support is effective. By addressing these underlying issues and enhancing social relationships in parenting may broaden information use patterns in parenting, leading to a transition to other categories.

Limitations

A few limitations of this study must be noted. First, causal inferences could not be made, given its cross-sectional design. Second, owing to the self-report questionnaire format, the possibility of information bias cannot be dismissed. Third, the convenience sampling approach adopted, collaborating with a specific survey company in Japan, does not eliminate the possibility of selection bias. In particular, online survey respondents may be biased toward higher online affinity and information literacy, thus limiting the generalizability of the results. Fourth, it is difficult to completely rule out the possibility of different clusters emerging from this study. It is crucial to confirm the reproducibility of the clusters identified in this study through cluster analysis using a larger, randomly sampled data set with more rigorous procedures. Fifth, this study did not consider information literacy when capturing the characteristics of the types of parenting information use patterns. Finally, the measure examining the availability of parenting support to investigate the characteristics of the clusters is a single-item scale, and its reliability and validity are not sufficiently guaranteed. It is also important to note the existence of parenting support networks, such as workplace colleagues, which could not be measured in this study.

Future research involving larger international samples and different methodologies not influenced by online affinity may increase the robustness of this study’s findings. In addition, it is expected that patterns of information use may change under the influence of various factors such as parents’ educational experiences and children’s age. Identifying the process of change and the factors involved could contribute to a more nuanced understanding of the characteristics of parenting information used in today’s digital society.

Conclusion

This study identified types of parenting information-seeking patterns among parents in today's digital society and explored their characteristics through comparisons of parental social support and parenting self-efficacy. The results indicated the following information-seeking patterns among parents: those who use both online and face-to-face information sources in a multichannel, hybrid manner; those with a bias toward either online or face-to-face information; and those with a generally low frequency of parenting information use. The type that used both online and offline resources exhibited the highest levels of parenting self-efficacy. The results of this study support the DIC framework and strengthen the evidence for the effectiveness of online information as a complement to and its limitations as a substitute for offline information in resolving parenting challenges. Parenting support professionals are encouraged to understand parents' current information use strategies and actively foster their social relationships, helping them to adopt more diverse and comprehensive approaches to information use.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey items.
[PDF File (Adobe PDF File), 672 KB - pediatrics_v7i1e58757_app1.pdf]

Multimedia Appendix 2
Gender differences in information and social support availability in child care.
[XLSX File (Microsoft Excel File), 15 KB - pediatrics_v7i1e58757_app2.xlsx]

Multimedia Appendix 3
The elbow methods.
[PNG File , 91 KB - pediatrics_v7i1e58757_app3.png]

Multimedia Appendix 4
The gap statistic method.
[PNG File , 99 KB - pediatrics_v7i1e58757_app4.png]

Multimedia Appendix 5
Cluster analysis results.
[XLSX File (Microsoft Excel File), 12 KB - pediatrics_v7i1e58757_app5.xlsx]

Multimedia Appendix 6
Comparison of availability of support by parenting information use patterns.
[XLSX File (Microsoft Excel File), 12 KB - pediatrics_v7i1e58757_app6.xlsx]

Multimedia Appendix 7
Results of multiple comparisons using Steel-Dwass test in the comparison of availability of supports across parenting information use patterns.
[XLSX File (Microsoft Excel File), 13 KB - pediatrics_v7i1e58757_app7.xlsx]

Multimedia Appendix 8
Results of multiple comparisons using Tukey's honest significant difference test in the comparison of parenting self-efficacy across parenting information use patterns.
[XLSX File (Microsoft Excel File), 10 KB - pediatrics_v7i1e58757_app8.xlsx]

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Abbreviations

CHERRIES: Checklist for Reporting Results of Internet E-Surveys
CROSS: Checklist for Reporting of Survey Studies
DIC: displacement–interference–complementarity
HSD: honest significant difference
PAM: partitioning around medoids
SNS: social networking site
SSE: sum of squared errors

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Use of Web-Based Surveys to Collect Long-Term Pediatric Outcomes in Patients With Twin-Twin Transfusion Syndrome Treated With Fetoscopic Laser Photocoagulation: Observational Study

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Abstract

Background: In the United States, patients with monochorionic diamniotic twins who undergo in utero fetoscopic laser photocoagulation (FLP) for twin-twin transfusion syndrome (TTTS) may travel great distances for care. After delivery, many parents cannot return to study sites for formal pediatric evaluation due to geographic location and cost.

Objective: The aim of this study was to collect long-term pediatric outcomes in patients who underwent FLP for TTTS.

Methods: We assessed the feasibility of using a web-based survey designed in REDCap (Research Electronic Data Capture; Vanderbilt University) to collect parent-reported outcomes in children treated for TTTS at a single center during 2011 - 2019. Patients with ≥1 neonatal survivor were invited via email to complete 5 possible questionnaires: the child status questionnaire (CSQ); fetal center questionnaire (FCQ); Ages & Stages Questionnaires, Third Edition (ASQ-3); Modified Checklist for Autism in Toddlers, Revised With Follow-Up (M-CHAT-R/F); and thank you questionnaire (TYQ). The R programming language (R Foundation for Statistical Computing) was used to automate survey distribution, scoring, and creation of customized reports. The survey was performed in 2019 and repeated after 12 months in the same study population in 2020.

Results: A total of 389 patients in 26 different states and 2 international locations had an email address on file and received an invitation in 2019 to complete the survey (median pediatric age 48.9, IQR 1.0 - 93.6 months). Among surveyed mothers in 2019, the overall response rate was 37.3% (145/389), and the questionnaire completion rate was 98% (145/148), 87.8% (130/148), 71.1% (81/100), 86.4% (19/22), and 74.3% (110/148) for the CSQ, FCQ, ASQ-3, M-CHAT-R/F, and TYQ, respectively. In 2020, the overall response rate was 57.8% (56/97), and the questionnaire completion rate was 96.4% (54/56), 91.1% (51/56), 86.1% (31/36), 91.7% (11/12), and 80.4% (45/56) for the CSQ, FCQ, ASQ-3, M-CHAT-R/F, and TYQ, respectively.

Conclusions: This is the first study to use both REDCap and computer automation to aid in the dissemination, collection, and reporting of surveys to collect long-term pediatric outcomes in the field of fetal medicine.

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KEYWORDS

automation; REDCap; data collection; reporting; response rate; response rates; survey; surveys; questionnaire; questionnaires; fetal medicine; pediatric outcomes; long-term outcomes; photocoagulation; twin; twins; blood; pregnant; pregnancy; pediatric; pediatrics; infant; infants; infancy; baby; babies; neonate; neonates; neonatal; newborn; newborns; maternal; in utero; TTTS; fetus; fetal; twin-twin transfusion syndrome

Introduction

Background

Twin-twin transfusion syndrome (TTTS) results from unbalanced vascular communications in a shared placenta between monochorionic diamniotic (MCDA) twins. Bidirectional vascular communications are present in up to 95% of MCDA twins and allow for a single, shared circulatory system [1]. However, in 9% - 15% of MCDA twins, unbalanced vascular communications produce a pathological state in which one fetus (the donor twin) overtransfuses the cotwin (the recipient) [2,3]. Compensatory mechanisms result in progressive recipient polyhydramnios (excess amniotic fluid) and donor oligohydramnios (low amniotic fluid). Expectant management of this condition results in a mortality rate greater than 70%, typically due to sequelae from circulatory overload, compensatory hormonal dysfunction, and preterm delivery due to worsening polyhydramnios [4]. The gold-standard treatment for TTTS is intrauterine fetoscopic laser photocoagulation (FLP) of placental vascular anastomoses, which halts the abnormal blood exchange and yields better outcomes [5]. Despite this therapy, twins who survive TTTS may experience major disability at birth likely secondary to hemodynamic changes that occur in utero or sequelae of prematurity, as the average gestational age at delivery is approximately 32 weeks [6]. However, long-term outcomes for these surviving twins in the United States remain understudied, largely because of the logistical challenges of following patients who traveled far from home for treatment.

Prior Work

The data on long-term pediatric outcomes in patients who undergo FLP for TTTS come almost entirely from centers outside the United States. Centers with a local and homogeneous referral base are more likely to report in-person pediatric evaluations [7-10], although telephone and mail-in surveys have also been reported [9,11,12]. To date, there have been few attempts to collect long-term pediatric outcomes using web-based methods in the field of fetal surgery [13].

In the United States, patients referred for treatment of TTTS may travel upward of 2000 miles to receive care at a tertiary center of excellence [14]. The majority of these patients will travel home postprocedure and deliver at remote sites, which makes tracking neonatal and long-term outcomes challenging. At our center, thanks to considerable efforts from full-time research staff to collect maternal delivery and neonatal discharge records from patients' delivering hospitals, we have reported on the immediate and short-term neonatal complications (from time of delivery until hospital discharge) in patients who undergo FLP for TTTS [15]. However, prospectively collected in-person long-term follow-up of twins born after FLP in the United States would be exceedingly challenging and resource-intensive. Therefore, web-based collection methods may provide a viable approach.

Goal of This Study

The primary outcome of this study was to assess the feasibility of using computer automation to obtain, to the fullest extent, long-term pediatric outcomes from patients who underwent FLP for TTTS at a fetal center (FC) over a 2-year period.

Methods

Ethical Considerations

Approval was obtained from the Institutional Human Research Ethics Committee (IRB) (HSC-MS-19‐0363), and the study was conducted between June 1, 2019, and September 30, 2020. The IRB determined that our study did not need ethical approval.

Study Design

This was a cohort study of patients who were referred to the UTHealth Houston Fetal Center in Houston, Texas, and who underwent FLP for TTTS between 2011 and 2019. Eligible patients were identified retrospectively from a registry of patients treated at our center who had previously consented to prospective follow-up of short-term maternal and neonatal outcomes (HSC-MS-10‐0059).

Patients with TTTS who underwent FLP at our center during the study period and had both an email address on file and at least 1 surviving child from a monochorionic pair at the time of neonatal hospital discharge were eligible for participation in this study. Exclusion criteria included patients without a registered email or cases of dual fetal or neonatal demise.

Patient Recruitment and Consent

Patients who received the survey via email were instructed to follow a hyperlink to a web-based REDCap (Research Electronic Data Capture; Vanderbilt University) consent form, where details regarding study participation and confidentiality were provided. After giving e-consent, patients were emailed copies of the study protocol and directed to a subsequent child status questionnaire (CSQ). After indicating the survival status of both the ex-donor and the ex-recipient twins, the user was directed to a queue of web-based questionnaires, specific to the number of surviving children and their age.

Questionnaires

We designed research surveys in REDCap, an HIPAA (Health Insurance Portability and Accountability Act)–compliant, secure research data collection tool, which can be used to distribute web-based, mobile-friendly surveys. Surveys consisted of several pediatric age–specific questionnaires distributed via email to consenting parents. Details regarding the purpose, age applicability, and atypical screening threshold are present in Table 1.

Table . Summary of questionnaires in surveys distributed to participants.[a]

Questionnaire	Purpose	Applicability	Atypical screening threshold
CSQ[b,c]	• Confirm child survival status • Confirm if the child was the ex-recipient or ex-donor twin	Single questionnaire delivered to all consenting patients	N/A[d]
FCQ[e]	• 20 questions with “yes/no” responses related to general health and the use of special services	Parent-reported questionnaire for each child regardless of current pediatric age	N/A
ASQ-3[f]	• 40 questions with “yes/no” or “yes/sometimes/not yet” responses completed by parents designed to detect developmental delays in 5 domains: communication, gross-motor, fine-motor, problem-solving, and personal-social	Parent-reported questionnaire for each child between the ages of 1 and 60 months	Score of greater than or equal to 2 SD below the mean on any of the 5 domains assessed
M-CHAT-R/F[g]	• 20 questions with “yes/no” responses completed by parents to screen for autism spectrum disorder	Parent-reported questionnaire for each child between the ages of 16 and 30 months	Atypical response in 3 or more questions
TYQ[h]	• Obtain permission to distribute repeat survey in 12 months • Obtain appropriate contact information	Single questionnaire delivered to all consenting participants	N/A

[a] All questionnaires delivered via email through REDCap (Research Electronic Data Capture). Does not include the consent questionnaire, which was distributed to all eligible patients via email through REDCap and used the REDCap e-consent framework.

[b] CSQ: child status questionnaire.

[c] Age corrected for prematurity until 24 months of age.

[d] N/A: not applicable.

[e] FCQ: fetal center questionnaire.

[f] ASQ-3: Ages & Stages Questionnaires, Third Edition

[g] M-CHAT-R/F: Modified Checklist for Autism in Toddlers, Revised With Follow-Up.

[h] TYQ: Thank You Questionnaire.

First, all participating patients were sent the CSQ, a series of 2 ‐ 4 questions for each child, which provided confirmation of the child status as alive, demised in utero (fetal demise), or demised after birth (neonatal demise). The parent also reported the recipient or donor status for each child so that prenatal parameters could be accurately correlated with the correct twin. Based on user input indicating both the number of surviving children and pediatric age, specifically designed computer algorithms automatically tailored the number and type of survey questionnaires. Participating parents were sent any questionnaires applicable to their child’s pediatric age.

The fetal center questionnaire (FCQ) was adapted from a prior publication of long-term outcomes in twin gestations and was applicable to every surviving child [16]. The questionnaire consisted of 20 questions, the majority with “yes/no” responses, related to general health and the use of specialized services related to movement, speech, hearing, behavior, and education. The complete questionnaire is included in Multimedia Appendix 1.

The Ages & Stages Questionnaires, Third Edition (ASQ-3), a validated developmental screening tool with approximately 40 “yes/no” or “yes/sometimes/not yet” questions designed to be completed by parents, was applicable to every child between the ages of 1 and 60 months. This evaluation tool has high sensitivity and specificity to detect developmental delays in 5 domains: communication, gross-motor, fine-motor, problem-solving, and personal-social [17-21]. After obtaining permission from the publishers, we integrated all 21 age-specific versions of the ASQ-3 into REDCap as separate questionnaires.

The Modified Checklist for Autism in Toddlers, Revised With Follow-Up (M-CHAT-R/F), a validated autism screening tool with 20 “yes/no” questions designed to be completed by parents, was applicable to children between the ages of 16 and 30 months [22,23]. With permission from the publishers, the M-CHAT-R/F was distributed as a REDCap questionnaire. Participants whose children had a positive M-CHAT-R/F screen received a phone call and completed a series of follow-up questions per screening protocol.

The ASQ-3 and M-CHAT-R/F have been tested and validated in populations of children who are at risk for prematurity, autism, and abnormal neurodevelopmental outcomes [17-23]. They were selected for this survey due to ease of completion and ease of distribution as REDCap questionnaires.

Finally, all surveys were finished with a brief thank you questionnaire (TYQ). The TYQ consisted of 5 free text and “yes/no”-style questions requesting the following: permission to send a repeat survey 1 year later, the patient’s preferred method of contact for future studies, and permission to contact the patient to validate any results or obtain prior results from their child’s pediatrician’s office.

Distribution

The current age of all children surveyed was calculated, adjusting for prematurity until 24 months. For children who were older than 60 months, the CSQ, FCQ, and TYQ were distributed at a single timepoint. For children who were eligible for the ASQ-3, the survey was automatically distributed on a rolling basis approximately 3 weeks prior to the date at which a child’s age-specific ASQ-3 would no longer be applicable. Depending upon the child’s age and the number of surviving children (determined via the CSQ), parents’ survey queue (not including the single CSQ and TYQ) could contain as few as 1 FCQ questionnaire (eg, 1 surviving child at 6 years of age) and as many as 6 questionnaires (eg, 2 living children at 24 months of age). Patients who did not respond to the initial survey invitation within 1 week received 2 additional weekly reminders via email, followed by a phone call.

Scoring and Questionnaire Reporting

Scripts in the R programming language (R Foundation for Statistical Computing) were used to automatically score completed ASQ-3, accounting for an age-specific scoring rubric and adjustment for any skipped questions, and the M-CHAT-R/F. The ASQ-3 was considered high risk if any of the 5 domains assessed scored greater than or equal to 2 SDs below the mean. The M-CHAT-R/F examination was considered high risk if 3 or more questions had an atypical response. R language scripting was also used to both identify any child who had a high-risk ASQ-3 or M-CHAT-R/F screen and to automate the creation of custom reports in Microsoft Word (Microsoft Corp) using the *WordR* [24] and *officer* [25] packages. These reports were distributed to parents via HIPAA secure email within 2 weeks of survey completion.

Repeat Surveys

Patients who indicated they were amenable to a repeat survey received a second survey invitation in 2020 approximately 12 - 13 months after their 2019 response. All applicable age-specific questionnaires were repeated as part of a prospective analysis of pediatric developmental outcomes in this population. As part of the repeat 2020 survey, patients received a single email reminder but did not receive phone calls due to a lack of available research staffing. Questionnaires and follow-up reports were generated and distributed automatically within 2 weeks of survey completion.

Statistical Analysis: Power

As a purely observational study, no official power analysis was performed, as the primary objective was to collect, to the fullest extent, parent-reported long-term outcomes in this population over a 2-year period.

Results

Figure 1 is a flow diagram of patient recruitment and responses. In total, 475 patients underwent FLP for TTTS at our center between September 23, 2011, and February 13, 2019. Among them, 86 patients were excluded from the study: 52 had no neonatal survivors, 32 did not have an email on file at the time of the initial survey, and 2 did not consent to be contacted for future studies. A total of 389 mothers met the inclusion criteria and received an invitation via email to participate in the 2019 survey. Of these, 148 (38%) patients signed consent, and 145 patients completed or partially completed the full survey (CSQ, FCQ, ASQ-3, M-CHAT-R/F, or TYQ; 37.3% response rate). A total of 108 patients who responded in 2019 agreed to a repeat survey in 2020, of which 11 participants did not receive a repeat survey due to a technical error. In 2020, 97 patients from the 2019 cohort received a repeat survey, of whom 56 patients signed consent (57.8%) and 54 patients completed or partially completed the full set of questionnaires (55.7% response rate).

The majority of patients surveyed in 2019 and 2020 were from the southern United States (2019: 336/389, 86.8% and 2020: 80/97, 82.5%), had 2 neonatal survivors (2019: 325/389, 83.5% and 2020: 82/97, 84.5%), and underwent FLP for stage III TTTS (2019: 205/389, 52.4% and 2020: 52/97, 52.6%; Table 2). Slightly more than half of patients each year were from Texas (2019: 215/389, 55.3% and 2020: 51/97, 52.6%), and relatively few delivered within the same hospital system as the FC (2019: 41/389, 10.5% and 2020: 8/97, 8.2%). Compared with nonresponders, patients who consented to participate in the 2019 survey were older (30.0 vs 28.0 years; *P*<.001) and had younger children at the time of the survey (42.0 vs 52.0 months of age; *P*=.005), were less likely to have male children (68/145, 46.9% vs 143/244, 58.6%; *P*=.02), had a higher incidence of coexisting twin-anemia polycythemia sequence (10/141, 7.1% vs 5/239, 2.1%; *P*=.02), and had lower rates of coexisting selective fetal growth restriction (51/144, 35.2% vs 114/244, 46.7%; *P*=.03) and donor twins weighed more at delivery (1360 g vs 1570 g; *P*=.03). In both 2019 and 2020, there were no differences between responders and nonresponders with respect to race, number of surveys to complete, incidence of triplet pregnancies, TTTS Quintero stage, cervical length, gestational age at FLP, gestational age at delivery, child survival status, region of origin, distance from the FC, or incidence of delivery within the FC hospital system.

The completion rates and time to completion based on recorded survey timestamps in REDCap for each questionnaire are listed in Table 3. Reported completion times are limited to less than 60 minutes to exclude outliers who opened the questionnaire and completed it later. In 2019, 38% of eligible patients signed consent. In total, 98% (145/148) of consenting and eligible participants completed the CSQ, 87.8% (130/148) completed the FCQ in a median (IQR) of 3 (2-5) minutes, 71.1% (81/100) completed the ASQ-3 in 4 (3-8) minutes, and 86.4% (19/22) completed the M-CHAT-R/F in 2 (1-3) minutes. Of the patients who signed consent, 74.3% (110/148) completed the entire survey. Among patients who received a repeat survey in 2020, 57.8% (56/97) of patients signed consent. In total, 96.4% (54/56) of consenting and eligible participants completed the CSQ, 91.1% (51/56) completed the FCQ in a median (IQR) of 3 (2-5) minutes, 86.1% (31/36) completed the ASQ-3 in 6 (4 - 8.5) minutes, and 91.7% (11/12) completed the M-CHAT-R/F in 2 (1-3) minutes. Of the patients who signed consent, 80.4% (45/56) completed the entire survey.

The rates of atypical developmental screens are listed in Table 4. When analysis of the ASQ-3 was limited to the oldest assessment performed at ≥24 months of age for each child obtained in either 2019 or 2020, the overall rate of atypical ASQ-3 was 18.9% (18/95; recipient twin: 9/46, 19.6% and donor twin: 9/49, 18.4%). In 2019 and 2020, the rate of atypical M-CHAT-R/F screens was 11.1% (2/18) and 18.2% (2/11), respectively, for ex-recipient twins and 6.67% (1/15) and 9.1% (1/11), respectively, for ex-donor twins. In 2019 and 2020, the follow-up M-CHAT-R/F telephone confirmation was not performed for 3 children (total 2 recipient and 1 donor) due to the inability to reach the patient.

Patient willingness to undergo repeat survey and their preferred method of communication are listed in Table 5. Nearly 100% of patients in both years were amenable to a repeat survey in the following year. Respectively, most patients in 2019 and 2020 indicated a preference for email communication (99/110, 90% vs 43/45, 95.6%), followed by telephone calls (44/110, 40% vs 17/45, 37.8%), and finally mail-in post (24/110, 21.8% vs 11/45, 24.4%). In 2019 and 2020, 92.7% (102/110) and 95.6% (43/45) of responders were amenable to a follow-up call to sign a release of information waivers to request medical records from their child's pediatrician's office.

Figure 1. Patient recruitment and responses. ASQ-3: Ages & Stages Questionnaires, Third Edition; CSQ: child status questionnaire; FCQ: fetal center questionnaire; FLP: fetoscopic laser photocoagulation; M-CHAT-R/F: Modified Checklist for Autism in Toddlers, Revised With Follow-Up; TTTS: twin-twin transfusion syndrome; TYQ: thank you questionnaire. *Some response to any of CSQ, FCQ, ASQ-3, or M-CHAT-R/F. **Completed all age-appropriate questionnaires (Qs).

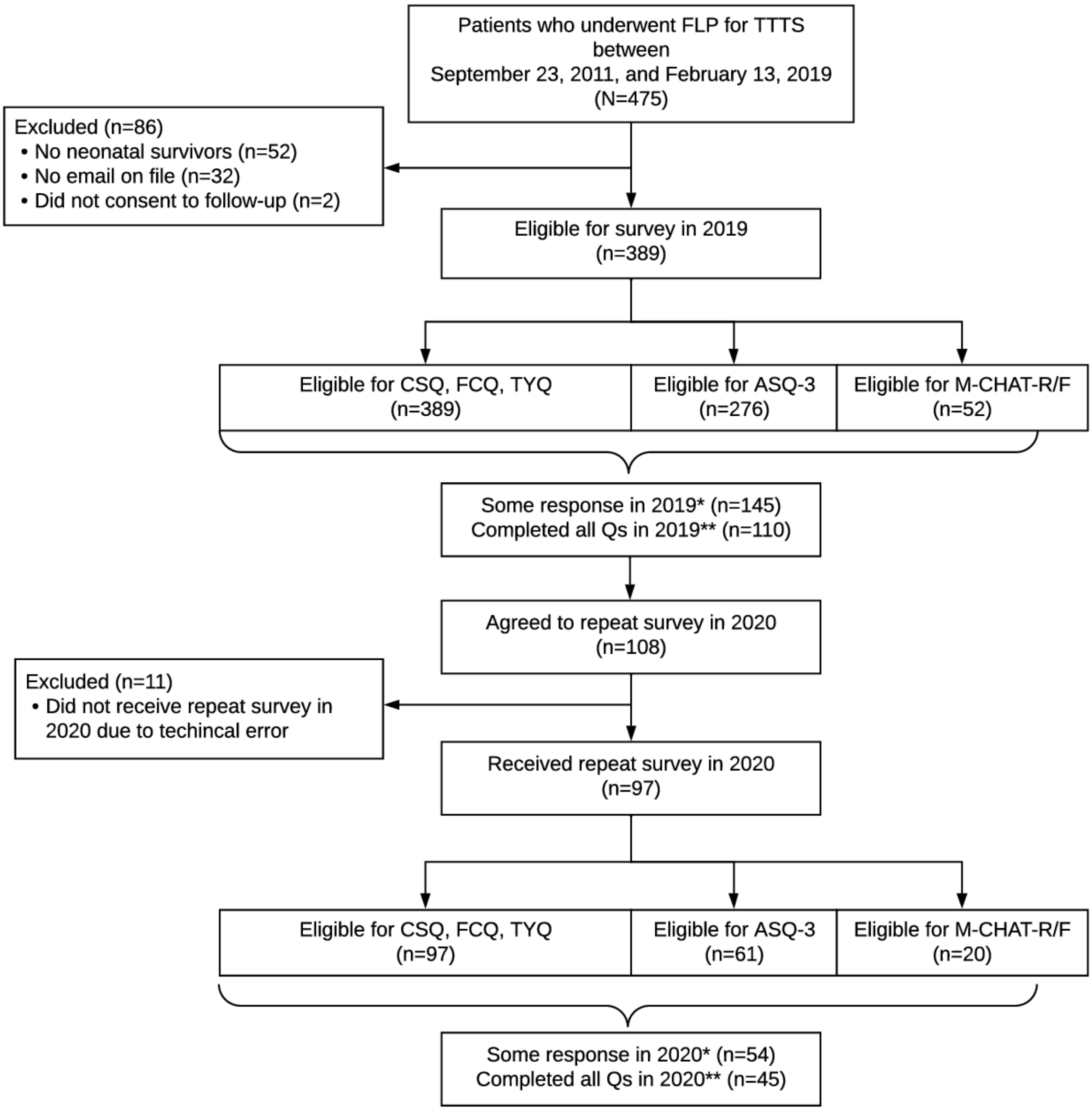

Table . Baseline characteristics of survey participants stratified by response.

Characteristic		2019			2020[a]		
		No response (n=244)	Some response (n=145)	*P* value[b]	No response (n=43)	Some response (n=54)	*P* value[b]
Maternal age (years), median (IQR)		28.0 (23.0-31.0)	30.0 (27.0-35.0)	*<.001*[c]	30.0 (27.0-33.5)	30.5 (27.0-34.0)	.50
Pediatric age (months, corrected)[d], median (IQR)		52 (32-72)	42 (17-64)	*.005*	55 (33-86)	51 (32-77)	.40
Race, n (%)				.13			.31
	African American	29 (11.9)	8 (5.5)		2 (4.7)	2 (3.7)	
	Asian	6 (2.5)	4 (2.8)		1 (2.3)	0 (0)	
	Hispanic	57 (23.4)	27 (18.6)		10 (23.3)	7 (13)	
	White	150 (61.5)	105 (72.4)		30 (69.8)	45 (83.3)	
	Other	2 (0.8)	1 (0.7)		0 (0)	0 (0)	
Questionnaire count [e] **, n (%)**				.11			.55
	3	12 (4.9)	5 (3.4)		3 (7)	3 (5.6)	
	4	92 (37.7)	37 (25.5)		17 (39.5)	20 (37)	
	5	9 (3.7)	5 (3.4)		2 (4.7)	0 (0)	
	6	110 (45.1)	81 (55.9)		15 (34.9)	19 (35.2)	
	8	21 (8.6)	17 (11.7)		6 (14)	12 (22.2)	
Sex: male, n (%)		143 (58.6)	68 (46.9)	*.02*	19 (44.2)	30 (55.6)	.27
Twin type, n (%)				.22			.63
	MCDA[f]	234 (95.9)	138 (95.2)		42 (97.7)	50 (92.6)	
	MCMA[g]	0 (0)	2 (1.4)		0 (0)	2 (3.7)	
	Higher order	10 (4.1)[h]	5 (3.4)		1 (2.3)	2 (3.7)	
Triplets, n (%)		9 (3.7)	5 (3.4)	>.90	1 (2.3)	2 (3.7)	>.99
Triplet type, n (%)				>.99			.33
	DCTA[i]	8 (88.9)	4 (80)		0 (0)	2 (100)	
	MCTA[j]	1 (11.1)	1 (20)		1 (100)	0 (0)	
TTTS[k] Quintero stage, n (%)				.74			>.90
	I	33 (13.5)	17 (11.7)		3 (7)	7 (13)	
	II	64 (26.2)	45 (31)		14 (32.6)	16 (29.6)	
	III	133 (54.5)	72 (49.7)		24 (55.8)	28 (51.9)	
	IV	9 (3.7)	7 (4.8)		2 (4.7)	2 (3.7)	
	Isolated TAPS[l,m]	5 (2)	4 (2.8)		0 (0)	1 (1.9)	
TTTS+TAPS[m], n (%)		5 (2.1)	10 (7.1)	*.02*	3 (7)	2 (3.8)	0.65
TTTS+sFGR[n,o], n (%)		114 (46.7)	51 (35.2)	*.03*	18 (41.9)	20 (37)	.63
FI [p] **procedure, n (%)**				.29			.63
	FLP[q] (percutaneous)	226 (92.6)	138 (95.2)		42 (97.7)	50 (92.6)	
	FLP (laparoscopic-assisted)	16 (6.6)	5 (3.4)		1 (2.3)	2 (3.7)	

Characteristic		2019			2020[a]		
		No response (n=244)	Some response (n=145)	*P* value[b]	No response (n=43)	Some response (n=54)	*P* value[b]
	Selective reduction	1 (0.4)[r]	2 (1.4)[s]		0 (0)	2 (3.7)[s]	
	Failed laser, amnioreduction only	1 (0.4)[t]	0 (0)		0 (0)	0 (0)	
Required repeat procedure, n (%)		2 (0.8)[u]	3 (2.1)[v]	.37	2 (4.7)[w]	1 (1.9)[x]	.58
Intertwin weight discordance (%)[y], median (IQR)		25 (16-34)	22 (13-30)	*.02*	21 (16-32)	22 (14-31)	.76
Cervical length (mm), median (IQR)		38 (31-45)	40 (32-47)	.26	42 (33-47)	39 (29-48)	.41
GA[z] at FLP (weeks), median (IQR)		20.43 (18.82-22.29)	20.43 (18.71-22.29)	.82	20.29 (18.36-22.14)	20.14 (18.75-22.25)	>.99
GA at delivery (weeks), median (IQR)		32.0 (29.4-34.1)	32.3 (29.4-34.3)	.49	32.86 (31.00-34.57)	32.00 (29.46-34.68)	.22
Recipient birth weight (g), median (IQR)		1725 (1283-2139)	1778 (1391-2193)	.22	1860 (1625-2248)	1830 (1326-2171)	.40
Donor birth weight (g), median (IQR)		1360 (975-1890)	1570 (1170-2000)	*.03*	1730 (1300-2094)	1570 (1170-2020)	.57
Child status, n (%)				.17			.21
	Ex-donor loss	40 (16.4)	14 (9.7)		7 (16.3)	5 (9.3)	
	Dual survivors	198 (81.1)	127 (87.6)		36 (83.7)	46 (85.2)	
	Ex-recipient loss	6 (2.5)	4 (2.8)		0 (0)	3 (5.6)	
Region of origin, n (%)				.12			.44
	Midwest	21 (8.7)	9 (6.2)		2 (4.7)	5 (9.3)	
	South	212 (87.6)	124 (85.5)		38 (88.4)	42 (77.8)	
	West	9 (3.7)	12 (8.3)		3 (7)	7 (13)	
Texas based, n (%)		134 (54.9)	81 (55.9)	.86	24 (55.8)	27 (50)	.57
Distance from FC[aa] (miles), median (IQR)		266 (189-454)	237 (150-489)	.12	237 (151-590)	232 (169-637)	.68

Characteristic	2019			2020[a]		
	No response (n=244)	Some response (n=145)	*P* value[b]	No response (n=43)	Some response (n=54)	*P* value[b]
Delivered within FC hospital system, n (%)	24 (9.8)	17 (11.7)	.56	5 (11.6)	3 (5.6)	.46

[a] Represents a subgroup of patients initially surveyed in 2019 who indicated they were amenable to repeat survey in 2020.

[b] Wilcoxon rank sum test, Fisher exact test, and Pearson chi-square test.

[c] Values in italics format indicate *P*<.05.

[d] Pediatric age corrected for prematurity until 24 months of age.

[e] Number of questionnaires to be performed based on child's age at the time of survey. Does not include child status questionnaire and thank you questionnaire.

[f] MCDA: monochorionic diamniotic.

[g] MCMA: monochorionic monoamniotic.

[h] All triplet gestations with the exception of a single quadruplet (dichorionic quadramniotic, nonrespondent).

[i] DCTA: dichorionic triamniotic.

[j] MCTA: monochorionic triamniotic.

[k] TTTS: twin-twin transfusion syndrome.

[l] TAPS: twin anemia polycythemia sequence.

[m] Defined as delta middle cerebral artery peak systolic value (MCA-PSV) ≥1. Excludes cases of isolated TAPS.

[n] sFGR: selective fetal growth restriction.

[o] Defined as ≥25% intertwin estimated weigh discordance and either donor or recipient twin estimated fetal weight <10 percentile at FI.

[p] FI: fetal intervention.

[q] FLP: fetoscopic laser photocoagulation.

[r] MCDA pregnancy in which cords too close for FLP, bipolar cord coagulation performed.

[s] Monochorionic monoamniotic with TTTS converted to bipolar after FLP (n=1); TTTS with sFGR, primary radiofrequency ablation of donor twin (n=1).

[t] Quintero stage II with poor visualization on diagnostic fetoscopy secondary to prior bleed, amnioreduction only performed (n=1).

[u] Quintero stage II FLP at 18 wk and 0 d, followed by recurrent TTTS or TAPS and ventriculomegaly in donor at 19 wk and 6 d and underwent radiofrequency ablation (n=1); Quintero stage II FLP for DCTA triplet gestation at 18 wk and 3 d with radiofrequency ablation of donor due to recurrent TTTS or TAPS at 20 wk and 1 d (n=1).

[v] Quintero stage III TTTS FLP at 21 wk and 2 d with recurrent TTTS at 24 wk and 5 d and underwent repeat FLP (n=1); Quintero stage IV at 16 wk and 3 d with recurrent TTTS at 24 wk and 0 d underwent repeat FLP (n=1); Quintero stage II TTTS FLP at 18 wk and 2 d with recurrent TAPS and amniotic band at 20 wk and 0 d had repeat FLP and amniotic band lysis from neck of plethoric fetus (n=1).

[w] Quintero stage III TTTS at 21 wk and 2 d with recurrent stage III TTTS underwent repeat FLP at 24 wk and 5 d (n=1); Quintero stage II TTTS FLP at 18 wk and 2 d with recurrent TAPS and amniotic band at 20 wk and 0 d had repeat FLP and amniotic band lysis from neck of plethoric fetus (n=1).

[x] Quintero stage IV FLP at 16 wk and 3 d with recurrent TTTS and repeat FLP at 24 wk and 0 d.

[y] Defined as intertwin estimated fetal weight discordance of ≥25% and either the donor or recipient estimated fetal weight <10%$^{(Hadlock)}$.

[z] GA: gestational age.

[aa] FC: fetal center.

Table . Survey response rate[a] among patients who had fetoscopic laser photocoagulation between September 23, 2011, and February 13, 2019.

	Eligible	Completed (% response rate)	Completion time (minutes)[b], median (IQR)
Questionnaire (2019 survey)			
Consent	389	148 (38)	—[c]
CSQ[d]	148[e]	145 (98)	—
FCQ[f,g]	148[e]	130[h] (87.8)	3 (2-5)
ASQ-3[i,j]	100[e]	81[h](71.1)	5 (3-8)
M-CHAT-R/F[h,k]	22[e]	19 (86.4)	2 (1-3)
TYQ	148[e]	110 (74.3)[l]	—
Questionnaire (2020 survey) [m]			
Consent	97	56 (57.8)	—
CSQ	56[e]	54 (96.4)	—
FCQ[g]	56[e]	51[n] (91.1)	3 (2-5)
ASQ-3[j]	36[e]	31 (86.1)	6 (4-8.5)
M-CHAT-R/F[h]	12[e]	11 (91.7)	2 (1-3)
TYQ	56[e]	45 (80.4)[l]	—

[a] Counts represent number of patients surveyed.

[b] Excluding outliers >60 minutes; time to complete the consent, CSQ, and TYQ was not recorded.

[c] Not available.

[d] CSQ: child status questionnaire.

[e] Represents the number of patients who signed consent and eligible for the survey.

[f] FCQ: fetal center questionnaire.

[g] All mothers eligible.

[h] Does not include 1 partial response.

[i] ASQ-3: Ages & Stages Questionnaires, Third Edition.

[j] Patients with children between ages 1 and 60 months eligible.

[k] M-CHAT-R/F: Modified Checklist for Autism in Toddlers, Revised With Follow-Up.

[l] Represents the percentage of patients who signed consent who finished the entire survey.

[m] Represents a subgroup of patients initially surveyed in 2019 who indicated they were amenable to repeat survey in 2020.

[n] Does not include 2 partial response.

Table . Atypical developmental screens in 2019 and 2020 by twin.

	Twin		Total, n (%)
	Ex-recipient, n (%)	Ex-donor, n (%)	
ASQ-3[a] (2019+2020 survey)≥24 months of age[b]			
Typical	37 (80.4)	40 (81.6)	77 (80.2)
Atypical[c]	9 (19.6)	9 (18.4)	18 (18.9)
M-CHAT-R/F[d] questionnaire (2019 survey)			
Typical	16 (88.9)	14 (93.3)	30 (90.9)
Atypical[e]	2 (11.1)[e]	1 (6.67)	3 (9.1)
M-CHAT-R/F questionnaire (2020 survey)			
Typical	9 (81.8)	10 (90.9)	19 (86.4)
Atypical[f]	2 (18.2)[f]	1 (9.1)[g]	3 (13.6)

[a] ASQ-3: Ages & Stages Questionnaires, Third Edition.

[b] Represents the oldest ASQ-3 assessment performed at ≥24 months of age for each child obtained in either 2019 or 2020.

[c] Indicates at least 1 domain on the ASQ-3 for which the score was ≥2 SD below the mean.

[d] M-CHAT-R/F: Modified Checklist for Autism in Toddlers, Revised With Follow-Up.

[e] Indicates 3 or more atypical responses.

[f] Unable to contact a single patient to confirm atypical response.

[g] Unable to contact a single patient (flagged recipient and donor) to confirm atypical response.

Table . Results of thank you questionnaire.

Survey year	Ok to contact for repeat survey?, n (%)	Preferred method of future contact			Ok to inquire about pediatrician records?, n (%)
		Telephone, n (%)	Email, n (%)	Post[a], n (%)	
2019	109 (99.1)	44 (40.4)	99 (90.8)	24 (21.8)	102 (92.7)
2020[b]	45 (100)	17 (37.8)	43 (95.6)	11 (24.4)	43 (95.6)

[a] Two patients who requested communication via post and provided their current home address had moved 115 and 1577 miles since the time of initial evaluation for FLP.

[b] Represents a subgroup of patients initially surveyed in 2019 who indicated they were amenable to repeat survey in 2020.

Discussion

Principal Findings

In this survey study, we effectively gathered long-term pediatric parent-reported outcomes in patients treated with FLP for TTTS via email and electronic questionnaires. The overall response rates to our survey were 37.3% (145/389) in 2019 and 55.7% (56/97) in 2020. Notably, slightly less than half of the patients who responded were from outside of Texas (in 2019: 64/145, 44.1% and in 2020: 27/54, 50%), and the majority (in 2019: 128/145, 88.3% and in 2020: 51/54, 94.4%) delivered outside the FC hospital system. Of the patients who consented to our survey, the overall completion rate was 74.3% (110/148) in 2019 and 80.4% (45/56) in 2020.

Comparison With Prior Work

Compared with patients in Europe, the long-term pediatric outcomes in patients who travel for the treatment of TTTS in the United States have been poorly studied. Several Western European centers in which centralized health care systems exist have reported on the in-person evaluation of large cohorts of pediatric survivors of TTTS with nearly 100% follow-up rates [8,26,27]. Conversely, there is but a single report of long-term cognitive outcomes in children treated for TTTS and assessed solely in the United States [7]. In that study, only 13% of patients from outside the study center state were available for in-person assessment. This lack of data on long-term outcomes represents a critically missing component with which to counsel patients who are evaluated and treated for TTTS in the United States.

There are several challenges that contribute to the difficulty in assessing long-term pediatric outcomes in patients treated for TTTS in the United States. First, the geographic distance patients travel for specialized fetal intervention care is a physical barrier to in-person follow-up [14]. As a niche specialty, few high-volume academic centers account for the majority of FLP procedures performed annually [28]. Consequently, patients who reside outside these locations will travel great distances to receive care during their pregnancy, only to return home for follow-up care. This is evidenced by the geographic distance from our center in the population of patients surveyed and the high proportion of patients who delivered outside the FC hospital system.

Second, compared with other high-income countries, the United States ranks last regarding measures of health care affordability and access to care [29]. As of 2023, approximately 25.3 million people were uninsured in the United States [30]. Furthermore, as of 2016, there were 626 individual health systems identified across the United States [31]. Both the lack of access to care and the complex system of health care networks may contribute to the challenges in the longitudinal assessment of pediatric patients.

Finally, in most health systems in the United States, a fetus is not assigned a medical record number despite being exposed to disease, medications, and even fetal surgical interventions prior to birth. Both technical and legal challenges have likely contributed to the barriers surrounding the creation of a fetal electronic health record. Historically, fetal data are linked to pediatric outcomes via the maternal chart, so any attempt to fully describe an individual's medical history, from the time of conception to pediatric and adult life, requires the additional step of linking these 2 individuals. Despite some recent strategies to create nested or embedded fetal records within a maternal record [32], this has not been universally adopted in the field of obstetrics and fetal surgery.

Considering the challenges in obtaining long-term pediatric outcomes in patients treated for TTTS, validated parent-reported screening questionnaires delivered via electronic media are a potential starting point toward addressing this problem. We acknowledge that the gold standard for pediatric neurodevelopmental evaluation is in-person assessment. However, in the context of a population of individuals spread across a large geographic area and among various health care networks with diverse levels of access to care, remote screening provides a unique opportunity to assess outcomes in this population.

The use of electronic patient-reported outcome tools has increased with the growth of electronic health technologies. Significant advantages of this strategy include the ability to obtain information remotely over great distances and doing so at relatively low cost with the help of computer programming and automation. Furthermore, the real-time analysis of patient-reported data allows for early detection of positive screens and improvements in patient-clinician communication [33]. In our study, we developed scripts to automatically generate both accurate and personalized reports for children who had positive screens, which were subsequently returned to participants to share with their primary physician, thereby illustrating the potential clinical utility of this tool.

Strengths and Limitations

To our knowledge, this is the first report in fetal medicine of the ASQ-3 and M-CHAT-R/F being delivered to study participants via the REDCap questionnaire. Previous studies of survivors of TTTS describe the distribution of the ASQ-3 to patients via post [34-37], email attachment [34], or telephone interview [34], but incorporating these surveys into a digital format for research in fetal medicine has not been previously reported. This novel approach allowed for the application of computer-based algorithms to schedule the timely distribution of surveys, automate questionnaire scoring, and generate individualized reports for atypical screening responses. Furthermore, the costs to implement this system within an academic university hospital system where REDCap is an established research tool were minimal and involved licensing of the ASQ-3 for distribution as a research questionnaire. Unlike in-person assessments, which require significant human capital, the entire project was developed and executed by a few individuals with a background in both medicine and computer programming. Using this system, we received a partial or full response from patients in 20 different states at an average of 355 (SD 335; range 5.61-1629) miles from our center. Furthermore, among patients who consented to the study, the questionnaire completion rate was very high, suggesting that collection of long-term parent-reported outcomes via electronic format is technically feasible and that the questionnaires chosen for the study were not overly burdensome to complete. Finally, among participants who completed the study, there was a strong willingness to repeat a future assessment and a high rate of participation in the second year.

Regarding limitations, it is important to remember that the results from this study represent screening examinations and cannot necessarily be used to diagnose atypical pediatric development. As the data are parent-reported, there is a possible bias toward either underreporting or overestimating a child's capabilities [24]. Furthermore, when compared to nonresponders, the intertwin fetal growth discordance, a marker of placental insufficiency, and a risk factor for increased neonatal morbidity or mortality were lower in the patients who responded to the survey, which may bias the results toward a healthier population of individuals. Although most patients indicated they would consider providing pediatric records for evaluation, the study resources did not let us validate the questionnaires. It is, however, reassuring that the rates of atypical ASQ-3 screens in our cohort are comparable with rates of neurodevelopmental impairment, as assessed via Bayley Scales of Infant Development, which is administered in person, in several large European cohorts of patients treated for TTTS [8,26,27].

Patients in this study were identified retrospectively and were approached via email. It is possible that over time, patients' contact information and email addresses changed, which may explain why nonresponders tended to have older children. A future study in which patients are enrolled prospectively and receive an in-person explanation of the study procedures and study purpose may lead to improved initial response rates.

Unfortunately, 32 patients were not eligible for the study due to not having an email on file. These patients, in addition to the nonresponders, may be less technically savvy and could represent a digital divide bias that favors participants who are more computer-literate or can afford a computer. For this study, we chose to use email as the method of survey distribution due to ease of use within REDCap. Potentially offering the survey via telephone, via post, or via alternative electronic media such as SMS text messaging may have improved response rates. In addition, the response rate may have been improved if participation had been incentivized, as participation was entirely voluntary.

The project was also only available in English. It is possible some patients for whom English was not their primary language received the study, although it is unlikely that they would have completed the questionnaires. Additional limitations include a lack of information regarding patient insurance status, which may be an important contributor to neurodevelopmental outcomes, and the absence of a control group for comparison. Finally, 11 patients who agreed to repeat the survey did not receive a repeat survey invitation in 2020 due to a technical coding error, which was not identified until after study completion. Furthermore, we were unable to reach several patients to confirm the results of atypical M-CHAT-R/F screens.

Conclusions

This study represents the largest cohort of long-term outcomes reported in a population of patients treated with fetoscopic laser photocoagulation for TTTS in the United States. The novel use of computer programming and REDCap allowed us to automate the distribution, scoring, and generation of custom reports with ease and at relatively low cost. Future longitudinal studies in this population may benefit from prospective enrollment, incentivized participation, and survey distribution via alternative electronic methods such as SMS text messaging.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Fetal center questionnaire.
[DOCX File, 15 KB - pediatrics_v7i1e60039_app1.docx]

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Abbreviations

ASQ-3: Ages & Stages Questionnaires, Third Edition
CSQ: child status questionnaire
FC: fetal center
FCQ: fetal center questionnaire
FLP: fetoscopic laser photocoagulation
HIPAA: Health Insurance Portability and Accountability Act
M-CHAT-R/F: Modified Checklist for Autism in Toddlers, Revised With Follow-Up
MCDA: monochorionic diamniotic
REDCap: Research Electronic Data Capture
TTTS: twin-twin transfusion syndrome
TYQ: thank you questionnaire

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Gender Inequalities in Employment of Parents Caring for Children With Autism Spectrum Disorder in China: Cross-Sectional Study

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Abstract

Background: The increasing need for child care is placing a burden on parents, including those with children with autism.

Objective: The aim of this study was to examine the employment status of Chinese mothers and fathers with children with autism spectrum disorder (ASD), as well as to investigate the factors that affected their employment decisions.

Methods: An online national survey was completed by the parents of 5018 children and adolescents with ASD aged 2-17 years (4837 couples, 181 single mothers, and 148 single fathers). The dependent variable was employment status—whether they kept working or quit to take care of their child. The independent variables were those characterizing the needs of the child and the sociodemographic characteristics of the family.

Results: The employment rate of mothers with children and adolescents with ASD was 37.3% (1874/5018), while 96.7% (4823/4988) of fathers were employed. In addition, 54.3% (2723/5018) of mothers resigned from employment outside the home to care for their children, while only 2.8% (139/4988) of fathers resigned due to caring obligations. Mothers' employment was positively associated with their single marital status, lower educational level, and having assistance from grandparents. Having the grandparents' assistance was positively associated with fathers' employment.

Conclusions: Gender inequalities in employment exist in China. Mothers caring for children with ASD had lower workforce participation than fathers. More female-friendly policies and a stronger gender equality ideology would be of benefit to Chinese society.

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KEYWORDS

autism spectrum disorder; family; employment status; influencing factors; autism; child care; children; China; parent; online survey; mother; father; adolescent; youth; ASD; children with autism

Introduction

Autism spectrum disorder (ASD) encompasses a range of neurodevelopmental disorders that are characterized by the following core deficits: (1) impairments in social interaction and communication, and (2) restricted, repetitive behaviors [1]. Due to the child's significant needs, daycare availability may be limited, leading to a parent needing to stay at home [2]. Comparative research suggests that parents of children with ASD spend more time providing care for their children at home than those of children without special health care needs [3]. There is strong evidence suggesting that having a child with ASD in the household adversely affects the employment status of the parents [4,5]. In the United States, approximately 30%-50% of caregivers of children with ASD have completely ceased working [6]. Studies have shown that the employment of parents of children with ASD is disproportionately affected when compared to families with children who have other disabilities [7,8]. In 2-parent households, the employment of mothers is disproportionately affected [9,10]. In Europe and the

United States, mothers, compared to their partners, are more likely to hold part-time, lower-status positions that do not offer commensurate compensation corresponding to their educational qualifications [11-13]. A systematic review and a case-control study in Israel showed that working mothers of children with ASD were at increased risk of not maintaining their working status over the 5 years following their child's birth [14,15]. It reported that US mothers of children with ASD were less likely to be employed and earned 56% less than mothers of children without ASD; simultaneously, there was no significant impact on the fathers' labor market participation [4].

Globally, women's labor participation and outcomes still fall behind those of men, primarily due to persistent gender inequality resulting from the impact of childbirth [16], which can be seen as a "motherhood penalty" [17]. It can doubly penalize mothers of children with ASD, as they face challenges related to both gender and their child's condition. Variations in family policies and societal gender norms across countries contribute to diverse circumstances for mothers. Scandinavian countries such as Denmark and Sweden demonstrate the lowest levels of the "motherhood penalty," while the United Kingdom and the United States fall in the middle, and Germany and Australia have the highest penalties [18].

Cultural factors, such as the traditional concept of "men outside and women inside" commonly found in East Asian cultures [19,20], as well as the evolving social norms influenced by market economics that emphasize the contributions of both women and men in Chinese society [21], may contribute to variations in the Chinese context. From a societal standpoint, higher rates of female labor force participation within extended families were observable in China [22,23], which was less prevalent in Europe and the Americas [24]. In China, there are no guaranteed free services; the significant economic burden this represents may drive women to seek employment. However, inadequate educational and childcare resources, along with inflexible employment arrangements, may compel women to leave the workforce after having a child with ASD. Unfortunately, the limited available evidence from China prevents a thorough examination of this topic. The employment situation for families with children with ASD remains uncertain, particularly in terms of gender dynamics, and the underlying mechanisms are not fully understood. Gender disparities in employment can be elucidated through 2 theories. First, the specialization theory suggests that the division of paid and unpaid work is a rational contract between partners driven by utility maximization [25]. The partner with the lower salary is expected to do more housework. Second, the gender role perspective posits that the ability to balance work and parenthood is influenced by individuals' identities as moral beings within their culture [26]. Different cultures may vary in their approach to these issues. Gaining a better understanding of the situation in China is crucial, not only for informing policymaking within the country, but also for providing valuable insights into the cultural ramifications. There are many factors that affect whether caregivers work or not. Previous research has found that caregivers' labor force participation is influenced by both individual factors (eg, child age, caregivers' age, educational level, marital status, the severity of ASD symptoms, or caregivers' medical conditions) and the availability of childcare resources or perceived social support [4,27-29]. Compared to mothers of children without exceptional health care needs, US mothers of children with mild ASD and moderate/severe ASD had a 12% and 25% lower probability of being employed, respectively [30]. Although literature from other countries has provided valuable insights, current research in this area still has limitations. First, there is a lack of in-depth discussion on gender differences in employment. Many studies focus on the impact of caregiving from a female perspective, ignoring gender inequalities within families. As most of the caregivers in these studies were mothers of children with ASD, the results may not be generalizable to fathers [31]. Second, there is a need for a better understanding of the factors associated with the employment of both mothers and fathers. By examining the factors that influence employment, policymakers can better target interventions toward the most vulnerable populations. Third, most studies have had small sample sizes and have predominantly focused on very young children. A broader age span sample can help capture the situation of families at different stages.

Parental employment in families with children with ASD is an area of particular significance. The employment status of parents in these families plays a vital role in reducing family stress, accessing essential resources, and promoting the well-being of both parents and children [32-34]. In this study, the primary goal was to uncover the employment status of parents in families with children and adolescents with ASD. The second goal was to investigate the factors associated with employment of mothers and fathers caring for children with ASD in China. The following assumptions were made: (1) parents' employment decisions can be influenced by both parental and child traits, and (2) there are differences between the factors influencing fathers' and mothers' employment decisions. A comprehensive understanding of how these factors influence parental employment could inform the development of effective policies to support these families.

Methods

Participants

This study used secondary data from the Survey on Family Circumstances and Demand for Support and Resources among Autistic Children in China in 2020. It was a survey that was distributed to members of an online parent community of children with ASD or other developmental disorders in China. The questionnaire was designed to collect information on various aspects of the families. Parents were asked to provide information about their employment status, including current work status, work history, and any work adjustments made due to their child's needs. Additionally, parents reported on their child's diagnosis. The other details of the survey have been described elsewhere [5]. A pilot field study (N=20) was conducted to refine the instrument and data collection procedures, and the results indicated that respondents generally understood the questionnaire, so only minor wording changes were made.

Data Collection

Families with children diagnosed with ASD were recruited if they met the following criteria: (1) they were between the ages of 2 and 17 years and were diagnosed with or suspected (children under 3 years old cannot be officially diagnosed) of having ASD at a hospital, and (2) the hospital had diagnostic qualifications and followed a Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition standard, not only through scale measurement but also via diagnosis by a medical professional. Exclusion criteria were individuals with ASD with severe comorbidities such as physical disability and cerebral palsy. The samples with obvious errors or omissions were also excluded in this study. Regarding omissions, we used the following strategies: (1) we needed complete data for the major variables that were essential to our primary analysis, and (2) we permitted some missing data for secondary variables and used multiple imputation to account for these omissions. Any questionnaire with a missing data rate exceeding 33% was excluded from the analysis. For questionnaires with a lower missing data rate, we used multiple imputation to handle missing values in noncore variables, maximizing the retention of data information. There were 8014 households investigated, with 5018 (62.62%) households included. This survey's gender ratio and family location distribution were consistent with China's overall population distribution. In total, 31 Chinese provinces and 380 cities or districts were included (see Table S1 and Table S2 in the Multimedia Appendix 1 for details).

Measures: Assessments of Employment Status

When assessing workforce participation, we used the primary categories of "work" and "nonwork" (as a stay-at-home parent). We used the term "nonwork" in this study to refer to parents who were either unemployed or out of the labor force. In order to further distinguish the effects of different employment types, this study constructed 4 employment status variables, namely "full-time," "flexible," "overtime," and "a long leave of absence." Full-time work generally refers to a person being formally employed, working a minimum of 40 hours per week, and enjoying corresponding wages, social insurance, and welfare benefits (as described in the Labor Law of the People's Republic of China). Flexible work refers to employment for which working hours (usually less than 30 hours per week) or working places are not fixed. Overtime work refers to working more than 40 hours per week. We created 2 variables for full-time parents so as to understand the reason for nonwork: "caregiving resignation" and "other." Caregiving resignation meant that the parent resigned after their child was diagnosed with ASD and that they were taking care of the child. Resigning due to caregiving responsibilities, which is considered an "involuntary resignation" or "involuntary unemployment," was considered as being beyond one's control. "Other" refers to those who resigned before their child's diagnosis of ASD or those who remained unemployed for other reasons after the child's birth (see Table S3 in the Multimedia Appendix 1 for definitions). In other words, "not working" referred to the current employment status, including those who resigned due to childcare needs and those who were not working for other reasons (including those who never worked). "Resigning" specifically referred to leaving a job due to childcare needs for their child with ASD.

Socioeconomic and Demographic Variables

The age of the children was their age at the survey point. The age of the children was divided into four age groups: 2 - 5 years, 6 - 9 years, 10 - 13 years, and 14 - 17 years. The severity of ASD was judged according to professional evaluation or the parents' subjective judgment. There were four categories: low-functioning autism (LFA), middle-functioning autism, high-functioning autism (HFA), and undetermined. The regional variables were "eastern," "central," and "western." The provinces in the eastern region were among the first to implement the coastal opening-up policy and have a high level of economic development. The provinces of the central region are economically underdeveloped, while those of the western region are even less so. We classified family income into 3 categories. According to the data distribution, the below-average group had an annual income of less than US $12,327 (80,000 yuan), the around-average group had an annual income of between US $12,327 (80,001 yuan) and US $23,112 (150,000 yuan), and the above-average group had an annual income of more than US $23,112 (150,000 yuan). Whether the children's grandparents were able to provide assistance was one way to measure informal social supports, so "grandparents' assistance" was included. The term "physical health status" was used to describe negative physical health status. We asked respondents about their subjective physical status using a 5-point Likert scale with 1="Extremely poor," 2="Poor," 3="Average," 4="Good," and 5="Very good" in response to the following question: "How do you evaluate your physical health generally?" The question referred to the 4 weeks preceding the survey. The answers to the items were divided, with 2 being the cutoff score for poor physical health status. A single-item question was used in previous research [35]; this single item has been reported to be reliable. Other background information was collected on children's gender, whether they have comorbidities or not, and parents' education and marital status.

Statistical Analysis

The mean (SD) of normally distributed data was used. The comparisons of characteristics (categorical) were analyzed using χ^2 tests and the comparisons of characteristics (continuous) were analyzed using F tests. Logistic regression models were used to identify the factors influencing employment status. Associations between predictors and independent variables were reported using odds ratios (ORs) and their 95% CIs. Group comparisons were made between mothers and fathers. All the estimated costs were converted to US dollar (US $) values in January 2021, when US $1 was equivalent to about 6.49 Chinese yuan. All statistical analyses were conducted using SPSS for Windows (version 22.0; IBM Corp).

Ethical Considerations

All families provided electronic informed consent before enrollment. All procedures involving human subjects/patients were approved by the ethics committee of the Peking University Institutional Review Board (approval number IRB00001052-20016). The informed consent process clearly outlined the study's purpose, procedures, and potential risks, with participants retaining the right to opt out at any time. Participant data were anonymized using unique identifiers to protect individual privacy. No direct financial compensation was provided, and no identifiable features of research participants were included in any research materials.

Results

Sample Descriptive Statistics

In total, 5018 households were included in this survey (Figure 1). Most of the children (4227/5018, 84.2%) were boys, and the mean age was 5.3 (SD 2.6) years old, with the leading ASD severity being middle function (2030/5018, 40.5%). In addition, 18.2% (913/5018) of the children had comorbidities such as attention-deficit/hyperactivity disorder and epilepsy. Most of the parents had a college degree (3430/5018, 68.4%) and 31.1% (1563/5018) of the parents received assistance from the children's grandparents. Mothers had a lower rate of employment than fathers. This survey revealed disparities regarding whether parents were employed, classified by the severity of ASD, parents' education level, whether parents were single, whether grandparents could give assistance, family income, and other factors. The results of the group comparisons can be seen in Table 1. There were statistically significant differences between the working and nonworking groups for parents (*P*<.05). From the perspective of whether children had comorbidities, there was no statistically significant difference between the parent working and nonworking groups (*P*<.05). The study population is further described in Table 1.

Figure 1. Flowchart of the selection procedure. ASD: autism spectrum disorder.

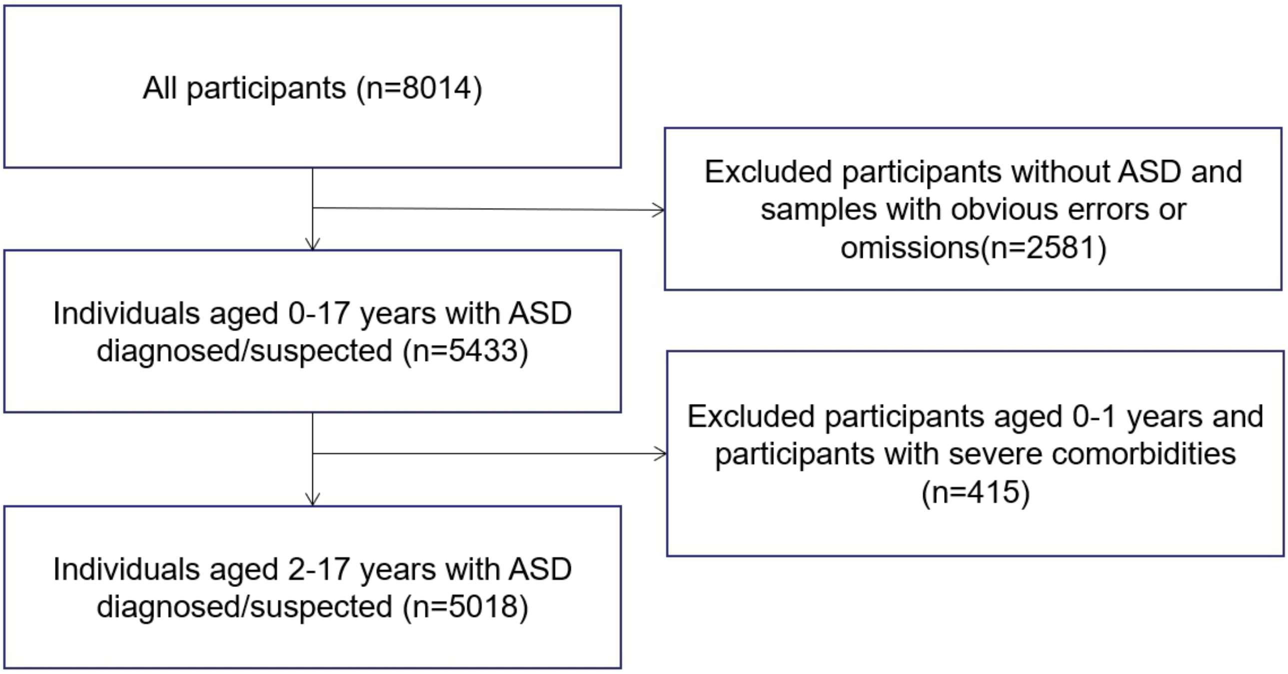

Table . Characteristics of children, fathers, and mothers.

Characteristics	Overall, n (%)	Mothers (n=5018), n (%)		Chi-square (*df*)	*P* value	Fathers (n=4988), n (%)		Chi-square (*df*)	*P* value
		Employed (n=1874)	Unemployed (n=3144)			Employed (n=4823)	Unemployed (n=165)		
Children's characteristics									
Age groups (years)				16.351 (3)	.001			9.299 (3)	.12
2 - 5	3119 (62.2)	1156 (61.7)	1963 (62.4)			3003 (62.3)	98 (59.4)		
6 - 9	1527 (30.4)	545 (29.1)	982 (31.2)			1472 (30.5)	47 (28.5)		
10 - 13	309 (6.2)	140 (7.5)	169 (5.4)			287 (6)	19 (11.5)		
14 - 17	63 (1.3)	33 (1.8)	30 (1)			61 (1.3)	1 (0.6)		
Gender of child				3.513 (1)	.03			1.824 (1)	.10
Male	4227 (84.2)	1602 (85.5)	2625 (83.5)			4056 (84.1)	144 (87.3)		
Female	791 (15.8)	272 (14.5)	519 (16.5)			767 (15.9)	21 (12.7)		
Autism spectrum disorder severity				115.284 (3)	<.001			1.805 (3)	.33
Low-functioning autism	1140 (22.7)	337 (18)	803 (25.5)			1088 (22.6)	44 (26.7)		
Middle-functioning autism	2030 (40.5)	730 (39)	1300 (41.3)			1955 (40.5)	64 (38.8)		
High-functioning autism	945 (18.8)	488 (26)	457 (14.5)			910 (18.9)	30 (18.2)		
Undetermined	903 (18)	319 (17)	584 (18.6)			870 (18)	27 (16.3)		
Comorbidity				0.363 (1)	.97			1.093 (1)	.17
Yes	913 (18.2)	333 (17.8)	580 (18.4)			872 (18.1)	35 (21.2)		
No	4105 (81.8)	1541 (82.2)	2564 (81.6)			3951 (81.9)	130 (78.8)		
Parents' characteristics									
Education				781.216 (1)	<.001			0.690 (1)	.22
College degree or above	3430 (68.4)	1657 (88.4)	1773 (56.4)			3302 (68.5)	108 (65.5)		
High school or below	1588 (31.6)	217 (11.6)	1371 (43.6)			1521 (31.5)	57 (34.5)		
Marital status: single parent				11.223 (1)	.001			9.739 (1)	.004
Yes	181 (3.6)	89 (4.7)	92 (2.9)			166 (3.4)	13 (7.9)		
No	4837 (96.4)	1785 (95.3)	3052 (97.1)			4657 (96.6)	152 (92.1)		
Grandparents' assistance				870.885 (1)	<.001			19.142 (1)	<.001
Yes	1563 (31.1)	1052 (56.1)	511 (16.3)			1530 (31.7)	28 (17)		
No	3455 (68.9)	822 (43.9)	2633 (83.7)			3293 (68.3)	137 (83)		
Self-reported physical state: poor				9.928 (1)	.002			6.176 (1)	.01
Yes	788 (15.7)	255 (13.6)	533 (17)			745 (15.4)	36 (21.8)		
No	4230 (84.3)	1619 (86.4)	2611 (83)			4078 (84.6)	129 (78.2)		
Household income				289.321 (2)	<.001			29.869 (2)	<.001
Below average	1556 (31)	332 (17.7)	1224 (38.9)			1252 (26)	86 (52.1)		

Characteristics	Overall, n (%)	Mothers (n=5018), n (%)		Chi-square (*df*)	*P* value	Fathers (n=4988), n (%)		Chi-square (*df*)	*P* value
		Employed (n=1874)	Unemployed (n=3144)			Employed (n=4823)	Unemployed (n=165)		
Around average	1627 (32.4)	576 (30.7)	1051 (33.4)			1696 (35.2)	46 (27.9)		
Above average	1835 (36.6)	966 (51.5)	869 (27.6)			1875 (38.9)	33 (20)		
Resident district				30.908 (2)	<.001			1.828 (2)	.40
Eastern	3061 (61)	1163 (62.1)	1898 (60.4)			2950 (61.1)	94 (57)		
Central	1483 (29.6)	489 (26.1)	994 (31.6)			1417 (29.4)	56 (33.9)		
Western	474 (9.4)	222 (11.8)	252 (8)			456 (9.5)	15 (9.1)		

Predictors of Employment for Fathers and Mothers

Mothers with children with HFA were more likely to be employed than mothers who had children with LFA (OR 1.94, 95% CI 1.46 - 2.56; Table 2). Mothers who had a high school education or less were 3.64 times more likely to be employed than mothers who had a college degree or above (OR 3.64, 95% CI 2.89 - 4.57). Single mothers had higher odds of having a job (OR 2.03, 95% CI 1.26 - 3.08). Having assistance from children’s grandparents’ meant that both mothers and fathers were more likely to be employed (mothers: OR 5.57, 95% CI 4.67 - 6.64; fathers: OR 2.31, 95% CI 1.39 - 2.84). Children’s gender and age were not significantly associated with mothers’ and fathers’ employment status.

Table . Predictors of employment for fathers and mothers.

Charactistics	Mother employed, OR[a] (95% CI)	Father employed, OR (95% CI)	Mother resigned, OR (95% CI)	Father resigned, OR (95% CI)
Gender of child (reference: male)				
Female	1.05 (0.84-1.32)	0.31 (0.77-2.22)	1.10 (0.90-1.35)	0.74 (0.41-1.34)
Age of child, years (reference: 2-5 years)				
6 - 9	1.48 (0.83-2.63)	0.60 (0.23-1.54)	0.74 (0.44-1.24)	1.72 (0.60-4.89)
10 - 13	1.01 (0.62-1.64)	0.61 (0.24-1.58)	0.99 (0.67-1.47)	1.14 (0.76-1.70)
14 - 17	1.14 (0.76-1.71)	0.56 (0.22-1.41)	0.80 (0.48-1.33)	1.25 (0.62-2.55)
Comorbidity (reference: no)				
Yes	0.87 0.67-1.13)	0.77 (0.47-1.26)	1.06 (0.84-1.34)	1.15 (0.65-2.05)
Autism spectrum disorder severity (reference: LFA[b])				
MFA[c]	1.18 (0.93-1.50)	1.04 (0.63-1.70)	0.93 (0.75-1.14)	0.93 (0.54-1.60)
HFA[d]	1.94 (1.46-2.56)	0.68 (0.38-1.21)	0.66 (0.51-0.86)	1.28 (0.67-2.45)
Undetermined	1.19 (0.91-1.55)	1.16 (0.66-2.03)	0.86 (0.68-1.08)	0.78 (0.47-1.47)
Education (reference: college degree or above)				
High school or below	3.64 (2.89-4.57)	0.68 (0.45-1.03)	0.58 (0.49-0.69)	1.50 (0.94-2.40)
Marital status: single parent (reference: yes)				
No	2.03 (1.26-3.08)	0.54 (0.25-1.16)	0.50 (0.32-0.80)	1.53 (0.59-3.53)
Grandparents' assistance (reference: no)				
Yes	5.57 (4.67-6.64)	2.31 (1.39-2.84)	0.26 (0.21-0.30)	0.30 (0.16-0.56)
Self-reported physical state: poor (reference: no)				
Yes	0.96 (0.75-1.24)	1.06 (0.64-1.74)	1.35 (1.09-1.68)	1.08 (0.62-1.86)
Household income (reference: below average)				
Around average	1.50 (1.19-1.90)	2.65 (1.69-4.15)	0.79 (0.65-0.96)	0.46 (0.28-0.75)
Above average	2.04 (1.61-2.57)	4.00 (2.36-6.76)	0.52 (0.42-0.64)	0.35 (0.20-0.63)
Resident district (reference: eastern)				
Central	0.95 (0.78-1.15)	1.16 (0.77-1.74)	1.02 (0.87-1.22)	0.88 (0.55-1.38)
Western	1.51 (1.13-2.02)	1.35 (0.66-2.75)	0.70 (0.53-0.93)	0.87 (0.41-1.86)

[a] OR: odds ratio.

[b] LFA: low-functioning autism.

[c] MFA: middle-functioning autism.

[d] HFA: high-functioning autism.

Resignations

We found that 37.3% (1874/5018) of children's mothers were employed; of these, 12.4% (622/5018) had a flexible job, 4.6% (232/5018) took an extended leave, and 1% (49/5018) chose to increase working hours. However, the proportion of fathers working full-time was much higher (3537/4988, 70.9%), while 7.5% (372/4988) of fathers worked flexible hours and 14.9% (743/4988) of fathers worked overtime (Table 3). In addition, 3.4% (171/4988) of fathers took a long leave of absence. Only 3.3% (165/4988) of fathers were unemployed, with the majority citing child care as the main reason. We found that 2.8% (138/4988) of fathers and 54.3% (2723/5018) of mothers resigned because they needed to care for their child with ASD.

Mothers with children with HFA were less likely to resign to take care of their children than the mothers with children with LFA (OR 0.66, 95% CI 0.51 - 0.86). Mothers who had no college degree were less likely to resign to take care of their children (OR 0.58, 95% CI 0.49 - 0.69). Single mothers had lower odds of resigning to take care of their children (OR 0.50, 95% CI 0.32 - 0.80). Mothers with poor physical health were more likely to resign to take care of their children (OR 1.35, 95% CI 1.09 - 1.68). Having assistance from the children's grandparents meant that both mothers and fathers were less likely to resign (mothers: OR 0.26, 95% CI 0.21 - 0.30; fathers: OR 0.30, 95% CI 0.16 - 0.56). Assistance from grandparents was the only factor influencing the fathers' decision to resign in this model.

Taking "salary of the last job before resignation was higher than the average" and "previous income's proportion of the total household income was higher than average" as independent variables, the logistic regression for involuntary resignation showed that even when mothers had a higher annual income from their previous employment or previously earned a higher proportion of the total household income, they were more likely to involuntarily resign. However, there was no such trend for fathers (Table 4). When we compared salaries between spouses, we found that 45.3% (63/139) of fathers who resigned to care for their children earned more than their spouses before resigning. On the other hand, only 13.7% (373/2723) of mothers who resigned to care for their children earned more than their spouses before resigning.

Table . Characteristics of employment status and reasons for not being employed by gender.

Characteristics	Father (n=5018), n (%)	Mother (n=5077), n (%)
Work		
Full-time	3537 (70.9)	971 (19.4)
Flexible	372 (7.5)	622 (12.4)
Overtime	743 (14.9)	49 (1)
Long leave	171 (3.4)	232 (4.6)
Nonwork		
Caregiving resignation	139 (2.8)	2723 (54.3)
Other	26 (0.5)	421 (8.4)

Table . The logistic regression for the higher income and proportion of household income for involuntarily unemployed parents.

Variables	Model 1 (n=2723, mothers), OR[a] (95% CI)	Model 2 (n=139, fathers), OR (95% CI)	Model 3 (n=2723, mothers), OR (95% CI)	Model 4 (n=139, fathers), OR (95% CI)
Involuntary resignation	1.57[b] (1.21 - 2.03)	0.24 (0.12 - 2.41)	1.25[c] (1.01 - 1.58)	0.55 (0.15 - 6.83)
Independent variable [d]				
Annual income from previous work was higher than average	√	√		
Previous annual income's proportion of the total household income was higher than average			√	√

[a] OR: odds ratio.

[b] *P*<.001.

[c] *P*<.01.

[d] Models 1-4 controlled the age of the children, autism spectrum disorder severity, children having comorbidities or not, parents having college degree or not, parents' marital status, and the family's residence region and annual income. Independent variables were the salary of the last job before resignation being higher than the average (1=yes, 0=no) and its proportion being higher than the average (1=yes, 0=no).

Discussion

Principal Findings

This study provided a comprehensive analysis of the employment status and factors influencing employment among mothers and fathers who cared for children with ASD in China. It is the first study to investigate the gender differences in influencing factors among Chinese parents. The results of the study highlight a notable disparity, indicating that females in China are more likely to be unemployed and more likely to resign from their jobs due to child care responsibilities compared to males. This trend persists even as the children grow older and reach school age.

This research has shed light on the existence of gender inequalities in employment within the context of caring for children with ASD. That having a child has an impact on the mother's job and career is not unusual, as evidenced by previous research [11,27,36-38]. Previous studies have reported that the employment rate for mothers of children with ASD was 67%, while for fathers, it was higher (92%) [14]. Additionally, it was found that 79% of fathers and 44% of mothers with children with ASD were engaged in full-time employment [39]. It is noteworthy that in China, the issue of gender inequality in employment may be particularly pronounced. In this study, it was found that only 37.3% of mothers of children with ASD were employed, while the employment rate for fathers was higher (96.7%). This finding was consistent with the trends found in previous studies [14,39], but the gender difference in employment rates was more pronounced. The employment rate for mothers in this study was even lower compared to previous findings from other countries for parents of children with developmental disabilities; for instance, the employment rates were reported as 49% in Japan [40]. The reasons could be summarized as a difference in cultures, diagnoses, and research designs. It should be noted that this study was conducted during the COVID-19 pandemic, a context that might have influenced our findings. The pandemic had a dual impact on employment opportunities for parents of children with ASD. First, the overall economic downturn might have reduced job prospects, particularly for those living in informal settlements who rely on informal, precarious employment with irregular income [41]. Second, increased caregiving demands, such as those resulting from school closures, might have further constrained these parents' employment options [42].

Utilizing data from the China Family Panel Study spanning the years 2010 to 2018, research found that the employment rate for women was 68.5%, whereas for men, it was 93.3% [43]. Similarly, based on national survey data, the employment rate for Chinese women was 66.7%, with a lower rate of 51.4% observed for women with children aged 0 - 3 years [44]. These findings highlight the disparities in employment rates between genders in China. The employment rate of women in our sample was lower than the average employment rate of women in China. Across nearly all age groups of children with ASD, the employment rate for mothers was below 40% in this study. The employment rate for fathers did not differ, suggesting that mothers were more likely to assume the primary caregiver role. These findings aligned with previous research that indicated that mothers were often the ones who exited the workforce when caring for a child with a disability [45,46].

For those mothers who were employed, they were less likely to work full-time or for longer working hours. Only 4.6% of mothers in this study took a long leave. In addition, while 15% of fathers reported working overtime, only 1% of mothers did. These findings highlighted the disparity in working hours and overtime between mothers and fathers. Fathers were still the primary breadwinners in their families. When a child has a disability, families must frequently make the difficult decision to have one parent leave their job to become the primary caretaker while the other parent continues to work. This decision is tough and challenging [47]. Two theories, namely the specialization theory proposed by Becker [25] and the gender role theory introduced by Finch [26], can help explain the gender inequalities observed in employment. Although our findings suggest that mothers' lower relative salary compared to their spouses may play a role in their decision to take on primary caregiving responsibilities, it is likely that a combination of factors—including cultural norms, personal preferences, and family circumstances—also influence these decisions. There is evidence supporting both theories. How individuals balance work and parenthood is also influenced by individuals' identities as moral beings within their specific culture. However, it is important to note that the applicability of this theory may vary across countries.

Some factors, including culture, household income, and women's role identity, can influence women's labor participation and types of participation, though the results are generally inconclusive [27]. In this study, we found that the severity of the ASD symptoms increased mothers' caregiving needs and thus decreased employment, which was consistent with previous findings that the more severe the child's condition, the more challenging it was for the parents to work [48,49]. For fathers, having children with more severe disabilities had little effect on their labor market participation, which was consistent with a previous finding [13]. There were similar findings in other studies [38,50]. The effect seems to be stronger among more educated mothers, signaling the existence of education inequalities in mothers, but not in fathers. Our study revealed that highly educated mothers were more prone to resign to care for their children. This was likely due to higher spousal incomes rather than a lack of social supports. In fact, these educated mothers were more likely to receive childcare assistance from the children's grandparents. Our findings indicated that mothers with higher previous incomes were more likely to resign involuntarily, while those with lower incomes tended to continue working. This trend raises concerns for families with children with ASD, particularly regarding reduced access to intensive early interventions and the potential negative impact of work-related stress on parent-child interactions in dual-income households.

Social supports were an important influencing factor for employment for parents. The assistance provided by grandparents had a significant impact on the decision to work, especially for mothers. In traditional Chinese culture, parents of children with ASD may tend to seek help from their family rather than from other sources [19,51], but this does support mothers' employment. In this study, we found that single mothers were more likely to work, supporting the previous finding that single mothers worked more out of economic necessity [52]. Single fathers, on the other hand, did not have this tendency to work more. One of the explanations for this was that fathers may face discrimination due to their single-parent status [53]. Another possible cause was Confucianism, which holds that men are superior to women. Fathers were more inclined to rely on their parents' resources, which alleviated financial concerns [54]. Although we did not explicitly measure discrimination and parental resources in our study, it was plausible that this phenomenon existed among our participants. Additional research is necessary to substantiate these claims.

Previous research found that mothers who experience involuntary unemployment tended to have a lower quality of life [48]. It emphasized the critical role of mothers in caregiving as well as the potential negative impact of additional caregiving responsibilities. In the short term, to care for their children, women may have to interrupt or leave their careers, which can hinder their professional development. In the long term, women may experience a decline in their social status and decision-making power within the family. More research is still needed to verify this hypothesis in the future.

When it comes to addressing gender inequalities, there are valuable practices that can serve as examples. One such instance can be observed in Australia, where the motherhood penalty had been severe. However, the government implemented a range of proactive family policies to address this issue. There was a notable policy focus on supporting parents in their return to the workforce as soon as they were able. This was achieved through various measures, including investments in the improvement of childcare systems and the provision of increased subsidies for working parents [28]. Family policies that promote a dual earner-dual carer model have played a pivotal role in raising female employment rates and reducing gender disparities in employment [55]. These policies have proven to be particularly beneficial for women with lower and moderate levels of educational qualifications.

Limitations

This study had a number of limitations. First, the sampling method was nonprobabilistic, relying on voluntary participation rather than random selection, which did not allow for control stratification in sampling. To improve future studies, we could use more robust sampling survey methodologies. Second, the design of the study prevents the establishment of causal relationships. We can only test correlations between influencing factors and parental employment. This research would benefit from more sophisticated modeling techniques to investigate the ways in which the variables interact. Third, the data regarding the severity of the ASD symptoms was not professionally approved using the validated scales but rather was based on parental reports. Improved symptom classification will facilitate the creation of more appropriate aids. Fourth, although parents of children with ASD share some commonalities with parents of children with other disabilities, it is not clear whether the current findings are applicable outside of this particular case. Further research is needed to understand the extent to which these differences are related to the structure and arrangement of services. Fifth, the data collection for this study was completed during the COVID-19 pandemic, which may have affected the generalizability of our findings. Although the results provide insights into the situation during this period, they may not fully represent the typical employment experiences of these parents under normal circumstances. Future research comparing prepandemic, mid-pandemic, and postpandemic data would be beneficial to differentiate between the pandemic's specific effects and the longer-term employment trends for this population.

Conclusions and Implications

This research examines employment and factors that affected fathers' and mothers' employment decisions. Our data show that a considerable proportion of mothers choose not to work, suggesting that women bear the majority of caring obligations. Gender inequality in employment exists in China and it is more pronounced than that in Western countries. The shortcomings of public assistance, the rigidity of the paid workforce regarding family medical leave, and the absence of compensation for informal care work make it challenging for women, particularly low socioeconomic status women, to find jobs. Policymakers should provide the necessary welfare supports, particularly for mothers caring for children with severe disabilities, allowing them to work fewer hours and offering a more flexible schedule or leave policy. Coordinating care for the entire family may result in improved health and economical outcomes. More maternal health care and social supports are required to increase the workforce involvement and well-being of these mothers. Furthermore, more research is needed to investigate the roles of fathers. A stronger gender equality ideology and more women-friendly policies are needed not only in China but around the world.

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Data Availability

The data that support the findings of this study are available on request from the corresponding author, XZ, upon reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Gender inequalities in employment of parents caring for children with autism spectrum disorder in China.

[DOCX File, 27 KB - pediatrics_v7i1e59696_app1.docx]

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Abbreviations

ASD: autism spectrum disorder
HFA: high-functioning autism
LFA: low-functioning autism
OR: odds ratio

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Acceptance of a French e–Mental Health Information Website (CléPsy) for Families: A Web-Based Survey

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Abstract

Background: Childhood mental health issues concern a large amount of children worldwide and represent a major public health challenge. The lack of knowledge among parents and caregivers in this area hinders effective management. Empowering families enhances their ability to address their children’s difficulties, boosts health literacy, and promotes positive changes. However, seeking reliable mental health information remains challenging due to fear, stigma, and mistrust of the sources of information.

Objective: This study evaluates the acceptance of a website, CléPsy, designed to provide reliable information and practical tools for families concerned about child mental health and parenting.

Methods: This study examines user characteristics and assesses ease of use, usefulness, trustworthiness, and attitude toward using the website. Platform users were given access to a self-administered questionnaire by means of mailing lists, social networks, and posters between May and July 2022.

Results: Findings indicate that the wide majority of the 317 responders agreed or somewhat agreed that the website made discussions about mental health easier with professionals (n=264, 83.3%) or with their relatives (n=260, 82.1%). According to the ANOVA, there was a significant effect between educational level and perceived trust (F_6=3.03; P=.007) and between frequency of use and perceived usefulness (F_2=4.85; P=.008).

Conclusions: The study underlines the importance of user experience and design in web-based health information dissemination and emphasizes the need for accessible and evidence-based information. Although the study has limitations, it provides preliminary support for the acceptability and usefulness of the website. Future efforts should focus on inclusive co-construction with users and addressing the information needs of families from diverse cultural and educational backgrounds.

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KEYWORDS

mental health education; children; family; child; pediatrics; pediatric; mental health; parent; parents; parenting; psychiatry; website; acceptance; patient education; online information; health information; ease of use; usefulness; survey; surveys; user; experience; questionnaire; questionnaires; families

Introduction

Childhood mental health (MH) issues concern up to 13.4% of children worldwide [1] and represent a major public health challenge [2]. However, parents’ and caregivers’ lack of knowledge in this area constitutes a major obstacle to their management of these issues [3]. Child and adolescent MH has substantially worsened in recent years, especially during the COVID-19 pandemic, notably in girls and vulnerable populations such as families with low income or children and adolescents with pre-existing MH difficulties [4].

The World Health Organization has promoted a shift from patient-centered health to family empowerment as a catalyst for health development especially in chronic diseases. This switch involved providing families with tools to understand their rights regarding health care and how to access health services [5]. For example, patient empowerment is known to enhance health literacy in people with diabetes through increasing expression, self-judgment, and critical thinking, especially communicative health literacy and critical health literacy that relies on interaction and communication skills [6]. Parent health literacy was also considered an essential element in minimizing childhood obesity in a meta-analysis [7]. In the specific case of MH, family empowerment is a mediator for positive changes by enabling better management of children's difficulties and providing a greater sense of confidence in parental problem-solving abilities, facilitating the resolution of future MH challenges [8].

Health literacy encompasses knowledge that helps individuals achieve and maintain good health, including the identification of symptoms and the ability to understand and evaluate health-related information effectively. More specifically, MH literacy has been defined as "understanding how to obtain and maintain positive MH; understanding mental disorders and their treatments; decreasing stigma related to mental disorders; and enhancing help-seeking efficacy" [9]. Parents and caregivers are in demand of MH knowledge—especially those concerned by previous experiences with MH. However seeking help and information might be limited by fear, stigma, and mistrust of the sources of information [10]. Indeed, the lack of MH knowledge and the stigma attached to mental impairments constitute major obstacles to health care access [11]. When faced with psychiatric difficulties in their children, many parents express a lack of knowledge and the necessary skills to address these issues effectively [12]. Consequently, almost all parents (96%) turn to online sources to find answers to health-related questions in general, with MH and parenting being the most frequently searched topics [13]. However, a study examining French-speaking MH websites conducted by Buteau-Poulin et al [14] revealed that only 43% of dedicated websites provided scientifically reliable content. Among these websites, only 42% addressed autism, 45% addressed learning disorders, and merely 10% covered language disorders and behavioral problems. Furthermore, MH information websites often employ language that exceeds the average parent's comprehension level [15].

Better functional and communicative health literacy was associated with reduced stigma and reluctance to seek MH support among adults [16]. Digital health interventions in particular have the potential to be an effective—and cost-efficient—method for increasing parental knowledge regarding MH difficulties in their children and adolescents. These interventions can assist parents in assessing valid information and understanding the organization of psychiatric services [17]. In line with this goal of supporting children and their families, we launched a website in March 2020, intended for families of children with MH disorders in the context of the first French lockdown during the COVID-19 pandemic. This website provides evidence-based knowledge on MH topics, practical tool kits, and know-how to deal with children's everyday difficulties. CléPsy is divided into categories (general information, anxiety and affective disorders, attention-deficit/hyperactivity disorder [ADHD], intellectual development disorder, addictology, autism spectrum disorders, language/learning disorders, and eating disorders). Examples of pages include information about augmentative and adaptive communication for children with autism spectrum disorders and how to use it, what early signs of ADHD should parents be aware of, or the mechanisms and risk factors of eating disorders. Authors are identified on each page and sources are mentioned when needed.

The main purpose of this study was to evaluate users' general acceptance of the design and the content of CléPsy, a website dedicated to helping families concerned with child MH through information and practical tools. A secondary objective was to evaluate the effect of users' characteristics on general acceptance.

Methods

Creation of the Online Platform

The first version of the website [18] was created and released in March 2020 by the authors of this paper as a rapid response to the MH concerns raised by families in the context of the COVID-19 crisis. A later version (rebranded as CléPsy [19]) was designed by a team of professional web developers and made available as of January 2021. The developer team sought general feedback from families and other website users to guide their strategy but did not implement specific focus groups. Since then, the platform has offered varied content covering a large array of MH topics in French. The content of the website was produced by the multidisciplinary staff of the Center of Excellence for Neurodevelopmental Disorders (Robert Debré Hospital, Paris), submitted to a proofreading committee, and had to follow specific editorial standards based on the eEurope 2002 Quality Criteria for Health Related Websites [20].

Questionnaires and Study Participants

A self-directed survey was made available through various methods between May and July 2022. First, the survey was directly sent to the CléPsy mailing list newsletter subscribers, which is usually used to give information about new content. Second, the survey was shared on social networks (Facebook, Twitter, and LinkedIn). Finally, posters with a QR code leading to the survey were displayed in Robert Debré Hospital. This web-based survey verified the recommendations of CHERRIES (Checklist for Reporting Results of Internet E-Surveys) for web survey quality [21] and was adapted from the questionnaire developed by Tlach et al [22] for the German e-portal Psychenet [23] and translated to French. The open survey was displayed on Lime Survey, and information about the aim and length of the survey was given before participants were asked if they consented to answer. No incentive was used to promote answering, and IP addresses were used to avoid multiple responses by the same visitor. The questionnaire first explores the baseline characteristics of respondents: age, gender, location, and educational level, as well as respondents' experience with MH. In a second acceptance/usability–related section, we used a 4-point Likert scale (1=disagree, 2=somewhat disagree, 3=somewhat agree, 4=agree) to explore four dimensions: "Perceived ease of use," which refers to the readability, design, and accessibility of the website; "Perceived usefulness," which refers more specifically to the content and how it helped participants; "Perceived trustworthiness," which is about how much the information on the website seems trustworthy and up to date; and finally, "general attitude toward the website" had questions about the tendency to recommend the website to others or to revisit it.

Web Analytics

Google Analytics was used to determine the number of connection sessions since the launch of the website as well as demographic information about the visitors, including the countries and cities associated with the users, the frequency and recency of the sessions, and the top site contents viewed. Google Analytics is a widely used web analytics service offered by Google that tracks and reports website traffic.

Data Analysis

The collected data on user characteristics and acceptance were analyzed on JMP statistical software (V17.0; JMP Statistical Discovery LLC). Our analysis was based on a similar work conducted by Tlach et al [22]. Only complete answers were analyzed. Means, SDs, and frequency distributions were calculated for each item to quantify the response. A total score for each of the four dimensions was calculated by summing the Likert score of all items in this dimension. One-way ANOVAs were conducted for interval-scaled variables (total scores of the four dimensions of acceptance and usability) to explore the effects of distinct participant characteristics (gender, age, educational level, experience with mental disorders, frequency of use) on the acceptance and usability of the website. A *P* value <.05 was considered to be significant for all analyses. The significance level was not adjusted as the tests served to generate hypotheses.

Ethical Considerations

This study was submitted to and approved by the local Assistance Publique - Hopitaux de Paris ethics board (2021 - 588).

Results

Overview

From May to July 2022, 53,911 pages were visited on CléPsy by 20,513 independent visitors. Among them, 693 (3.4%) accessed the web-based questionnaire and 614 (3%) consented to participate. Among these 614 respondents, half responded completely (n=317, 51.6%), of which almost all were female (n=297, 94%) with an average age of 46.2 (SD 10.1) years. We observed that 63.1% (n=200) of the complete respondents were MH professionals and 65.6% (n=208) were highly educated (master’s degree or a doctorate). Almost all respondents used the internet daily (n=298, 94%), and 49.2% (n=156) learned about CléPsy through social networks. Finally, 60.6% (n=192) of respondents visited CléPsy >5 times (Table 1).

Participants’ responses to the four dimensions are summarized in Table 2.

Table . Descriptive characteristics of access paths and website use (n=317).

Variable		Participants
Gender (female), n (%)		297 (94.0)
Age		
	Participants, n (%)	297 (94.0)
	Years, mean (SD)	46.2 (10.1)
Education level, n (%)		
	GCSE[a]	2 (0.6)
	IB[b] level	15 (4.7)
	Undergraduate education	7 (2.2)
	Bachelor’s degree	85 (26.9)
	Master’s degree	149 (47.0)
	Doctorate degree	59 (18.6)
Experience with mental disorders, n (%)		
	Professional	200 (63.0)
	Family	88 (27.8)
	Individually	10 (3.2)
	Other	13 (4.1)
	Not concerned	6 (1.9)
Internet usage, n (%)		
	(Almost) every day	298 (94.0)
	At least once a week	7 (2.2)
	At least once a month	11 (3.5)
	Almost never	1 (0.3)
Access to portal, n (%)		
	Directly	60 (18.9)
	Via search engine	97 (30.6)
	Via referring website	160 (50.5)
Awareness of the portal through, n (%)		
	Poster	5 (1.6)
	Recommendation from a health professional	75 (23.7)
	Via social networks	156 (49.2)
	Word of mouth	18 (5.7)
	Press	8 (2.5)
	Other	55 (17.3)
How many times have you been on CléPsy, n (%)		
	Only once	56 (17.6)
	<5	69 (21.8)
	≥5	192 (60.6)

[a] GCSE: General Certificate of Secondary Education.

[b] IB: International Baccalaureate.

Table . User rating on perceived ease of use, perceived usefulness, attitude toward using the portal, and perceived trust (n=317).

Variables		Agree, n (%)	Somewhat agree, n (%)	Somewhat disagree, n (%)	Disagree, n (%)
Perceived ease of use					
	The font of the website is easy to read	176 (55.5)	129 (40.7)	8 (2.5)	4 (1.3)
	The website is easy to use	152 (48.0)	152 (48.0)	8 (2.5)	5 (1.5)
	The presentation of the information is clearly arranged	141 (44.5)	151 (47.6)	19 (6.0)	6 (1.9)
	The information is easy to understand	184 (58.0)	121 (38.2)	8 (2.5)	4 (1.3)
	The design of the website is appealing	146 (46.1)	158 (49.8)	10 (3.2)	3 (0.9)
	The colors of the website are pleasant	168 (53.0)	132 (41.7)	15 (4.7)	2 (0.6)
	The pictures on the website are appropriate	143 (45.1)	159 (50.2)	13 (4.1)	2 (0.6)
	I can quickly find the information that is important to me	124 (39.1)	162 (51.1)	28 (8.9)	3 (0.9)
Perceived usefulness					
	The content of the website is interesting	224 (70.7)	87 (27.4)	2 (0.6)	4 (1.3)
	All in all, the website is useful for me	196 (61.8)	112 (35.3)	5 (1.6)	4 (1.3)
	The amount of information presented on the website is appropriate	158 (49.8)	138 (43.5)	17 (5.4)	4 (1.3)
	The website contains information that I need	157 (49.5)	141 (44.5)	17 (5.4)	2 (0.6)
	The information on the website has helped me with my concerns	152 (48.0)	148 (46.7)	14 (4.4)	3 (0.9)
	Through the website, I received references to other sources	114 (36.0)	160 (50.5)	41 (13.0)	2 (0.6)
	Through the website, I learned something new	145 (45.7)	145 (45.7)	23 (7.3)	4 (1.3)
	Now I’m able to talk better about mental disorders with my health professional	105 (33.1)	159 (50.2)	51 (16.1)	2 (0.6)
	Now I’m able to talk better about mental disorders with my relatives	101 (31.9)	159 (50.2)	54 (17.0)	3 (0.9)
Attitude toward using					
	I would recommend the website to others	232 (73.2)	76 (24.0)	5 (1.6)	4 (1.2)
	I will revisit the website if needed	249 (78.5)	62 (19.6)	2 (0.6)	4 (1.3)
Perceived trust					

Variables		Agree, n (%)	Somewhat agree, n (%)	Somewhat disagree, n (%)	Disagree, n (%)
	The information on the website is trustworthy	231 (72.9)	77 (24.3)	6 (1.9)	3 (0.9)
	The information on the website is up to date	184 (58.0)	120 (37.9)	10 (3.2)	3 (0.9)

Perceived Ease of Use

Almost all participants (n=304, 96%) stated that the website was easy to use, with 90.2% (n=305) indicating that they could easily find the information important to them. Additionally, 96% (n=304) found the design appealing. None of the main participants' characteristics had a specific effect on the perceived ease of use (Table 3).

Table . Effects of participants' characteristics on the perceived ease of use (n=317).

		Participants, n	Perceived ease of use score		*F* test (*df*)	*P* value
			Mean	SD		
Gender					0.97 (1)	.33
	Female	297	6.77	0.06		
	Male	20	6.52	0.24		
Age (years)					1.93 (1)	.16
	≤46	172	6.67	0.08		
	>46	144	6.84	0.09		
Educational level					1.44 (6)	.20
	GCSE[a]	2	7.37	0.76		
	IB[b] level	15	6.58	0.28		
	Undergraduate degree	7	6.68	0.40		
	Bachelor's degree	85	6.62	0.12		
	Master's degree	149	6.77	0.09		
	Doctorate degree	59	6.93	0.14		
Experience with mental health					0.71 (4)	.58
	Professional	200	6.82	0.07		
	Family	88	6.64	0.11		
	Individually	10	6.65	0.34		
	Other	13	6.58	0.30		
	Nonconcerned	6	6.46	0.44		
Frequency of use					2.44 (2)	.09
	Only once	56	6.47	0.14		
	<5	69	6.79	0.13		
	≥5	192	6.82	0.08		

[a] GCSE: General Certificate of Secondary Education.

[b] IB: International Baccalaureate.

Perceived Usefulness

The majority of respondents agreed or somewhat agreed with the statement "All in all, the website is useful for me" (n=308, 97.1%). A significant percentage agreed or somewhat agreed that the website facilitated discussions about MH with professionals (n=264, 83.3%) or with their relatives (n=260, 82.1%). According to the ANOVA, there was a significant effect between frequency of use and perceived usefulness (F_2=4.85; *P*=.008; Table 4).

Table . Effects of participants' characteristics on the perceived usefulness (n=317).

		Participants, n	Perceived usefulness score		*F* test (*df*)	*P* values
			Mean	SD		
Gender					0.01 (1)	.91
	Female	297	7.60	0.06		
	Male	20	7.62	0.25		
Age (years)					0.15 (1)	.71
	≤46	172	7.62	0.08		
	>46	144	7.57	0.09		
Educational level					0.22 (6)	.95
	GCSE[a]	2	8.25	0.80		
	IB[b] level	15	7.48	0.29		
	Undergraduate degree	7	7.39	0.42		
	Bachelor's degree	85	7.62	0.12		
	Master's degree	149	7.60	0.09		
	Doctorate degree	59	7.60	0.15		
Experience with mental health					0.33 (4)	.86
	Professional	200	7.62	0.08		
	Family	88	7.56	0.12		
	Individually	10	7.77	0.35		
	Other	13	7.54	0.31		
	Nonconcerned	6	7.17	0.46		
Frequency of use					4.85 (2)	.008
	Only once	56	7.33	0.15		
	<5	69	7.38	0.13		
	≥5	192	7.75	0.08		

[a] GCSE: General Certificate of Secondary Education.

[b] IB: International Baccalaureate.

Perceived Trust and General Attitude Towards Using CléPsy

The vast majority of respondents described the website as trustworthy (n=308, 97.3%) and up to date (n=304, 95.9%), and would recommend it to other people (n=308, 97.2%). None of the main participants' characteristics had a specific effect on their attitude toward using CléPsy (Table 5). According to the ANOVA, there was a significant effect relating perceived trust with the educational level (F_6=3.03; P=.007) and the frequency of use (F_2=5.30; P=.006; Table 6).

Table . Effects of participants' characteristics on attitudes toward the website (n=317).

		Participants, n	Attitudes toward the website score		*F* test (*df*)	*P* value
			Mean	SD		
Gender					0.44 (1)	.50
	Female	297	3.42	0.02		
	Male	20	3.47	0.07		
Age (years)					0.46 (1)	.50
	≤46	172	3.44	0.02		
	>46	144	3.41	0.02		
Educational level					0.64 (6)	.70
	GCSE[a]	2	3.75	0.23		
	IB[b] level	15	3.43	0.08		
	Undergraduate degree	7	3.36	0.12		
	Bachelor's degree	85	3.40	0.03		
	Master's degree	149	3.43	0.03		
	Doctorate degree	59	3.45	0.04		
Experience with mental health					0.32 (4)	.86
	Professional	200	3.43	0.02		
	Family	88	3.40	0.03		
	Individually	10	3.45	0.20		
	Other	13	3.46	0.09		
	Nonconcerned	6	3.50	0.13		
Frequency of use					0.09 (2)	.91
	Only once	56	3.41	0.04		
	<5	69	3.43	0.04		
	≥5	192	3.43	0.02		

[a] GCSE: General Certificate of Secondary Education.

[b] IB: International Baccalaureate.

Table . Effects of participants' characteristics on the perceived trust (n=317).

		Participants, n	Perceived trust score		*F* test (*df*)	*P* value
			Mean	SD		
Gender					0.09 (1)	.76
	Female	297	3.61	0.03		
	Male	20	3.57	0.12		
Age (years)					0.09 (1)	.76
	≤46	172	3.60	0.04		
	>46	144	3.62	0.04		
Educational level					3.03 (6)	.007
	GCSE[a]	2	2.50	0.38		
	IB[b] level	15	3.37	0.20		
	Undergraduate degree	7	3.64	0.20		
	Bachelor's degree	85	3.53	0.06		
	Master's degree	149	3.650	0.04		
	Doctorate degree	59	3.72	0.07		
Experience with mental health					0.31 (4)	.87
	Professional	200	3.62	0.04		
	Family	88	3.61	0.06		
	Individually	10	3.55	0.17		
	Other	13	3.46	0.15		
	Nonconcerned	6	3.58	0.22		
Frequency of use					5.30 (2)	.006
	Only once	56	3.41	0.07		
	<5	69	3.59	0.06		
	≥5	192	3.67	0.04		

[a] GCSE: General Certificate of Secondary Education.

[b] IB: International Baccalaureate.

Discussion

Principal Findings

In this web-based study, we investigated the acceptance of the design and content of a new website dedicated to children's MH information with the aim of gaining a better understanding of active users and areas for improvement to reach target users more effectively.

Among complete responders (n=317), almost all agreed (n=152, 47.9%) or somewhat agreed (n=152, 47.9%) with the affirmation that the website was easy to use. Those results were in line with previous studies exploring the ergonomics of online MH information. When evaluating the Psychenet website, Tlach et al [22] found equivalent rates of perceived ease of use. Engagement and perceived ease of use were equivalent regarding the Together for Wellness website, developed during the COVID-19 pandemic [24]. A preference for English and higher behavioral changes during the pandemic were predictors for higher comfort in using the Together for Wellness website. Concerning the design of the CléPsy website, most participants evaluated the font, the colors, the presentation of information, the illustrations, and the accessibility of information positively. User experience (UX) is an important feature of online MH information, and it can be a major barrier for end users [25]. In our study, perceived ease of use did not differ with participants' characteristics. This underlines the importance of working with UX and design professionals to create state-of-the-art internet navigation interfaces that are easy to use. This is especially true when implementing online health information.

The usefulness of the CléPsy website was largely appreciated by the respondents. This could be in line with an almost complete lack of accessible digital information about child and adolescent MH written in French. Furthermore, two-thirds of French people believe that digital tools can help them better understand health care strategies [26]. This is especially the case for MH information, which is one of the main topics researched by parents online when they are looking for pediatric health information [13]. Parents could also be more aware of their children's difficulties with the increasing awareness of MH issues in children and adolescents, especially since the COVID-19 pandemic [27]. For example, the online search for ADHD information has been increasing for several years, which could partially be explained by destigmatization induced by media coverage [28]. The perceived usefulness had a positive influence on the user's ability to discuss MH with health professionals (including their general practitioners) or family members. Indeed, as reported in a systematic review by Kubb and Foran [29], most parents expressed difficulties in talking to their physicians about health information found online. The main reasons expressed by parents for not talking to the physicians were a lack of time, a fear of disapproval, or difficulties in understanding technical medical terminology. Interestingly, physicians express reservations on the subject. In a qualitative study, Karatas et al [30] explored the main attitude of pediatricians confronted with eHealth-based questions. Most of them expressed concerns about inaccurate health information that could lead to detrimental decisions by families. They highlighted an increased length of consultations to answer the questions but acknowledged that it helped build a more collaborative relationship with parents. In our study, most respondents were MH professionals. This could reflect a need for regular updates on practices, especially regarding evidence-based interventions, even if the therapist's behavior seems to change not only with information but also with specific training [31]. A quantitative study confirmed the positive and bidirectional influence of the perceived usefulness of eHealth information on patient-physician interaction and trust [32]. From the patient's perspective, it enriches participation and cooperation through enhanced resource integration, and from the physician's perspective, it can improve the patient's understanding and the relationship.

The CléPsy website was considered trustworthy by 97.2% (n=308) of respondents, but ANOVAs found an effect of educational level on the perceived trust, contrary to the evaluation of Psychenet by Tlach et al [22]. Parents generally have difficulties evaluating the trustworthiness of their source of information when searching for child health information [33], but most of them would like health care professionals to help them identify reliable sources [34]. When parents from Switzerland were asked about their relationship to online health information seeking, most of them were skeptical about the correctness of the information, but one-third of them did not, or rarely, check the reliability of the website [35]. Interestingly, first-time parents and parents with high levels of education made higher use of web pages targeted at parents. Trust in online health information is predicted by sociodemographic factors such as higher income and educational level [36], but online information remained the least trusted source, behind media sources and interpersonal information.

Limitations

This study must be considered with regard to several limitations. First, contrary to our expectations regarding the main audience, the majority of respondents were MH professionals, whereas the website was created to address inquiries from families. Furthermore, a significant proportion of respondents had a high level of education (master's or doctorate). This may be attributed to the distribution method of the questionnaire, in particular via professional social networks, and to the institutional credibility of the Center of Excellence for Neurodevelopmental Disorders in France. In our analysis, the characteristics of the respondents did not have any effect on their answers. Considering the accessibility and usability of health websites, the literature shows that primary users and MH professionals tend to have the same opinion [37]. MH professionals could also be interested in our website due to the necessity to get valid information about the state-of-the-art practice in MH. Indeed, an important part of the French psychology curriculum is dedicated to psychoanalysis. Future studies would need to consider the differences between these audiences. Moreover, the representativeness of the respondent must be interpreted with caution as the response rate was very low compared to the total number of users during the same period. Second, the CléPsy website was created initially to address families' questions about their children's MH at the onset of the COVID-19 pandemic and facilitate the transmission of relevant content. However, due to this unique timeline, the current version of the website insufficiently meets the standard framework that recommends the co-construction of health information websites together with families and other users [38]. Focus groups with families have since been held by our team along with the UX professionals, resulting in a qualitative evaluation of parents' needs. Third, as expressed by Tlach et al [22], there is a lack of standardized instruments to evaluate the acceptability and usefulness of digital content, which limits comparison. However, the questionnaire was designed based on recent recommendations such as the CHERRIES checklist. Finally, adverse effects of online health information seeking such as cyberchondria were not evaluated and should be taken into account in further research [39].

Conclusion

Our study provides preliminary support for the acceptability and usefulness of a French MH information website dedicated to children and adolescents. Results show that users are in demand of trustworthy information on this matter. In the future, special attention should be given to the co-construction of such websites with concerned users to improve the pertinence, inclusiveness, and accessibility of the contents to a wide and varied public. Moreover, parental role and child diagnosis should be identified in future research.

Conflicts of Interest

None declared.

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Abbreviations

ADHD: attention-deficit/hyperactivity disorder
CHERRIES: Checklist for Reporting Results of Internet E-Surveys
MH: mental health
UX: user experience

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Original Paper

The Relationship Between Symptom Change and Use of a Web-Based Self-Help Intervention for Parents of Children With Externalizing Behavior Disorders: Exploratory Study

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Abstract

Background: Web-based self-help (WASH) has been found to be effective in the treatment of child externalizing behavior disorders. However, research on the associations of caregivers' use of WASH and symptom changes of child externalizing behaviors is lacking.

Objective: This study examined the longitudinal and reciprocal associations between the use of WASH by caregivers of children with externalizing behavior disorders and their children's externalizing behavior symptoms.

Methods: Longitudinal data of 276 families from 2 intervention conditions of a randomized controlled trial (either unguided or supported by a therapist over the phone) were analyzed. Caregiver- and clinician-rated child externalizing behavior symptoms were assessed before (T1), in the middle (T2), and after the 6-month WASH intervention (T3). Additionally, 2 indicators of the caregivers' use of the WASH intervention were considered: number of log-ins (frequency) and the percentage of completed material (intensity). Associations of caregivers' use during early (T1-T2) and late (T2-T3) treatment with child externalizing behavior symptoms were analyzed using path analyses (structural equation modeling).

Results: Frequency and intensity of use were higher during the first 3 months than during the next 3 months of the intervention period. The number of log-ins at early treatment was significantly but weakly associated with caregiver-reported child externalizing behavior symptoms in the long term (T3). Moreover, caregiver-reported child externalizing severity at T2 predicted the number of log-ins in the late treatment. The results were not replicated when considering the percentage of completed material as a measure of use or when considering clinician ratings of child externalizing behavior symptoms.

Conclusions: The findings provide the first, albeit weak, evidence for longitudinal associations between caregivers' use of WASH and improvements in caregiver-rated child externalizing behavior symptoms. However, as the associations were rather weak and could not be replicated across different rater perspectives and operationalizations of use, further research is needed to better understand these relations and their interplay with other putative influence factors (eg, quality of the implementation of the interventions, changes in parenting behaviors).

Trial Registration: German Clinical Trials Register DRKS00013456; https://www.drks.de/DRKS00013456

International Registered Report Identifier (IRRID): RR2-10.1186/s12888-020-2481-0

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KEYWORDS

web-based self-help; eHealth; parent management training; externalizing symptom; ADHD; attention-deficit hyperactivity disorder; self-help; use; child; children; parent; parents; management; management training; symptom; symptoms; caregiver; ODD; oppositional defiant disorder; treatment; web-based; caregivers; longitudinal data

Introduction

Parenting interventions have been shown to reduce oppositional defiant behavior problems in children [1,2]. Behavioral parent management training (PMT) has led to a reduced number of problematic situations of caregiver-child interactions reported by caregivers of children with attention-deficit hyperactivity disorder (ADHD) [3]. Although previous research has demonstrated both self-directed and face-to-face PMT to be effective in reducing child externalizing behavior disorders, outcome ratings of PMT vary across different assessors (eg, parents, clinicians, objective observations), with stronger evidence for PMT in caregiver reports [4,5]. Improvements have been reported by caregivers (completers) for conduct problems (P=.001) and hyperactivity symptoms (P<.001) [6]. Moreover, it remains unclear what drives symptom-related improvements: Although some studies indicate that parental attendance and engagement in face-to-face PMT are associated with greater symptom reduction for disruptive behavior, ADHD, and oppositional defiant disorder (ODD) symptoms [7], others indicate no differences in child behavior outcomes between mothers who complete versus mothers who drop out of PMT [6]. In a systematic review of preventive child mental health programs, higher levels of caregiver participation engagement (CPE) were associated with greater improvements in child internalizing and externalizing behavior symptoms [8]. Additionally, parental outcomes (eg, warm interactions, reduced physical punishment) seem to be associated with the quality of participation (rated by a therapist, eg, completion of between-session homework or the amount of participation in the group) rather than with mere attendance in PMT for conduct problems [9].

Web-based PMT is an easily accessible treatment alternative to face-to-face PMT, with proven effectiveness in the treatment of, for example, externalizing behavior disorders [10,11] and anxiety disorders [12]. There is evidence for the efficacy of web-based PMT regarding the reduction in conduct disorder and ADHD symptoms, with mostly small-to-moderate effect sizes [13-18]. However, self-help interventions often fail to keep caregivers engaged, rendering them difficult to complete [19,20]. In a 3-arm randomized controlled trial (RCT), we demonstrated that web-assisted self-help (WASH) combined with therapist telephone support (Döpfner et al, unpublished data, August 2024) is superior to routine clinical care, as well as WASH alone, in reducing clinician-rated child externalizing behavior symptoms [21]. Compared to face-to-face therapy and in line with other research on online interventions, our study revealed a relatively low intensity of use (average 35%), although the majority of participants (89.4%) logged in to the intervention at least once [22].

Considering self-directed interventions based on booklets for caregivers of children with externalizing behaviors (eg, booklets), parental adherence is associated with improved child externalizing behaviors [23]. Research on attrition and usage provides indications that more frequent users of eHealth report a decline in their perceived burden compared with an increased perceived burden reported by nonusers [24]. Regarding web-based PMT for caregivers of children with anxiety and depressive symptoms, parental engagement (defined as stronger orientation toward recommended use, ie, task completion) predicted (caregiver-rated) preventive parenting and lower impairment in the child's quality of life [25]. However, parental engagement did not predict changes in (caregiver- and child-reported) internalizing symptoms. By contrast, the self-reported frequency of practicing skills (during the "Cool Little Kids" online program) was associated with a greater decrease in child anxiety symptoms [12].

Conversely, children's severity of externalizing behaviors at baseline for the intervention on which this research is based has previously been found to be 1 of the predictors for the use of WASH [22]. There is evidence that parental perception of the severity of a child's symptoms is predictive of their help-seeking behaviors [26]. However, factors that are associated with parental engagement in children's mental health treatment have yielded divergent results, with some research indicating, for example, child mental health symptoms as a predictor for parental engagement and others not [8,27].

Clearly, the actual use of web-based interventions is a prerequisite for their efficacy. To date, there is no common sense of how the use of web-based interventions is conceptualized and operationalized, with measures ranging from direct measures (ie, self-report) to objective measures (ie, automatic data tracking of, eg, the number of log-ins) [28]. In the context of face-to-face treatment, the terms "engagement," "participation," and "adherence" are often used interchangeably; however, they include different therapy-related behaviors, from active participation during a session to practice implementation between sessions (eg, practically adapting parenting behaviors) [27]. In a systematic review, the most commonly reported measure for adherence is the number of log-ins to e-therapies [29]. However, a unidimensional operationalizing of the term's use has been criticized by researchers [30,31]; for example, one can often log in to the intervention (frequency), while making little progress (intensity) in the intervention. These parameters, though, seem to be associated with one another [22,27].

To the best of our knowledge, no study on web-based PMT for child externalizing behaviors has analyzed the relationships between parental use and changes in child externalizing behavior symptoms. Moreover, associations between the use of online interventions and symptom changes have rarely been examined in other child mental health conditions. The few available studies differ regarding the type of intervention (eg, preventive program, booklet self-help, face-to-face group PMT), the target group (affected individuals, mostly adults, vs parents), operationalization of treatment use, outcome measures, and how outcome measures are assessed. In behavioral face-to-face PMT, research on the association between attendance and child externalizing symptom severity has yielded divergent results [8,27].

This study took an exploratory approach to examine the longitudinal and reciprocal associations between the use of WASH and child externalizing symptom severity using 3 subsequent assessment points of child externalizing behavior symptoms and in-between assessments of WASH uses. Although it might seem self-evident that the actual use of an intervention is a prerequisite for it to affect child externalizing behavior symptoms, previous research has yielded mixed findings in this regard [8,27]. Thus, we did not formulate specific a priori hypotheses for possible associations. Moreover, as a previous study using baseline data of the same data set as this study demonstrated the predictive value of baseline symptom severity for the subsequent use of WASH [22], we also exploratively examined longitudinal associations between previous symptom severity and subsequent use. As the agreement of different raters on child externalizing symptom severity is typically only low to moderate [4,5], we considered both caregiver and clinician ratings of child externalizing behavior symptoms to obtain a more comprehensive impression of their associations with use. Moreover, as previous research has often been criticized for considering only 1 possible measure of use, we considered both the number of log-ins (frequency of use) and the percentage of completed materials (intensity of use) to operationalize use. However, we chose to consider the number of log-ins for our primary analyses, as this is the measure most often used in previous research [29]. The study was based on the use of WASH PMT in terms of automatically tracked objective measures (number of log-ins, percentage of processed content) of using an online treatment, in which caregivers are free to take an interest-based approach in processing the training [22]. Findings for associations between the percentage of completed materials and child externalizing behavior symptoms are presented in a supplementary manner. The ultimate aim is to provide a basis for improving internet-delivered interventions, in turn contributing to the further development of an effective therapeutic supply for children with externalizing behavior disorders.

Methods

Study Design

Data for the analyses were collected as part of an effectiveness study on WASH [21]. The research compared 3 study conditions: (1) WASH alone, (2) WASH plus telephone-based support (WASH+SUPPORT), and (3) treatment as usual (TAU). The analyses included data from the first 2 conditions only. There were no restrictions regarding the use of further treatment options during study participation.

The RCT from which data for the analyses were gathered was registered at the German Clinical Trials Register (identifier: DRKS00013456; registered on January 3, 2018).

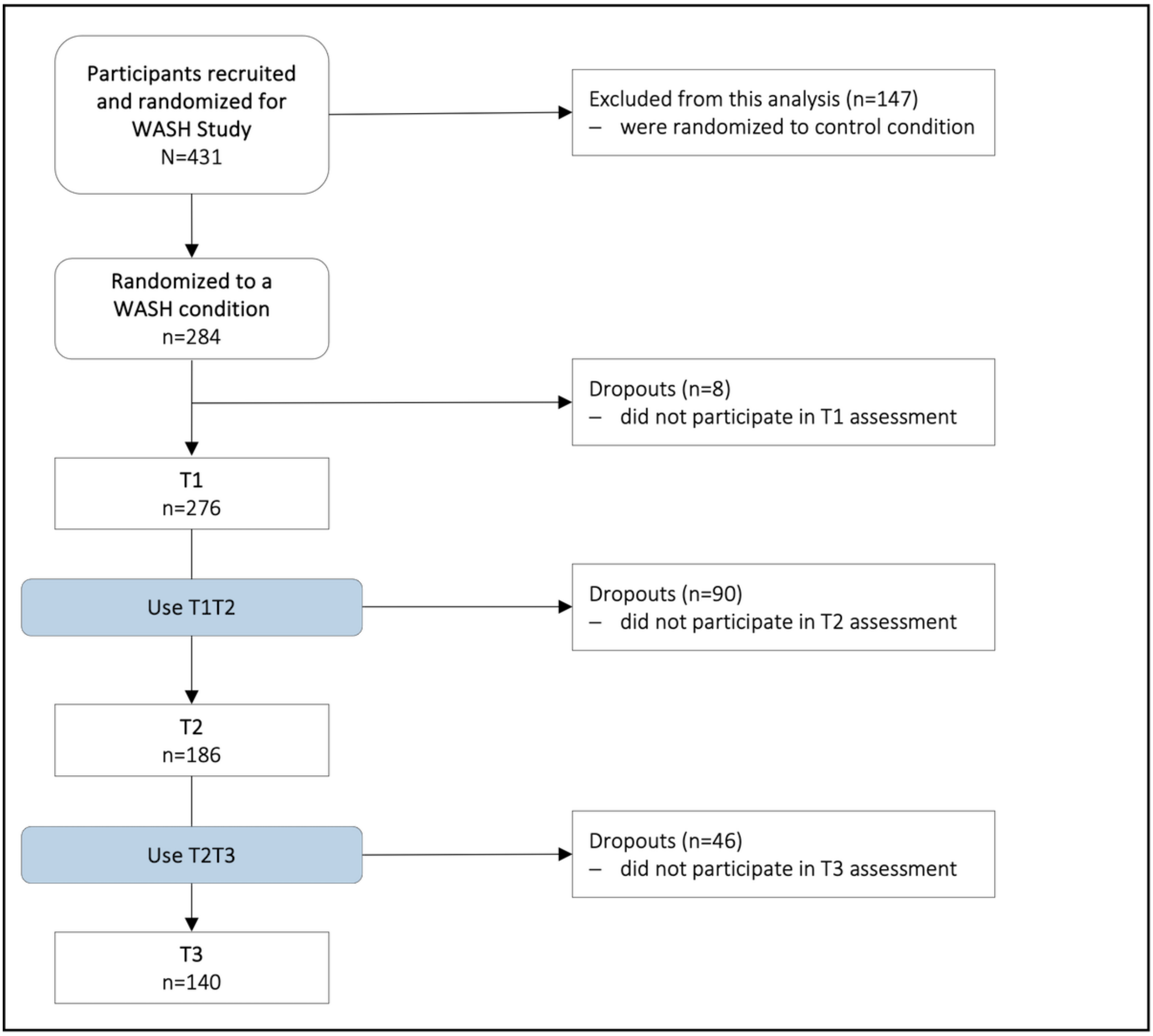
Ethical Considerations

This study was approved by the Ethics Committee of the Medical Faculty of the University Hospital Cologne (Germany; approval number: 17-273) and was performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. All participating caregivers provided written informed consent before randomization.

Participants

Participants were caregivers of children with externalizing behavior symptoms. The inclusion criteria were child age between 6 and 12 years and elevated levels of ADHD or ODD symptoms at the first assessment point (clinician rated during the caregiver interview). A diagnosis of mental retardation or autism spectrum disorder or an indication for inpatient treatment led to exclusion from the study. For subsequent analyses, we used a subsample of 276 caregivers who were randomized to the 2 intervention conditions: WASH (n=135, 48.9%) and WASH+SUPPORT (n=141, 51.1%); see Figure 1. Participating caregivers (n=147) in the control condition (TAU) were excluded from the analyses as they did not use the intervention, and thus, we could not assess use in this group.

Figure 1. Participant flow. Note. T1: before the intervention; T2: in the middle of the intervention; T3: after the 6-month intervention; WASH: web-based self-help.



Intervention

The online intervention was based on previous manual-based self-help programs that have proven effective in reducing children's ADHD or ODD symptoms [32-34]. The WASH intervention comprises 4 modules: solving behavioral problems, positive relationship with your child, self-care, and psychoeducation. We provided recommendations regarding usage, but caregivers were generally free to navigate the program according to their interests. Participants in the WASH+SUPPORT group received up to 6 support calls from a trained and supervised professional. A detailed description is provided in the published study protocol [21]. Participants in both study conditions received reminders if they had not logged in within 5 days after randomization. Users in the WASH group were then free to use the program and were contacted for assessment (12 weeks, T2; 24 weeks, T3 after T1). Although there was a significant overall intervention effect on child externalizing behaviors, as rated by a blinded clinician (Döpfner et al, unpublished data, August 2024), the superiority of the WASH+SUPPORT condition over the WASH condition, revealed by subsequent pairwise comparisons, was compensated in this analysis by using the condition as a covariate.

Measures

Data were collected using a semistructured, telephone-based caregiver interview by a trained clinician and caregiver-rated online questionnaires before the intervention (T1), at a 3-month interim assessment point during the intervention (T2), and after the intervention (ie, at 6 months, T3).

Child Externalizing Behavior Symptoms

At each assessment point, a clinician rated the child's externalizing behavior symptoms based on a semistructured interview with the participating caregiver ("Diagnostic Checklist for Externalizing Behavior Disorders," DCL-EXT), conducted over the phone [35]. The interview covered ADHD symptoms (18 items) and ODD symptoms (8 items) according to the *International Classification of Diseases, 10th Revision* (*ICD-10*) and the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) and has been proven to be a high-quality diagnostic instrument for externalizing behavior disorders [36].

For our analyses, an overall externalizing symptom score was calculated by averaging all item scores. In the study sample, the internal consistency of this score was satisfactory (Cronbach α=.79).

Corresponding to the clinician ratings, at each assessment point, caregivers rated their children's externalizing behavior symptoms using 18 items of the German Symptom Checklist for ADHD and 8 items of the ODD subscale of the Symptom Checklist for Disruptive Behavior Disorders ("Symptom Checklist for Externalizing Behavior Disorders," SCL-EXT) [35]. The items were answered on a 4-point Likert scale (ranging from 0 for *not at all* to 3 for *very much/particularly severe*) [35]. Again, the total externalizing symptom score (SCL-EXT) was computed by averaging all item scores. The instruments have demonstrated factorial validity and satisfactory internal consistency [35,37,38]. The internal consistency in the study sample was satisfactory (Cronbach α=.90) for the combined total SCL- EXT score.

Intervention Use

For each caregiver, an automatically generated log file was extracted 3 months after baseline (at T2) and 6 months after baseline (at T3), including the number of log-ins (ie, frequency of use) in the first 3 months (T1-T2) and the next 3 months (T2-T3), respectively [39,40]. Beyond that, we calculated the percentage of completed tasks/videos (ie, intensity of use, %) between T1 and T2 or between T2 and T3 for each participant by dividing the number of finished tasks and videos in a module/for a specific situation by the maximum number of tasks and videos provided in that module [22]. Reliability analyses for this processing progress scale yielded an acceptable internal consistency (Cronbach α=.78).

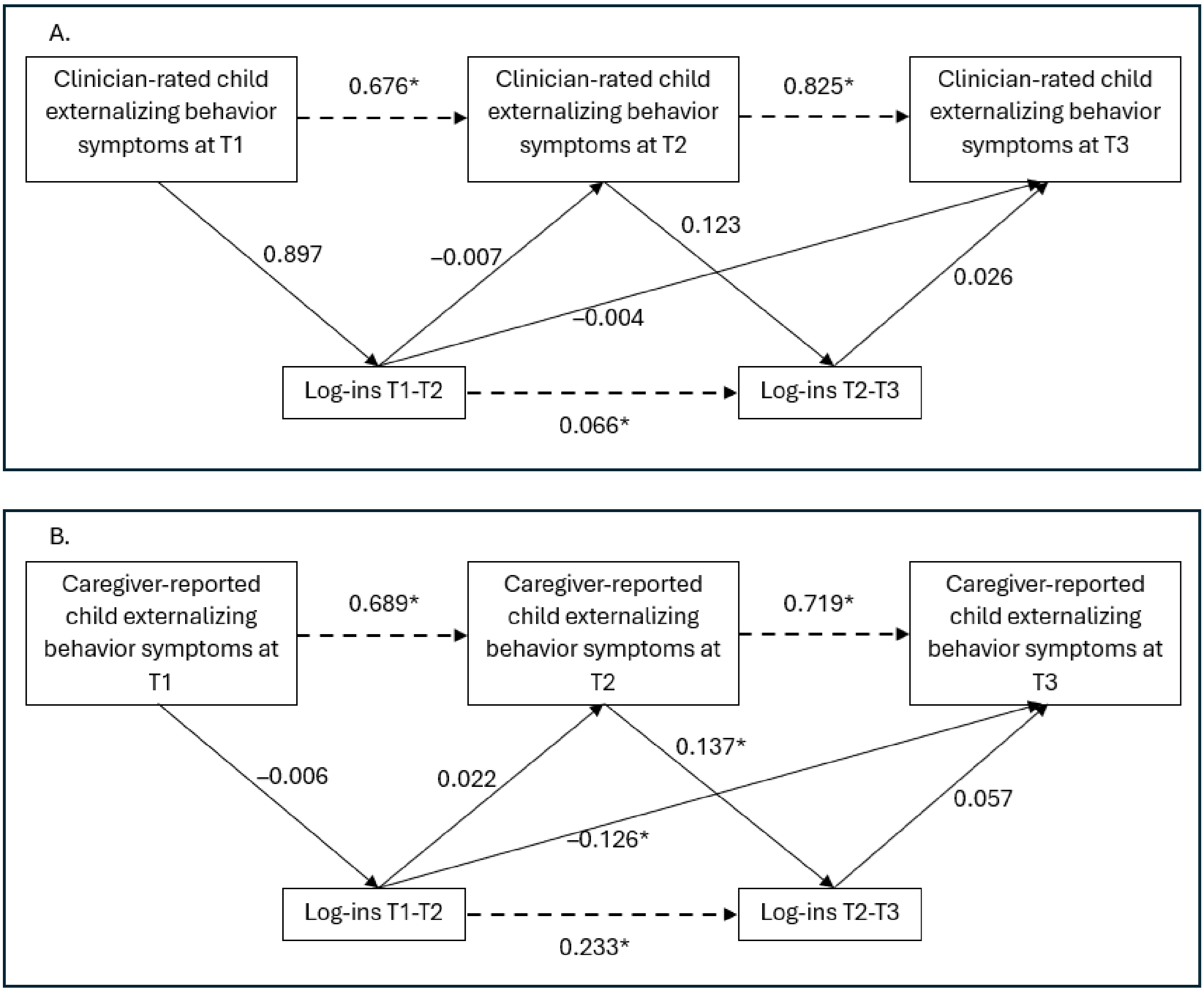
Statistical Analysis

Analyses were conducted on the sample with complete questionnaires for at least T1. Before the main analyses, which included data from participants in both study conditions, independent samples *t* tests were performed to test for differences in child externalizing behavior symptoms between the study conditions at T1. To examine whether child externalizing behavior symptoms affect caregivers' use of the WASH intervention and vice versa, we performed path analyses. In these analyses, we considered associations between the severity of child externalizing behavior symptoms at T1 and the caregivers' use of the WASH intervention in the early intervention period (between T1 and T2), as well as associations between caregivers' use in the early intervention period and child externalizing symptom severity at T2. Accordingly, we regarded the associations between symptom severity at T2 and caregivers' use of the program during the late intervention period (between T2 and T3), as well as associations between this use in the late intervention period and symptom severity at T3. In addition to these paths, to account for temporal stability, we considered autoregressive correlations between child externalizing behavior symptoms measured at the different assessment points and between the use parameters assessed between the assessment points (see Figure 2).

The use of WASH took place between the measurements of children's externalizing behavior symptoms. For our main analyses, we examined 2 different models, with externalizing behavior symptoms rated by either clinicians (see Figure 2A) or caregivers (see Figure 2B) and with caregivers' frequency of use of WASH operationalized by the number of log-ins (log-ins in months 0-3 and log-ins in months 3-6). We chose this measure of use for our primary analyses as it has been reported in most of the previous research on use-symptom association and, thus, allows for comparability with previous findings. Moreover, due to automatic data tracking, this measure seems reliable. However, we additionally conducted analogous analyses on the question of whether the results can be replicated when using a different operationalization of use (ie, percentage of completed materials; intensity of use). The findings for these additional analyses are presented in the online supplement for this paper. In all analyses, we controlled for the effect of the study condition (WASH and WASH+SUPPORT) on the use parameters and on symptoms.

We reported standardized parameter estimates (ß). To evaluate the model fit, we considered the comparative fit index (CFI) and the standardized root mean square residual (SRMR), in addition to χ^2. In line with current recommendations, we considered CFI>0.90 and SRMR<0.08 as acceptable [22,41]. Despite its frequent use, we refrained from relying on the root mean square error of approximation (RMSEA), as this index is not suitable in the case of low degrees of freedom [42]. The analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 27 (IBM Corp) for descriptive statistics and *t* tests and Mplus version 7.4 (Muthén & Muthén) for path analyses.

Figure 2. Results of the path models examining the association between the caregiver's number of log-ins to the WASH intervention and clinician-rated (A) or caregiver-rated (B) child externalizing behavior symptoms. Note. Log-ins T1-T2: number of log-ins during the early intervention phase (months 0-3); log-ins T2-T3: number of log-ins during the late intervention phase (months 3-6); Tx: measuring time; dashed line indicates autoregressive directional correlations; **P*<.05.



Results

Sample Description

Table 1 summarizes the demographic and clinical characteristics of the participating caregivers and their children. At T1, on average, clinicians indicated elevated levels of child externalizing behavior symptoms (DCL-EXT: mean 1.52, SD 0.36). Likewise, caregivers reported clinically relevant child externalizing behavior symptoms (SCL-EXT: mean 1.70, SD 0.46). The independent samples *t* tests revealed no significant differences between the 2 intervention conditions in caregiver-reported child externalizing behavior symptoms at baseline (t_{282}=1.32, *P*=.19). After 6 months (DCL-EXT T3: mean 1.08, SD 0.44; SCL-EXT T3: mean 1.36, SD 0.50), symptom levels were still considered as elevated, according to orienting evaluation without normative standards [35]. However, both clinician-rated (t_{193}=16.33, *P*<.001) and caregiver-rated (t_{158}=10.70, *P*<.001) child externalizing behavior symptoms declined significantly between T1 and T3.

On average, caregivers logged in to the WASH intervention 5 times (SD 4.38, range 0-18) during the early intervention period (months 0-3), with significantly fewer log-ins (mean 0.53, SD 1.20, range 0-9) during the late intervention period (months 3-6; t_{275}=17.40, *P*<.001). Additionally, the percentage of completed material was significantly higher in the first intervention period (mean 31.88, SD 26.08, range 0-96.70) than in the second intervention period (mean 1.93, SD 5.83, range 0-31.20; t_{275}=18.76, *P*<.001).

Table 1. Demographic information about caregivers and children (N=276).

Variable	Value
Caregivers	
Sex (women), n (%)	254 (92.0)
Age (years), mean (SD, range)[a]	42.93 (5.95, 26.61-1.54)
Children	
Sex (boys), n (%)	226 (81.9)
Age (years), mean (SD, range)	9.35 (1.73, 6.00-12.97)
***ICD-10*[b] diagnosis by local health care provider, n (%)**	
Suspected ADHD[c]	64 (23.2)
F90.0 Hyperkinetic Disorders, Disturbance of Activity and Attention	160 (58.0)
F90.1 Hyperkinetic Conduct Disorder	42 (15.2)
F90.8 Other Hyperkinetic Disorders or Hyperkinetic Disorder and F90.9 Hyperkinetic Disorders or Hyperkinetic Disorder, Unspecified	4 (1.4)
F98.8 Attention-Deficit Disorder without Hyperactivity	6 (2.2)

[a] Reduced N=253 due to 1 missing value at baseline.

[b] *ICD-10*: *International Classification of Diseases, 10th Revision*.

[c] ADHD: attention-deficit hyperactivity disorder.

Associations of Caregivers’ Use With Symptoms of Children

Results of the path analyses on the associations between the number of log-ins and changes in child externalizing symptom severity are reported in Figure 2 and Table S1 in Multimedia Appendix 1. The model fit was acceptable for both models (associations between clinician-rated child externalizing behavior symptoms and the number of log-ins: CFI=0.97, SRMR=0.03; associations between caregiver-rated child externalizing behavior symptoms and the number of log-ins: CFI=0.92, SRMR=0.04). Although significant, the χ^2 value depends strongly on the degrees of freedom, which, at *df*=2, were considered acceptable (see Table S2 in Multimedia Appendix 1) [43,44]. The primary analyses yielded no significant associations between the number of log-ins and clinician-rated child externalizing behavior symptoms (see Figure 2 and Table S1 in Multimedia Appendix 1). A small significant negative association was found between the number of log-ins (months 0-3) and the caregiver-reported child externalizing behavior symptoms in the long term (T3; ß=–.13, *P*=.29). Moreover, the caregiver-reported severity of child externalizing behavior symptoms at T2 was significantly associated with a higher number of log-ins in the later phase (ß=.14, *P*=.29). The significant results must be classified as small effects based on the standardized ß coefficient [45]. To examine whether the findings for the use-symptom associations may be replicated when using a different operationalization of use, we conducted secondary analyses according to the main analyses but applied the percentage of completed materials as a measure of use (see Table S3 in Multimedia Appendix 1). The model fit and χ^2 for both secondary models were acceptable, too (see Table S2 in Multimedia Appendix 1). No significant associations were found, neither when considering clinician ratings nor when regarding caregiver ratings of child externalizing behavior symptoms.

Discussion

Principal Findings

To the best of our knowledge, this study is the first to systematically investigate the relationship between caregivers’ use of an online intervention and changes in their children’s externalizing behavior symptoms. Overall, use was low, especially during the second half of the intervention period. Our results hint at a bidirectional, albeit small, association between the caregiver’s frequency of use (ie, number of log-ins) and changes in caregiver-reported child externalizing behavior symptoms. That is, first, the more log-ins during the early phase, the less severe the externalizing behavior symptoms reported by caregivers in the longer term. Second, in contrast, the more severe the caregiver-rated externalizing behavior symptoms, the more frequent the log-ins to the intervention in the subsequent late intervention phase (months 3-6). However, none of the other use-symptom associations in this model were significant. Moreover, we were not able to replicate these findings when we considered clinician-rated rather than caregiver-rated externalizing behavior symptoms, nor when we operationalized caregivers’ use by the percentage of completed materials (intensity of use).

Consistent with research on the use of online treatment for depression, we found both more log-ins and higher task completion rates (frequency and intensity) in the first than in the second half of the intervention [46]. For the second intervention phase (months 3-6), the mean overall number of log-ins was low. Furthermore, the overall progress during the 6-month treatment was relatively low, with only about one-third of the program being processed, on average. In view of previous research, it is clear that low completion rates are a general problem of internet-delivered interventions [20,47]. In fact, participants did not receive clear guidelines regarding use but were allowed to work on the intervention and content according to their interests, and full program completion was neither recommended nor necessary, since the program offers a wide range of options for usage and parents are asked to choose the components that best suit their needs. As previous analyses of the data used in this study revealed that personal telephone contact is a main predictor of enhanced use [22], the lack of counseling support calls (during months 3-6) might explain the significantly lower use in this period. The lower use in this period, which was additionally associated with lower variance (see Table S4 in Multimedia Appendix 1), may contribute to the explanation of the small effect sizes and the nonsignificant associations in the models, including clinician-rated child externalizing behavior symptoms or the percentage of completed materials as a measure of use.

Considering the findings of at least some associations between caregivers' use of the intervention and child externalizing behavior symptoms, the low use underlines the need for measures to foster engagement in online PMT to improve intervention outcomes. Previous research has demonstrated that use can be enhanced by some kind of support (eg, personal contact over the phone or chat functions, reminders) [22,48]. Contrary to previous findings of no significant use-symptom associations for PMT in the field of child anxiety disorders [25], our results hint at some longitudinal associations between the number of log-ins to the WASH intervention and caregiver-reported child externalizing behavior symptoms.

Notably, we not only found that (1) single aspects (frequency) of parental use of WASH are associated with externalizing behavior symptoms in the longer term but also observed that (2) externalizing symptom severity during treatment predicts later frequency of use. Although the effects were rather weak, and findings varied for different (but correlated) operationalizations of use ($r=0.73$, $P\leq.001$) [22], we consider these results as providing initial exploratory evidence for use-symptom associations. The different results for frequency and intensity of use underline the need for a differentiated consideration of these 2 parameters [30], as they capture 2 different facets of use. Although the number of log-ins merely reflects participation in the program, the percentage of use provides an indication of the depth of processing of the program content. Based on the available information from the study, we cannot conclude why significant associations with symptoms were found for the number of log-ins and not for the percentage of use. Maybe the different findings might be explained by influences of child characteristics, disorder characteristics (eg, symptom severity), or caregiver characteristics (ie, own inattention problems), which might be related to either use behavior and child externalizing symptom severity or both. However, further research is needed first to determine whether the results of this study may be replicated and then to examine further reasons for the differing results for the number of log-ins and the percentage of use.

The negative association between frequency of use and subsequent symptom severity could not be replicated when regarding clinician-rated child externalizing behavior symptoms. Previous research on PMT aiming to compare/validate different outcome measures across different assessors (caregiver, teacher, clinician) has likewise found a lack of congruence across different raters [5]. The authors concluded that caregivers may overestimate the effects of PMT, potentially due to the resources they have invested in treatment use (effort justification). Moreover, changes in caregivers' perceptions of children's externalizing behavior symptoms lead to greater tolerance, leading them to rate behavioral problems as less severe [22]. Future research is needed to replicate our findings.

Overall, despite significant findings on some variables, the relationship between frequency of use and change in caregiver-rated child externalizing behavior symptoms is not strong. Thus, we may conclude that simply improving the use of the WASH program is insufficient to enhance treatment outcomes in clinical practice. Other factors that were not controlled for in these analyses may be more important for explaining the differences in outcomes and might be a more favorable starting point for improving interventions (eg, emotional and behavioral problems and competencies of the parents, quality of intervention implementation). For example, internet-delivered PMT—from a theoretical and practical perspective—seems to affect parenting skills or parental psychopathology [12,25], and previous research has demonstrated that the effects of PMT on child externalizing behavior symptoms are mediated by a change in (mainly negative) parenting behaviors [49]. A deeper examination of such additional factors and their interplay is necessary to obtain a more comprehensive impression of the processes leading to symptom changes and to draw conclusions on how to improve treatment outcomes in clinical practice. It is conceivable that the use of web-based PMT is a prerequisite for change in both child- and parent-related variables and that there is a complex interplay between these variables.

Future studies should examine more complex models, including additional moderators and mediators of the effects of web-based PMT on child externalizing behavior symptoms (eg, parental skills practice [12], parenting behaviors), and additionally focus on the use of individual techniques (eg, stimulus control, contingency management) to gain a deeper understanding of the relative contribution of treatment use and of the particular mechanisms that lead to symptom improvements. A combination of objective and subjective measures of the individual model components should be used to increase the validity of the findings. Moreover, measures to enhance treatment use (eg, additional support calls) and their relative importance for enhancing treatment outcomes should be examined in more detail. Recently, microtrials have examined the effectiveness of specific elements of face-to-face PMT (eg, stimulus control techniques vs contingency management) [50,51]. Transferring this approach to web-based PMT and linking it to the measures of treatment use may help further study and explain the associations between use parameters and symptom changes.

Strengths and Limitations

Although the study sample is larger than in many other studies, it is nevertheless small for this type of analysis, limiting the possibility of detecting significant associations [52]. Moreover, several analyses were performed, increasing the risk of detecting significant effects by chance. Unfortunately, no measures on the practice and implementation (homework practice) of, for example, problem-solving strategies and contingency management into daily life were conducted. Moreover, we cannot guarantee that users engaged with the content rather than merely absolving the intervention, as we did not conduct knowledge quizzes to prove the CPE. The use variables are objective measures extracted from the program but do not indicate whether a caregiver changed parenting behaviors following treatment. Future research should include these variables (CPE in sessions and between sessions and parenting behaviors) to examine their contribution to symptom changes connected with caregivers' use of WASH.

The strengths of the study are that we used 2 objective measures of use metrics (log data) and assessed child externalizing behavior symptoms from 2 different perspectives (ie, caregivers and clinicians).

Conclusion

The analyses in this study provide some, albeit limited, support for the directional, longitudinal associations of (1) the caregiver's early number of log-ins to WASH with child externalizing behavior symptoms in the longer term and (2) the severity of child externalizing behavior symptoms as an immediate predictor of following frequency of log-ins during the late intervention period. Although the results were inconsistent across different operationalizations of treatment use and raters (clinician vs caregiver) and although the effects were rather weak, these analyses provide the first evidence for use-symptom associations in web-based PMT for child externalizing behavior problems. Future research could try to replicate the results and consider complex models, including mediators and moderators of treatment outcomes (eg, parenting behaviors, parental psychopathology, sociodemographic variables, and effective elements). Ultimately, the respective results could be used to develop measures to improve the use of (web-based) PMT in clinical practice to enhance treatment outcomes.

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Data Availability

The data sets used and analyzed during the study are available from the corresponding author upon reasonable request.

Conflicts of Interest

CD receives royalties for self-help books for parents and teachers of children with attention-deficit hyperactivity disorder, published by Hogrefe. MD and JP receive royalties from publishing companies as authors of books and treatment manuals on parent management training and assessment manuals. None of the other authors of this study report any conflicts of interest.

Multimedia Appendix 1

Parameters for main analyses, model fit for all path models calculated on the association of use with the child's overall externalizing symptoms, parameters for secondary analyses, and description of usage parameters (early and late).

[DOCX File , 25 KB - pediatrics_v7i1e54051_app1.docx]

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Abbreviations

ADHD: attention-deficit hyperactivity disorder
CFI: comparative fit index
CPE: caregiver participation engagement
DCL-EXT: Diagnostic Checklist for Externalizing Behavior Disorders
ICD-10: *International Classification of Diseases, 10th Revision*
ODD: oppositional defiant disorder
PMT: parent management training
RCT: randomized controlled trial
SCL-EXT: Symptom Checklist for Externalizing Behavior Disorders
SRMR: standardized root mean square residual
TAU: treatment as usual
WASH: web-based self-help

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Original Paper

The Impact of Parental Electronic Health Literacy on Disease Management and Outcomes in Pediatric Type 1 Diabetes Mellitus: Cross-Sectional Clinical Study

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Abstract

Background: Despite the growing uptake of smart technologies in pediatric type 1 diabetes mellitus (T1DM) care, little is known about caregiving parents' skills to deal with electronic health information sources.

Objective: We aimed to assess the electronic health literacy of parents caring for children with T1DM and investigate its associations with disease management and children's outcomes.

Methods: A cross-sectional survey was performed involving 150 parent-child (8-14 years old with T1DM) dyads in a university pediatric diabetology center. Parents' electronic health literacy (eHealth Literacy Scale [eHEALS]), general health literacy (Chew questionnaire and Newest Vital Sign [NVS]), and attitudes toward T1DM care (Parental Self-Efficacy Scale for Diabetes Management [PSESDM] and Hypoglycemia Fear Survey [HFS]) were investigated. Children's treatment, HbA$_{1c}$ level, and quality of life (Pediatric Quality of Life Inventory Diabetes Module [PedsQL Diab] and EQ-5D-Y-3L) were assessed. Multiple linear regression analysis was performed to investigate the determining factors of 6-month average HbA$_{1c}$.

Results: Of the 150 children, 38 (25.3%) used a pen, 55 (36.7%) used a pen plus a sensor, 6 (4.0%) used an insulin pump, and 51 (34.0%) used an insulin pump plus a sensor. Parents' average eHEALS score (mean 31.2, SD 4.9) differed significantly by educational level (P=.04) and the children's treatment (P=.005), being the highest in the pump + sensor subgroup. The eHEALS score showed significant Pearson correlations with the Chew score (r=−0.45; P<.001), NVS score (r=0.25; P=.002), and PSESDM score (r=0.35; P<.001) but not with the children's HbA$_{1c}$ (r=−0.143; P=.08), PedsQL Diab (r=−0.0002; P>.99), and EQ-5D-Y-3L outcomes (r=−0.13; P=.12). Regression analysis revealed significant associations of the child's HbA$_{1c}$ level with sex (β=0.58; P=.008), treatment modality (pen + sensor: β=−0.66; P=.03; pump + sensor: β=−0.93; P=.007), and parents' self-efficacy (PSESDM; β=−0.08; P=.001).

Conclusions: Significantly higher parental electronic health literacy was found in T1DM children using a glucose sensor. The electronic health literacy level was associated with parents' diabetes management attitude but not with the child's glycemic control. Studies further investigating the role of parental electronic health literacy in T1DM children managed at different levels of care and the local context are encouraged.

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KEYWORDS

electronic health literacy; parents; caregivers; diabetes mellitus; child

Introduction

Type 1 diabetes mellitus (T1DM) is one of the most common chronic diseases in children, with an increasing incidence and prevalence globally [1-3], which poses a significant social and economic burden on pediatric patients, their caregivers, and the society [4-11]. To reduce the effects of these consequences, efficient disease management and treatment strategies are needed.

Pediatric T1DM care has become increasingly technology-driven, with improved therapeutics, such as automated insulin delivery systems and continuous glucose monitoring sensors, being increasingly used in treatment [12-15]. These advanced technologies have a positive effect on disease outcomes as they can facilitate reaching glycemic targets and thus reducing diabetes-related complications [16]. Accordingly, international treatment guidelines recommend the use of the most advanced therapeutics that are readily available, affordable, and considered appropriate for pediatric patients with T1DM to maintain appropriate disease control and improve glycemic outcomes [17,18]. When introducing a new device into the treatment, patient and caregiver training is also recommended for proper device operation and use. Likewise, engagement in disease management and appropriate behavior are key factors to obtain the best results and achieve treatment goals. To meet these expectations, proper education of both patients and caregivers, considering their interest in and barriers to technology uptake, is of utmost importance, along with health literacy improvement, which was found to be associated with diabetes outcomes [18-24].

As a constantly evolving concept, there is a wide range of definitions for health literacy [25]. According to the most common and widely accepted interpretation, health literacy broadly refers to people’s ability to find, evaluate, understand, and use health-related information needed to make appropriate and informed health decisions [26]. As it follows from the definition, parents must have a certain level of health literacy to play an effective role in their child’s disease management and to be able to make informed and responsible health-related decisions [27]. However, as indicated by Sanders et al [28], parents often struggle with understanding their child’s health information owing to its increasing complexity, with approximately one-third of parents in the United States having insufficient health literacy. [29]. Furthermore, a low level of parental health literacy is associated with children’s poor health status [30] and may lead to poor disease outcomes such as insufficient glycemic control [31].

Owing to the recent significant growth in internet use, changing consumer habits, and widespread use of digital products, electronic information sources and even artificial intelligence–based technologies play an increasingly important role in the management of pediatric diabetes [32-35]. In a study by Macken et al [36], 43.5% of families of pediatric T1DM patients with internet access used the internet monthly or more often to find T1DM-related health information. At the same time, new sources pose challenges for parents, who need the appropriate abilities to deal with health information to manage their child’s disease properly [28,37]. In relation, the concept of electronic health literacy has been developed, which, building on general health literacy, can be defined as the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to address or solve a health problem [38].

Although the growing importance of health literacy has been accompanied by an increase in the number of tools used to measure it, diabetes-specific instruments are rarely available, which makes it difficult to assess parents’ diabetes-related health literacy in a pediatric setting. In a recent systematic review, out of 19 condition-specific instruments, 8 were diabetes-specific, but all were for use in the adult population, and none of them were designed specifically for T1DM [39]. The authors also identified 11 electronic health literacy measurement tools; however, none of them were diabetes-specific. Furthermore, only 3 instruments that assess parental health literacy were identified, but they were not related to pediatric diabetes. Consistently, in studies examining the association of caregiving parents’ general health literacy with their child’s diabetes outcomes and glucose control, parental health literacy was assessed with general tools such as the Short Test of Functional Health Literacy in Adults (S-TOFHLA) [31,40], Newest Vital Sign (NVS) [41,42], Parental Diabetes Numeracy Test (PDNT) [31], and National Adult Reading Test (NART) [43]. However, despite its increasing significance, the role of parental electronic health literacy in pediatric diabetes has not been investigated extensively, and its associations with the child’s disease characteristics and glycemic outcomes have remained unexplored.

The impact of the therapy on the course of the disease, complications, and overall life expectancy can be seen only over a long period, during which a large amount of data is accumulated. The therapeutic goal is to empower the parents and treat pediatric patients effectively at home rather than in the hospital, which is partly to reduce social costs. Hence, parents have become key players in the management of the disease, and it is therefore necessary to obtain an insight into their role in achieving the desired treatment outcome. Given the increasing use of digital technologies and the fact that many of today’s parents, mainly due to their age, have not received any or sufficient formal training at school on searching and using electronic information, their ability to navigate electronic health information requires particular attention.

In this study, we sought to fill the gap in the knowledge of this area. Our primary aim was to assess the electronic health literacy of the parents of children with T1DM, in light of their general health literacy. Moreover, we intend to investigate the associations of parents’ electronic health literacy with diabetes management (including treatment types, parental self-reported attitudes, and diabetologists' perceptions) and the child's disease outcomes (including medical and patient-reported outcomes).

Methods

Study Design and Participants

A cross-sectional, noninterventional, single-center survey study was performed in 2021-2022 at a university pediatric diabetology center in Hungary. Parents or caregivers and their children with T1DM attending routine diabetology care were invited to participate. Adult caregivers (≥18 years old) living part-time with the child and children (8-14 years old) diagnosed with T1DM for at least 3 months were included. Respondents were informed that participation was voluntary and that their data would remain anonymous and impersonal and would be used solely for scientific purposes. The survey consisted of 3 modules filled in by parents of the child with T1DM (Module 1), the child with T1DM (Module 2), and the child's treating diabetologist (Module 3). Module 1 was completed on the Qualtrics online survey platform. Modules 2 and 3 were administered on paper, and the responses were digitized and entered into the Qualtrics system. No personal data were recorded online.

Ethical Considerations

Written informed consent was obtained from all participants upon entry into the study. Ethical approval was obtained from the Hungarian Medical Research Council (IV/3848-1/2021/EKU; BMEÜ/1620-1/2022/EKU).

Parents' Survey (Module 1): Main Characteristics, Health Literacy, and Attitudes Toward the Child's T1DM

Basic demographic characteristics (sex, age, education, residence, marital status, and employment), household data (income and number of persons living in a household), and childcare circumstances were recorded. Parents' electronic and general health literacy and their attitudes toward the child's diabetes were assessed using standard measurement tools (eHealth Literacy Scale [eHEALS], Chew questionnaire, NVS questionnaire, Parental Self-Efficacy Scale for Diabetes Management [PSESDM], and Hypoglycemia Fear Survey [HFS]).

The eHEALS was developed to measure electronic health literacy, which refers to the respondent's self-assessed confidence; knowledge; and ability to find, understand, and use electronic health information [44]. The self-administered questionnaire contains 8 statements on respondents' awareness of health resources on the internet (items 1 and 2), internet searching skills (items 3 and 4), appraisal of health resources (items 6 and 7), and use of health information (items 5 and 8). Statements are rated on a 5-point Likert scale (possible answers: 1, strongly disagree; 2, disagree; 3, undecided; 4, agree; 5, strongly agree). Item scores are summed, resulting in a final score of 8-40, with a higher score indicating better eHealth literacy. In this study, the validated Hungarian version of the eHEALS questionnaire was used [45].

The Chew questionnaire is a prescreening tool to identify people with low health literacy. It comprises 3 questions concerning the frequency with which respondents feel confident to fill in forms independently, need help in interpretation, and have problems with understanding hospital documents [46,47]. Response options range from 0 (never) to 4 (always). To calculate the final score (range 0-12), the values of the answers are added together. Higher scores indicate lower health literacy [48].

The NVS questionnaire was developed to identify people with limited health literacy [49,50]. Respondents are presented with a nutrition chart and asked 6 questions. Basic reading comprehension skills and simple mathematical calculations are required to answer. The likelihood that a person has limited health literacy is determined by the number of correct answers as follows: 0-1 correct answers indicate a high likelihood of limited health literacy (50% or more); 2-3 correct answers indicate a possibility of limited health literacy; and 4-6 correct answers indicate adequate health literacy.

The PSESDM questionnaire was developed to assess parents' confidence in their ability to effectively manage their child's diabetes [51]. It consists of 8 statements with which the level of agreement can be indicated on a 5-point Likert scale (1 [strongly disagree] to 5 [strongly agree]). The final score is calculated by adding up the scores of responses, resulting in a total score of 8-40. A higher score indicates a parent's greater confidence in caring for their child's diabetes.

The HFS measures parents' fear of their children's hypoglycemic episodes [52]. The first part assesses the parent's actions to avoid hypoglycemia and related problems (10 statements), and the second part assesses the parent's concerns about their child's hypoglycemic episodes (15 statements). Parents are asked to indicate on a 5-level scale how true the statement is for them (response options: 0 [never] to 4 [almost always]). The final score (range: 0-100) is calculated by adding up the individual scores given for each item. Higher scores indicate a greater fear of hypoglycemia.

T1DM Children's Survey (Module 2): Health-Related Quality of Life

To assess health-related quality of life (HRQoL), participating children completed 2 validated measurement tools (Pediatric Quality of Life Inventory [PedsQL] and its Diabetes Module [PedsQL Diab] and EQ-5D-Y-3L) for evaluating their general and diabetes-specific quality of life.

The general module of the 23-item PedsQL assesses the following domains: physical functioning ("my health and activities" involving 8 questions), emotional functioning ("my feelings" involving 5 questions), social functioning ("my relationships with others" involving 5 questions), and school functioning ("school" involving 5 questions) [53,54]. Questions are asked for the past month, and responses are given on a 5-point Likert scale (possible answers: 0, never; 1, rarely; 2, sometimes; 3, often; 4, almost always). To calculate the final score, the answers to each question are transformed into a scale from 0 to 100 by inverse scoring (ie, the score for each answer is 0=100, 1=75, 2=50, 3=25, and 4=0), and then, the simple arithmetic average of the scores obtained for each answer is taken. A higher score indicates a better HRQoL.

Version 3.0 of the diabetes module of the PedsQL consists of 28 items and covers the following domains: symptoms of diabetes (“about my diabetes” involving 11 questions), difficulties with treatment (“treatment I” involving 4 questions), acceptance of treatment (“treatment II” involving 7 questions), worry about the disease (“concerns” involving 3 questions), and difficulties with communication (“communication” involving 3 questions) [55]. Response options and the evaluation of the questionnaire are the same as described for the general module. For both the general and diabetes modules, the validated Hungarian version of the questionnaire was used in this study [56,57].

EQ-5D-Y-3L is specifically designed to assess children’s and adolescents’ general HRQoL [58,59]. Its descriptive part contains 5 questions covering the following domains: mobility; taking care of myself; doing usual activities; feeling pain or discomfort; and feeling worried, sad, or unhappy. Each domain is rated on a 3-point Likert scale (1, no problems; 2, some problems; 3, a lot of problems). In this study, EQ-5D-Y-3L index values were calculated using the Hungarian value set [60]. EQ-5D-Y-3L includes a visual analog scale (EQ VAS) on which respondents can indicate their current health status on a vertical scale ranging from 0 (worst “health you can imagine”) to 100 (best “health you can imagine”).

Diabetologists’ Survey (Module 3): Children’s T1DM Disease Characteristics, Perceptions of Parents, and Disease Management

The following medical information was collected from treating diabetologists: child’s weight, height, duration of disease, duration of care at the center, route of insulin administration and blood glucose measurement (treatment modalities: pen without sensor, pen plus sensor, pump without sensor, and pump plus sensor), HbA_{1c} level, T1DM-related serious acute events (hypoglycemia, hyperglycemia, or other events requiring medical intervention or acute hospitalization) or device malfunction in the last 3 months, chronic complications, and comorbidities. Actual and 6-month average HbA_{1c} levels were recorded as percentage. Treating diabetologists were also asked about the management of T1DM (parents’ cooperation, diabetes knowledge, and knowledge of device use; T1DM being difficult to treat) with responses given on a visual analog scale (VAS), with 0 indicating the worst option and 10 indicating the best option.

Statistics

Variables were analyzed with descriptive statistical methods (mean, SD, minimum, maximum, and number of items). The average eHEALS score of the study sample was compared to the previously published Hungarian population norm with the Welch test. The effect size was measured with Cohen *d* (small effect=0.2; medium effect=0.5; large effect=0.8) [61]. Two-way ANOVA was carried out to test differences by sex, age, and education.

Subgroup comparisons by sociodemographics, treatment modalities, and T1DM complications were performed with the Welch and ANOVA tests.

Correlations between eHEALS and other measures were assessed by calculating the Pearson correlation coefficient (>0.5=strong; 0.5-0.3=moderate; <0.3=weak) [62].

Multiple linear regression analysis was performed to investigate the factors determining glucose control (6-month average HbA_{1c}). A total of 9 regression models were developed to examine the associations of variables and changes in model performance. The following explanatory variables were included: T1DM children’s characteristics (Model 1); parents’ demographic characteristics (Model 2); treatment modalities (Model 3); parental electronic and general health literacy (Model 4: eHEALS; Model 5: Chew; Model 6: NVS); and parents’ self-reported attitudes toward their child’s illness (Model 7: PSESDM; Model 8: HFS).

The model construction was systematic so that the variables included in Models 1 to 3 were included in all subsequent models, while for Models 4 to 8, the variables mentioned above were included one by one in a mutually exclusive manner. The final Model 9 included all variables together.

Statistical analysis was performed using Stata 17 software (StataCorp LCC).

Results

Parents’ Main Characteristics, Health Literacy, and Attitudes Toward Their Child’s T1DM

Altogether 150 parent-child dyads were involved in the study. Parents’ mean age was 42.5 (SD 5.8; range: 19-62) years, and 80.0% (120/150) were women. The sociodemographic characteristics are summarized in Table 1. Only 2 (1.3%) caregivers were not parents, and the majority (144/150, 96.0%) lived together with the child full-time in the same household. Moreover, 10 (6.7%) parents had diabetes mellitus themselves.

The distribution of responses by eHEALS items is presented in Figure 1 [44]. All 150 parents responded to all items. The proportion of “strongly agree” responses varied between 15.3% (23/150) and 26.0% (39/150) (mean 20.7%, SD 3.0%) across the 8 eHEALS items, indicating remarkable uncertainty of parents dealing with electronic health information resources, especially on having “the skills I need to evaluate the health resources I find on the internet” (item 6).

Table 1. Parents’ demographics, electronic and general health literacy, and attitudes as a caregiver for a child with type 1 diabetes mellitus.

Variable	Value (N=150), n (%)[a]	eHEALS[b] (score range: 8-40)		Chew (score range: 0-12)[c]		NVS[d] (score range: 0-6)		PSESDM[e] (score range: 8-40)		HFS[f] (score range: 0-100)[g]	
		Score, mean (SD)	*P* value[h]	Score, mean (SD)	*P* value[h]	Score, mean (SD)	*P* value[h]	Score, mean (SD)	*P* value[h]	Score, mean (SD)	*P* value[h]
Sex			.40		.41		.14		.36		.07
Male	30 (20.0)	31.8 (4.3)		2.3 (1.6)		4.8 (1.5)		33.6 (4.7)		29.7 (13.1)	
Female	120 (80.0)	31.0 (5.0)		2.6 (2.1)		4.3 (1.8)		32.7 (5.6)		34.7 (12.0)	
Age group (years)			.50		.58		.09		.13		.55
18-24	1 (0.7)	29.0 (0.0)		2.0 (0.0)		2 (0.0)		40.0 (0.0)		25.0 (0.0)	
25-34	13 (8.7)	29.5 (6.1)		3.2 (2.9)		3.4 (1.9)		31.2 (7.1)		35.7 (12.4)	
35-44	72 (48.0)	31.8 (4.5)		2.4 (1.8)		4.5 (1.8)		32.6 (5.2)		35.0 (13.0)	
45-54	62 (41.3)	30.9 (5.0)		2.5 (2.0)		4.6 (1.7)		33.6 (5.2)		31.9 (11.4)	
55-64	2 (1.3)	29.0 (1.4)		4.0 (0.0)		3.5 (2.1)		26.5 (0.7)		30.5 (20.5)	
Education (missing=1)			.04		<.001		<.001		.006		.24
Primary	15 (10.0)	29.5 (5.6)		3.1 (2.9)		2.7 (1.7)		29.5 (6.9)		31.7 (11.0)	
Secondary	70 (46.7)	30.5 (4.7)		3.0 (1.8)		4.0 (1.8)		32.4 (5.2)		32.2 (11.5)	
Tertiary	64 (42.7)	32.3 (4.7)		1.7 (1.5)		5.4 (1.1)		34.2 (4.9)		35.6 (13.4)	
Residence			.71		.57		.002		.50		.09
Capital	39 (26.0)	31.1 (4.8)		2.3 (1.7)		4.9 (1.6)		33.4 (5.4)		36.3 (12.4)	
Town	79 (52.7)	31.0 (5.1)		2.5 (1.9)		4.6 (1.6)		33.0 (5.2)		31.6 (11.3)	
Village	32 (21.3)	31.8 (4.2)		2.8 (2.4)		3.5 (2.0)		31.9 (6.0)		35.6 (14.0)	
Living in a relationship			.58		.55		.87		.34		.56
Yes	128 (85.3)	31.3 (4.9)		2.5 (2.0)		4.4 (1.8)		33.0 (5.4)		33.9 (12.7)	
No	22 (14.7)	30.7 (4.5)		2.8 (2.0)		4.5 (1.8)		31.9 (5.3)		32.4 (10.4)	
Paid work			.14		.45		.11		.20		.19
Yes	145 (96.7)	31.4 (4.8)		2.5 (1.9)		4.5 (1.7)		33.0 (5.3)		33.4 (12.3)	
No	5 (3.3)	26.4 (6.0)		3.6 (3.0)		2.4 (2.3)		28.0 (7.4)		41.8 (11.8)	
Monthly net income per capita (missing=34)			.05		.03		<.001		<.001		.58
1st quintile	24 (16.0)	29.5 (5.7)		3.3 (2.5)		3.1 (1.7)		29.5 (5.2)		34.7 (10.6)	
2nd quintile	17 (11.3)	29.7 (4.4)		3.3 (1.3)		3.9 (1.7)		31.5 (4.7)		30.6 (9.5)	
3rd quintile	17 (11.3)	31.1 (3.6)		2.5 (1.6)		4.9 (1.4)		32.0 (5.0)		32.6 (13.9)	
4th quintile	3 (2.0)	30.7 (2.3)		3.7 (3.5)		3.3 (2.1)		30.0 (6.0)		26.0 (8.0)	
5th quintile	55 (36.7)	32.5 (4.5)		2.0 (2.2)		5.2 (1.3)		34.3 (4.1)		35.0 (14.2)	
Living in the same household with the T1DM[i] child			.40		.19		.23		.75		.07
Full-time	144 (96.0)	31.1 (4.9)		2.6 (2.0)		4.4 (1.8)		32.8 (5.4)		33.8 (12.6)	
Part-time	6 (4.0)	32.8 (4.5)		1.8 (1.2)		5.2 (1.3)		33.5 (4.7)		29.8 (4.1)	
Having diabetes			.84		.87		.95		.42		.46
Yes	10 (6.7)	30.8 (6.3)		2.4 (2.6)		4.4 (2.2)		30.9 (7.8)		36.8 (13.5)	
No	140 (93.3)	31.2 (4.8)		2.5 (1.9)		4.4 (1.7)		33.0 (5.2)		33.4 (12.3)	
Total sample		31.2 (4.9)		2.5 (2.0)		4.4 (1.8)		32.9 (5.4)		33.7 (12.3)	

[a] Percentages may not add up to 100% due to rounding.

[b] eHEALS: eHealth Literacy Scale.

[c] Higher scores indicate lower literacy levels.

[d] NVS: Newest Vital Sign.

[e] PSESDM: Parental Self-Efficacy Scale for Diabetes Management.

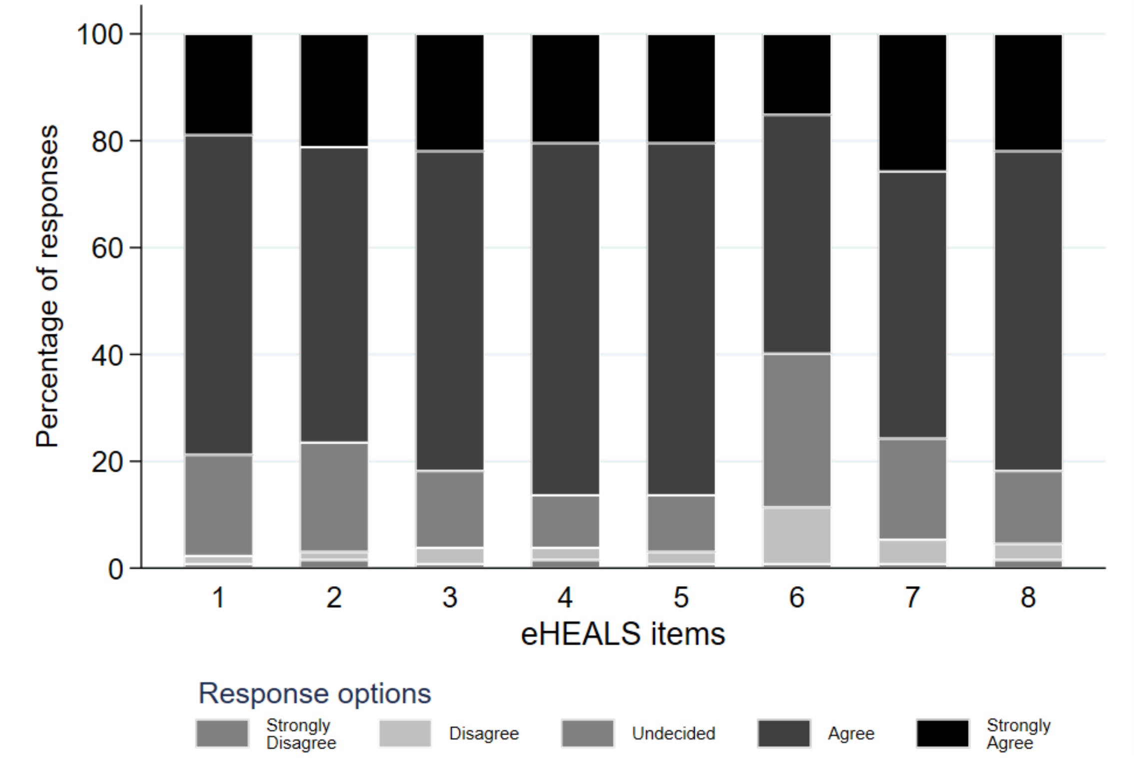
[f] HFS: Hypoglycemia Fear Survey.

[g] Higher scores indicate greater fear of hypoglycemia.

[h] Differences between groups were compared using Welch and ANOVA tests.

[i] T1DM: type 1 diabetes mellitus.

Figure 1. Distribution of responses by eHealth Literacy Scale (eHEALS) items. 1: "I know what health resources are available on the internet;" 2: "I know where to find helpful health resources on the internet;" 3: "I know how to find helpful health resources on the internet;" 4: "I know how to use the internet to answer my questions about health;" 5: "I know how to use the health information I find on the internet to help me;" 6: "I have the skills I need to evaluate the health resources I find on the internet;" 7: "I can tell high-quality health resources from low-quality health resources on the internet;" 8: "I feel confident in using information from the internet to make health decisions" [44].



In the total sample, the average parental eHEALS score was 31.2 (SD 4.9), which was significantly higher (P=.002) than that in the Hungarian general population [45]. The effect size was small, with a Cohen d of 0.41 (95% CI 0.16-0.67). Differences were observed between the study sample and the general population by sex, age group, and education, but the 2-way ANOVA revealed no significant associations (Multimedia Appendix 1) [45].

Parents' average Chew and NVS scores were 2.5 (SD 2.0) and 4.4 (SD 1.8), respectively, indicating adequate general health literacy in the total sample. Parental self-efficacy regarding diabetes management was generally high, with an average PSESDM score of 32.9 (SD 5.4). The average HFS score was 33.7 (SD 12.3).

Subgroup comparisons by sociodemographic characteristics revealed that parents' health literacy (eHEALS, Chew, and NVS) and self-efficacy (PSESDM) differed significantly by their educational level but not their fear of hypoglycemia (HFS) (Table 1).

Children's T1DM Disease Characteristics and HRQoL

In total, 150 children (girls: 69/150, 46.0%) were included, with a mean disease duration of 5.3 (SD 2.8) years. Their mean age, height, and weight were 11.7 (SD 1.9) years, 150.6 (SD 16.4) cm, and 45.9 (SD 16.3) kg, respectively. Altogether, 106 (70.7%) children used a glucose sensor. The most frequent insulin treatment modality was pen plus sensor, followed by pump plus sensor, pen, and pump (Table 2).

Table 2. Characteristics of children with type 1 diabetes mellitus and diabetologists' perceptions in the total sample and by treatment modality.

Variable	Total sample (N=150)	Pen (n=38)	Pen + sensor (n=55)	Pump (n=6)	Pump + sensor (n=51)	*P* value[a]
Age (years), mean (SD)	11.7 (1.9)	11.7 (2.0)	11.9 (1.9)	11.3 (1.6)	11.6 (1.8)	.84
Disease duration (years), mean (SD)	5.3 (2.8)	5.4 (3.1)	4.2 (2.3)	7.2 (2.8)	6.2 (2.8)	<.001
Duration of care at the center (years), mean (SD)	4.8 (2.6)	5.2 (2.7)	3.7 (2.3)	7.0 (2.7)	5.5 (2.3)	<.001
Current HbA_{1c} (%)[b], mean (SD)	7.6 (1.4)	8.6 (2.0)	7.4 (1.1)	7.2 (0.5)	7.2 (0.8)	<.001
6-month average HbA_{1c} (%)[b], mean (SD)	7.6 (1.3)	8.5 (1.9)	7.3 (1.0)	7.2 (0.5)	7.2 (0.7)	<.001
PedsQL[c] (range: 0-100), mean (SD)	81.4 (13.2)	78.3 (17.8)	81.5 (12.0)	86.4 (14.0)	82.9 (9.7)	.30
PedsQL physical subscore (range: 0-100), mean (SD)	85.7 (13.0)	82.9 (17.6)	87.0 (11.7)	86.5 (11.8)	86.3 (10.2)	.49
PedsQL psychosocial subscore (range: 0-100), mean (SD)	79.1 (14.7)	75.8 (19.6)	78.6 (13.6)	86.4 (16.1)	81.2 (10.8)	.22
PedsQL Diab[d] (range: 0-100), mean (SD)	74.4 (12.8)	72.0 (15.7)	73.8 (11.6)	84.4 (10.1)	75.7 (11.5)	.13
EQ-5D-Y-3L index (range: −0.485 to 1.000), mean (SD)	0.940 (0.097)	0.915 (0.119)	0.939 (0.097)	0.964 (0.058)	0.957 (0.077)	.21
Parents' cooperation (VAS[e,f]), mean (SD)	7.1 (2.4)	4.7 (2.0)	7.7 (2.1)	6.5 (1.6)	8.3 (1.7)	<.001
Parents' diabetes knowledge (VAS[f]), mean (SD)	6.9 (2.3)	4.6 (1.7)	7.5 (1.9)	5.7 (1.5)	8.1 (1.6)	<.001
Parents' device use knowledge (VAS[f]), mean (SD)	6.2 (2.7)	2.7 (1.6)	7.1 (1.9)	5.5 (1.0)	7.9 (1.7)	<.001
T1DM[g] being difficult to treat (VAS[f]), mean (SD)	6.6 (2.4)	4.3 (2.0)	7.2 (2.2)	5.8 (1.3)	7.7 (1.8)	<.001

[a] Differences between treatment modalities were compared with ANOVA.

[b] A higher HbA_{1c} level indicates worse glycemic control.

[c] PedsQL: Pediatric Quality of Life Inventory.

[d] PedsQL Diab: Pediatric Quality of Life Inventory Diabetes Module.

[e] VAS: visual analog scale.

[f] Based on diabetologists' assessments. Lower scores indicate worse cooperation and knowledge, and more difficulties in treatment.

[g] T1DM: type 1 diabetes mellitus.

The average EQ-5D-Y-3L index and PedsQL score in the sample were 0.940 (SD 0.097) and 81.4 (SD 13.2), respectively, indicating that the general HRQoL of children living with T1DM was high. The PedsQL Diab score was moderately low (mean 74.4, SD 12.8).

Any type of comorbidity was observed in 43 children (29 had T1DM-related thyroid disease; 12 had coeliac disease; and 1 each had growth hormone deficiency, juvenile idiopathic arthritis, congenital adrenal hyperplasia, and epilepsy). An acute event requiring a physician or a device malfunction in the past 3 months was reported in 4 children (3 had a severe hyperglycemic episode or ketoacidosis and 2 had device malfunction). T1DM-related chronic kidney complication was noted in 1 child.

Children's characteristics and differences by treatment modality are presented in Table 2. Both disease duration and time of care in the pediatric diabetology center were the longest among patients using an insulin pump (without sensor), while the highest average HbA_{1c} levels were observed in the subgroup using a pen (without sensor). HRQoL results (PedsQL, PedsQL Diab, and EQ-5D-Y-3L) did not differ significantly across treatment modality subgroups. No meaningful difference in the occurrence of comorbidities was found across treatment types.

Diabetologists' Perceptions of Parents and Disease Management

In the total sample, the average scores for parents' cooperation, diabetes knowledge, device use knowledge, and difficulty in managing the child's disease were 7.1 (SD 2.4), 6.9 (SD 2.3), 6.2 (SD 2.7), and 6.6 (SD 2.4), respectively. The relationship of these characteristics with parental age showed a nonsignificant concave pattern (Multimedia Appendix 2). Parents' cooperation with their child's diabetes management and disease-related knowledge (both of diabetes and device use) significantly differed by treatment modality (being the highest in the pump + sensor subgroup, followed by the pen + sensor subgroup). Treating the child's T1DM was found to be the least difficult in the pump + sensor subgroup and the most difficult in the pen (without a sensor) subgroup (Table 2).

Analysis by Treatment Modality and T1DM Complications

Parents' health literacy and attitudes toward their child's diabetes by major subgroups are presented in Table 3. The eHEALS score differed significantly by treatment modality, being the highest in the pump + sensor subgroup, followed by the pen + sensor, pen (without sensor), and pump (without sensor) subgroups. However, no differences were detected in terms of the occurrence of serious acute events, device malfunction, or prevalent comorbidities.

Table 3. Parents' health literacy and attitudes toward their child's diabetes by major subgroups.

Variable	Value (N=150), n	eHEALS[a]		Chew[b]		NVS[c]		PSESDM[d]		HFS[e,f]	
		Score, mean (SD)	*P* value[g]	Score, mean (SD)	*P* value[g]	Score, mean (SD)	*P* value[g]	Score, mean (SD)	*P* value[g]	Score, mean (SD)	*P* value[g]
Treatment modality			.005		.09		<.001		.002		.32
Pen	38	29.5 (5.0)		3.2 (2.5)		3.4 (2.0)		30.3 (5.7)		33.5 (12.7)	
Pen + sensor	55	31.7 (5.0)		2.4 (1.8)		4.6 (1.6)		32.9 (5.2)		35.0 (11.8)	
Pump	6	27.0 (5.3)		2.7 (1.9)		3.8 (2.6)		33.0 (4.9)		39.8 (7.3)	
Pump + sensor	51	32.4 (4.0)		2.2 (1.7)		5.1 (1.3)		34.7 (4.7)		31.6 (13.0)	
Any acute T1DM[h]-related event requiring medical intervention or a device malfunction in the last 3 months			.34		.35		.04		.31		.049
Yes[i]	4	29.8 (2.6)		1.5 (1.9)		1.5 (1.7)		28.5 (7.3)		27.8 (4.3)	
No	146	31.2 (4.9)		2.6 (2.0)		4.5 (1.7)		33.0 (5.3)		33.8 (12.5)	
Any comorbidity			.76		.87		.64		.93		.47
Yes	43	31.0 (5.0)		2.6 (1.8)		4.5 (1.6)		32.8 (5.5)		32.6 (10.4)	
No	104	31.3 (4.9)		2.5 (2.1)		4.4 (1.8)		32.8 (5.4)		34.1 (13.2)	
Total sample		31.2 (4.9)		2.5 (2.0)		4.4 (1.8)		32.9 (5.4)		33.7 (12.3)	

[a] eHEALS: eHealth Literacy Scale.

[b] Higher scores indicate lower literacy levels.

[c] NVS: Newest Vital Sign.

[d] PSESDM: Parental Self-Efficacy Scale for Diabetes Management.

[e] HFS: Hypoglycemia Fear Survey.

[f] Higher scores indicate greater fear of hypoglycemia.

[g] Differences between groups were compared using Welch and ANOVA tests.

[h] T1DM: type 1 diabetes mellitus.

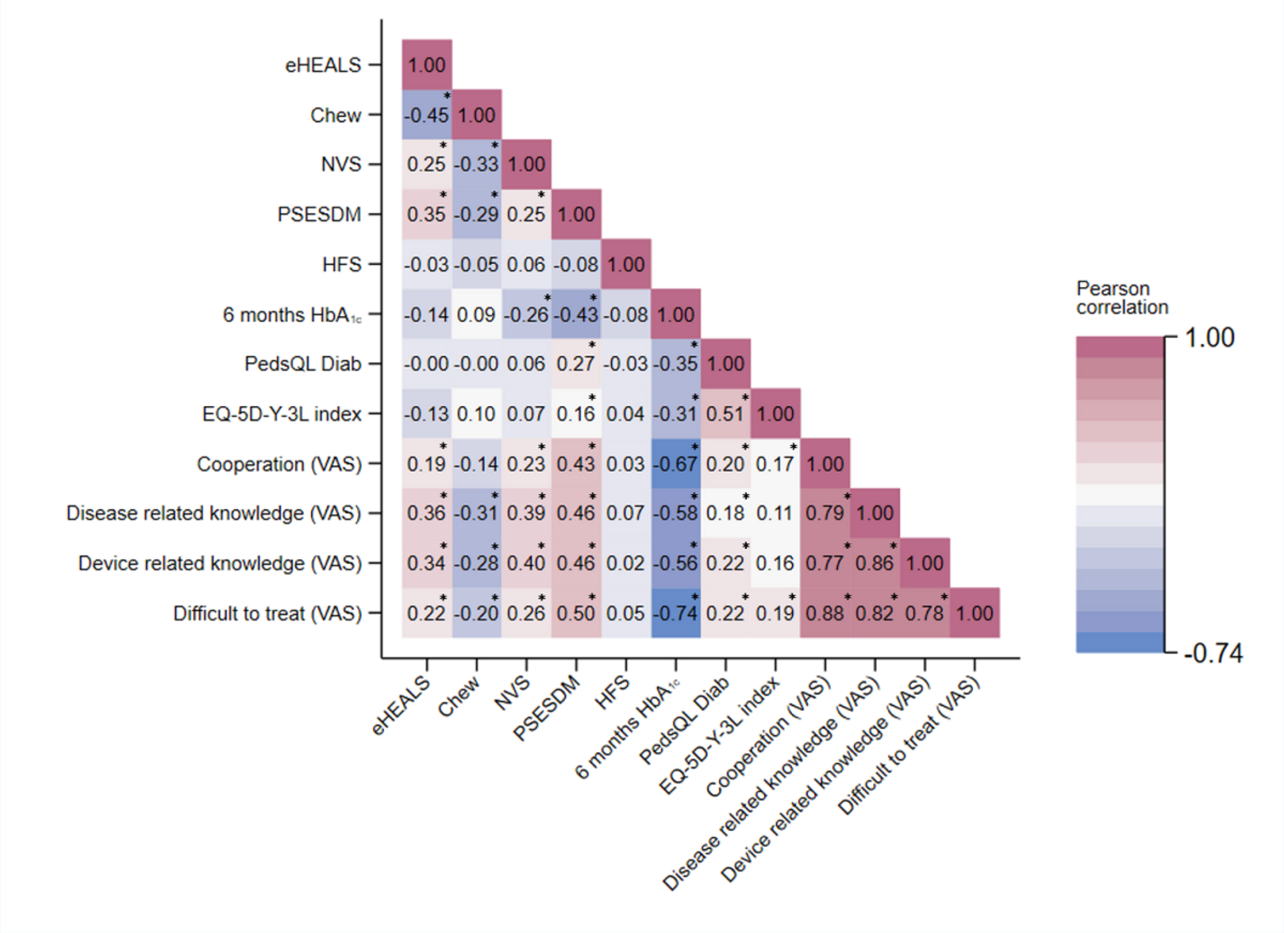
[i] The events reported by the diabetologists were hyperglycemia or ketoacidosis requiring medical intervention and device malfunction.

Parents' NVS and PSESDM scores differed significantly by treatment modality, but there were no differences in the Chew and HFS scores. Parents whose children experienced any T1DM-related serious acute event or device malfunction in the last 3 months had lower general health literacy (NVS) and lower fear of hypoglycemia (HFS). The Chew score showed no significant difference by subgroups.

Correlations Between eHEALS and Other Measures

The correlation of the parental eHEALS score was moderate with the Chew score (r=−0.45; *P*<.001) and weak with the NVS score (r=0.25; *P*=.002). Moreover, a moderate positive correlation was seen with the PSESDM score (r=0.35; *P*<.001) but not with the HFS score (r=−0.03; *P*=.70). Regarding children's T1DM outcomes, the parental eHEALS score did not correlate significantly with children's 6-month HbA_{1c} level (r=−0.143; *P*=.08) and HRQoL outcomes (PedsQL Diab: r=−0.0002; *P*>.99; EQ-5D-Y-3L: r=−0.13; *P*=.12). Significant but low or moderate correlations were observed between the eHEALS score and how diabetologists perceived parents' cooperation (r=0.19; *P*=.02), diabetes knowledge (r=0.36; *P*<.001), device use knowledge (r=0.34; *P*<.001), and level of difficulty in managing the disease (r=0.22; *P*=.008). The results are shown in Figure 2.

Figure 2. Correlation of parents' electronic health literacy with child-related outcome measures and diabetologists' assessment scores (Pearson correlation). eHEALS: eHealth Literacy Scale; HFS: Hypoglycemia Fear Survey; NVS: Newest Vital Sign; PedsQL Diab: Pediatric Quality of Life Inventory Diabetes Module; PSESDM: Parental Self-Efficacy Scale for Diabetes Management; VAS: visual analog scale. *P<.05.



	eHEALS	Chew	NVS	PSESDM	HFS	6 months HbA1c	PedsQL Diab	EQ-5D-Y-3L index	Cooperation (VAS)	Disease related knowledge (VAS)	Device related knowledge (VAS)	Difficult to treat (VAS)
eHEALS	1.00											
Chew	-0.45*	1.00										
NVS	0.25*	-0.33*	1.00									
PSESDM	0.35*	-0.29*	0.25*	1.00								
HFS	-0.03	-0.05	0.06	-0.08	1.00							
6 months HbA1c	-0.14	0.09	-0.26*	-0.43*	-0.08	1.00						
PedsQL Diab	-0.00	-0.00	0.06	0.27*	-0.03	-0.35*	1.00					
EQ-5D-Y-3L index	-0.13	0.10	0.07	0.16*	0.04	-0.31*	0.51*	1.00				
Cooperation (VAS)	0.19*	-0.14	0.23*	0.43*	0.03	-0.67*	0.20*	0.17*	1.00			
Disease related knowledge (VAS)	0.36*	-0.31*	0.39*	0.46*	0.07	-0.58*	0.18*	0.11	0.79*	1.00		
Device related knowledge (VAS)	0.34*	-0.28*	0.40*	0.46*	0.02	-0.56*	0.22*	0.16	0.77*	0.86*	1.00	
Difficult to treat (VAS)	0.22*	-0.20*	0.26*	0.50*	0.05	-0.74*	0.22*	0.19*	0.88*	0.82*	0.78*	1.00

Regression Results

The determinants of glucose control in different regression models are presented in Table 4. Neither parental electronic and general health literacy (eHEALS, Chew, and NVS) nor fear of hypoglycemia (HFS) showed a significant association with the child's 6-month HbA_{1c} level. The final model (Model 9) that included all variables explained 47.0% of the total variance in HbA_{1c}, which was significantly associated with the child's sex (girls having a higher HbA_{1c} compared to boys), treatment modality (pen + sensor and pump + sensor users having a lower HbA_{1c} compared to pen users), and parental self-efficacy in managing their child's diabetes (PSESDM; a higher parental self-efficacy was associated with a lower child HbA_{1c} level).

Table 4. Determinants of glucose control (6-month average HbA_{1c}) in different regression models (N=150).

Variable	Model								
	M1	M2	M3	M4	M5	M6	M7	M8	M9
Age (child)	0.051	0.121	0.096	0.091	0.099	0.096	0.091	0.096	0.082
Sex (child) (reference: boy)									
Girl	0.277	0.512[a]	0.469[a]	0.495[a]	0.459[a]	0.470[a]	0.550[b]	0.467[a]	0.578[b]
T1DM[c] duration	−0.037[d]	0.105	0.100	0.093	0.112	0.103	0.104	0.100	0.102
Duration of care at the center	0.199[a]	0.084	0.106	0.120	0.097	0.105	0.089	0.107	0.100
Age (parent)	—[e]	−0.007[d]	−0.016[d]	−0.014[d]	−0.012[d]	−0.016[d]	−0.026[d]	−0.016[d]	−0.023[d]
Sex (parent) (reference: male)									
Female	—	−0.051[d]	−0.110[d]	−0.085[d]	−0.117[d]	−0.110[d]	−0.149[d]	−0.108[d]	−0.109[d]
Education (reference: primary)									
Secondary	—	−0.851[a,d]	−0.364[d]	−0.357[d]	−0.318[d]	−0.370[d]	−0.379[d]	−0.362[d]	−0.321[d]
Tertiary	—	−1.369[b,d]	−0.731[d]	−0.762[d]	−0.768[d]	−0.751[d]	−0.706[d]	−0.726[d]	−0.762[d]
Residence (reference: capital)									
Town	—	−0.178[d]	0.001	−0.026[d]	0.005	−0.004[d]	0.037	−0.001[d]	−0.011[d]
Village	—	−0.285[d]	−0.123[d]	−0.178[d]	−0.105[d]	−0.119[d]	−0.131[d]	−0.123[d]	−0.181[d]
Income	—	−0.001[d]	0.000	0.000	0.000	0.000	0.000	0.000	0.000
Living in the same household (reference: full-time)									
Part-time	—	−0.207[d]	−0.158[d]	−0.198[d]	−0.082[d]	−0.170[d]	−0.282[d]	−0.161[d]	−0.322[d]
Treatment modality (reference: pen)									
Pen + sensor	—	—	−0.745[a,d]	−0.754[a,d]	−0.754[a,d]	−0.751[a,d]	−0.643[a,d]	−0.746[a,d]	−0.660[a,d]
Pump	—	—	−1.269[a,d]	−1.149[d]	−1.214[a,d]	−1.271[a,d]	−1.240[a,d]	−1.270[a,d]	−1.018[d]
Pump + sensor	—	—	−1.081[b,d]	−1.081[b,d]	−1.097[b,d]	−1.091[b,d]	−0.919[b,d]	−1.083[b,d]	−0.927[b,d]
eHEALS[f]	—	—	—	0.024	—	—	—	—	0.034
Chew	—	—	—	—	−0.063[d]	—	—	—	−0.061[d]
NVS[g]	—	—	—	—	—	0.012	—	—	0.015
PSESDM[h]	—	—	—	—	—	—	−0.068[b,d]	—	−0.082[b,d]
HFS[i]	—	—	—	—	—	—	—	0.000	−0.004[d]
Constant	6.074[j]	6.744[j]	7.264[j]	6.511[j]	7.259[j]	7.232[j]	9.742[j]	7.281[j]	9.317[j]
R^2	0.126	0.328	0.396	0.402	0.403	0.396	0.444	0.396	0.470

[a] $P<.05$.

[b] $P<.01$.

[c] T1DM: type 1 diabetes mellitus.

[d] Negative coefficients represent a decrease in the HbA_{1c} level for a 1 unit increase in a given variable, which consequently represents an improvement in glucose control.

[e] Variable was not part of the model.

[f] eHEALS: eHealth Literacy Scale.

[g] NVS: Newest Vital Sign.

[h] PSESDM: Parental Self-Efficacy Scale for Diabetes Management.

[i] HFS: Hypoglycemia Fear Survey.

[j] $P<.001$.

Discussion

In this cross-sectional clinical study, we investigated the electronic health literacy of parents caring for children with T1DM, using the eHEALS self-reported measurement tool, and results were analyzed alongside their general health literacy. Associations of eHEALS with disease management and disease outcomes were also investigated. On the eHEALS questionnaire, parents reported substantial problems with finding, understanding, and using electronic health information. Regarding disease management, eHEALS scores differed significantly according to the children’s treatment modality, being the highest in the pump + sensor subgroup, and there was a significant association of eHEALS scores with parents’ self-efficacy in managing diabetes (PSESDM) and the diabetologists’ perceptions of parents as T1DM caregivers. Regarding disease outcomes, we found no significant associations with parental eHEALS scores. Regression analysis revealed that the 6-month average HbA_{1c} level was associated with the child’s sex, treatment modality, and PSESDM score, but not with the electronic and general health literacy scores. To our knowledge, this is the first study to investigate parental electronic health literacy (eHEALS) in pediatric T1DM.

Comparisons with the international literature are hampered by the lack of electronic health literacy studies in this patient group and the variability of the general health literacy measurement tools used. In our study, more educated parents had significantly higher electronic (eHEALS) and general (Chew and NVS) health literacy, and these 2 differed significantly by income level as well. In contrast, previous studies involving young children [31] and adolescents [40] have reported no significant differences in parents’ general health literacy (assessed by the S-TOFHLA) by sociodemographic subgroups. Moreover, Al-Abdulrazzaq et al [41] found no association between parents’ NVS score and their educational level in a validation study of the Arabic version of the NVS. Parental self-efficacy in the child’s diabetes management (PSESDM) showed an increasing trend by educational level and income in our study, but parental fear of hypoglycemia (HFS) did not differ by sociodemographic subgroups. Marchante et al [51] reported that PSESDM was associated with the child’s sex. In the study by Amiri et al [63], neither parental self-efficacy (assessed by the Self-Efficacy for Diabetes Scale-Parent questionnaire) nor the HFS score differed significantly by demographic characteristics. These controversial results regarding the role of sociodemographics in parental health literacy and caregiver attitude need further investigation in large epidemiological studies. We consider it important to highlight the female dominance of parents (80%) in our sample. We acknowledge that we could have obtained different results in other care settings and that the child’s T1DM might affect the quality of life and employment perspectives of other family members. These points definitely deserve further exploration. Nevertheless, our results suggest that mothers play a key role in the T1DM care of their children. It is therefore worth paying particular attention to their electronic health literacy, capability, and willingness to operate modern devices, considering their preferences, and measuring how they can benefit from new digital technologies.

Our study revealed significantly higher parental electronic health literacy (eHEALS) in children using a digital sensor to measure their blood glucose level. The results suggest that parental electronic health literacy might affect the choice of insulin administration and glucose measurement mode. This choice may depend on various factors, including the judgement of the treating diabetologist, reimbursement rules, availability of devices, and access to devices, as well as on the acceptability of different treatment modalities (ie, parental consent and the child’s preferences). Further studies involving pediatric diabetes care providers from different levels and diverse patient groups are encouraged to explore in depth the decision-making process. Parents’ average NVS score also differed significantly by treatment groups, suggesting that general health literacy (focusing on skills for both words and numbers) might play a significant role in treatment decisions. This is in contrast with findings by Pulgaron et al [31], as parents’ reading and numeracy abilities were not associated with treatment modalities. However, it is important to note that much younger (aged 3-9 years; mean age 6.8 years) T1DM children were involved in their study.

HbA_{1c} is an important indicator of T1DM management. We found no significant correlation with parental eHEALS and Chew scores, but there were weak and moderate relationships with parental general health literacy (NVS) and self-efficacy (PSESDM), respectively. In the study by Pulgaron et al [31], parents’ numeracy skills were negatively correlated with the child’s HbA_{1c} level ($r=-0.52$), which strengthens our results with the NVS measure that also has a strong numerical focus. However, 2 other studies found no association between parental health literacy (S-TOFHLA and NVS) and the child’s HbA_{1c} level [40,41]. Ross et al [43] reported that glycemic disease control was worse for those children whose caregivers had lower literacy skills as measured by the National Adult Reading Test (NART).

An important observation of our study was that parental electronic and general health literacy scores and parental fear of hypoglycemia were not associated with the child’s HbA_{1c} level in the regression analyses, and contributed minimally to the total variance explained (R^2), indicating that these factors have a negligible effect on the child’s glucose control. We also found that apart from the child’s sex and parents’ PSESDM score, only pen + sensor and pump + sensor treatment modalities remained significantly associated with the HbA_{1c} level in the final regression model, when all relevant variables were added together. Thus, a digital glucose sensor can have a meaningful positive effect on the child’s glucose control. Our observations are consistent with previously published results. In most previous studies, higher HbA_{1c} levels were found among female young children than among male children both at diagnosis and during treatment [64]. Pulgaron et al [31] reported that parents’ numeracy skills could significantly predict HbA_{1c}, but the significance was lost when parents’ education was added as a covariate in the regression analysis. In their final model, only parental self-efficacy regarding diabetes management (Perceived Diabetes Self-Management Scale) remained a significant predictor of HbA_{1c}. Furthermore, Al-Abdulrazzaq et al [41] found that adequate health literacy was inversely associated with optimal HbA_{1c} levels, but adjusting for the treatment regimen cancelled its significant effect. We think, however, that the child's HbA_{1c} level is multifactorial, and not all relevant factors were taken into account in our research. For instance, at this university-based center, patients are closely monitored and have opportunities for consultation with highly qualified pediatric diabetologists and a multidisciplinary team. This tight control may partly balance the differences in parental disease management capabilities in terms of HbA_{1c} outcome. It is necessary to note that we ran the regression for HbA_{1c}, but it is not the only significant outcome of the disease. The benefits of new digital technologies, if used by properly trained users with great digital skills, can also be seen in areas not covered in our study. For instance, the possibility of remote control of the child's status might put the parents into a much better position in terms of feeling more safe and flexible in managing other family members and their own life. It would be worth also investigating how the electronic health literacy of main caregivers (mothers in our study) impacts long-term management decisions and disease outcomes in the patient's later adolescence and adulthood.

Some limitations of our study have to be mentioned. First, this was a single-center cross-sectional study in a university clinic, which limits the generalizability of our results. It would be interesting to investigate whether the role of eHEALS for HbA_{1c} levels is similarly negligible in jurisdictions where parents have less access to resources and high-quality, personalized, family-centered diabetology care [65], and are more reliant on information from the internet. It would be worthwhile to also assess in a follow-up study how parents' digital health literacy changes with digital device use and participation in diabetes care. Second, the tools used to measure parental health literacy were not specific to diabetes. Therefore, we may not have been able to capture all relevant aspects of parental knowledge. Third, only 4 children had serious acute events requiring medical intervention or device malfunction in the past 3 months. Hence, the importance of parental electronic health literacy in acute events needs further research. Fourth, only 6 children used an insulin pump without a sensor, which limits the generalizability of the results of this subgroup. Our study showed that disease duration and follow-up at this university-based clinic were the longest for this subgroup. Discussions with treating diabetologists confirmed that these patients have usually been using pump treatment for a long time and often struggle with switching from conventional blood glucose measurement to sensor measurement.

This first exploratory study provides insights into the electronic health literacy of parents caring for their child with T1DM. Parents' educational level was identified as an important sociodemographic factor affecting parental electronic health literacy and attitudes toward their child's diabetes. Meaningful differences in parental eHEALS and NVS scores were found by treatment modality, suggesting that parental electronic and general health literacy may be important factors in treatment decisions. In addition to being a male child, higher parental self-efficacy in diabetes management and sensor use were positively associated with better child glucose control. However, a lack of a direct association between this core outcome and parental electronic and general health literacy raises the issue of further influencing factors not considered in this study, as well as the need for diabetes-specific electronic health literacy measurement tools. Further prospective multicenter studies involving heterogeneous settings and care providers are recommended to strengthen and refine our observations.

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Data Availability

The data supporting the findings of this study are available from the corresponding author upon request.

Authors' Contributions

ÁH contributed to data curation, formal analysis, methodology, software, visualization, and writing–original draft. AL contributed to conceptualization, data curation, investigation, resources, and writing–review and editing. PTH contributed to conceptualization, data curation, investigation, resources, and writing–review and editing. EM contributed to data curation, investigation, and writing–review and editing. EV contributed to conceptualization, data curation, investigation, resources, and writing–review and editing. AJS contributed to conceptualization, data curation, investigation, resources, and writing–review and editing. PB contributed to validation and writing–review and editing. LK contributed to funding acquisition and writing–review and editing. LG contributed to conceptualization, methodology, funding acquisition, project administration, and writing–review and editing. ZZ contributed to conceptualization, methodology, and writing–review and editing. MP contributed to conceptualization, methodology, funding acquisition, project administration, supervision, and writing–original draft.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Comparison of eHealth Literacy Scale scores observed in the current study and the Hungarian population sample.
[DOCX File , 18 KB - pediatrics_v7i1e54807_app1.docx]

Multimedia Appendix 2
Diabetologists' perceptions of parental cooperation, diabetes knowledge, device use knowledge, and difficulty of disease management by the parents' age group.
[DOCX File , 54 KB - pediatrics_v7i1e54807_app2.docx]

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Abbreviations

eHEALS: eHealth Literacy Scale
HFS: Hypoglycemia Fear Survey
HRQoL: health-related quality of life
NVS: Newest Vital Sign
PedsQL: Pediatric Quality of Life Inventory
PedsQL Diab: Pediatric Quality of Life Inventory Diabetes Module
PSESDM: Parental Self-Efficacy Scale for Diabetes Management
S-TOFHLA: Short Test of Functional Health Literacy in Adults
T1DM: type 1 diabetes mellitus
VAS: visual analog scale

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Original Paper

Telebehavioral Health for Caregivers of Children With Behavioral Health Needs to Address Caregiver Strain: Cohort Study

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Abstract

Background: Behavioral health conditions among children have worsened over the past decade. Caregivers for children with behavioral health conditions are at risk for two types of caregiver strain: (1) an objective strain, that results directly from the child's condition and (2) subjective strain, that arises from the caregiver's feelings regarding these events.

Objective: This study aimed to evaluate the impact of a technology-enabled pediatric and family behavioral health service on caregivers' strain among a commercially insured population. We also explore the common symptom clusters of caregiver strain to better understand the caregiver presentation to inform future care planning.

Methods: We examined changes in caregiver strain using the Caregiver Strain Questionnaire-Short Form 7 over the course of their child's web-based behavioral health care between 2021 and 2023 using a pre-post study design. Common caregiver strain symptom clusters were identified using Ward hierarchical agglomerative clustering.

Results: The majority of children were White 60.8% (1002/1647), female 53.6% (882/1647), and aged between 5 and 9 years (33.7%, 555/1647). Families fall broadly into 4 groups based on what drives caregiver strain the most, namely those experiencing (1) disrupted family relationships and time interruption, (2) missed work, (3) worried about their child's future and feeling tired and sad, and (4) financial strain. Caregiver strain, which was associated with the child's disease severity (*P*<.001), decreased significantly in all therapeutic groups.

Conclusions: Web-based family-oriented behavioral health care can improve caregiver strain and reduce family and time disruptions, missed work, and financial strain. Sources of caregiver strain vary and may be overlooked when relying on the conventional scoring of the Caregiver Strain Questionnaire-Short Form 7.

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KEYWORDS

adolescent; child; caregiver; family health; resilience; psychological; mental health; pediatric; pediatrics; paediatric; paediatrics; children; youth; adolescents; teen; teens; teenager; teenagers; strain; burden; caregiving; caregivers; carer; carers; informal care; family care; spousal care; telehealth; telemedicine; technology-enabled; mobile phone

Introduction

Over the past decade, the prevalence of behavioral health conditions among children has steadily worsened [1,2]. Currently, 17% of children aged 2 to 8 years are diagnosed with a mental health condition [3] and 37% of adolescents aged 12 to 17 years report persistent feelings of sadness or hopelessness [1,4]. The adults who care for these children are at risk for 2 types of caregiver strain, that are (1) an objective strain, that results directly from the child's condition (eg, disrupted family relationships, financial strain, and interruptions at work) and (2) subjective strain, that arises from the caregiver's feelings regarding these events (eg, guilt, anger, and sadness) [5]. Although the severity of the child's problems is often the best predictor of caregiver strain, poor access to convenient, affordable in-network providers is a common source of caregiver strain, even among commercially insured families [5]. Given evidence that reducing parental strain can improve the effectiveness of evidence-based treatments for children with mental illness [6,7], a robust understanding of the sources of caregiver strain may lead to more beneficial approaches for the whole family. While previous studies have evaluated caregiver strain in terms of internalizing and externalizing domains [8], specific sources of strain have not been documented.

The costs for outpatient behavioral care for commercially insured populations increased by 84% between 2018 and 2021 compared with an increase of 60% in overall behavioral health costs during that interval [9]. Self-insured employers pay a disproportionate share of these costs because they provide direct payment for mental health services, and bear indirect costs, such as reduced employee productive work time [10]. In response to the increased prevalence of mental health concerns and these escalating costs, approximately 80% of self-insured employers report implementing behavioral health benefits, including employee assistance programs and others that increase access to low-cost mental health services, including telemental health [9]. However, telehealth use among children and teenagers lags behind adults, despite recent telehealth expansions for behavioral health services [11].

In response to these trends, we implemented a comprehensive, technology-enabled pediatric and family behavioral health service for commercially insured populations. The intervention provides access to educational content, telebehavioral health coaching, and web-based psychotherapy and medication management. Children are triaged to either telebehavioral health coaching, telepsychotherapy, or telepsychiatry based on their clinical acuity.

In this study, we hypothesize that a telebehavioral health service is effective in reducing strain among parents caring for a child with a mental health condition. We also explore the common symptom clusters of caregiver strain to better understand the caregiver presentation to inform future care planning. In a secondary analysis, we evaluate the relationship between caregiver strain and child behavioral health severity, which were strongly correlated in a previous study [5]. We hope that this study will provide important observations around remediable symptoms and patterns of caregiver strain that will inform the development of telebehavioral health offerings for children and their families.

Methods

Overview

This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline for cohort studies [12]. STROBE guidelines are used in observational studies to improve the quality, transparency, integrity, and reproducibility of scientific literature.

Intervention

Brightline is a technology-enabled behavioral health care platform for children (aged 18 months to 17 years) and their families [13,14]. Briefly, the web-based platform is provided to commercially insured populations in all 50 states through their employer-sponsored health benefits. Families have the option to receive care through a computer or smartphone. There are 4 main intervention offerings available, that are (1) psychoeducational content, (2) telebehavioral health coaching, (3) telepsychotherapy, and (4) telepsychiatry. A previous study from Brightline showed that 75% of children in coaching and 69% of children in telepsychotherapy and telepsychiatry demonstrated reliable improvement in their psychosocial functioning [14]. All families using the service have access to a rich library of scientifically informed educational content, including videos and exercises on a wide range of topics, including modules for children and their caregivers (eg, parent management training [PMT]). Families also have access to coaching support through chat.

Children and their caregivers, with preclinical or subclinical concerns, have access to a protocolized, evidence-informed 1:1 telecoaching program. Coaching programs typically last 4 to 6 sessions beginning with a structured assessment of the child's needs followed by either caregiver- or child-caregiver dyad–focused coaching. For example, caregiver skills training often includes understanding how to identify and focus on positive behaviors (as opposed to focusing on the child's negative behaviors), understanding and demonstrating effectiveness in using praise and other types of rewards to reinforce the child's positive behavior, and setting up behavioral plans and troubleshooting their implementation—modules developed based on best practices of PMT [15].

Families with children with higher acuity needs are referred to licensed therapists for evidence-based, family-centric telepsychotherapy. Interventions are derived from evidence-based approaches, including cognitive behavioral therapy, components of dialectical behavior therapy, and caregiver-mediated interventions (eg, PMT), rooted in trauma-informed and culturally responsive approaches to care. Standardized pathway-driven approaches, such as the Modular Approach to Therapy for Anxiety, Depression, Trauma, or Conduct Problems model (MATCH-ADTC), are used to support how care is implemented [16]. Children and teens who indicate plans to harm themselves or others have required admission to a psychiatric hospital or residential treatment facility within the previous 30 days, complicating substance use, or severely disordered eating are externally referred for immediate care and related care coordination.

In some instances, where the child can appropriately receive care from more than 1 type of program, families are able to enroll in a program of their preference.

Including a caregiver in care is standard. The focus of interventions differs based on age and presenting concerns, such that either a PMT (caregiver-only within sessions) or a dyadic care model (caregiver and child sessions; caregiver-only sessions are included) are used. In PMT, the child remains the focus, but the caregiver attends sessions alone, and the focus is on strategies to reduce negative behaviors in the home and improve positive connections between caregivers and their child. In dyadic care, the child and caregiver both participate in the course of care.

Participants

We included child-caregiver dyads who enrolled in the intervention between October 2021 and July 2023. Dyads must have completed at least 1 coaching, psychotherapy, or psychiatry session and completed a baseline and follow-up assessment. If participants' needs change as they progress through care and a different level of care is indicated, they may move to a different program. For this study, we exclude dyads that participated in more than 1 program.

Data Collected

Within each dyad, caregivers completed validated, self-reported assessments to evaluate the clinical effectiveness of receiving telebehavioral health coaching, telepsychotherapy, and telepsychiatry services. Baseline assessments were collected on the web before engagement with coaches and psychotherapists, and follow-up assessments were collected every 4 weeks during care [17].

Caregiver Strain

Caregivers completed the Caregiver Strain Questionnaire-Short Form 7 (CGSQ-SF7) [18], a caregiver-completed assessment of objective and subjective caregiver strain experienced over the past month. Potential causes of caregiver strain are rated on a scale from 1 (not at all) to 5 (very much). A total of 4 items assessing interruption of personal time, missing work, financial strain, and disruption of familial relationships due to the child's current challenges comprise the CGSQ-SF7 objective strain subscale, and 3 items assessing their own experience of sadness, worry, and fatigue or strain as a result of their child's challenges make up the CGSQ-SF7 subjective strain subscale. Subscale scores are calculated by taking the average of the item ratings. The CGSQ-SF7 total score is determined by adding the subscale scores together. The reliability and validity of the CGSQ-SF7 objective and subjective strain subscales are comparable to the full-length CGSQ [18].

Pediatric Symptoms

Caregivers completed the Pediatric Symptom Checklist-17 (PSC-17). The PSC-17 is a caregiver-completed survey that measures a child's total psychosocial functioning, with subscales that measure function in the areas of internalizing, attention, and externalizing concerns [19].

Analyses

For this retrospective cohort analysis, a pre-post study design was used based on CGSQ-SF7 assessments collected at baseline and discharge. If dyads were lost to follow-up, last-value-carried-forward imputation was implemented.

We separated the dyads into 2 groups, those with high caregiver strain and those with nonelevated caregiver strain. High strain was defined as having either a CGSQ-SF7 total score of 7.0 or more, objective score of 3.0 or more, or subjective score of 4.0 or more at baseline, and caregivers that did not meet any of these criteria were categorized as having nonelevated strain [20]. Counts of caregivers with reliable improvement were determined among dyads with high caregiver strain. Reliable improvement was defined as having a minimum detectable change of 1.13 or more on the total score, 0.66 or more for the objective score, or 0.76 or more for the subjective score [20]. Counts of caregivers that achieved maintenance were calculated for dyads with nonelevated strain at baseline. Maintenance was defined as having a minimum detectable change no less than –1.13 on the total score, –0.66 for the objective score, and –0.76 for the subjective score [20].

To evaluate patterns of symptom clustering among those with high caregiver strain at baseline, we used Ward hierarchical agglomerative clustering with Euclidean distances. Euclidean distance is the length between 2 points in a multidimensional space and is used to measure similarity among objects in cluster analyses [21]. Hierarchical agglomerative clustering is an unsupervised machine learning algorithm that progressively aggregates objects based on the distance metric and linkage criterion [22] and has been used for symptom clustering in previous studies [23]. Paired, 2-tailed *t* tests were used to evaluate changes in scores from baseline to follow-up across symptom clusters and CGSQ-SF7 subscales among caregivers with high strain at baseline. Cohen *d* was used to measure the effect size within each grouping.

To evaluate the relationship between caregiver strain and child behavioral health severity, we performed univariate linear regressions to test the association between CGSQ-SF7 and PSC-17 scores at baseline and the change in CGSQ-SF7 and PSC-17 scores from baseline to follow-up.

All statistical analyses were performed in R software (version 4.1.2; R Foundation for Statistical Computing).

Ethical Considerations

This study was classified as exempt from consent requirements under human subjects review by the Western Institutional Review Board (WIRB)-Copernicus Group Institutional Review Board, per Federal Regulations for the Protection of Human Research Subjects (45CFR 46.104(d)(4)) (protocol Brightline.004) [24].

Results

Participants

Demographics of the children are reported in Table 1. Of the 1647 children, 806 (48.9%) completed a course of care in coaching, 750 (45.5%) in psychotherapy, and 91 (5.5%) in psychiatry. Dyads, including teenagers (aged 13-17 years), made up the largest proportion of children in psychiatry and psychotherapy (56%, 51/91 and 39.1%, 293/750), compared with those who received coaching (23.1%, 186/806). The majority of children in the dyads were White (60.8%, 1002/1647); however, 12.8% (210/1647) reported identifying as multiracial. There were no differences in baseline CGSQ-SF7 scores by race of the child (Table 2). Overall, 882 (53.6%) of children in dyads were female. Notably, the proportion of females was larger than males in psychiatry and psychotherapy (63.7%, 58/91 and 57.1%, 428/749) compared with those who received coaching (49.1%, 396/806). On average, dyads completed 6.7 (SD 4.3) sessions in coaching, 10.6 (SD 6.8) sessions in psychotherapy, and 19.2 (SD 11.7) sessions in psychiatry.

Table 1. Demographic characteristics of children in the study.

Demographics	Total (N=1647)	Children in coaching (n=806)	Children in psychotherapy (n=750)	Children in psychiatry (n=91)
Race, n (%)				
White	1002 (60.8)	465 (57.7)	484 (64.5)	53 (58.2)
Multiracial	210 (12.8)	115 (14.3)	85 (11.3)	10 (11.0)
Hispanic	146 (8.9)	63 (7.8)	65 (8.7)	18 (19.8)
Black	99 (6.0)	53 (6.6)	43 (5.7)	3 (3.3)
Asian	97 (5.9)	56 (7.0)	36 (4.8)	5 (5.5)
Prefer not to say	47 (2.9)	24 (3.0)	22 (2.9)	1 (1.1)
Other	40 (2.4)	26 (3.2)	14 (1.9)	—[a]
Sex, n (%)				
Female	882 (53.6)	396 (49.1)	428 (57.1)	58 (63.7)
Male	764 (46.4)	410 (50.9)	321 (42.8)	33 (36.3)
Age at enrollment (years), n (%)				
<5	73 (4.4)	71 (8.8)	2 (0.3)	—
5-9	555 (33.7)	315 (39.1)	220 (29.3)	20 (22.0)
10-12	489 (29.7)	234 (29.0)	235 (31.3)	20 (22.0)
13-17	530 (32.2)	186 (23.1)	293 (39.1)	51 (56.0)
Completed sessions, mean (SD)	9.2 (6.8)	6.7 (4.3)	10.6 (6.8)	19.2 (11.7)
Baseline PSC-17[b] total score, mean (SD)	14.2 (5.6)	13.2 (5.5)	14.8 (5.7)	15.8 (5.1)

[a] Not applicable.

[b] PSC-17: Pediatric Symptom Checklist-17 is a caregiver-completed survey that measures a child’s total psychosocial functioning.

Table 2. Baseline caregiver strain score (Caregiver Strain Questionnaire-Short Form 7 total) by child race, gender, and age.

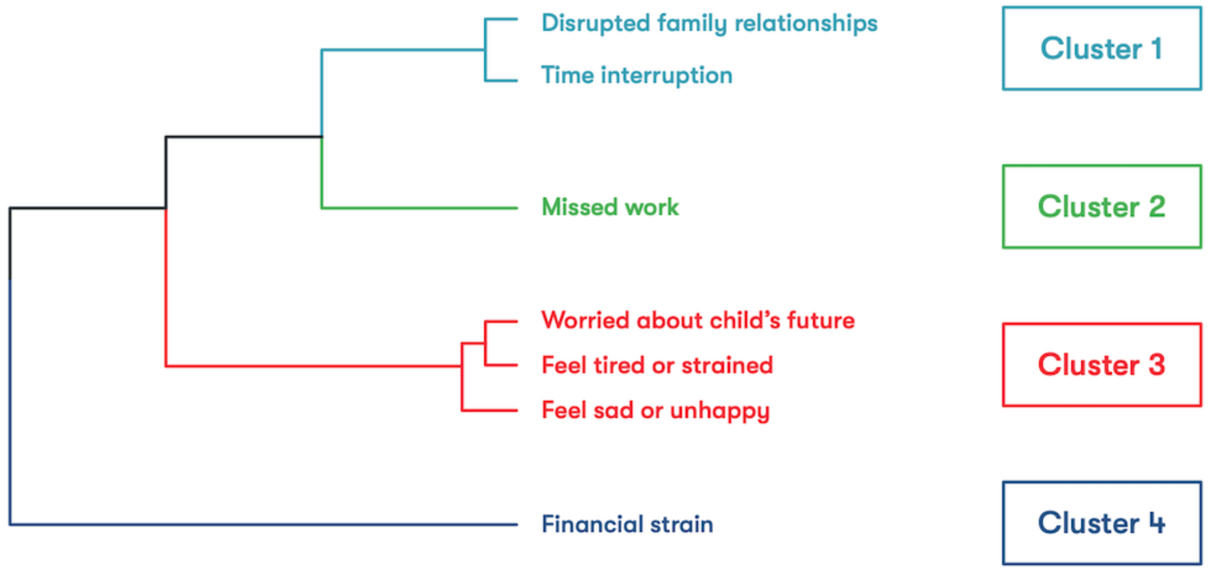
Demographics	Coaching		Psychotherapy		Psychiatry	
	Mean (SD)	*P* value	Mean (SD)	*P* value	Mean (SD)	*P* value
Race		.30		.96		.46
White	5.1 (1.6)		5.5 (1.7)		5.8 (1.7)	
Multiracial	4.8 (1.5)		5.6 (1.4)		5.7 (1.3)	
Hispanic	4.7 (1.8)		5.4 (1.9)		6.3 (2.1)	
Black	5.0 (2.0)		5.4 (1.5)		6.9 (1.7)	
Asian	5.0 (1.8)		5.5 (1.8)		4.9 (.8)	
Sex		.01		.01		.01
Female	4.8 (1.6)		5.4 (1.7)		5.5 (1.7)	
Male	5.2 (1.7)		5.7 (1.7)		6.5 (1.6)	
Age at enrollment (years)		.01		.01		.09
<5	5.7 (1.8)		3.8 (0.24)		—[a]	
5-9	5.0 (1.6)		5.8 (1.7)		6.5 (1.3)	
10-12	5.0 (1.7)		5.6 (1.6)		6.0 (1.9)	
13-17	4.8 (1.7)		5.3 (1.8)		5.5 (1.8)	

[a] Not applicable.

Caregiver Strain Symptom Clusters

The structure of the dendrogram produced from the hierarchical agglomerative clustering procedure suggests that four symptom clusters fit the data well (Figure 1), with key drivers of caregiver strain being (1) disrupted family relationships and time interruption, (2) missed work, (3) worry about their child's future and who felt tired and sad, and (4) financial strain. At baseline, 71.4% (1176/1647) of caregivers experienced symptoms in Cluster 1, 61.0% (1004/1647) experienced symptoms in Cluster 2, 80.4% (1325/1647) experienced symptoms in Cluster 3, and 20.8% (342/1647) experienced symptoms in Cluster 4.

Figure 1. Caregiver strain symptom clusters among caregivers with a high Caregiver Strain Questionnaire-Short Form 7 at baseline. This figure shows the key drivers of strain for caregivers of children with mental illness.



The Euclidean distance at which the symptoms merged for Cluster 3 was small and aligned with the grouping of symptoms defined in the CGSQ-SF7 subjective strain subscale. Therefore, further analysis of Cluster 3 was not conducted. However, the financial strain and missed work symptoms merged with other clusters at large Euclidean distances, suggesting that these symptoms are distinct from each other. Consequently, we treated the financial strain and work symptoms as independent clusters. This observation is a departure from the CGSQ-SF7 objective strain subscale grouping that clusters financial strain, missed work, time interruption, and disrupted family relationship symptoms together [18].

Caregiver Strain

Overall, the highest baseline caregiver strain was in the group receiving psychiatry and lowest in the group receiving coaching (Table 3). Baseline subjective measures of caregiver strain were higher in all groups than objective measures of caregiver strain (Table 3). Among those with high strain, a reliable improvement in the CGSQ-SF7 total was demonstrated in 78.9% (90/114) caregivers in coaching, 68.5% (113/165) caregivers in psychotherapy, and 65.2% (15/23) caregivers in psychiatry (Table 4). Maintenance on the CGSQ-SF7 total was achieved among caregivers without high strain for (93.2% (645/692) caregivers in coaching, 90.4% (529/585) of caregivers in psychotherapy, and 83.8% (57/68) of caregivers in psychiatry (Table 4). Rates of reliable improvement and maintenance were high for CGSQ-SF7 objective and subjective scores (Table 4). CGSQ-SF7 total, subscale, and cluster scores decreased from baseline to follow-up across all programs (Table 5).

Table 3. Caregivers with high and low-to-moderate Caregiver Strain Questionnaire-Short Form 7 scores at baseline.

Child-enrolled program	Total			Objective			Subjective		
	Baseline, mean (SD)	High strain[a], n (%)	Low-to-moderate strain[b], n (%)	Baseline, mean (SD)	High strain[a], n (%)	Low-to-moderate strain[b], n (%)	Baseline, mean (SD)	High strain[a], n (%)	Low-to-moderate strain[b], n (%)
Coaching	5.0 (1.7)	114 (14.1)	692 (85.9)	2.1 (0.8)	127 (15.8)	679 (84.2)	2.9 (1.0)	171 (21.2)	635 (78.8)
Psychotherapy	5.5 (1.7)	165 (22.0)	585 (78.0)	2.3 (0.8)	180 (24.0)	570 (76.0)	3.2 (1.0)	235 (31.3)	515 (68.7)
Psychiatry	5.8 (1.7)	23 (25.3)	68 (74.7)	2.4 (0.9)	25 (27.5)	66 (72.5)	3.4 (1.0)	37 (40.7)	54 (59.3)

[a] High strain was defined by having a total score of 7.0 or more, an objective score of 3.0 or more, or a subjective score of 4.0 or more at baseline.

[b] Low-to-moderate strain was defined as having a total score less than 7.0, an objective score less than 3.0, or a subjective score less than 4.0.

Table 4. Rates of reliable improvement and maintenance among caregivers on the Caregiver Strain Questionnaire-Short Form 7.

Child-enrolled program	Total		Objective		Subjective	
	Reliable improvement[a], n (%)	Maintained[b], n (%)	Reliable improvement[a], n (%)	Maintained[b], n (%)	Reliable improvement[a], n (%)	Maintained[b], n (%)
Coaching	90 (78.9)	645 (93.2)	93 (73.2)	633 (93.2)	119 (69.6)	596 (93.9)
Psychotherapy	113 (68.5)	529 (90.4)	114 (63.3)	506 (88.8)	160 (63.8)	477 (92.6)
Psychiatry	15 (65.2)	57 (83.8)	17 (68.0)	58 (87.9)	18 (48.6)	48 (88.9)

[a] Reliable improvement was determined among caregiver-child dyads with high strain and defined as having a minimum detectable change of −1.13 or lower on the total score, −0.66 for the objective score, and −0.76 for the subjective score.

[b] Maintained was determined among caregiver-child dyads with nonelevated strain and defined as having a minimum detectable change no less than −1.13 on the total score, −0.66 for the objective score, and −0.76 for the subjective score.

Table 5. Caregiver Strain Questionnaire-Short Form 7 total, subscales, and cluster scores among caregivers at baseline and follow-up.

Child-enrolled program	Baseline, mean (SD)	Follow-up, mean (SD)	Paired mean difference (95% CI)	Percent change (%)	*t* test (*df*)	*P* value[a]	Cohen *d*
Coaching							
Total	7.8 (0.8)	5.3 (1.6)	2.5 (2.2-2.8)	–32.1	16.8 (113)	<.001	1.9
Objective	7.5 (1)	5.3 (1.7)	2.2 (1.9-2.5)	–29.3	14.9 (126)	<.001	1.6
Subjective and Cluster 3[b]	7.3 (1)	5.1 (1.6)	2.2 (1.9-2.4)	–30.1	17.0 (170)	<.001	1.6
Cluster 1[c]	6.4 (1.7)	5.5 (1.5)	0.9 (0.7-1.1)	–14.0	10.3 (409)	<.001	0.6
Cluster 2[d]	2.7 (0.8)	1.8 (0.9)	0.9 (0.7-0.9)	–33.3	17.2 (445)	<.001	0.9
Cluster 4[e]	2.7 (0.9)	1.7 (0.9)	1.0 (0.8-1.2)	–37.0	9.4 (130)	<.001	1.1
Psychotherapy							
Total	7.8 (0.6)	5.8 (1.9)	2.0 (1.7-2.3)	−25.6	13.7 (164)	<.001	1.4
Objective	7.5 (0.9)	5.7 (1.9)	1.8 (1.5-2.1)	−24.0	13.1 (179)	<.001	1.2
Subjective and Cluster 3[b]	7.3 (0.9)	5.5 (1.9)	1.8 (1.6-2.0)	−24.7	15.2 (234)	<.001	1.2
Cluster 1[c]	6.7 (1.6)	5.8 (1.7)	1.0 (0.8-1.2)	−13.4	10.2 (373)	<.001	0.7
Cluster 2[d]	2.7 (0.8)	2.0 (1.1)	0.7 (0.6-0.8)	−25.9	15.0 (491)	<.001	0.8
Cluster 4[e]	2.7 (0.9)	2.0 (1.1)	0.7 (0.5-0.9)	−25.9	7.5 (186)	<.001	0.7
Psychiatry							
Total	8.1 (0.8)	6.1 (1.8)	2.0 (1.3-2.7)	−24.7	5.9 (22)	< .001	1.2
Objective	7.9 (1.0)	6.3 (1.7)	1.6 (0.8-2.2)	−20.3	4.5 (24)	<.001	1.1
Subjective and Cluster 3[b]	7.4 (1.1)	5.7 (1.8)	1.7 (1.2-2.3)	−23.0	6.4 (36)	<.001	1.1
Cluster 1[c]	6.8 (1.6)	6.0 (1.7)	0.8 (0.3-1.3)	−11.8	3.3 (54)	<.001	0.5
Cluster 2[d]	2.9 (0.9)	2.2 (1.1)	0.7 (0.5-1.1)	−24.1	5.5 (65)	<.001	0.8
Cluster 4[e]	2.8 (1.0)	1.9 (0.8)	0.9 (0.5-1.4)	−32.1	4.1 (23)	<.001	1.0

[a] *t* test *P* value is significant at .008 after adjusting for multiple comparisons using Bonferroni correction.

[b] Cluster 3 is made up of the same items as the Caregiver Strain Questionnaire-Short Form 7 subjective subscale.

[c] Cluster 1 includes disrupted family relationships and time interruption items.

[d] Cluster 2 includes the missed work item.

[e] Cluster 4 includes the financial strain item.

Association Between Caregiver Strain and Child Behavioral Health Severity

There was a strong positive association between baseline CGSQ-SF7 total score and PSC-17 total score (coaching: $\beta=.16$, $P<.001$; psychotherapy: $\beta=.13$, $P<.001$; and psychiatry: $\beta=.14$, $P<.001$; Table S1 in Multimedia Appendix 1). There was also a strong positive association between the change in CGSQ-SF7 total score and PSC-17 total score from baseline to follow-up (coaching: $\beta=.14$, $P<.001$; psychotherapy: $\beta=.13$, $P<.001$; and psychiatry: $\beta=.09$, $P=.01$; Table S1 in Multimedia Appendix 2).

Discussion

Principal Findings

Although there is a growing literature supporting digital mental health models for the adult population [25-27], there is far less research evaluating specific digital mental health models for children, teens, and their families [28]. In this study, we evaluated the effect of a web-based, multitiered pediatric mental health care intervention on caregiver strain and identified symptom clusters of caregiver strain measured within the CGSQ-SF7 associated with caring for a child with a mental health condition.

This analysis has 2 key findings. First, overall caregiver strain as measured by the CGSQ-SF7 total score, which is highly associated with their child's symptom severity, can improve with a mix of clinical interventions for the child and caregiver including coaching, psychotherapy, and psychiatry delivered on the web. Our results were consistent with previous studies that demonstrated that the severity of the child's problems is a key predictor of caregiver strain [29]. By matching patients and their families to the appropriate care pathway (ie, coaching vs psychotherapy vs psychiatry) based on both the child's symptom severity and family preference, this study suggests that these sources of caregiver strain can be improved. Not surprisingly, given their baseline acuity, families in coaching required fewer sessions and could be cared for in a shorter timeframe than families receiving the most intensive psychiatric care, which suggests that lower-intensity interventions may be an important part of the overall care landscape for families. Although other authors have found caregiver strain to vary by race and ethnicity in the adult mental health literature [6], we did not. This would be worth evaluating in a future analysis of caregivers for children.

Second, the drivers of caregiver strain measured within the CGSQ-SF7 vary among families with children in need of behavioral health services. While providing care focused on the child is beneficial for caregiver outcomes, it may also be valuable to target additional care to the specific needs of the caregiver. Targeted interventions may be more possible with the identification of key drivers of caregiver strain, which may be overlooked when relying on the CGSQ-SF7 total, objective, or subjective subscales alone. Specifically, disrupted family relationships and time interruptions, missing work, and financial strain are distinct caregiver strain symptoms within the CGSQ-SF7 that independently clustered in our population. Despite these symptoms being objective measures of caregiver strain, it may be insightful for providers to not only administer the CGSQ-SF7, but also to individually evaluate these distinct symptom clusters within the CGSQ-SF7 objective subscale, and include these considerations in care planning, as they may provide insights into the specific action plan and supportive interventions for each family. For example, for those caregivers for whom disrupted family relationships and time interruption were key drivers of caregiver strain, whole-family counseling or marital counseling may be warranted [30]. Similarly, those caregivers most worried about their child’s future who feel tired and sad may benefit from individual care or respite programs [31]. In addition, employers may have a role in mitigating strain among caregivers of children with mental illness. For caregivers for whom missed work was a key driver of strain, a more flexible work schedule may be helpful, and a robust benefit offering of no and low-cost mental health solutions may be particularly helpful for caregivers for whom the financial strain of caring for their children was the key driver of their strain. Future research should specifically evaluate additional interventions for caregivers, and whether those are most impactful delivered separately for caregivers or embedded within care for the family.

Limitations

Our analysis had several limitations; the first being our retrospective, observational design that did not include randomization or a control group. The second limitation is driven by our limited demographic data on each dyad which only included the age, gender, and race and ethnicity of the child. This lack of broad demographic data meant we were unable to control other important demographic variables, such as socioeconomic status, rurality, and family structure, since users are not currently required to provide this information to receive care. Third, while uncommon, it is possible for multiple caregivers to be involved in care. Fourth, we do not account for the number of care sessions completed by each dyad and how dose may moderate outcome estimates. Finally, this analysis aggregated all mental health diagnoses and concerns into one group. Specific diagnoses and concerns may have varying outcomes to web-based behavioral health programs and have different sources of caregiver strain. Future studies will address these limitations.

Conclusion

This analysis of a web-based, multi-tiered pediatric mental health care model demonstrates a positive impact on caregiver strain among a privately insured population with access to a computer or smartphone. We also identified common sources of caregiver strain measured within the CGSQ-SF7 among parents caring for a child with a mental health condition. We hope this work will inform the ongoing development of web-based pediatric mental health models and the designs of health benefits for commercially insured populations.

Data Availability

The data sets generated during and/or analyzed during this study are not publicly available but are available from the corresponding author on reasonable request. STROBE guidelines were adhered to and submitted as Multimedia Appendices.

Authors' Contributions

All authors reviewed the manuscript and approved the final submission. TL participated in the design, analysis, editing, and writing of the manuscript. MA, DG, JLG, and DB participated in the study design, editing, and writing of the manuscript.

Conflicts of Interest

TL, DG, MA, and JLG are employees of Brightline, Inc. DB is on the advisory board of Brightline, Inc.

Multimedia Appendix 1

Univariate linear regressions examining the relationship between Caregiver Strain Questionnaire (CGSQ-SF7 Total score) and Pediatric Symptom Checklist (PSC-17 Total score).

[DOCX File , 14 KB - pediatrics_v7i1e59475_app1.docx]

Multimedia Appendix 2
Univariate linear regressions examining the relationship between the change in Caregiver Strain Questionnaire (CGSQ-SF7 Total score) and Pediatric Symptom Checklist (PSC-17 Total score) from baseline to follow-up.
[DOCX File , 14 KB - pediatrics_v7i1e59475_app2.docx]

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Abbreviations

CGSQ-SF7: Caregiver Strain Questionnaire-Short Form 7
MATCH-ADTC: Modular Approach to Therapy for Anxiety, Depression, Trauma, or Conduct Problems
PMT: parent management training
PSC-17: Pediatric Symptom Checklist-17
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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An Online Resource for Monitoring 24-Hour Activity in Children and Adolescents: Observational Analysis

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Abstract

Background: The Singapore integrated 24-hour activity guide for children and adolescents was introduced to promote healthy lifestyle behaviors, including physical activity, sedentary behavior, sleep, and diet, to enhance metabolic health and prevent noncommunicable diseases. To support the dissemination and implementation of these recommendations, a user-friendly online resource was created to help children and adolescents adopt these behaviors in Singapore.

Objective: This study aimed to assess the acceptability of the online resource in the adoption of healthier lifestyle behaviors, and the change in the users’ behaviors with the use of this online resource.

Methods: Participants aged 7-17 years were required to log their activity levels of the past 7 days at the beginning and at the end of a 3-month period using the browser-based online resource, including information on the duration and frequency of moderate-to vigorous-intensity physical activity (MVPA), length of sedentary behavior, duration and regularity of sleep, and food portions. User satisfaction, on the length, ease of use, and relevance of the online resource, was also recorded using a 10-point Likert scale. Descriptive statistics and statistical analyses, including the Wilcoxon signed rank test and McNemar test, were carried out at baseline and at the end of 3 months.

Results: A total of 46 participants were included for analysis. For physical activity, the number of days of MVPA increased from a median of 3 (IQR 2 - 5) days to 4 (IQR 2 - 5) days (P=.01). For sedentary behavior, the median daily average screen time decreased from 106 (IQR 60 - 142.5) minutes to 90 (IQR 60 - 185) minutes. For sleep, 10% (5/46) more participants met the recommended duration, and the number of days with regular sleep increased from a median of 6 (IQR 5 - 7) days to 7 (IQR 5 - 7) days (P=.03). For diet, there was a decrease in the portion of carbohydrates consumed from a median of 42% (IQR 30 - 50) to 40% (IQR 30 - 48.5; P=.03), and the number of days of water and unsweetened beverage consumption remained stable at a median of 5 days but with a higher IQR of 4 - 7 days (P=.04). About 90% (39-41/46) of the participants reported that the online resource was relevant and easy to use, and the rating for user satisfaction remained favorable at a median of 8 with a higher IQR of 7 - 9 (P=.005).

Conclusions: The findings support the development of a dedicated online resource to assist the implementation of healthy lifestyle behaviors based on the Singapore integrated 24-hour activity guide for children and adolescents. This resource received favorable ratings and its use showed the adoption of healthier behaviors, including increased physical activity and sleep, as well as decreased sedentary time and carbohydrate consumption, at the end of a 3-month period.

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KEYWORDS

online; physical activity; sedentary behaviour; sleep; diet; 24-hour activity; child; adolescent

Introduction

The World Health Organization (WHO) has identified the adoption of healthy lifestyle behaviors as a key preventive strategy against noncommunicable diseases (NCDs), such as cardiovascular diseases, cancers, and diabetes [1]. This strategy is best implemented when one is young, as children are not immune to the adverse health effects of suboptimal lifestyle behaviors [1]. Local longitudinal studies have also shown that children suffer adverse health effects from suboptimal lifestyle behaviors, including higher BMI from a lack of physical activity [2], longer screen time [3,4], and insufficient sleep [5]. Shorter sleep was also associated with decreased body length in the first 2 years of life [5]. This is even more concerning given the rise in the percentage of local overweight school-going children from 11% in 2013 to 17% in 2021 [6], and that less than half of these children are achieving the recommended amount of physical activity [7].

To improve the metabolic health of Singaporean children and adolescents aged 7-17 years, Singapore integrated 24-hour activity guide for children and adolescents was introduced to provide up-to-date and evidence-based recommendations on physical activity, sedentary behaviors, sleep and eating habits, framed within a 24-hour period [7]. During the development of this guide, Quah et al [8] surveyed 100 parents of school-going children revealing that they were concerned about the lack of physical activity and excessive screen-viewing time in their children, but only about half of these parents were aware of what the recommendations are for these activities. The findings from this study also highlight the importance of dissemination and implementation of the guide, including the development of resources to improve the awareness and adoption of this guide in the community [8].

Therefore, the aim of this pilot study was to create a user-friendly online resource to assess a child's or adolescent's activity levels based on the guide, with advice on improving or maintenance of the respective behaviors. The objectives were to assess the acceptability of the online resource in the adoption of healthier lifestyle behaviors, and the change in the user's behaviors with the use of this online resource.

Methods

Study Sample

The participants were recruited using a convenience sampling method via posters and social media advertisements. Eligible participants had to be of school-going age from 7 to 17 years, have access to electronic devices with an internet connection, and be able to participate in physical activity. Participants were required to log their activity levels using the online resource at the beginning and the end of a 3-month period (ie, baseline entry during the first week and final entry during the 12th week of the 3-month period).

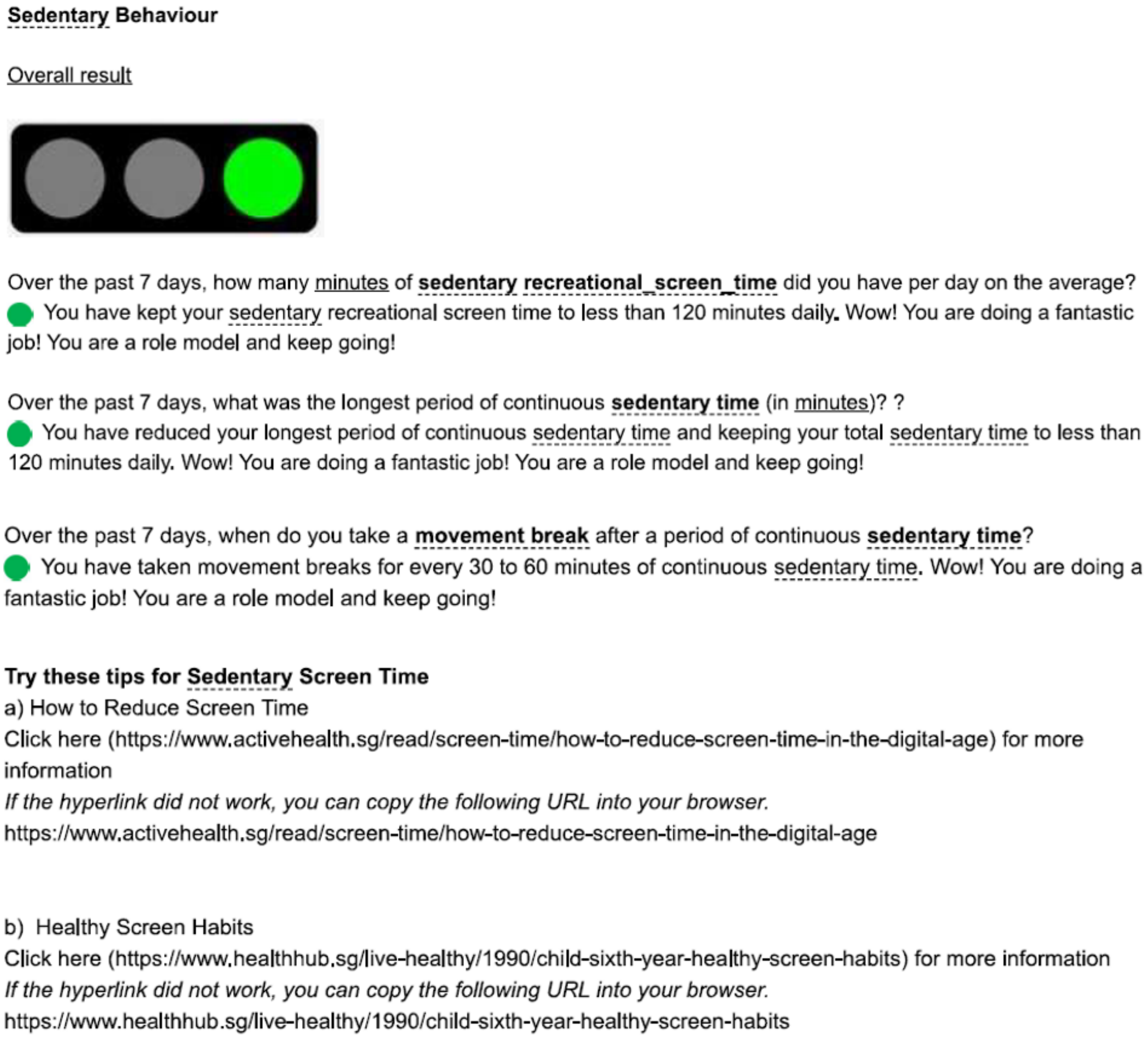
Ethical Considerations

This study obtained ethics approval with an exempt review from the SingHealth Centralised Institutional Review Board (reference number 2021/2403). Informed consent from parents and assent from participants were obtained before using the online resource, and they were allowed to withdraw from the study at any time. All data were de-identified using unique study IDs. All participants received SGD 20 (US $15.07) upon completing each survey as compensation for their time.

Resource Design and Data Collection

The online resource was designed as a browser-based activity diary. This resource was accessed via both computer and mobile devices. Each participant was assigned a unique username and a random password was generated for each entry. To improve the user interface and to minimize incomplete or missing data, participants were required to key in their information or activity level using a drop-down list or along a numerical bar. The questions for each activity domain were presented on a single page and were in sequential order (ie, all questions for physical activity were on the first page and all questions for sedentary behavior were on the next page). After entering all required data, the participant proceeded to the report page and was prevented from returning to edit the entered data. The resource was programmed to generate a report based on the data for each activity domain in the form of traffic light colors. Green was shown when the participant had met all recommendations for that domain, yellow if he or she met some, and red if none of the recommendations was achieved. Following the report, messages of encouragement and advice were displayed to help the participants maintain or improve their lifestyle behaviors (refer to Figures 1-3 for samples of reports, messages, and advice generated). Several links to recommendations and resources including the Singapore integrated 24-hour activity guide were also provided [7].

Figure 1. Sample of report, messages and advice generated in the online resource tool (green color shown) when recommendations are met for sedentary behavior.



Sedentary Behaviour

Overall result

Over the past 7 days, how many minutes of **sedentary recreational_screen_time** did you have per day on the average?
● You have kept your sedentary recreational screen time to less than 120 minutes daily. Wow! You are doing a fantastic job! You are a role model and keep going!

Over the past 7 days, what was the longest period of continuous **sedentary time** (in minutes)? ?
● You have reduced your longest period of continuous sedentary time and keeping your total sedentary time to less than 120 minutes daily. Wow! You are doing a fantastic job! You are a role model and keep going!

Over the past 7 days, when do you take a **movement break** after a period of continuous **sedentary time**?
● You have taken movement breaks for every 30 to 60 minutes of continuous sedentary time. Wow! You are doing a fantastic job! You are a role model and keep going!

Try these tips for Sedentary Screen Time
a) How to Reduce Screen Time
Click here (https://www.activehealth.sg/read/screen-time/how-to-reduce-screen-time-in-the-digital-age) for more information
If the hyperlink did not work, you can copy the following URL into your browser.
https://www.activehealth.sg/read/screen-time/how-to-reduce-screen-time-in-the-digital-age

b) Healthy Screen Habits
Click here (https://www.healthhub.sg/live-healthy/1990/child-sixth-year-healthy-screen-habits) for more information
If the hyperlink did not work, you can copy the following URL into your browser.
https://www.healthhub.sg/live-healthy/1990/child-sixth-year-healthy-screen-habits

Figure 2. Sample of report, messages, and advice generated in the online resource tool (yellow color shown) when some recommendations are met for sleep.

Sleep

Overall result

Over the past 7 days, how many hours of **sleep** did you have per night on the average?
🔴 This seems really tough but every effort counts. Let's try with a little more this week and progress towards having 6/7/8 hours or more of daily sleep. We are cheering for you!

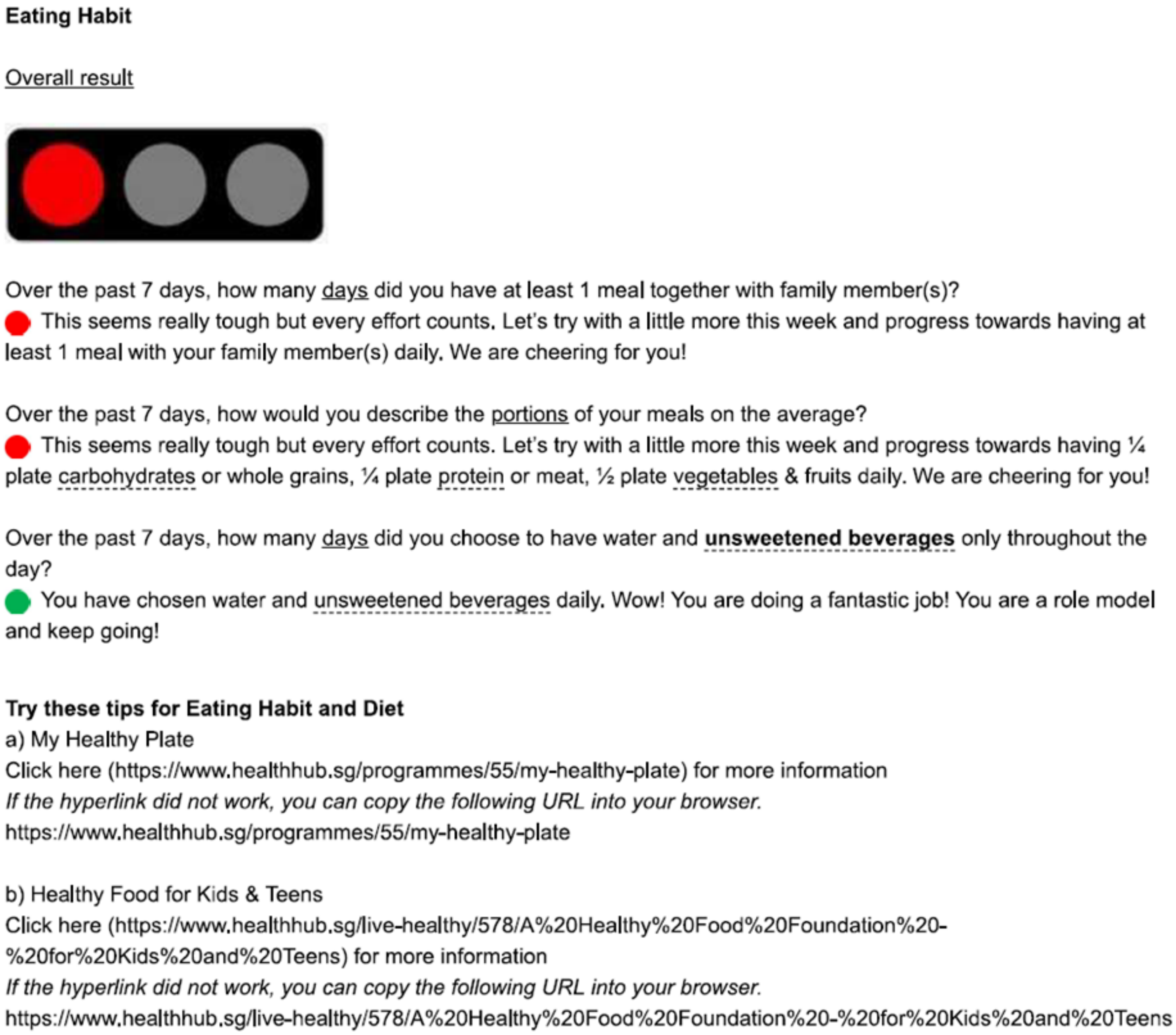
Over the past 7 days, how many days did you have a **regular_sleep_and_wake_up_time**?
🟢 You have had a regular sleep and wake up time daily. Wow! You are doing a fantastic job! You are a role model and keep going!

Over the past 7 days, how many days of **uninterrupted_sleep** did you have?
🟢 You have had uninterrupted sleep daily. Wow! You are doing a fantastic job! You are a role model and keep going!

Try these tips for Sleep
a) Having Good Sleep
Click here (https://www.healthhub.sg/programmes/117/goodsleep) for more information
If the hyperlink did not work, you can copy the following URL into your browser.
https://www.healthhub.sg/programmes/117/goodsleep

b) Holiday Sleeping Tips
Click here (https://www.healthhub.sg/live-healthy/1860/should-kids-sleep-in-when-schools-out) for more information
If the hyperlink did not work, you can copy the following URL into your browser.
https://www.healthhub.sg/live-healthy/1860/should-kids–sleep-in-when-schools-out

Figure 3. Sample of report, messages, and advice generated in the online resource tool (red color shown) when recommendations are not met for eating habits.



Eating Habit

Overall result

Over the past 7 days, how many days did you have at least 1 meal together with family member(s)?

🔴 This seems really tough but every effort counts. Let's try with a little more this week and progress towards having at least 1 meal with your family member(s) daily. We are cheering for you!

Over the past 7 days, how would you describe the portions of your meals on the average?

🔴 This seems really tough but every effort counts. Let's try with a little more this week and progress towards having ¼ plate carbohydrates or whole grains, ¼ plate protein or meat, ½ plate vegetables & fruits daily. We are cheering for you!

Over the past 7 days, how many days did you choose to have water and **unsweetened beverages** only throughout the day?

🟢 You have chosen water and unsweetened beverages daily. Wow! You are doing a fantastic job! You are a role model and keep going!

Try these tips for Eating Habit and Diet

a) My Healthy Plate

Click here (https://www.healthhub.sg/programmes/55/my-healthy-plate) for more information

If the hyperlink did not work, you can copy the following URL into your browser.

https://www.healthhub.sg/programmes/55/my-healthy-plate

b) Healthy Food for Kids & Teens

Click here (https://www.healthhub.sg/live-healthy/578/A%20Healthy%20Food%20Foundation%20-%20for%20Kids%20and%20Teens) for more information

If the hyperlink did not work, you can copy the following URL into your browser.

https://www.healthhub.sg/live-healthy/578/A%20Healthy%20Food%20Foundation%20-%20for%20Kids%20and%20Teens

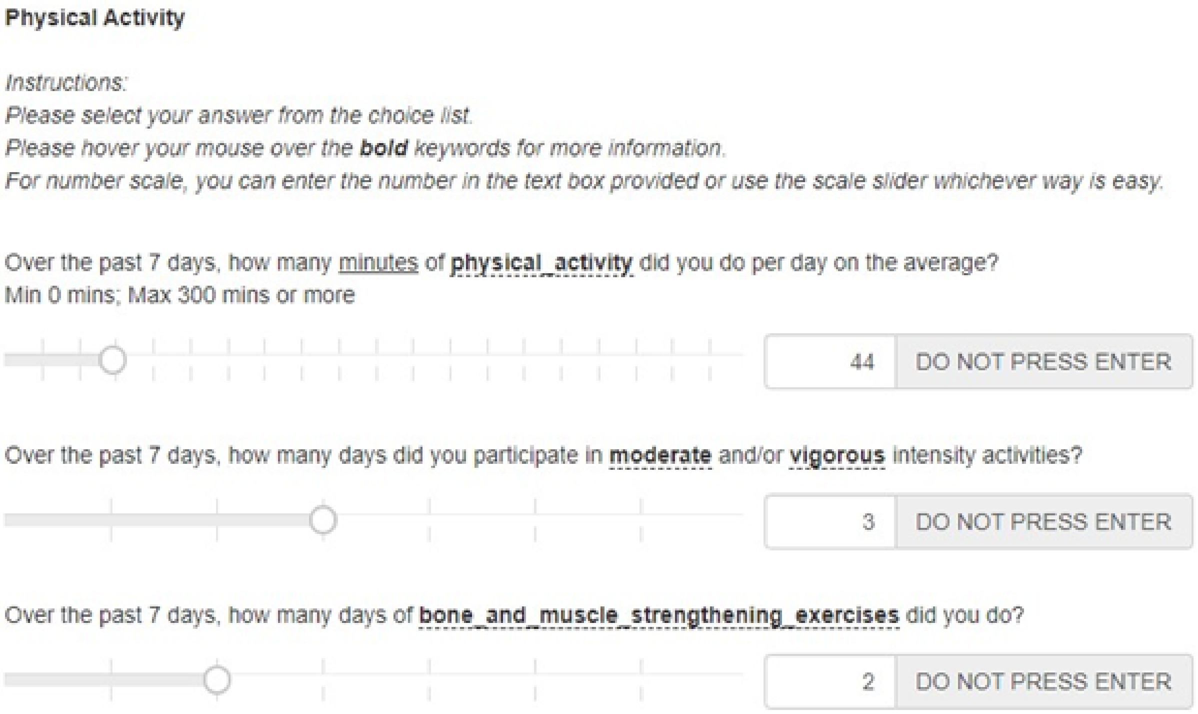
Question Design and Content Validation

A total of 27 questionnaire items garnered data on demographics, physical activity, sedentary behavior, sleep, eating habits, and user satisfaction. Participants aged 9 years and younger were recommended to enter the data together with their parents, and those older than 9 years did by themselves and sought their parent's guidance as needed. The participants were required to answer the activity questions based on their lifestyle activities over the past 7 days. Demographic information was solicited only when the participants used the resource for the first time, which included age, gender, ethnicity, height, and weight. The level of motivation for exercise of the participants was assessed using 4 questions adapted from Exercise Is Medicine, Australia [9]. In total, 3 questions were created for each activity domain based on the recommendations stated in the Singapore integrated 24-hour activity guide for children and adolescents. As there was no prior resource tool developed on the basis of this guide, all questions were created de novo by the guide developers. To improve the understanding and acceptability by local participants, the questions were written using similar language and styles used in the guide, and local resources were quoted whenever applicable. These questions were content validated qualitatively and quantitatively (content validity index of 0.94) for relevance and representativeness by two independent content experts using the response process validation procedure–an advocated best practice procedure outlined by Yusoff [10]. The content validity index of 0.94 is within the recommended acceptable range of at least 0.80 [10].

Assessment of Physical Activity and Sedentary Behavior

To assess the quantity of physical activity participation in the past 7 days, the participants were asked about the number of minutes of physical activity (inclusion of all intensities) engaged per day on average, the number of days they participated in activities of moderate to vigorous intensity, and the number of days they participated in muscle- and bone-strengthening exercises (refer to Figure 4). The recommended amount of physical activity is to engage in 420 minutes or more of moderate- to vigorous-intensity physical activity (MVPA) and to participate in 3 or more days of muscle- and bone-strengthening activities in a week [7].

Figure 4. Questions asked and sample response in the online resource tool for physical activity.



Physical Activity

Instructions:
Please select your answer from the choice list.
*Please hover your mouse over the **bold** keywords for more information.*
For number scale, you can enter the number in the text box provided or use the scale slider whichever way is easy.

Over the past 7 days, how many minutes of **physical_activity** did you do per day on the average?
Min 0 mins; Max 300 mins or more

44

Over the past 7 days, how many days did you participate in **moderate** and/or **vigorous** intensity activities?

3

Over the past 7 days, how many days of **bone_and_muscle_strengthening_exercises** did you do?

2

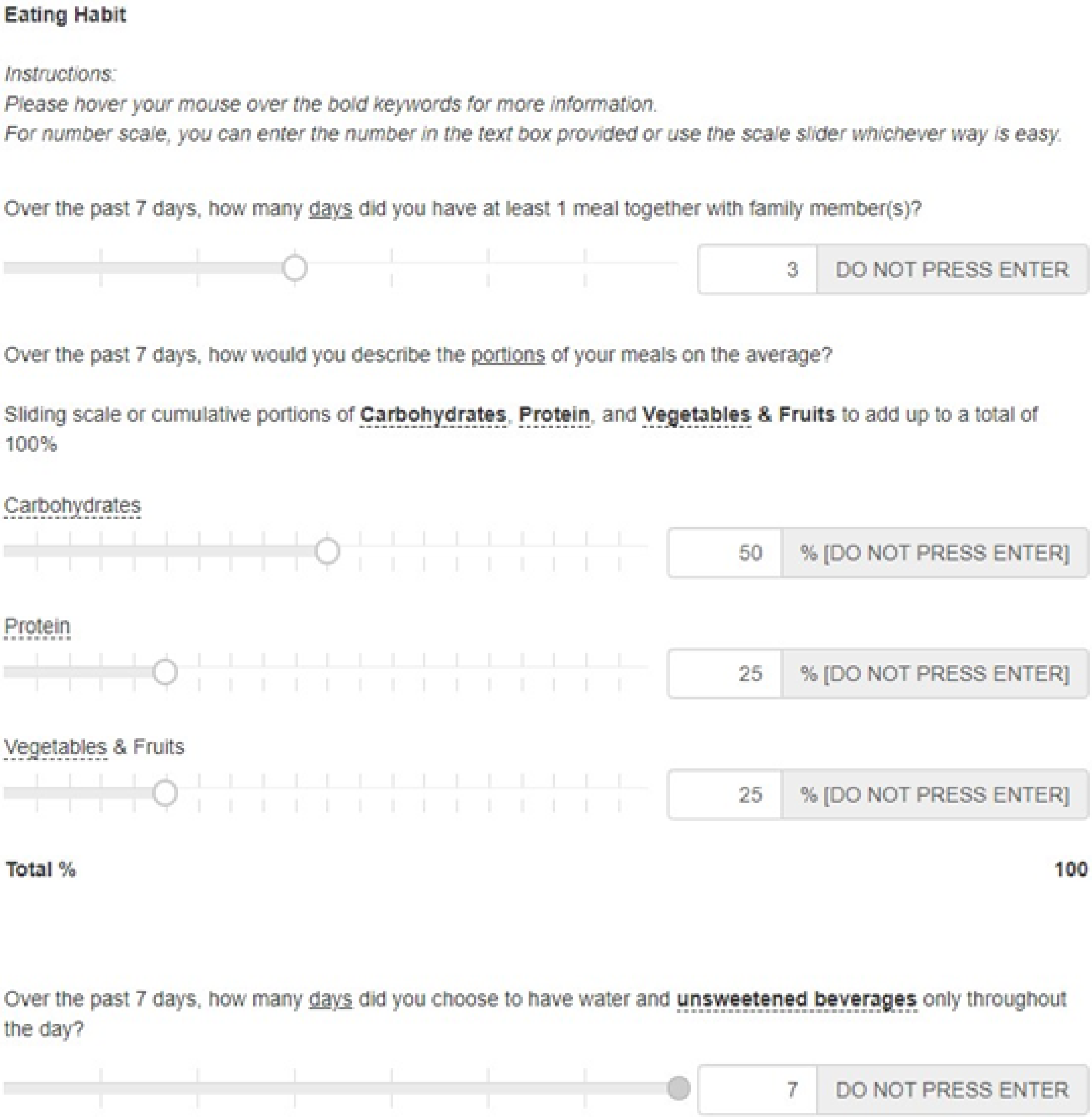
To assess the amount of sedentary behavior over the past 7 days, the participants were asked the daily average of sedentary recreational screen time, the longest period of continuous sedentary time, and when they took a movement break after a period of sedentary time. All these periods were participant-reported in minutes. The recommended average amount of screen time and continuous sedentary time is 120 minutes or less, and the recommended movement break is after every 60 minutes or less of sedentary time [7].

Assessment of Sleep and Eating Habits

To assess the quantity and quality of their sleep in the past 7 days, the participants were asked the average number of hours of sleep per night, the number of days they had regular sleep, and the number of times they woke up from sleep as well as the number of days of uninterrupted sleep. The recommended duration of sleep is according to the participant's age group (9-11 h for 7-13 y and 8-10 h for 14-17 y), and they are recommended to have regular and uninterrupted sleep daily (ie, 7 d per week) [7].

To assess the characteristics of their eating habits over the past 7 days, the participants were asked the number of days they had at least one meal with their family members, the average portions of carbohydrate, protein, vegetable and fruit consumed per meal (adding to a total of 100%), and the number of days they drank water and unsweetened beverages (refer to Figure 5). The recommended portion of food is 25% of carbohydrate, 25% of protein, and 50% vegetables and fruit, and it is recommended to have at least one meal with their family members and to choose water and unsweetened beverages daily (ie, 7 d per week) [7].

Figure 5. Questions asked and sample response in the online resource tool for eating habits.



Eating Habit

Instructions:
Please hover your mouse over the bold keywords for more information.
For number scale, you can enter the number in the text box provided or use the scale slider whichever way is easy.

Over the past 7 days, how many days did you have at least 1 meal together with family member(s)?

3 DO NOT PRESS ENTER

Over the past 7 days, how would you describe the portions of your meals on the average?

Sliding scale or cumulative portions of **Carbohydrates**, **Protein**, and **Vegetables & Fruits** to add up to a total of 100%

Carbohydrates 50 % [DO NOT PRESS ENTER]

Protein 25 % [DO NOT PRESS ENTER]

Vegetables & Fruits 25 % [DO NOT PRESS ENTER]

Total % **100**

Over the past 7 days, how many days did you choose to have water and **unsweetened beverages** only throughout the day?

7 DO NOT PRESS ENTER

User Satisfaction

The participants were asked about their opinion of the length of the survey (too short, just right, or too long), if the questions were easy to understand and if the online resource was easy to use (yes or no), if they thought that the questions were relevant to their health (important, somewhat important, not sure, somewhat not important, or not important), and their user satisfaction of the online resource using a 10-point Likert scale rating (1=very poor; 10=very good).

Statistical Analyses

Data analyses were conducted using the IBM SPSS Statistics for Windows (version 28.0). Continuous variables were presented as median and IQR and categorical variables as numbers and percentages. The Wilcoxon signed rank test and McNemar test were used to compare continuous variables and categorical variables, respectively, between the baseline and 3-month follow-up responses. Statistically significant results were determined at two-sided *P* values of less than .05. Effect size was measured using probability superiority with a value of more than 0.5 indicating a large effect for the 3-month follow-up assessments when compared with baseline assessments.

Results

Study Participants

A total of 57 participants were recruited from July to December 2022 and 11 participants were excluded due to incomplete data entry (ie, N=46). The details of the participants included are presented in Table 1. The mean age of the participants was 9.9 (SD 2.6) years with 52% (24/46) males, and the majority being Chinese (40/46, 87%). Most of the participants (37/46, 81%) reported that they have been physically active for the past 6 months (ie, maintenance phase in the 5 stages of change), and 9% (4/46) in the preparation phase with the remaining in the contemplation or precontemplation phase of exercise motivation [9].

Table . Characteristics of participants including their level of motivation (N=46).

Characteristics		Included participants (N=46)
Age (years), mean (SD)		9.9 (2.6)
Sex, n (%)		
	Male	24 (52)
	Female	22 (48)
Ethnicity, n (%)		
	Chinese	40 (87)
	Others	6 (13)
Exercise motivation level, n (%)		
	Maintenance	37 (81)
	Action	0 (0)
	Preparation	4 (9)
	Contemplation	2 (4)
	Precontemplation	3 (7)

Survey Satisfaction

A survey of participants' first-time usage of the online resource showed that 89% (41/46) agreed that the survey length was just right, and 85% (39/46) found the online resource easy to use. Almost 90% (41/46) of the participants reported that the questions were at least somewhat important to their health and 94% (43/46) found the questions easy to understand. The user satisfaction rating of the online resource was favorable at a median of 8 (IQR 6 - 8), based on a 10-point Likert scale. The results of the participants' 3-month follow-up rating showed that all aspects remained consistent and the rating was still favorable at a median of 8 with a higher IQR of 7 - 9 (P=.005). The survey rating was statistically significant (refer to Table 2).

Table . Rating of online resource tool at baseline and 3-month follow-up.

Domain		Baseline	3-month follow-up	*P* value[a]
Length of survey, n (%)				
	Too short	1 (2)	0 (0)	.56
	Just right	41 (89)	42 (91)	
	Too long	4 (9)	4 (9)	
Easy to understand, n (%)				
	Yes	43 (94)	43 (94)	>.99
	No	3 (7)	3 (7)	
Easy to use, n (%)				
	Yes	39 (85)	43 (94)	.12
	No	7 (15)	3 (7)	
Questions that are relevant to health, n (%)				
	Important	20 (44)	23 (50)	.53
	Somewhat important	21 (46)	17 (37)	
	Not sure	1 (2)	4 (9)	
	Somewhat not important	4 (9)	2 (4)	
	Not important	0 (0)	0 (0)	
User satisfaction rating of tool, median (IQR)				
	Median rating	8 (6 - 8)	8 (7 - 9)	.005

[a] *P* values are calculated using Wilcoxon signed rank test and McNemar test for continuous variables and categorical variables, respectively.

Baseline Activity Assessment

The duration of physical activity per day (for the past 7 d) recorded was a median of 60 (IQR 30 - 120) minutes, and the number of days of MVPA (for the past 7 d) and muscle- and bone-strengthening activities (for the past 7 d) were a median of 3 (IQR 2.0 - 5.0) days and 2 (IQR 1 - 3) days, respectively. The daily sedentary screen time per day (for the past 7 d) recorded was a median of 106 (IQR 60 - 142.5) minutes, and 21.8% (10/46) reported that their longest period of continuous sedentary behavior was above 120 minutes. The median period of daily sedentary behavior when the participants would take a movement break was 52.5 (IQR 30 - 60) minutes.

In terms of sleep, the number of hours slept per day (for past 7 d) was a median of 8 (IQR 8 - 9) hours, with 36.9% (17/46) meeting the recommended duration. The number of days with regular and uninterrupted sleep (for past 7 d) was a median of 6 (IQR 5 - 7) days and 7 (IQR 5 - 7) days, respectively. Just over 80% (37/46) of the participants reported having meals with their family daily over the past 7 days, and the median portions of carbohydrate, protein, and vegetable and fruit were 42% (IQR 30 - 50), 30% (IQR 28 - 35), and 30% (SD 20 - 32.8), respectively. The number of days of drinking water and unsweetened beverages in the past 7 days was a median of 5 (IQR 1 - 6) days with 20% (9/46) of the participants reporting doing so daily.

3-Month Follow-Up Activity Assessment

In a pre-to-post context, the average daily physical activity for the past 7 days remained stable at a median of 60 minutes but with a smaller IQR of 30 - 62.5 minutes (P=.03), while the number of days of MVPA and muscle- and bone-strengthening activity increased to a median of 4 (IQR 2 - 5.3) days (P=.01) and 3 (IQR 1 - 5) days (P=.02), respectively. There was a decrease in the daily average sedentary screen time to a median of 90 (IQR 60 - 185) minutes (P=.54), and fewer participants (14.3%, 7/46) reported their longest continuous period of sedentary time was more than 120 minutes. The median period of sedentary time before the participants took a movement break was also reduced to 30 (IQR 18.8 - 60) minutes (P=.08). The changes in the average physical activity duration, number of days of MVPA, and number of days of muscle- and bone-strengthening exercises were statistically significant (refer to Table 3).

Table . Level of physical activity, sedentary behavior, sleep and eating habits over the past 7 days–baseline and 3-month follow-up assessments using the online resource tool.

Domain	Baseline	3-month follow-up	*P* value	Probability superiority
Physical activity, median (IQR)				
Daily average amount (min)	60 (30-120)	60 (30-62.5)	.03	0.40
Moderate to vigorous physical activity (days)	3 (2 - 5)	4 (2 - 5.3)	.01	0.66
Muscle- and bone-strengthening activity (days)	2 (1 - 3)	60 (30 - 62.5)	.02	0.70
Sedentary behavior (min), median (IQR)				
Daily average screen time	106 (60 - 142.5)	90 (60 - 185)	.54	0.58
Longest continuous period	90 (60 - 120)	90 (60 - 120)	.79	0.52
Period of sedentary time before taking a break	52.5 (30 - 60)	30 (18.8 - 60)	.08	0.58
Sleep, median (IQR)				
Daily average amount (h)	8 (8 - 9)	8 (8 - 9)	.003	0.63
Regular sleep (days)	6 (5 - 7)	7 (5 - 7)	.03	0.60
Uninterrupted sleep (days)	7 (5 - 7)	7 (6 - 7)	.02	0.59
Eating habits, median (IQR)				
Meals with family members (days)	7 (0)	7 (0)	.34	0.48
Average portion of carbohydrate (%)	41.5 (30 - 50)	40 (30 - 48.5)	.03	0.64
Average portion of protein (%)	30 (28 - 35)	30 (28.8 - 36.3)	.22	0.40
Average portion of vegetable (%)	30 (20 - 32.8)	30 (20 - 35.3)	.10	0.62
Water and unsweetened beverages (days)	5 (1 - 6)	5 (4 - 7)	.04	0.66

The sleep duration remained stable at a median of 8 (IQR 8 - 9) hours (*P*=.003) but the increase in the minimum number of hours from 5 to 6 hours and the mean from 8.09 (SD 1.1) to 8.46 (SD 1.0) hours (data not shown) likely accounted for the significant *P* value. The percentage of participants meeting the recommended duration also increased to 48% (22/46; data not shown). The number of days with regular sleep increased to a median of 7 (IQR 5 - 7) days (*P*=.03) while the number of days with uninterrupted sleep improved to a median of 7 (IQR 6 - 7) days (*P*=.02). In terms of diet, there was a decrease in the percentage of participants having meals with their family daily (36/46, 78%). The median proportion of carbohydrate decreased to 40% (IQR 30 - 48.5*;* *P*=.03), whereas the proportions of protein and fruit and vegetable remained stable at 30% (IQR 28.8 - 36.3*;* *P*=.22) and 30 (IQR 20 - 35.3*;* *P*=.10), respectively. The number of days of water and unsweetened beverage consumption also remained stable at a median of 5 days but with a higher IQR of 4 - 7 days (*P*=.04). The average duration of sleep, number of days of regular sleep, number of days of uninterrupted sleep, portions of carbohydrate, and number of days of water and unsweetened beverage consumption were statistically significant (refer to Table 3).

Discussion

Principal Findings

This pilot study demonstrated that the novel online resource for improving lifestyle behaviors received consistent favorable ratings from the participants, with 87% to 89% agreeing that it was relevant to their health, and 85% to 94% agreeing that it was easy to use. These results help to reinforce the usefulness of online resources in assisting lifestyle behavioral changes and these may be in the form of a web-based tool [11,12], mobile app [13], or a combination of both [14]. van der Weegen et al [14] demonstrated that incorporating mobile and web-based tools in clinical practice increased the amount of participants' physical activity and the effect was still evident after 3 months. Online dietary tools were also developed in the United States and the United Kingdom as a part of their strategy to intervene in dietary habits at the population level. However, most of these tools focus only on a single lifestyle behavior and there is a paucity of available online resources that support the contemporary 24-hour activity approach. Therefore, it is imperative to develop an online resource to support the Singapore integrated 24-hour activity guide for children and adolescents as a concerted effort to improve the lifestyle behaviors in this pediatric population.

The assessment of the participants' activities also revealed that a significant proportion was unable to meet the recommendations in each activity domain. For instance, the calculated duration of MVPA in a week was 180 minutes (median average physical activity duration multiplied by median MVPA days – 60 min multiplied by 3 d), which was less than the recommended 420 minutes per week. Similarly, 63% (29/46) of the participants did not achieve the recommended sleep duration, and yet, the median sedentary screen time was close to 120 (IQR 60-142.5) minutes. Although the current recommendation on sedentary screen time is to be as low as possible, many parents might still be familiar with the previous recommendation of less than 120 minutes per day by the American Academy of Pediatrics [15]. In terms of their diet, the mean proportions of the main food groups also fell short of the recommended 25% of carbohydrate and protein, respectively, and 50% vegetable and fruit. These findings are consistent with studies in recent years, highlighting similar concerns that many children and adolescents in Singapore are not meeting these recommendations and hence not adopting healthy lifestyle habits [8,16,17]. Therefore, there is an ongoing need to educate the public on these recommendations and provide resources to aid them to adopt these lifestyle behaviors more easily.

Improvements in most lifestyle behaviors were observed when comparing the participants' 3-month follow-up activity assessments with their baseline assessments. In terms of physical activity, the number of days engaging in MVPA and muscle- and bone-strengthening activities increased from a median of 3 (IQR 2.0-5.0) days and 2 (IQR 1.0-3.0) days to 4 (IQR 2.0-5.3) days and 3 (IQR 1.0-5.0) days, respectively. Consequently, the calculated median duration of MVPA for the week also increased to 240 minutes. The average sedentary screen time decreased from a median of 106 (IQR 60.0-142.5) minutes to 90 (IQR 60.0-185.0) minutes, and the participants were taking earlier movement breaks after a median sedentary period of 30 (IQR 18.8-60.0) minutes as compared with the initial 52.5 (IQR 30.0-60.0) minutes. There were also improvements seen in sleep and dietary habits. The number of days with regular sleep increased from a median of 6 (IQR 5.0-7.0) days to 7 (IQR 5.0-7.0) days, and their carbohydrate intake decreased from a median of 41.5% (IQR 30.0%-50.0%) to 40% (30.0%-48.5%). Other components showed consistent results, such as the average daily amount of physical activity, the daily average amount of sleep, and the number of days consuming water and unsweetened beverages when compared with their baseline assessments; no deteriorating trend was found. These results showed the promising potential of using the online resource to tackle multiple lifestyle behavior domains of a subgroup within a population, and the effects could be enhanced by combining its use with clinical services and extending its adoption over a longer period [14].

The current movement guidelines toward an integrated 24-hour activity approach are built upon the evidence that similar health benefits can be achieved by meeting the recommendations of various combinations of activity domains [18,19]. Children and adolescents who meet all the recommendations have been shown to receive the best health benefits [20,21]. With the inclusion of dietary recommendations in the Singapore integrated 24-hour activity guide, a more comprehensive and holistic behavioral guidance approach of eating, moving, sleeping, and sitting is adopted. At the start of the pilot study, only 1 participant reported meeting the 3 movement recommendations (ie, physical activity, sedentary behavior, and sleep) but none met all recommendations including the dietary ones. These data improved by the end of the 3-month pilot study with 5 participants meeting the 3 movement recommendations and 2 meeting all, including the dietary recommendations. This improvement was likely because of improved participant and parental awareness of current recommendations and monitoring of their activities.

The next phase includes expanding this online resource to other age groups and developing it as a mobile app to improve user accessibility and community penetration. Leveraging on the experience of Singapore Paediatric Activity–Related Evaluation (SPARE) tool development, current team members have joined another work group to develop a similar digital resource for children aged 0 to 2 years. The eventual aim is to integrate all these resources into the institution's mobile health app so that a wider community can access and use these resources for themselves or their children.

Strengths and Limitations

This study is the first pilot on a single online resource that integrated multiple lifestyle behavior domains based on the latest 24-hour recommendations for Singaporean children and adolescents. The strength of the study lies in the assimilation of multiple lifestyle behavior activities in a single resource, and with the survey questions adapted to the local context. The limitations of the study include selection bias from the convenience sampling method and recall bias as participants were required to report their past activities. The decision for a 7-day recall was because it is a standard duration to capture habitual behaviors across weekdays and weekends. The small sample size and short timeframe of this study limit the generalizability of the findings to the national population and observations of long-term behavioral changes. Another limitation is the expectancy effects with self-reporting measures, which may influence participants' reporting toward socially acceptable norms.

Conclusions

This study showed that there were consistent favorable ratings from participants on its use. There was also the adoption of healthier lifestyle behaviors when comparing the participants' 3-month follow-up activity assessments with their baseline assessments after using the online resource, including increased physical activity and sleep while decreased sedentary time and carbohydrate consumption. The findings from this pilot study therefore support the role of developing a dedicated resource for the Singapore integrated 24-hour activity guide to assist in the promotion and implementation of the guide in children and adolescents [8]. Building a single resource catering for all activities provided easy access and likely catalyzed the awareness and adoption of these recommendations. The next phase would be to scale up the online resource in order to provide more convenient access, such as a mobile app, and to incorporate it into daily clinical practice.

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Authors' Contributions

All authors contributed to the design of the study. BKGL and FF collected the data. BKGL and SHT analyzed the data. BKGL provided the first draft of the manuscript; all authors provided critical reviews of the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

MVPA: moderate- to vigorous-intensity physical activity
NCDs: non-communicable disease
SPARE: Singapore Paediatric Activity–Related Evaluation
WHO: World Health Organization

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Perspectives of Children and Adolescents on Engaging With a Web-Based Mental Health Program: Focus Group Study

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Abstract

Background: Despite accessibility and clinical benefits, open access trials of self-guided digital health interventions (DHIs) for young people have been plagued by high drop-out rates, with some DHIs recording completion rates of less than 3%.

Objective: The aim of this study was to explore how young people motivate themselves to complete an unpleasant task and to explore perceived motivators and demotivators for engaging with a DHI.

Methods: In this qualitative research study, 30 children and adolescents aged between 7 and 17 years were recruited to participate in 7 focus groups conducted over a 3-month period. Focus group activities and discussions explored sources of motivation to complete tasks and engage in a hypothetical 6-week DHI for anxiety.

Results: Children (aged 7-11 years) reported greater reliance on external motivators such as following parent instruction to complete unpleasant tasks, while adolescents (aged 12-17 years) reported greater internal motivation such as self-discipline. Program factors, such as engaging content, were the most commonly mentioned motivators for engaging with a DHI across both age groups. After that, internal sources of motivation were most commonly mentioned, such as perceived future benefits. External factors were the most commonly mentioned demotivators across all ages, with time commitment being the most frequently mentioned.

Conclusions: The study’s findings have implications for enhancing adherence in future DHIs targeted to children and adolescents. Recommendations include the need for supportive parental involvement for children, while adolescents would likely benefit from mechanisms that promote autonomy, establish a supportive environment, and align with personal interests and values. Belief that a DHI will provide short-term benefits is important to both children and adolescents, as well as having confidence that future benefits will be realized.

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KEYWORDS

motivation; demotivation; external motivation; internal motivation; digital health interventions; engagement; internet interventions; mental health; eHealth; youth; children; adolescents

Introduction

Self-guided digital health interventions (DHIs) represent a potential pathway to improve the mental well-being of children and adolescents [1,2]. DHIs use technology to deliver health care and support well-being. DHIs can be fully self-guided (eg, apps and web-based programs) or clinician supported (eg, helplines or web chat) and fulfill a range of purposes such as psychoeducation, cognitive behavioral therapy, self-assessment, or monitoring [3]. Compared to traditional face-to-face therapy, DHIs are inexpensive and widely available; approximately 86% of young Australians have access to DHIs delivered through internet services [4]. However, despite their accessibility and therapeutic appeal, open access trials of DHIs for children and adolescents have been plagued by high drop-out rates, with some DHIs recording completion rates of less than 3% [5].

Posttrial evaluations of DHIs have identified a range of factors that may explain why children and adolescents drop out and fail to complete prescribed web-based treatments. Common reasons include perceived low quality of content, usability issues, lack of support, and privacy concerns [2,6,7]. Although these studies provide useful insights, they tend to focus on program factors such as design, usability, and content, rather than individual factors such as motivation for engagement more broadly [8,9].

From a theoretical perspective, self-determination theory [10] suggests motivation is driven by an interplay of internal and external sources. Applied to motivation to complete DHIs, internal motivators may include engaging in a web-based program because it is enjoyable (eg, “I enjoy the activity”), while external motivators cover a range of motives outside the self, which may or may not interact with internal sources. These include participating in the program to avoid punishment (eg, “If I don’t do it I will get in trouble”), to receive a reward (eg, “I’m doing this to earn a certificate”), or because the program aligns with a partially or fully integrated value (eg, “This program is important to me”) [11]. Previous research has found that higher internal motivation, expressed as treatment readiness, predicted DHI adherence in adults treated for alcohol misuse [12] and completion of a 12-week DHI for anxiety [13]. However, to our knowledge, no previous study has explored how external and internal factors may influence children’s and adolescents’ motivation to complete a DHI. Factors that contribute to “loss of motivation” have also received limited research attention. Described as the “negative counterparts of motives” [14], demotivators represent influences that subtract from an ongoing action [15]. The aim of this study was to explore factors that motivate and demotivate children and adolescents to complete tasks. This knowledge could inform future strategies to enhance motivation for children and adolescents to engage in and complete DHIs.

Methods

Study Design

This qualitative study utilized focus group methodology to explore factors that motivate and demotivate young people to complete tasks. This was examined in two contexts: (1) while completing a task in their general life that they find unpleasant or boring, and (2) during hypothetical engagement in a self-guided DHI for anxiety. A focus group methodology was chosen due to the exploratory nature of the research questions.

Recruitment

Children and adolescents aged between 7 and 17 years were recruited to participate in focus group sessions. The potential for developmental differences in comprehension and expression across the age spectrum [15] was addressed by separating participants into age-based groupings that spanned a maximum of 3 years. Participants were recruited by posting advertisements and news posts on Facebook targeting users residing within 15 kilometers of the university precinct. Study information was also sent to faculty staff throughout the university. Communication material was directed at parents and included both parent and child study information.

Measures

Demographic Questions

Demographic data were collected prior to participation in focus groups. Adolescents (aged 12 years and older) and guardians (for children under 12 years) completed a brief questionnaire containing items on age, gender, year level at school, and history of mental health problems (“Has your child/have you ever experienced an emotional health problem?”).

Qualitative Questions

To support expression and mitigate the risk of groupthink [16], participants were encouraged to draw or write their ideas in response to stimulus material presented by the moderator (Textbox 1).

Textbox 1. Question guide.

Part A: Motivating Self

Think about something that you have to do each week that you really don’t like doing, but have to do anyway. Something you have to get done by yourself without help from anyone else.

1. Draw yourself doing it.
2. Put some feeling stickers on there.
3. Draw or write what it is that makes you get it done.

Part B: Engaging with Digital Health Interventions

I want you to imagine that you have signed up for this program, because you’ve been feeling scared, worried, or sad. To do the program, you have to log in on your computer every week for 6 weeks.

1. Start by putting some feeling stickers on there.
2. What do you think about having to keep going with it? Are there any reasons you don’t want to keep doing the program each week? What are the thoughts going through your head about that?
3. What are some things in your life that might get in the way of you logging on and doing the program?
4. What are some reasons why you would keep doing the program every week, even if you didn’t feel like doing it?
5. Draw or write down some things that might help you keep going with the program, even if you don’t feel like doing it?

Procedure

Eligible participants self-referred to the study by completing a web-based registration form. They were then contacted by email by a member of the research team and offered a place in a focus group based on availability specified during registration. Focus groups were held at a Brisbane, Australia, university campus between October and December 2021. On arrival, written consent was obtained from parents or guardians of participants under 16 years while those aged 16 and 17 years provided their own written consent. The demographic survey was completed by parents or guardians of children younger than 12 years, while adolescents aged 12 years and older completed their own. Participants were seated evenly around a large table, accompanied by a moderator (CC) who steered the discussions, as well as a supporting investigator (JC or SC, both clinical psychologists) responsible for note-taking and offering assistance to any child requiring attention during the focus group session. Participants were grouped together with children and adolescents of comparable ages to facilitate a conducive environment for interaction and sharing.

Parents were invited to remain in the room at a distance from the group or return at the conclusion of the session. Each focus group included two creative activities. In the first task, participants were provided with a blank piece of A4 paper, a set of 12 feeling/emotion stickers, and a pack of colored pens. They were invited to draw or write about a regular task they dislike doing and to then indicate how they felt about doing it using the stickers provided or by drawing their own. They were then asked to draw or write what it is that makes them get the task done. After completing their sheet, participants were invited to share their picture with the group if they were comfortable doing so (see Figure 1 for sample outputs).

For the second task, participants were provided with an A3 piece of paper featuring a color graphic of a young person facing a computer screen with thought bubbles to the side, a second set of 12 feeling/emotion stickers, and a pack of colored pens. Participants were introduced to a hypothetical DHI and shown a sample image of the dashboard of a web-based program for youth anxiety currently under development. We purposefully maintained a level of ambiguity regarding the application to prevent any potential biasing of participants' responses. Participants were asked to imagine they had signed up for the program because they had been feeling anxious. Participants completed 5 activities to draw out internal and external motivators and demotivators. They first indicated how they felt about doing the program using the sheet of stickers. They were then asked to write in one of the thought bubbles what they thought about doing it and any reasons why they would not want to continue with the program. Following this, they wrote or drew any things that would get in their way. Next, they were asked to use another thought bubble on the other side of the page to write down any reasons why they would keep doing the program even if they did not want to do it. Finally, they were asked to write or draw some things that would help them keep going with the program and get it done (see Figure 2 for an example output). The procedure for sharing and discussion was similar to the first task. All focus group sessions were audio-recorded and lasted between 60 and 80 minutes (including a break). A pilot test was conducted with 3 children to test engagement with drawing activities and general task comprehension. No changes to the guide were considered necessary; pilot group responses were not included in the analysis.

Figure 1. Examples of participant drawings about motivating self. (A) The left drawing was created by a 7-year-old female participant. (B) The right drawing was created by a 15-year-old female participant.

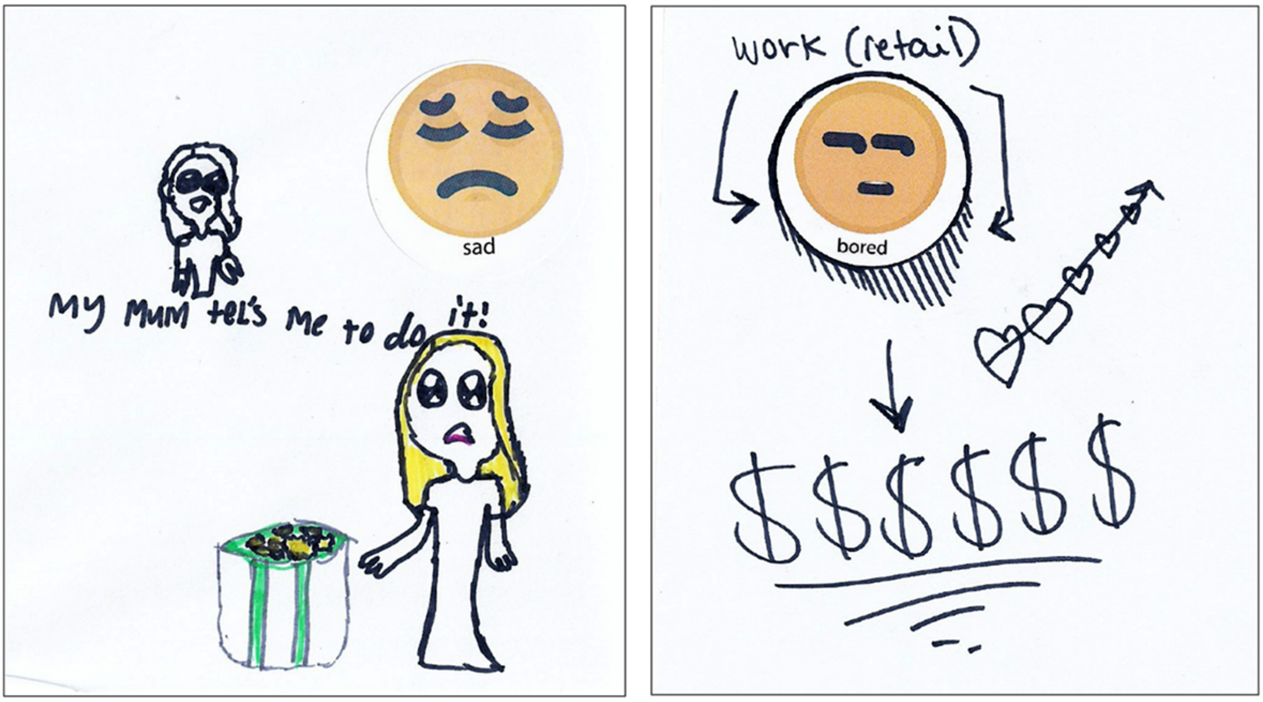
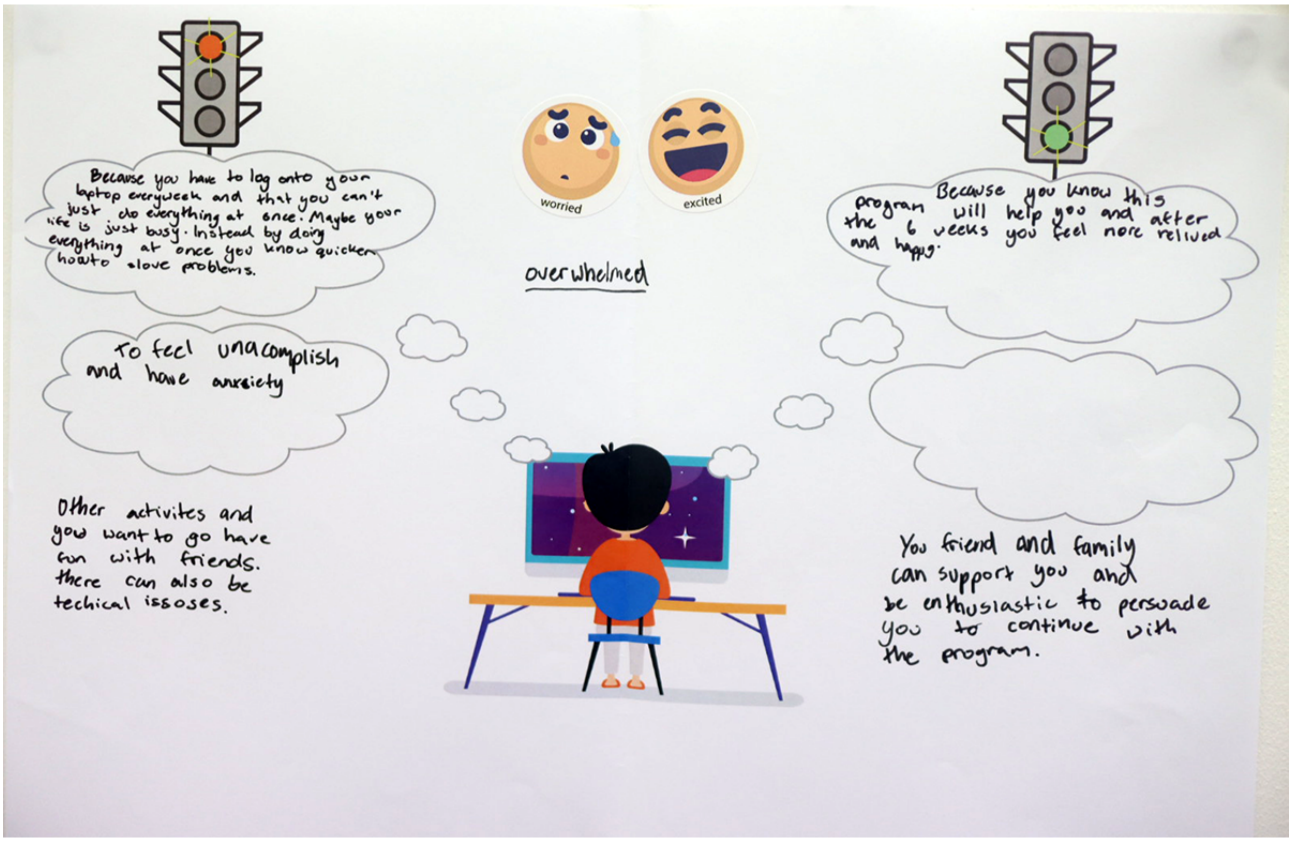


Figure 2. Example of a participant's drawings about engaging with a digital health intervention, created by a 12-year-old female participant.



Data Analysis

Audio recordings from each focus group were transcribed and entered into QSR NVivo computer software (version 13; Lumivero). Thematic analysis [17] was used to analyze the data. Research team member CC initially reviewed and coded the transcripts. These codes were reviewed by a second researcher (SA) and both researchers independently generated preliminary themes. Any theme discordance was reconciled in discussions with a third researcher (JC). The final step involved all authors reviewing the theme labels and quotes for consistency and relevance and grouping subthemes.

Ethical Considerations

The study was approved by the Queensland University of Technology University Human Research Ethics Committee (Reference 4312-HE31). Written consent was provided by guardians of children under 16 years while those aged 16 and 17 years provided their own written consent. Participant responses were deidentified prior to analysis. Participants and their guardian were compensated with gift cards valued at Aus $30 (US $20.30) and Aus $40 (US $27.07), respectively.

Results

Participant Characteristics

A total of 31 participants were recruited; however, one (female, 16 years) was excluded due to inability to participate in the focus group due to severe anxiety. The final sample consisted of 30 children (18/30, 60% female) in 7 focus groups, with group sizes ranging from 3 to 6 participants (mean 4.3, SD 0.96). The age range within each group spanned 1-3 years. Specifically, the groups were conducted with participants aged 7-9 years, 7-10 years, 8-10 years, 10-13 years, 11-14 years, 14-16 years, and 16-17 years. Demographic characteristics are presented in Table 1.

Table . Participant characteristics.

	Children (7-11 years)	Adolescents (12-17 years)	Total (N=30)
Participants, n (%)	17 (57)	13 (43)	30 (100)
Female, n (%)	11 (65)	7 (54)	18 (60)
History of emotional problems, n (%)	8 (47)	7 (54)	15 (50)

Motivation to Complete Unpleasant Tasks

Home-based chores and routines (eg, unloading the dishwasher, taking a bath) were the most common unpleasant task type identified by children (12/17, 70%). In contrast, the majority of adolescents (9/13, 70%) chose tasks that originated out of the home (eg, homework or a part-time job).

Emotions

Participants selected an average of two stickers to represent their feelings about doing the task (mean 1.8 stickers, SD 0.8). Feeling bored (16/30, 53% of participants) and annoyed (15/30, 50%) were the most commonly selected feelings associated with things they did not like doing but had to do anyway. The popularity of these two emotions was common to both children and adolescents.

Motivational Sources

As shown in Table 2, children and adolescents identified a range of internal and external sources that underlie their motivation to complete unpleasant tasks. Adolescents were generally more expressive than children, identifying an average of 2.8 (SD 1.2) versus 1.1 (SD 0.9) sources, respectively. Internal motivation sources outnumbered external sources for adolescents, while external sources were more frequently mentioned by children.

Table . Internal and external motives experienced by children and adolescents during an unpleasant task.

	Number of responses from children (n=15)	Number of responses from adolescents (n=13)	Total (n=28)[a]
Internal motivational sources	4	28	32
Self-discipline	2	14	16
Sense of achievement	1	6	7
Fear of negative consequences	0	6	6
Making it fun	1	2	3
External motivational sources	12	9	21
Receive a reward	7	2	9
Avoid parental disapproval	1	4	5
Follow parent instruction	4	0	4
Social desirability	0	3	3
Total	16	37	53

[a] The data represent participant responses. Two children did not share motivational sources.

Internal Motivational Sources

The most common internal motivation source across all focus groups was self-discipline (16 responses). Included in this theme were reflections on responsibility and strategies that young people use to stay on task, including the use of self-talk and choosing to focus on the moment, as shown in the following comments.

> *I'll be like, "Come on man, you've committed to these subjects, You need to do it." And so I feel like that's a bit of my discipline.* [4R-17]
>
> *Yeah, you kind of just have to, so you force yourself to.* [6J-15]
>
> *Just kind of thinking, like, "This is my responsibility and it's helping me by doing it.* [5G-13]

A sense of achievement derived from completing the task was another common theme, expressed in comments from 6 adolescents and 1 child in the focus group discussions.

> *But when I have managed to finish it, then I've actually spent my time doing something useful, like I've achieved something.* [3Z-13]
>
> *It feels rewarding, so then sometimes I use a bit of that, like I tell myself, oh come on, just get it done and then you'll feel better afterwards that you've just done it.* [4R-17]

In addition, 6 adolescents (46% of adolescent participants) stated they were motivated by considering the negative consequences of not completing the task. For several participants, this appeared to be linked to a previous unpleasant experience (their own or observed in others). There was one adolescent that mentioned fear of failure and demonstrated the use of positive reappraisal as their language changed from fear of failure to focusing on the positive in order to motivate themselves to complete a difficult task.

> *So basically, I just remind myself of examples of people around me and just kinda kick myself up the pants.* [6L-16]
>
> *I'm just like, "If I don't do this, then it'll lead to this." So, it's just kind of, "Do it so that stuff doesn't happen.* [6E-14]
>
> *And then fear, I don't wanna get a bad end result, year 12. I need to put in a lot of effort into these things if I wanna do well…* [4R-17]

There were 3 participants who mentioned using various methods to make the task fun, such as thinking about other things or using music, either by listening to it or singing.

> *One thing that just pushes me to make sure I do it is I just think about other things while I do it.* [3E-13]
>
> *We make up a little song and then it helps us like, and then we like, sing it and then we get it done really quickly.* [7A-9]

External Motivational Sources

The most frequent external motivation was to receive a reward. For children, this often represented the opportunity to do other things (7 responses), while adolescents referred to financial rewards for unpleasant jobs (2 responses).

> *After I do it I can play.* [2E-10]
>
> *And something that helps me get through it is that I realize what I could do after I'm done, like, something good I can do it after I'm done.* [5S-11]
>
> *Obviously motivated by money 'cause yeah, that's the only reason people work.* [6J-15]

Parent or guardian influence on a child's motivational decision-making was evident in several responses, including inclination to follow parental instructions (4 responses).

> *Well, I normally ask my mom: "What do I have to do?", I do it.* [7E-9]
>
> *My mom told me to, so I have to do it.* [1H-10]

Avoiding parental disapproval from parents or guardians was mentioned by 4 adolescents and 1 child.

> *I sometimes don't have time to do it, which makes like my dad or my mom mad because I haven't done my chore.* [3E-13]
>
> *…and the thing that motivates me to do it is my parents will get mad at me if I don't do it.* [3L-14]
>
> *I don't get in trouble, so I have to do it.* [1J-8]

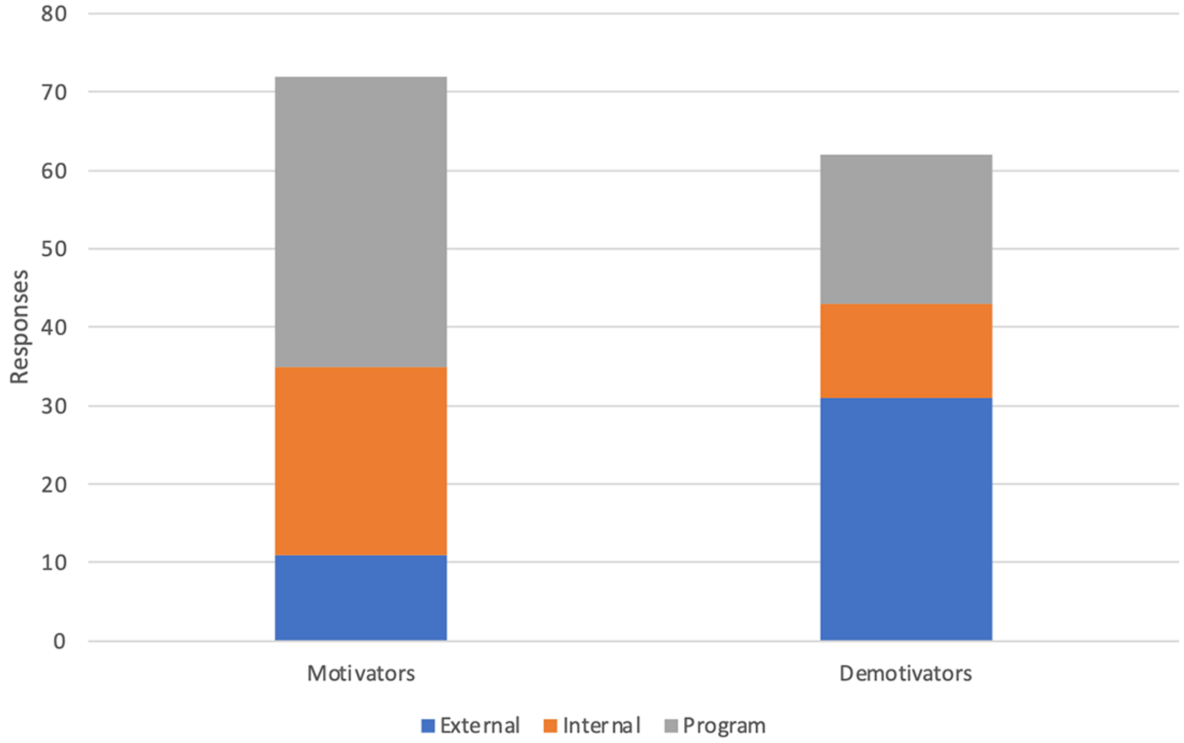
Social desirability was mentioned by 3 adolescents, 2 of whom highlighted peer comparison, while the third was motivated by a desire to meet the expectations of their parents and people around them.

> *I'm quite competitive and I know if I'll get a bad mark or compared to other people I'll get pretty sad so I just make myself do what I can.* [6E-14]
>
> *I'll say with me, my friend group is also pretty academic, so you think, "Oh, if I don't get a good mark, then other people are gonna be, "Oh, why are they friends with her? She's not as smart as them." You see.* [6V-15]
>
> *Of course, (I'm concerned about) my parents and then the people around me.* [6E-14]

Engaging With a DHI

Participants identified a range of motivating (72 responses) and demotivating (62 responses) sources that were categorized into internal, external, and program factors. As shown in Figure 3, program factors were the most frequently mentioned motivators (34 responses), while external sources were the most frequently mentioned demotivators (31 responses).

Figure 3. Motivation sources to engage in digital health interventions.



Emotions

Participants selected an average of 3 emotions to represent how they would feel about completing a 6-week DHI (mean 3.1, SD 1.3). The 5 most common emotions reflected a mix of negative emotions (15/30, 50% were worried; 10/30, 33% anxious; 9/30, 30% scared) and positive emotions (13/30, 43% excited; 12/30, 40% happy).

Motivating Sources That Support Engagement in DHIs

As shown in Table 3, participants identified a range of motivational sources they perceived would help them complete a 6-week DHI. The highest number of responses were program-specific factors (37 responses), followed by internal sources (24 responses) and external motivational sources (11 responses). Across all categories, perceived future benefits (14 responses), engaging content (10 responses), and gamification (7 responses) were the most commonly mentioned motivators.

Table . Sources of motivation to engage with digital health interventions.[a]

	Number of responses from children (n=17)	Number of responses from adolescents (n=13)	Total (N=30)
Internal	7	17	24
Perceived future benefits	5	9	14
Sense of accomplishment	1	4	5
Commitment	1	4	5
External	4	7	11
Social pressure	0	4	4
Social support	1	3	4
Rewards	3	0	3
Program factors	11	26	37
Gamification	0	7	7
Program reminders	2	3	5
Rewards in the program	0	6	6
Incremental benefit from each component	3	2	5
Engaging content	5	5	10
Program design features	1	3	4
Total	22	50	72

[a] The data represent participant responses.

Internal Motivators

Perceived future benefits of the program were the most commonly cited motivating factor. This theme covered several related concepts, including expectations of improved mental health, a sense of confidence they will be happier in the long run, improved coping self-efficacy, and a desire for self-improvement. Although most responses were from adolescents (9/14, 64%), participants as young as 9 years old expressed a relatively long-term view. Notably, child responses expressed confidence (denoted by the use of words such as “you know”), while adolescents appeared to temper belief (“there is a chance it could work”).

> *And you know you’ll be much happier after and you feel loved and safe.* [1A-10]
>
> *I might not like this, (but) it will help me in the long run.* [7A-9]
>
> *The desire of better mental health, that’s self-motivated. I wanna get that kind of thing self-improvement.* [4E-17]
>
> *Probably the chance it could actually work. So, obviously after the first one, if I feel like maybe there is a chance it will work out, I’ll be more committed to keep doing it.* [4R-17]

Among all participants, 5 suggested that thinking about the DHI as an accomplishment would help motivate and inspire them to complete the program.

> *Accomplished feelings, I guess, like your mental health is kind of improved, and if it feels kind of easy to keep going, then it makes it a whole bunch easier to keep going.* [5G-13]
>
> *I would be proud of myself for actually sticking to the program. It would make my parents happier, and I would have achieved something.* [3Z-13]

Classified under the theme of commitment, 4 adolescents and 1 child stated they felt obligated to finish what they started.

> *And then like think just guilt of giving up. I feel like I would just let myself down and then probably, just my…. Just discipline…. Oh, I made a commitment, I need to do it.* [4R-17]
>
> *Since it’s like a program. I think I’d kinda feel obligated to finish it so afterwards* [6V-15]
>
> *Just like five weeks to go or something, like…* [3C-11]

External Motivators

External influence from others, expressed as social support (eg, encouragement from family) or social pressure (eg, pressure to meet expectations from parents), represented the most commonly mentioned external motivator by participants. A total of 4 participants identified family members or therapists as a source of social support to complete a DHI, as highlighted in the following responses.

> *Friends and family that can help support you and keep you…keep enthusiasm up.* [5A-12]

> *Having your parents motivate you.* [3L-14]

There were 4 adolescents who identified aspects of social pressure from parents and therapists would influence them to complete the DHI.

> *Parents making me, therapists making me. If they're like, "You have to," then I'm like, "Okay, I have to.* [6J-15]
>
> *And then there's the external pressure, I guess it's like no external pressure, but wanting to make others happy.* [4E-17]

Rewards for participation, including games and tangible treats, were identified by 3 children as potential sources of motivation to complete the DHI.

> *Like getting a reward afterward. Like getting to play games or something.* [2E-10]
>
> *Food.* [3C-11]

Program-Specific Motivators

Engaging content was the most common program-specific motivator mentioned by participants. Participants believed that a DHI program that was fun (3 responses), enjoyable to use (3 responses), and interesting (2 responses) would encourage them to complete the assigned program. Almost one-third (5/17, 29%) of child participants made a comment about engagement, making this the most common facilitator within the younger age group.

> *You could have enjoyed last time, so you can't wait to come back.* [1A-10]
>
> *If you see something exciting you will have a go at it. It might be really exciting, so you'll just keep doing it.* [2V-8]

A program that offered tangible rewards for completion was recognized by adolescents (6 responses) as something that would help them complete a multisession DHI over 6 weeks.

> *Well, maybe if it was in the actual thing. Each one you get completed, that could be like, not necessarily a real-life reward but something in the game.* [6E-14]
>
> *Probably if I felt like there was a reward. If I wasn't doing it just for my own personal gain. If I felt like there was actually some kind of tangible thing at the end that I get.* [4R-17]
>
> *A voucher. If you finish a full six weeks.* [6J-14]

Gamification elements (eg, integrated games, end goals, and customizable avatars) were identified by 7 adolescents as program features that could support engagement. This theme was not mentioned by children.

> *Just more games to engage in, then maybe a couple more things during the week. Just so it can keep your mind off the mental illness* [6J-14]
>
> *People like avatars, customizing avatars. That was a thing when I was a kid.* [6J-15]

A total of 5 participants mentioned that they would persist with a DHI that demonstrated incremental benefits from what is learned in each component. Although one adolescent explicitly described the benefit as a "feeling of progress," other participants explained they would be willing to continue if the program was teaching them something or providing strategies they could immediately use to improve their mental health.

> *It might be helpful, so it can teach me something.* [1J-8]
>
> *I will have…. After doing the first week of the program, if I find it fun to do and I find the topics interesting and I'm learning about it, I'd be willing to continue doing it and have fun at it.* [4A-16]
>
> *And you know that it helps relieve stress, and they give strategies to manage your anxiety.* [5S-11]
>
> *Feeling of like progress. Like I'm actually getting somewhere.* [4R-17]

There were 4 participants who identified that program design features, including easy access and short session duration (one participant suggested a 15-minute time frame), may increase engagement in a DHI.

> *Just easy to access on your computer and stuff.* [5G-13]
>
> *I don't really know too much about it but if it's a small time like 15 minutes at a time or whatever then I'm like, "Okay, well, I might as well."* [6J-15]
>
> *Stuff like maybe an easy URL to type up or something.* [5G-13]

A DHI program that reminded users to log in was identified as a potential motivator by several adolescents and 1 child.

> *Something that might help me keep on doing it is gentle reminders, to do it throughout the week, or encouraging messages.* [3Z-13]
>
> *The things that can motivate you, like a word on motivation, reminders, like it being fun to people, encouraging phrases.* [3C-11]

Demotivating Sources

As shown in Table 4, time commitment (25 responses) was the most commonly mentioned demotivator. Other demotivators typically mentioned were apathy toward continuing (7 responses), concerns about effectiveness (7 responses), and content engagement (6 responses).

Table . Sources of demotivation to engage with digital health interventions.[a]

	Number of responses from children (n=17)	Number of responses from adolescents (n=13)	Total (N=30)
Internal	5	7	12
Anxiety	1	1	2
Negative emotions	2	1	3
Apathy toward continuing	2	5	7
External	12	19	31
Access to equipment	0	2	2
Lack of social support	0	4	4
Time commitment	12	13	25
Program factors	4	15	19
Concerns about effectiveness	1	6	7
Content engagement	1	5	6
Length of program	0	2	2
Privacy concerns	2	2	4
Total	21	41	62

[a] Data represents a count of responses, not participants.

Internal Demotivators

Apathy toward continuing was identified in focus groups with both adolescents (5 responses) and children (2 responses). Children described apathy in terms of “can’t be bothered” or “you don’t want to do it,” while adolescents used the term “motivation” and reflected on a sense of disregard for the program.

> *And then just again…. Just my own motivation, how much I’d care.* [4R-17]
>
> *And then just generally your own self-motivation to do it.* [6J-14]

Several adolescents linked lack of motivation to depressive symptoms, as shown in the following comments.

> *General mental illness, a lack of motivation, if I’m physically not able to do it, I’m not up to it, then I’m mostly not going to.* [6J-15]
>
> *Or maybe just your feelings or thoughts, ‘cause if you have depression in the first place you might not be very happy.* [3L-14]

Comments from 3 participants indicated that negative emotions connected to needing help could act as potential barriers to completing a DHI. These feelings included shame and hopelessness.

> *On the red side, the emotions could be like ashamed at yourself...* [3C-11]
>
> *Disappointed at the fact that they need this extra support, if it’s something.... If it’s obvious enough that this is a mental health thing.* [4E-17]
>
> *You don’t believe anything will make you feel better.* [1A-10]

Recognizing that the hypothetical DHI would be used by people with anxiety, 2 participants highlighted that participation in the program may exacerbate their anxiety, which could be a barrier to completion.

> *The kind of thoughts that would stop me would be lots of anxiety about it, like feeling unaccomplished, like I haven’t kind of done anything, and if it feels really hard to keep going.* [5G-13]
>
> *And you are worried about sharing your ideas.... Thinking about the past. If something’s happened in the past, something like anxiety.* [5S-11]

External Demotivators

Concerns about time was the most common reason participants would not engage with the program. Time commitment encompassed a range of related obligations that impacted young people’s perceived available time, including schoolwork, part-time work, social activities, household chores, and fatigue resulting from these tasks, as highlighted in the comments below.

> *Because you can be really busy, and...because you said how it’s every six weeks, and maybe a person doesn’t have that much of time.* [5A-12]
>
> *It takes time away from me. It might not even help me, and it’s a waste of energy.* [3Z-13]
>
> *I swim. I’m really busy. I do athletics and I’m really tired after school.* [1A-10]
>
> *Just school and work and just stuff outside like extracurriculars and stuff.* [6V-15]

Mirroring the motivating factor of social support identified above, lack of social support was identified as a demotivator faced by adolescents (4 responses).

> *Peer groups, I guess, if they're not that supportive. That could be peer pressure.* [5G-13]
>
> *There's a lack of support from family, well that's I think the main thing that would get them doing this in the first place. So, if that support begins to wear off then they are just not gonna keep doing it.* [4E-17]

Concern about access to equipment that was perceived to be necessary to complete the program was identified in 2 comments by adolescents.

> *And then objective things like access to an electronic device and access to the internet.* [4E-17]
>
> *So it's just a bit more of a hassle if I'm having to do that at my dad's, I'd be more discouraged to do it.* [4R-17]

Program-Specific Demotivators

The most common program-specific demotivator was concerns about program effectiveness. Responses from 7 participants suggested that any doubts about perceived effectiveness of the program would undermine their motivation to complete a DHI.

> *Probably doubt, like "Is this actually gonna work? Is this worth my time?"* [4R-17]
>
> *That I've had to do this kind of stuff before, and it never really does anything so what's the point? And then I'm not sure 'cause obviously I haven't done it.* [6J-15]

Similar to concerns about effectiveness, young people highlighted the importance of content engagement (6 responses), suggesting that repetitive, uninteresting, unenjoyable, or patronizing content would diminish motivation to complete DHIs.

> *If it just feels it's sort of the same thing again every five weeks, I'll lose motivation to keep doing it. If I feel.... It's not like...getting anywhere.* [4R-17]
>
> *Most likely not keep doing the program. If I was not learning anything I find interesting. So, I'd probably be bored and I wouldn't wanna come again.* [4A-16]
>
> *If it's too childish then I'll feel kind of patronised and annoyed so that's a hypothetical based on what it's actually like.* [6J-15]

Comments from adolescents highlighted that privacy is crucial to users of DHIs, and anxiety related to potential privacy breaches could be a major demotivator for users.

> *That's a massive problem with people who have anxiety and depression, 'cause they don't want people to know.* [6J-14]
>
> *Yeah they start panicking that it's gonna get leaked or something, yeah.* [6J-15]

The length of program was identified as a potential demotivator by 2 adolescents who felt that young people with symptoms of anxiety or depression may find it difficult to commit to ongoing, web-based therapeutic sessions.

> *And why am I spending so much time on it? It's like five weeks is a long time.* [6E-14]
>
> *If you know of anxious children, I'm sure something like being on a computer for maybe like an hour at a time, would be a daunting task.* [4E-17]

Discussion

Principal Findings

This study aimed to investigate factors that motivate and demotivate children and adolescents in completing challenging tasks with the goal of informing future strategies to enhance engagement in DHIs. We found that when faced with a task they do not want to do, children (7 - 11 years old) tended to be motivated by external sources. Short-term extrinsic rewards were the most common source, evidenced by children's desire to get the task done so they can do other things. In comparison, internal sources were more commonly reported by adolescents, who commonly spoke about the importance of self-discipline and a sense of accomplishment.

There are several factors that may explain the difference in motivational source between children and adolescents. First, it is likely that as children age and gain autonomy, they have more opportunities to face challenges, develop coping strategies, and derive internally regulated motivation, while younger children have limited experience beyond seeking support from caregivers [18,19]. Another factor that may explain the differences between age groups was task context, such that most adolescents chose a learning task, which offered potentially greater rewards for effort (ie, attainment value) compared to household chores, which were the common choice for children.

The findings from this study suggest that adolescents draw equally on positive motivations (achievement and reward) and negative motivations (fear of negative consequences and punishment) to persist with everyday unpleasant tasks. Although previous research tends to suggest that positive motivations are associated with greater long-term well-being, the findings from discussions with adolescents show that negative motivations can lead to positive outcomes. This is consistent with several studies that have shown that negative motivation (ie, fear of failure) can support positive change in children and adolescents [20,21].

Turning to the challenge of completing a hypothetical 6-week DHI program, perceived future benefits of the program was the most frequently mentioned motivation theme across both age groups, though the theme was more commonly mentioned among adolescents. This aligns with educational studies that have observed that differentiation between interest in and importance of academic tasks grows with age, as adolescents see beyond immediate desire for engagement ("will I enjoy it?") and may be more motivated by attainment value ("will this help me?") [22].

According to expectancy-value theory of achievement [22], persistence requires that young people not only recognize future benefits, but also believe that those outcomes are achievable. In this study, belief in a positive outcome was expressed in child and adolescent focus group discussions. Closely linked to the concept of success expectancy [22], belief is widely recognized as a predictor of adherence in therapeutic settings [23]. Previous research suggests that success expectancy—the belief that one will be successful in achieving a desired outcome—may be amplified by personal interaction [24], a factor that is not offered in self-guided DHIs. This underlines the challenge faced by DHIs to build belief in an online environment where personal contact with therapists or counselors is not available. Although therapist support is exogenous to self-guided DHIs, social support provided by family and friends may inspire belief. Social pressure was also mentioned as an external motivational source among adolescent participants. This is consistent with developmental studies that have shown social influences (positive and negative) are amplified during adolescence, when young people become increasingly exposed to a range of contextual factors, including social comparison in peer relationships, school culture, and family involvement [25]. Previous reviews have investigated the use of social platforms as a DHI program feature (ie, texting, social networking, web-based message boards, discussion forums) to support engagement [2]. However, our findings suggest that young people value support from family members as an important external motivation source rather than a feature embedded in the DHI. Family support strategies have shown to be effective for addiction recovery [26] and eating disorders [27] in adolescents, therefore a similarly designed family-based social support strategy may assist adolescents to complete self-guided DHIs.

Consistent with previous research [2,9], our findings highlighted that engaging content was considered an important motivator for both children and adolescents. For children, engaging content was the most mentioned motivator to stay engaged in a multisession DHI. Although also important, adolescents valued other program features more highly, including gamification and tangible rewards (such as certificates and rewards outside the DHI). However, given the nature of this study, it is not possible to make inferences about the relative importance of content versus gamification, although the observed difference between age groups may be explained by children having less exposure to games-related content online compared to older participants.

Time commitment was the most frequently mentioned demotivator in both child and adolescent groups. This result corresponds with previous DHI reviews where “lack of time” [28], “inability to find time” [9], and “time constraints” [29] were raised as issues by young people. This suggests that the benefits of convenience and accessibility offered by DHIs compared to traditional therapies [30] may not be valued by young users. Outside of time commitment, adolescents also expressed concerns about effectiveness. This is in line with a recent systematic review of DHIs, which identified “credibility” in relation to evidence of the intervention’s effectiveness as a common contributor to high retention rates for children and young adults [2].

Implications for the Development of Youth DHIs

Our focus group findings led to a number of recommendations for improving adherence in future DHI developments for children and adolescents. For children, engaging content combined with immediate, extrinsic rewards are important motivators to complete a DHI. Children also demonstrated a capacity to seek attainment value in a difficult task, however this needs to be nurtured with developmentally appropriate language as the majority of children did not consider the future benefits of a DHI in our discussions. Another implication for DHI designers is that children seek pleasurable online experiences at each point of engagement, while adolescents may respond more effectively to strategies designed to reinforce attainment value of the therapy goal (such as progression charts). The involvement of parents/guardians also appears to be a motivator valued by children, who identified parental instruction, approval, and reward-seeking in our focus group discussion. This highlights the importance of continuous parental engagement [31] in DHIs for children, which may include coaching-style support and the administration of rewards upon completing each step of a multisession program.

For adolescents, a sense of achievement was an important internal motivator for completing tasks they do not want to do. Recognizing that sense of achievement is closely linked to an adolescent’s sense of personal control [32], future DHIs can benefit from strategies designed to provide autonomy, create a supportive environment, and connect with adolescents’ interests. Granting autonomy can increase engagement with DHI tasks. This can be achieved by allowing them to select topics aligned with their interests. Strategies designed to provide social support from family and friends may help to amplify attainment value and buffer against concerns they may express about program effectiveness. Youth DHIs should also seek to incorporate interests into the content whenever possible, and tailor sessions and homework to align with their extracurricular interests. By making the program personally relevant, adolescents are more likely to see the value in completing the program.

Another implication for DHI designers is that negative motivations are frequently expressed by adolescents. In particular, fear of negative consequences was used for completing tasks they do not want to do. Negative motivations can provide initial drive; however, available evidence suggests that negative motivations may not sustain longer-term engagement [20]. Although acknowledging the importance of consequences for nonadherence, DHI programs need to provide mechanisms for adolescents to address these negative motivations in positive ways while also building self-confidence. Strategies could include providing mechanisms for adolescents to set their own deadlines, inviting others to hold adolescents accountable, or establishing tangible repercussions for inaction.

Finally, DHI developers also need to consider practical strategies to address concerns that both children and adolescents have about time required to complete a DHI. The issue of time commitment could be addressed in several ways, including providing brief, targeted content that can be quickly consumed on a regular basis. DHIs should also consider ways to integrate content with other applications and smart devices (eg, wearables) that children and adolescents access regularly to reduce learning time and support busy lifestyles, in and out of the home.

Limitations

Several limitations need to be acknowledged. First, while having a history of mental health or emotional problems was common in our sample, they were not a DHI-seeking population.

Generalization of results must therefore be approached with caution. Another limitation was that participants were not required to have previous experience with DHIs. Some responses from children reflected limited understanding of DHIs and web-based programs more generally. This implies that differences in responses from older participants may reflect online experience rather than developmental differences. Future work should assess children's and adolescents' perspectives in the context of their prior DHI and online experience more generally. Another potential limitation was group structure. Some children chose not to share their story about their artwork and so there was some potential loss of data. Although the moderator actively redirected conversation to younger participants, older participants were the predominant voices in most groups, and this may have contributed to a lack of sharing.

Conclusions

Results of this study indicate that engagement strategies that engender belief that a DHI will provide short-term benefits are important to both children and adolescents. Additionally, confidence that future benefits will be realized was also articulated by adolescents, but this appeared to be less important to children, reflecting potential age-related responses and online experience. The study also found that social support may be an effective source of engagement for young people; however, more research is required to explore how persuasion from family members can nurture belief and confidence in future benefits from DHIs. Finally, future research should consider how engagement strategies can be used to shift children's and adolescents' perception that self-guided DHIs are time-consuming.

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Authors' Contributions

CC, JC, and MJW were responsible for conceptualization. CC and SA completed the formal analysis. JC and MJW provided supervision. CC wrote the original draft. JC, MJW, and SA reviewed and edited the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

DHI: digital health intervention

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Review

Digital and Hybrid Pediatric and Youth Mental Health Program Implementation Challenges During the Pandemic: Literature Review With a Knowledge Translation and Theoretical Lens Analysis

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Abstract

Background: The pandemic brought unprecedented challenges for child and youth mental health. There was a rise in depression, anxiety, and symptoms of suicidal ideation.

Objective: The aims of this knowledge synthesis were to gain a deeper understanding of what types of mental health knowledge translation (KT) programs, mental health first aid training, and positive psychology interventions were developed and evaluated for youth mental health.

Methods: We undertook a literature review of PubMed and MEDLINE for relevant studies on youth mental health including digital and hybrid programs undertaken during the pandemic (2020-2022).

Results: A total of 60 studies were included in this review. A few KT programs were identified that engaged with a wide range of stakeholders during the pandemic, and a few were informed by KT theories. Key challenges during the implementation of mental health programs for youth included lack of access to technology and privacy concerns. Hybrid web-based and face-to-face KT and mental health care were recommended. Providers required adequate training in using telehealth and space.

Conclusions: There is an opportunity to reduce the barriers to implementing tele–mental health in youth by providing adequate technological access, Wi-Fi and stationary internet connectivity, and privacy protection. Staff gained new knowledge and training from the pandemic experience of using telehealth, which will serve as a useful foundation for the future. Future research should aim to maximize the benefits of hybrid models of tele–mental health and face-to-face sessions while working on minimizing the potential barriers that were identified. In addition, future programs could consider combining mental health first aid training with hybrid digital and face-to-face mental health program delivery along with mindfulness and resilience building in a unified model of care, knowledge dissemination, and implementation.

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KEYWORDS

mental health; knowledge translation; KT; flourishing; youth; teenagers; mindfulness; positive psychology; telehealth; implementation; knowledge dissemination; pandemic; COVID-19; service delivery

Introduction

Background

The COVID-19 pandemic and resultant closures of schools during lockdowns worldwide brought on major challenges for child and youth mental health [1-3]. A systematic review found that, as a result of school closures, there was a rise in depression, anxiety, emotional and behavioral problems, stress, and suicidal attempts in children and teenagers during the pandemic period [4]. Many teenagers reported challenges with coping with their mental health due to isolation from staying at home and a lack of social contact with peers [2]. In particular, there were unique challenges for children and teenagers with existing mental health problems when it came to accessing timely basic mental health care services during the pandemic. This was due to pandemic-related closures of medical clinics [5] and school-based health services [2], limited capacity of medical doctors, and prioritization of patients with COVID-19, which left many patients with chronic health problems with lower levels of accessibility to care [6]. A study in the United Kingdom found that 26% of teenagers felt that they had reduced access to mental health care [1]. Furthermore, a study in Italy found reduced emergency department admissions for mental health problems as patients remained at home and socially isolated distanced themselves to reduce their risk of infection [7]. However, it should be noted that not all studies found that everyone had been equally impacted by COVID-19 and had experienced mental health challenges, with some studies finding improvements in some individuals, particularly those without a preexisting mental health condition [8]. Nevertheless, child and youth mental health was a critical public health challenge during the pandemic for many.

As a result of the mental health crisis in youth during the pandemic, medical doctors had to quickly transition to digital tele–mental health care services to meet the pressing mental health needs of children and teenagers and increase their accessibility to care [9]. Many service providers had to implement digital mental health care for the first time, which came with its unique challenges [9]. Before the COVID-19 pandemic, tele–mental health was less prevalent and often used in rural and remote patient settings [10]. However, as medical providers adjusted to the “new normal,” tele–mental health and other digital mental health approaches became more mainstream [11]. Nevertheless, it is also important to examine what other mental health programs, including face-to-face or combined digital programs, were implemented during the pandemic to better understand differences in program preferences and experiences.

Understanding the key challenges and experiences with these different approaches and models of psychiatric mental health care is essential to make recommendations for future best practice guidelines and pandemic preparedness. Understanding the facilitators of effective implementation of youth mental health services in clinical medical settings and how to overcome barriers is necessary for making recommendations for effective tele–mental health and in-clinic program implementation. Moreover, it is important to understand implementation challenges, including barriers to implementation, considering determinant frameworks that assess barriers to implementation rather than solely examining structural process models of implementation that describe how the program was implemented and the specific procedural steps [12]. Analyzing studies that used both structural and process frameworks and the models used when implementing studies during the pandemic will provide deeper insights into what was specifically developed, the processes that were undertaken, and the challenges that were experienced.

In addition to implementing psychiatric programs in clinical settings that are administered through clinical mental health professionals, there is also a need to better understand what mental health programs were implemented in the community setting, such as in schools through school-based officials and in charities, and understand and what efforts by key stakeholders to promote youth mental health and build resilience in children and youth (preteenagers, teenagers, and young adults). It is of particular interest to investigate whether stakeholders working to support children (eg, community-based organizations such as the YMCA) and mental health–specific organizations implemented youth mental health programs during the pandemic in schools and the general community setting. It is also of interest to understand any key program implementation challenges to make recommendations for implementation and policy research.

Furthermore, there is a need to evaluate the barriers to and facilitators of psychological programs, including self-guided ones in the home setting that taught youth how to manage their emotions during isolation and times of crisis and uncertainty. In particular, positive psychology and especially mindfulness-based approaches have been found to foster greater gratitude and well-being in children and youth [13-15], and it is of interest to evaluate what approaches were used to assist youth during pandemic times of crisis from the perspective of adoption and uptake challenges. In addition, there is a need to evaluate the implementation and knowledge dissemination efforts associated with mental health supportive aid programs such as mental health first aid [16].

Within the context of youth mental health, including psychiatric and psychological supportive programs, little is known about what knowledge translation (KT) strategies and theories were used to educate key stakeholders, including mental health practitioners when they transitioned to new models of care and implemented digital technology. Research is needed to evaluate what KT theories and models were used when disseminating knowledge to key stakeholders. Effective KT is a fundamental element of the public health research process [17]. Without effective translation of evidence into practice, research remains simply an academic area without real-world community health impact [18]. Understanding the key challenges and facilitators of KT, including implementing evidence-based mental health programs and interventions, is necessary. This way, future recommendations may be made for best practice guidelines during crisis times and for future pandemic preparedness. Given that there was an unprecedented rise in mental health issues during this time, it is important to know whether there were any KT strategies for parents, schools, and medical providers.

Aims and Objectives

The purpose of this literature review was to gain deeper insights into strategies, programs, and services for child and youth mental health during the pandemic period. Recommendations for future program and intervention implementation, research, and best practice guidelines were made.

This review had the following aims:

1. To better understand the experiences, barriers, and facilitators regarding youth mental health service delivery, including telehealth, face-to-face, hybrid (combined face-to-face with digital), and school-based mental health service implementation, as well as psychological supportive services during the pandemic.
2. Secondary aims were to better understand what types of pediatric and youth mental health programs were implemented, including digital, face-to-face, and hybrid programs; the key stakeholders involved; and what KT theoretical models and strategies (if any) were applied during their implementation throughout the pandemic.

Methods

Overview

A literature review using PubMed and MEDLINE was undertaken to identify relevant studies on youth mental health programs and services, including school-based and hospital-based telehealth or hybrid implementation (combined in-person with digital services), and psychological supportive studies undertaken during the pandemic. Google Scholar and manual hand searches were also undertaken. We included studies that were undertaken during the pandemic period between March 2020 and October 2022. The studies must have mentioned that they were undertaken during the pandemic. The search was then updated and rerun with refined and more specific search terminology after consulting with a medical librarian to include studies that may have been undertaken during the pandemic but published at a later time up until December 31, 2023. Studies that were undertaken before the pandemic but continued throughout the pandemic were also included. The studies must have been published in the English language with public full-text accessibility. The rationale for including studies undertaken during the pandemic was to gain a greater understanding of key implementation challenges specifically during pandemic times of crisis and uncertainty. Google Scholar and manual hand searches were also undertaken to identify any additional studies. General studies on mental health service use or program trends without an assessment of experiences, preferences, and barriers were excluded. Psychological supportive studies were only included if they were part of a mental health service program or service implementation that assessed barriers, perceptions, and recommendations for implementation. Psychological studies that evaluated the effectiveness of the intervention on mental health outcomes rather than primarily focusing on stakeholder or user perspectives on the implementation of mental health services or overall telehealth experiences were excluded as they were outside the scope of this review. We included general positive psychology studies including mindfulness-based, cognitive behavioral, acceptance-based, emotional regulation, and behavioral activation strategies from stakeholder and user perspectives. Studies on the provision of mental health first aid training were only included if they evaluated implementation experiences or KT specifically. Studies that focused on framework development or development of implementation or KT models were included, but reviews or general opinion pieces were excluded.

The keywords included word variations of “knowledge translation” or “dissemination” or intervention and “mental health” or “resilience” or “stress” and “young adult” or “teenager” or “youth” or “child” and “health services” or “implementation” or “telehealth” or “psychological services,” among others.

An example of the search strategy is detailed in Textbox 1.

Textbox 1. PubMed search strategy example.

Search strategy

- (“teen” [titleabstract] OR “teens” [title/abstract] OR “teenage*” [title/abstract] OR “adolescen*” [title/abstract] OR “youth” [title/abstract] OR “youths” [title/abstract] OR “young people” [title/abstract] OR “young adult” [title/abstract] OR “young adults” [title/abstract] OR “Child” [Medical Subject Heading (MeSH) term] OR “child*” [title/abstract] OR “student*” [title] OR “family” [MeSH term] OR “caregivers” [MeSH terms] OR “parent” [title] OR “parents” [title] OR “parental” [title] OR “familial” [title] OR “family” [title] OR “families” [title] OR “mother*” [title] OR “father*” [title] OR “caregiver” [title]) AND (“Depression” [MeSH term] OR “Depressive Disorder” [MeSH term] OR “Anxiety” [MeSH term] OR “Anxiety Disorders” [MeSH term] OR “stress, psychological” [MeSH term] OR “Mood Disorders” [MeSH term] OR “Depression” [title/abstract] OR “Depressive” [title/abstract] OR “melancholia*” [title/abstract] OR “suicide, attempted” [MeSH term] OR “Suicidal Ideation” [MeSH terms] OR “Suicidal Ideation” [title/abstract] OR “mental” [title] OR “psych*” [title]) AND (“mindfulness” [MeSH terms] OR “mindfulness” [title/abstract] OR “MBCT” [title/abstract] OR “MBSR” [title/abstract] OR “mindfulness based cognitive therapy” [title/abstract] OR “mindfulness based stress reduction” [title/abstract] OR “MBI” [title/abstract] OR “mindfulness-based interventions” [title/abstract] OR “meditation” [title/abstract] OR [“Mental Health”(MeSH term) AND “First Aid”(MeSH term)] OR “Psychological First Aid” [MeSH term] OR “mental health first aid” [title/abstract] OR “Psychological First Aid” [title/abstract] OR “resilience, psychological” [MeSH term] OR “resilience” [title/abstract] OR “hardiness” [Title] OR “posttraumatic growth” [title/abstract] OR “post-traumatic growth” [title/abstract] OR “personal growth” [title/abstract] OR “psychological well-being” [title/abstract] OR “stress related growth” [title/abstract] OR “coping behavior” [title/abstract] OR “emotional stress” [title/abstract] OR “flourishing” [title] OR “flourish” [title] OR “Emotions” [MeSH major topic] OR “positive psychology” [title/abstract] OR “Psychological Recovery” [title/abstract] OR “Mental Health Services” [MeSH terms] OR “psychological support” [title/abstract] OR “virtual” [title/abstract] OR “Teletherapy” [title/abstract] OR “eHealth” [title/abstract] OR “Telemedicine” [title/abstract] OR “telepsychiatry” [title/abstract] OR “cognitive behavioral therapy” [MeSH major topic] OR “mindfulness” [title/abstract] OR “meditation” [title/abstract] OR “mindfulness based stress reduction” [title/abstract] OR “MBSR” [title/abstract] OR “mindfulness based cognitive therapy” [title/abstract] OR “MBCT” [title/abstract] OR “acceptance-based” [title/abstract] OR “acceptance-based” [title/abstract] OR “acceptance and commitment” [title/abstract] OR “behavior therapy” [MeSH term] OR “behavioral activati*” [title/abstract] OR “behavioural activati*” [title/abstract] OR “activity scheduling” [title/abstract] OR “pleasant event*” [title/abstract] OR “pleasant activit*” [title/abstract] OR “daily diar*” [title/abstract] OR “behavioral therap*” [title/abstract] OR “behavioural therap*” [title/abstract]) AND (“diffusion of innovation”[MeSH term] OR “diffusion of innovat*” [title/abstract] OR “information dissemination”[MeSH terms] OR “knowledge util*” [title/abstract] OR “knowledge uptake” [title/abstract] OR “knowledge transfer*” [title/abstract] OR “knowledge implement*” [title/abstract] OR “knowledge disseminat*” [title/abstract] OR “knowledge translat*” [title/abstract] OR “research utiliz*” [title/abstract] OR “research uptake” [title/abstract] OR “research transfer*” [title/abstract] OR “research implement*” [title/abstract] OR “implementation” [title/abstract] OR “research disseminat*” [title/abstract] OR “research translat*” [title/abstract] OR “health services research” [title/abstract] OR “utili*” [title] OR “program*” [all fields] OR “school-based” [all fields] OR “implement*” [all fields] OR “train*” [all fields]) AND (“2019 NCOV” [title/abstract] OR “coronavirus” [MeSH term] OR “coronavirus” [title/abstract] OR “COV” [title/abstract] OR “COVID-19” [MeSH term] OR “COVID-19” [title] OR “COVID-19” [MeSH terms] OR “NCOV” [title/abstract] OR “Pandemics” [MeSH terms] OR “sars cov 2” [title/abstract] OR “sars cov 2” [MeSH term] OR “sars cov 2” [title/abstract] OR “severe acute respiratory syndrome coronavirus 2” [title/abstract]) AND (2020/01/01:3000/12/12 [publication date] AND “english” [language])

Screening and Data Extraction

Titles were screened for relevance followed by screening of abstracts against the inclusion and exclusion criteria. The full texts of abstracts meeting the inclusion criteria were further screened. If the full-text articles met all the inclusion criteria, they were included in the literature review.

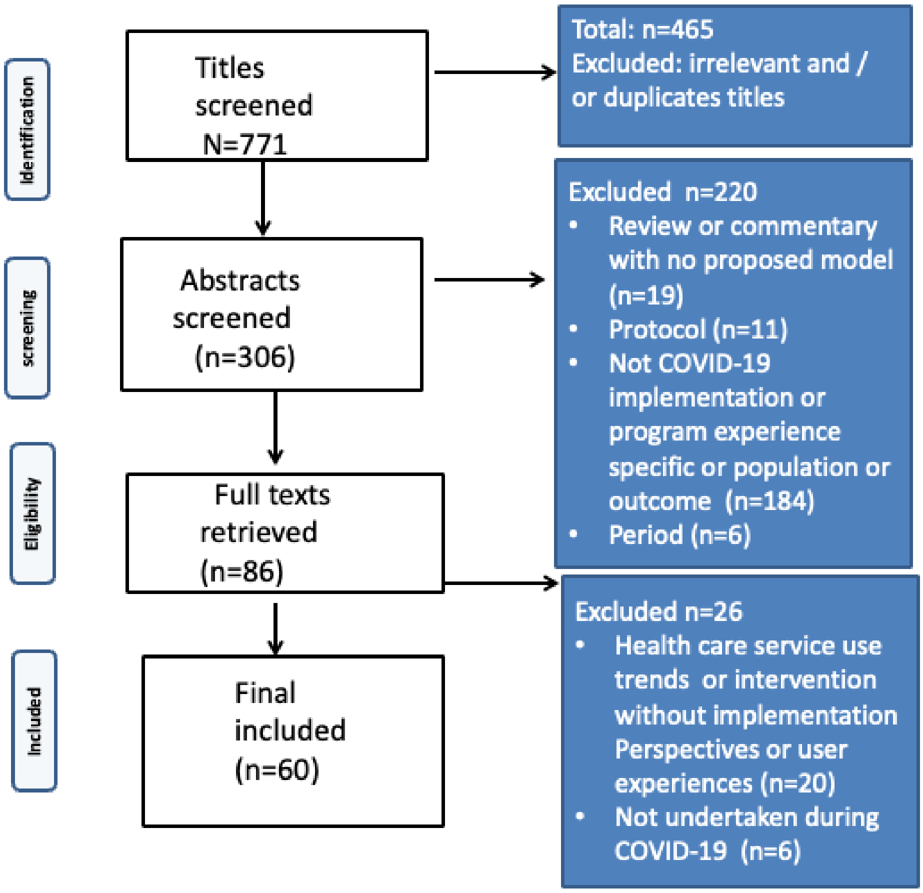
To ensure that the studies were undertaken during the pandemic period, we screened titles with the words “COVID-19” followed by checking the full texts to ensure that the programs were implemented within a COVID-19 context or with relevance to the pandemic, where lessons could be learned. Where it was unclear, authors of selected papers were contacted directly to confirm.

Data were extracted and summarized in tabular format. This included the study general characteristics, measures, outcomes (mental health, knowledge, and program implementation), KT media, and KT theories and behavior change theories.

Results

A total of 60 studies on youth mental health service or program implementation were included in the final review [9,19-77]. Figure 1 illustrates the search and screening process.

Figure 1. Flowchart.



Mental Health Outreach Services and Programs for Children and Teenagers With Mental Health Problems

Youth Mental Health Service Implementation

We identified and included 60 studies on mental health program initiatives to promote child and youth mental health during the pandemic that focused on the delivery and implementation of a wide range of mental health services, programs, and supports as well as knowledge dissemination during the pandemic. The results are summarized in Table 1. The study types were qualitative studies, case studies, and cross-sectional studies, as well as studies with mixed methodology. The countries spanned Canada, the United States, and Australia. One large study was undertaken in Europe across 8 countries: Austria, Germany, the Netherlands, Slovenia, Switzerland, Italy, Sweden, and the United Kingdom [29].

Table 1. Child and youth mental health knowledge translation (KT) tools, strategies, and interventions among stakeholders.

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Zbukvic et al [46], 2022	Australia; case study on workforce development KT	4400 MH workers	Teenagers with depression, anxiety, psychosis, trauma, borderline personality disorder, and self-harm (needs before and especially during the COVID-19 pandemic)	Work with stakeholders such as GPs[c], psychiatrists, psychologists, social workers, peer support workers, teachers, the legal justice system, police, and addiction specialists	Training in person and web-based (also outreach visits to clinical practice areas to change practice based on best practice evidence); diverse media: fact sheets, videos, webinars, web-based modules, and games to enhance engagement; focused on sharing knowledge from research; used behavior change theory; used the i-PAR-IHS[d] model (usability, context, innovation, facilitation, and recipients)	Orygen—youth MH organization focused on KT; primary, secondary, and tertiary health service delivery; offers professional development and continuing education support to enhance MH youth outreach	Difficulties with web-based e-MH care during the pandemic; levels of readiness across different organizations and adaptability; need for advice and recommendation and frameworks for implementation in a digital world using digital media
Parrot et al [37], 2022	Canada; focus groups and surveys	—[e]	Depression, anxiety, and germaphobia (pandemic related); kids (aged 6-16 years)	Work with key stakeholders at schools: parents (mean age 40 years; families), teachers, retired school board staff, retired teachers, and MH practitioners	Training in person and on the web on the DREAM[f] program—founded on the Knowledge Transitional Integration Framework (4 pillars: sustainability, accessibility, credibility, and feasibility; developing a digital program and a social literacy program, and creating meaning through creative engagement [eg, music and arts]); online classes founded on positive concept; new learning mindset or beginner mind and gratitude; incorporated rational emotive behavioral therapy and rational emotional logotherapy (identifying emotions)	KT and dissemination; stakeholders actively engaged (addressed needs of stakeholders) and participated in the research process and in the KTA[g] process—development, implementation, and evaluation stages; stakeholders were involved in surveys, focus groups, and interviews	Grounded theory informed; evaluated the credibility (hybrid program for those who do not agree with web-based methods), acceptability (stakeholders tried the web-based technology, and exposure increased positive perceptions; need for diverse music options with lyrics), accessibility, feasibility (ensuring extra teachers offer e-version in addition to the school-based version), and sustainability (memory aids, booklets, reminders, and program games based on key emergent themes from the interviews); recommendations for a hybrid in-person and web-based model for all students; the implementation stage of the aforementioned recommendations is still underway
Hou et al [30], 2022	Canada; cross-sectional survey	94; 84% female	Impact of COVID-19 on MH: depression, anxiety, and PTSD[h]; teenagers and young adults aged 13-39 years (cancer survivors)	Lived experience—childhood cancer survivors	Young adult cancer survivors had worse MH during the COVID-19 pandemic; infographic with information on meeting the needs of cancer survivors for MH during the COVID-19 pandemic (after a preliminary survey on MH); KT on coping strategies	Provided the infographic to those with lived experience with statistics on MH during the COVID-19 pandemic as well as coping strategies that were evidence based: increase sleep, improve diet and activity, and practice mindfulness	Infographic is just one medium; more research is needed on feasibility and the use of diverse media or resources for KT and dissemination; recommendation of personalized interventions with enhanced accessibility; more context research is needed (qualitative)

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Hanson et al [29], 2022	Europe; mixed methods—country case studies, analyses, implementation of KT, and implementation of a prevention intervention (clinical trial in 6 countries in the EU[i])	9437	AYC[j] of family members aged 15-17 years; promote MH, well-being, and resilience	8000 stakeholders at national and international levels: health care professionals, schools, teachers, nurses, psychologists, politicians, social workers, and researchers across Austria, Germany, the Netherlands, Slovenia, Switzerland, Sweden, the United Kingdom, and Italy; expert panel on AYC	Intervention founded on ACT[k] and the Discoverer, Noticer, Advisor model (derived from ACT); diverse media: in person, over Zoom, and using an app	ME to WE project involved several stages: knowledge synthesis via reviews, surveys of those with lived experience (needs), prevention intervention, qualitative interviews, and understanding of national policies and laws; participatory design with evaluation and impact of KT; KT and dissemination targeted stakeholders at meetings and networking efforts centered on raising awareness, engaging stakeholders, and involving them in the policy process	Key messages: identify young carers and offer supportive services, apps for support, peer and family support, and respite
Nicholas et al [35], 2021	Australia; cross-sectional survey	308 youths aged 12-25 years; 92 clinicians	General youth MH	Youth with lived experience and physicians	Telehealth implementation	Strategies to implement and improve the implementation of telehealth or tele-MH during the COVID-19 pandemic	Telehealth was not viewed as negative by young people in terms of attendance and perceptions of willingness to attend MH care relative to MH practitioners; technology issue barriers reported in 31% of cases; accessibility to e-MH and privacy were important
Eapen et al [25,78]	Australia; lexical analysis	6	Children with MH issues	Clinicians	e-MH service implementation	Strategies to ameliorate the implementation of e-MH by assessing the barriers and facilitators	Barriers to implementing e-MH included space, privacy, and technology (including internet accessibility); recommendations included a hybrid model with face-to-face interaction for real-life clinical assessment and web-based assessment to increase accessibility
Barney et al [20], 2020	United States; case analysis of the young adult medicine clinic telemedicine intervention implementation	—	General MH and addiction in teenagers and young adults	Clinicians (informing clinical practice) and MH practitioners (nurses, students, social workers, and administrative staff)	Telemedicine consultation implementation	Implementation of telemedicine	Increase in use by 97% during the COVID-19 pandemic; benefits were being feasible and acceptable, but barriers included privacy and technological barriers (eg, accessibility to devices); Zoom was preferred for privacy; need for clear guidelines for effective implementation

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Al-Rasheed et al [19], 2022	United States; survey	285	Children and teenagers; depression, anxiety, trauma, and behavioral issues	Telehealth practitioners and children and youth with lived experience	Telehealth implementation	CBT[l]+psychology telehealth implementation barriers and acceptability	Difficulties interacting with children; privacy issues (teenagers less willing to speak about discrete matters at home); high acceptability among clinicians (78.2%)
Carretier et al [22], 2022	France; qualitative interviews	20	Depression, anxiety, and PTSD	Telehealth practitioners, parents, and youth with lived experience	Telehealth implementation	Tele-psychiatry implementation barriers and facilitators	Hybrid method recommended: face-to-face with web-based methods; practitioners felt that nonverbal communication could be a challenge; the quality of the therapeutic relationship influenced care and the severity of their patients' MH problems; preference to select phone versus video calls; teenagers appreciated having their parents involved
Conradi et al [9], 2022	United States; case study implementation of telehealth at a children's advocacy center	—	Children; general MH and trauma	Telehealth providers and children at a children's advocacy center and their families	Informed by the Consolidated Framework for Implementation Research; online telehealth media	Implementation of telehealth; 3 areas: agency requirements, the needs of the telehealth professionals and training, and use of technology+effective communication strategies	Challenges included health professional burnout and need for support; need for clear communication and effective planning; patients should receive a virtual tour+"welcome kit"+frequent feedback on the sessions; ameliorate body language in front of technology; provide families with technology and adequate internet connection and play kits for the children; kids had "Zoom fatigue"; implementation of team managers for creativity+innovation; technology needs a consideration of space
Craig et al [23], 2021	United States; case study Affirm we-based group session	1 transgender youth	General MH in youth	Telehealth practitioners and LGBTQ[m] youth social workers	Implementation of affective CBT; AFFIRM[n] behavioral approaches; cognitive restructuring approaches; affirm social support networks; online and app support media	Evaluate the implementation of AFFIRM by engaging with LGBTQ youth	Recommendations: adapt to using Zoom (eg, chat and screen sharing) and become experienced with technology, include frequent check-ins and icebreaker questions to reduce virtual awkwardness, implement document sharing and Microsoft PowerPoint for engagement and dissemination, integrate calming strategies, and facilitate social networking via social apps for support

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Doan et al [24], 2021	Canada; framework development proposal analysis of the 6 Pillars framework at the Hospital for Sick Children	—	General MH; children+teenagers	Clinicians, children, teenagers, and families	Implementation of virtual MH care for children	Implementation of the telehealth 6 Pillars framework at the Hospital for Sick Children, Toronto, Ontario, Canada; plan to do act assisted clinicians to come with guidelines for virtual care (2 weeks of meetings)	The physical space is important—private and clean for training and practice; providers should be accepting and ready to use technology; need for a safety plan in virtual meetings for emergencies or unexpected events; parents must be present during consultations; patients must find telehealth acceptable, and the environment must be suitable (eg, safe, technology, accessible, and private); patients need adequate physical space for privacy; clinicians must follow and adhere to clinical practice standards and laws during telehealth
Gorny et al [27], 2021	United Kingdom; case analysis of London ward	36 hospitalized during the first-wave lockdown in March 2020	General MH problems, depression, and anxiety	Physicians, politicians, the national health care regulator (Care Quality Commission), hospital staff, social workers, children, parents, and leadership representatives from MH trusts	Implementation of a child and youth MH ward; —	Ward was created for child and youth MH to meet the COVID-19 challenges with a change in organizational structure and leadership; multidisciplinary team morning meetings to plan and work on patient cases	Challenges with implementing a young people and children MH ward in a pediatric setting; plan to set up a new ward involved integrating physical+MH care; MH nurses and child psychiatrists were allocated to one place in proximity to patients; dynamics changed with a multidisciplinary team and new managerial or leadership approaches for managing MH; tailoring treatment to patient needs
Lal et al [32], 2022	Canada; cross-sectional	51	General MH	Young adults	Telehealth implementation	Assess implementation barriers and experiences with youth telehealth	Main barriers included technological (technological support needed for the preliminary sessions) and privacy (secure private connections) barriers; overall, those with lived experience or knowledge users found the telehealth platform to be acceptable
Moorman [34], 2022	United States; analysis of practice data	100; 40 clinicians and 60 families	General MH	Practitioners, children and teenagers, and parents	Telehealth implementation (digital media)	Assessment of implementation challenges and experiences	Benefits of telehealth included higher attendance and access to MH; challenges with younger kids; difficult to understand body language web-based (nonverbal communication); privacy concerns

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Palinkas et al [36], 2021	United States; qualitative interviews via Zoom	21 state MH authorities	Range of MH problems in children+teenagers	State MH authorities	MH care provision, including telehealth	Rapid assessment procedure used to analyze key implementation themes regarding youth MH service delivery	Barriers to telehealth: technology+internet, privacy issues, challenges with using telehealth with younger children, and need for greater training of health professionals and an integrated system of reimbursement of costs of treatment
Power et al [39], 2022	Ireland; toolkit design	—	General MH promotion via+MH	Children and primary and secondary MH practitioners	Print resources (leaflet) for KT for promotion+MH; coping strategies; mindfulness; positive psychology; hand model of the brain	KT; happiness toolkit of essential MH resources created; KT of 6 evidence-based techniques for MH and resilience building; kids had to build an actual box; includes advice on social support or building healthy relationships; mindfulness; positive visualization—smile a vision; gratitude; hugs; hand model of the brain to identify emotions	Focused on the development of a model for MH care; the MH needs of children (pediatric MH population) are not met when physicians are not adequately trained; the toolkit may enhance mental well-being as a model of MH care
Randall et al [40], 2021	Australia; mixed methods—health data sets and surveys	140	General MH	Children and teenagers with MH problems and MH clinicians	Digital telehealth (psychiatry)	Challenges and opportunities in the implementation of telehealth	Barriers: technological issues identified as barriers, lack of human contact, and younger kids preferred face-to-face over video consultations; benefits were convenience; provider challenges included adequate training—developing skills for interviewing
Sharma et al [42], 2020	United States	57 faculty members and 97 clinicians in need of training	General MH in children and teenagers	MH clinicians at Seattle Children's Hospital: nurses, psychologists, psychiatrists, and behavioral therapists	Telehealth; tele–group training	Tele-psychiatry implementation involved phone consultations as a bridge before the full transition; took 6 weeks to implement tele–group training for MH practitioners; TeleMed Home scheduling visits and administrative staff trained	Clinicians have limited training in tele-psychiatry; tele-MH has barriers: need for special training for the DTC[o] virtual platform; privacy issues regarding using third-party applications for consultations; technological issues with the DTC platform crashing
Skar et al [43], 2022	Norway; clinical treatment data analysis	382 therapists treating 1240 patients	Children and teenagers with trauma	MH practitioners; 66 clinics	Trauma-focused CBT implementation	Issues with the implementation of CBT	Adequately trained (high intense) therapists linked with patient response and continued attendance; leadership training also important (secondary) to intense training for higher fidelity and nondropout; nonresponse linked to older children

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Somaiya et al [44], 2022	Australia; qualitative focus groups	44	General MH; youth	Youth with MH problems	Digital telehealth	Experiences with implementation of telehealth	Successful implementation of telehealth, acceptable+feasible; preference for face-to-face as an option after the pandemic in youth; benefits included accessibility, convenience, and web-based social interaction; barriers with technology, internet issues, lack of human contact and privacy, space, comfort with being on the internet, and meeting time or scheduling problems
McMellon and MacLachlan [33], 2021	Scotland; case or policy analysis	Aged 10-18 years	General MH	Observatory of Children's Human Rights in Scotland, Children and Young People's Commissioner Scotland, and children	Impact analysis of MH legislation for children during the COVID-19 pandemic	Recommendations by the ICRA[p] made for KT and implementation for the government	Increase resources for children's MH, including in schools (eg, training more staff to meet capacity and enhance access or reduce barriers to e-MH via technology and internet access for kids); offer in-person support for special groups who need it; undertake more research on special needs in diverse groups
Zickafoose et al [47], 2022	United States	29,000 surveys; 400 randomly selected who undertook trauma-informed training interventions	Children and teenagers; MH trauma	MH America schools and MH professionals	Dissemination and training for trauma-informed classroom practices	Implementing informal MH training and help via schools combined with formal professional medical help	Trauma-informed classroom practices can be implemented with effective dissemination via professionals and school staff; there were no differences in knowledge acquired when school staff versus health professionals delivered the MH material in trauma-informed classroom discussions; requirements include quality training
Rodriguez-Quintana et al [41], 2021	United States	982 trainees for the session; 155 needs assessment surveys	Ages from kindergarten to 12th grade; general MH	TRAILS[q] program	Group manual for school-based health professionals for youth MH; coping skills; promotes CBT+mindfulness (includes emotion recognition and gratitude); implementation of TRAILS program in schools; digital media: virtual support and information or tools; informed by therapeutic principles	Handbook or manual for knowledge dissemination and training for youth MH website with materials or information; 3-hour virtual training	The study focused on the development and early implementation; overall satisfaction among health professionals with the training materials; overall acceptability; some providers reached out for support with using virtual meetings and interactive web-based material; lack of internet may be a barrier for students and providers

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Podar et al [38], 2022	Germany; mixed methods—semistructured qualitative interviews+longitudinal data	12 gatekeepers and 216 adolescents	General MH; teenagers (refugees and migrants)	YOURCARE research project participants; schools+teachers, teenagers, parents, and psychologists	Needs assessment and case analysis of COVID-19 MH; media: —	Implementation and dissemination needs and barriers	Lack of integrated MH care in schools; segregation and stigma among young refugees; barriers to accessing MH care; need for antidiscrimination policies in schools; COVID-19 perpetuated inequalities; diversity is needed in implementation and research by including migrants
Weineland et al [45], 2020	Sweden; qualitative semistructured interviews	14	General MH in youth	Primary care therapists; youth MH centers in Sweden	Internet implementation of CBT	Implementation experiences with iCBT[r] training and program delivery	Barriers included motivating patients and the therapeutic relationship when communication is not in person
Goddard et al [26], 2020	United States; qualitative case analysis	308	General MH in youth	Listening and Learning attendees from the School-Based Health Alliance; school-based health centers	KT strategies to adjust to the pandemic on the Listening and Learning platform; digital implementation of telehealth (general); MH as a topic; digital media: Zoom, Skype, and online platform	Listening and Learning KT platform developed to help providers during the COVID-19 pandemic; experiences with implementing telehealth and strategies; physical art supplies and kits for children for MH (eg, dialectical therapy mailed to their homes)	Most providers adapted to virtual MH care using Zoom, Skype, FaceTime, Google Classroom and Voice, and Doxy; most barriers were technological issues such as troubleshooting; benefits included greater parental involvement; concerns about the privacy of the teenagers
Khan et al [31], 2021	United States; development of training and dissemination	—	General MH in children and teenagers	American Academy of Child and Adolescent Psychiatry, American Psychiatric Association, and directors of psychiatric training websites	6-stage model of curriculum development by Kern	Web-based curriculum for KT on pediatric tele-psychiatry; implementation addressing patient needs; 6 areas of competency; resources; evaluation tools for practitioners	Currently available on the internet for training; further results will come
Birkenstock et al [21], 2022	United States; virtual MH workshop implementation, community-based participatory research study	11	Immigrant youth with MH problems	Refugee immigrant center; youth with lived experience; university+art and health collective; Sanctuary Philadelphia Independent Cultural Youth project	Art workshops for MH; developing strategies for youth MH based on needs or planning	Implementation of an MH project for youth migrants on the web from face-to-face due to COVID-19	Issues with implementation due to COVID-19; challenges with switching to a digital system; fatigue from web-based meetings; more complex artwork was not possible on the web; alternative expression included photos, videos, and memes; activities mainly centered on virtual discussions; care packages sent to participants; program terminated early due to lack of participation

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Haliwa et al [28], 2022	United States; qualitative	191	General MH in school-age youth	—	Mindfulness on the web	Kidding around; yoga; implementation of a school-based digital training of teachers mindfulness program; knowledge, attitudes, and perceptions regarding implementation of mindfulness in schools	Misperceptions of mindfulness may act as barriers to implementing it in schools; cultural acceptance issues potentially; benefits for emotions and coping skills
Danseco et al [54], 2021	Canada; multilevel mixed methods implementation research—surveys+focus groups	192 youth and 97 agency leaders (surveys only)	General youth MH (virtual)	Families and youth, agency leaders, and MH service providers	Virtual care platform	Implementation of a virtual care platform for youth; adapted the Consolidated Framework for Implementation Research	Common barriers to implementation: privacy, internet connection, resources (eg, laptops and phones), and safety (sudden disconnection and unknown risk to the patient or a connection issue); less engaging than face-to-face for some (eg, children)+nonverbal cues harder to assess than face-to-face; work-life balance between home and the office and loneliness for MH practitioners; facilitators: engaged with adequate training and leadership as well as collaboration and good relationships with patients
Davenport et al [55], 2020	Australia; proposal for a model of care[h]	—	General MH	Tailored to MH for youth	Web-delivered care; digital toolkit	Brain and Mind Centre model of care; health IT for model deliverance; web-delivered care; Innowell platform	Need to implement necessary technological infrastructure for this model of care (implementation experiences not described)
Dhonju et al [57], 2020	Nepal; implementation of a multitier platform	100 health care professionals; 1206 parents, teachers, and caregivers	General MH	MH care professionals, teachers, and parents	Web-based platform with the use of apps for training, such as Zoom, Microsoft Teams, and Google Hangouts	Implementation of an MH platform or telehealth with face-to-face in-person programs	Challenges with participation (finding MH professionals to engage with); remote issues; connection issues with the internet and resources (access to technological devices); challenges with learning how to use Zoom for de novo users; barriers with timing and scheduling virtual sessions; resource issues: not all remote schools have access to the technology for virtual sessions and fewer interactional possibilities on the web versus in person; stigma is also a barrier
Havewala et al [75], 2023	United States	35	MH first aid training	Youth	Digital MH training	MH first aid training implemented virtually	Improvements in MH literacy, knowledge, confidence in MH first aid, help-seeking attitudes, and stigma

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Hawke et al [61], 2021	Canada; survey+open-ended questions	491	General MH in youth	Youth with and without lived MH experience	Explored use of virtual care, including web-based video sessions, phone calls, and use of messages	Not a specific implementation study but one on general experiences with accessing virtual care	Youth preferred MH virtual services that involved web-based video sessions, followed by phone calls; messages were the least preferred; technology had to run smoothly, including preferences for quality internet connection and technology; ease of booking and free MH care preferred; privacy and ability to mute were important; desired content on mindfulness and fitness and engaging content with education; preference for one-on-one over group sessions; need for human personal connection
Markoulakis et al [65], 2022	Canada; qualitative study, semistructured interviews	46	General MH	Youth and caregivers (from the standpoint of carers)	General virtual care and face-to-face services	Not implementation specific but about experiences with MH services, including digital ones, in Ontario, Canada	Fragmented MH services with difficulty accessing them; virtual care benefits included accessibility without the need to travel; issues with engagement with virtual (being easily distracted and it feeling less personal) versus in-person care; barriers with technology issues, including Wi-Fi
McQueen et al [66], 2022	Australia; qualitative (3 participant groups)	167 health care professionals and 68 parents	General MH	Parents and MH care providers	General MH services and virtual care	Not implementation specific but about experiences with MH services	Telehealth barriers included privacy; technology issues with Wi-Fi, sound, and camera (image quality); benefits of telehealth included accessibility; preferences for a hybrid on the web+in-person approach
Meininger et al [77], 2021	Germany; survey	561 therapists and 227 parents	General MH	Parents and MH professionals	Telehealth	Not implementation specific; general experiences with MH services and telehealth at an outpatient unit	One-quarter transitioned from in-person care to telehealth; high satisfaction+acceptance of telehealth; 47% of therapists preferred in-person care over telehealth (over returning to the latter); technology requirements were a barrier in 19% of cases (did not undertake telehealth)
Purtle et al [68], 2022	United States; surveys	159 state officials	General MH	State officials	General MH services+telehealth	Not implementation specific; general experiences with nationwide MH services+telehealth	Main barriers to telehealth were due to remote location, access to technology, and internet connection

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Rudnik et al [69], 2021	Poland	—	General MH	Students	Psychological support delivered via email+Skype; video calls; self-care behaviors; relaxation	Academic Psychological Support Centre in Gdańsk, Poland; applied the pandemic management theory; psychoeducation	Proposed model of care; initial challenges concerned a lack of clear guidelines
Brahmbhatt et al [49], 2021	United States and Canada	22 hospitals	General pediatric MH	Hospitals and MH practitioners	Tele-psychiatry; use of Zoom, WebEx, FaceTime, Microsoft Teams, Epic, Google, phone calls, video consultations, and a combination of media	Tele-psychiatry implementation	Rapid transition to tele-psychiatry used in 16/22 practices (PCLPs[s]); challenges with resources, including access to technology in 75% of cases; access to essential technology rose later on in the pandemic; quality of care not a challenge during virtual as well as hybrid delivery of MH services; lower levels of preference for virtual MH care among primary care providers; challenges faced due to a lack of continuity between primary care physicians and psychiatry in their use of tele-psychiatry
Campbell et al [50], 2023	Canada	48 for the semistructured interviews and 1300 for the mixed methods survey	General MH	MH practitioners, caregivers, and patients	Telehealth	General telehealth implementation experiences	Telehealth is helpful, but hybrid models are preferred; there was diversity in preferences; preference for in-person care for stronger therapy cases; need for private, safe space for consultations and access to technology; usefulness of telehealth included accessibility and no need to travel+social distancing; personal factors need to be considered when deciding the treatment modality and setting; facilitation of telehealth enabled through technological assistance guided by MH care providers

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Campos-Castillo and Laestadius [51], 2022	United States; cross-sectional	532	General MH; teenagers (AmeriSpeak Teen panel)	Teenagers	Telehealth and chat-based messages	Experiences with using the MH care system; not specific to one implemented program	Support from the teenagers' parents critical for enabling access to telehealth, including the provision of space; barriers to equitable access to in-person care among Black teenagers with preferences for in-person support; greater use of messaging and chat-based approaches for ethnic minority groups; need to ensure racial equity in MH diverse digital service accessibility
Childs et al [53], 2020	United States; observational implementation study at a psychiatric hospital	—	General MH	MH care providers at a psychiatric hospital managing teenage patients with MH problems	Zoom, Epic, video group-based psychotherapy, and Telephonic	Telehealth, including Telephonic, MyChart, and video consultation; implementation of youth psychotherapy at the hospital	Telehealth is feasible for group-based psychotherapy; need for an integration of telehealth with the electronic medical record for long-term sustenance
DeJong et al [56], 2022	United States; cross-sectional survey	138	General MH	Psychiatrists	Telehealth	Evaluation of telehealth training, education, and care	Large uptake of telehealth linked to a greater ability to manage the technology; fewer barriers in clinical care training using telehealth reported and greater training relative to prepandemic levels; barriers that remain need for greater equity in telehealth accessibility and funding
Garbutt et al [59], 2022	United States; qualitative interviews	19 pediatricians and 2 nurses	General MH	Pediatricians and nurses	—; provision of general MH support	Experiences with providing MH services; the Child Psychiatry Access Project	Discontinuity between care provided by pediatricians and MH specialists; need for greater accessibility to advice from colleagues on integrating MH care in the home setting; need for comprehensive MH care implementation for remote patients
Gorfinkel et al [60], 2023	Canada; cross-sectional survey	1928	General MH	Teenagers	Video, phone calls, chat-based support, and in-person support	Perspectives and experiences with receiving MH services	Preference for in-person MH care, followed by SMS text messages; phone calls were less preferred, second to video tele-MH consultations
Lal et al [63], 2023	Canada; longitudinal survey	26	General MH	MH care providers: clinicians, nurses, social workers, occupational therapists, and peer support	First-episode psychosis telehealth platform	Tele-psychiatry perspectives using the Reacts platform	Preliminary barriers that subsided with use included technology issues: sound, image quality, and internet connectivity; benefits: patient engagement+accessibility to continued MH care; benefits of Reacts: user centered and private

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Malik et al [64], 2023	India; mixed methods—survey+qualitative interviews	34	General MH	Teenagers and counselors	Digital behavioral problem-solving; tailored behavioral model; voice and video calls	Remote stepped-care model of mental health	Teenagers: preference for voice calls, which felt more private and required less technology; counselor barriers: timely remote support and need for teamwork from both the patient and provider to meet specific needs
Olson et al [67], 2020	—	—	Suicide prevention training	Families+caregivers	Zoom; Northwest Mental Health Technology Transfer Center	Involved patients with their families in the process; Northwest Interconnected Systems Framework; outreach efforts informed by Consolidated Framework for Implementation Research	Switching from in-person to web-based suicide prevention training resulted in greater participation levels than in prepandemic times; increases in knowledge+changes in behavior
Rusu et al [70], 2023	The Netherlands	1065	Cross-sectional survey on experiences	Psychiatrists	Telehealth	—; general experiences with telehealth	The stakeholders were more accepting of telehealth if they had previous training and clinical experience; recommendations to provide both for its successful implementation
Schriger et al [71], 2022	United States; mixed methods—survey and interviews	45	General MH	MH clinicians	Telehealth	—; general telehealth experiences	Training is essential for telehealth; need for resources; engagement is impacted during telehealth+discussion focus or topics; telehealth is not uniformly great for everyone and is contingent on patient characteristics and preferences; higher level of involvement, engagement, and creativity in some patients and families in virtual settings; barriers: privacy and internet accessibility
Stuart et al [72], 2023	Canada; cross-sectional survey+focus groups	29	General MH	ED[t] physicians	Telehealth	—; general telehealth experiences	Barriers to finding the time for telehealth and lack of resources or support from others; need for a greater level of training and comprehension on specific duties and roles in telehealth in the ED setting; benefits: value in providing services virtually for assessing MH

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Sullivan et al [73], 2022	Semistructured interviews	207 (121 school-based health centers)	General MH	School-based centers	Zoom; School-Based Health Alliance (60-min session)	—; discussion over Zoom about school-based mental health support recommendations	Key barriers included limited availability of in-person support and staffing; community-based partnerships were important for the sustained provision of support; other barriers were language, cultural, privacy, and technology related (internet and Wi-Fi)
Williams et al [74], 2023	United States; pre- and posttest analysis of the electronic health record	—	General MH	Pediatric MH care providers at the hospitals	Telehealth	—; assessment of the electronic health record	Barriers and accessibility issues for pediatric telehealth in patients from racial minority groups
Kaar et al [62], 2023	Single-arm pilot study that transitioned during the pandemic from Colorado to Alabama (Ally)	—	General MH	Schools, students, and MH volunteers	Web-based delivery of Ally (advocates for all youth)	Health equity implementation framework—FRAME; use of volunteers	Adaptation to the new community setting and implementation required greater community support with volunteers to drive the program; 30-minute sessions each week; challenges with maintaining an equity perspective and health literacy level diversity; need for representation in group leaders from the same backgrounds; the benefit of virtual delivery was a greater reach
Banks [48], 2022	United States; open-ended survey	33	General MH	Teenagers	—	—; general health care use experiences	Financial problems were a main barrier for Black teenagers when it came to accessing MH services
Childs et al [52], 2021	United States; pretest-posttest analysis of attendance rates during the pandemic	—	General MH	Youth and adults (only youth information included)	Telehealth compared with in-person care	Telehealth implementation	Telehealth helped increase accessibility; benefits for group therapy during the pandemic; racial inequities in accessibility to telehealth in Hispanic and Latino youth
Bhat [76], 2021	United States; survey	6393	MH in patients with ASD[u]	Families	Web-based MH services	Experiences with web-based MH services for children with ASD	Web-based MH was not always suitable for many families with children with ASD; recommendations for hybrid (in-person and on the web) MH care

Study, year	Location and design	Sample size, N	MH[a] outcome and target group	Stakeholders	KT media—theory, BCT[b], and diverse media?	KT dissemination plan or efforts or implementation plan?	Key findings and messages
Endale & Birm an et al [58], 2020	United States Case study commentary on program experiences	N/A	General mental health	Key stakeholders at the Kovier Centre Child Trauma Program	Transition to an online delivery of care with video calls outreach	Psychological first aid training Knowledge dissemination to families Translation to various language over text messages sent to families School coordination planning	Digital literacy barriers Access to technology and internet barriers Privacy barriers (space)

[a] MH: mental health.

[b] BCT: behavior change technique.

[c] GP: general practitioner.

[d] i-PARHIS: Integrated Promoting Action on Research Implementation in Health Services.

[e] Not applicable.

[f] DREAM: Developing Resilience Through Emotions, Attitudes, and meaning.

[g] KTA: Knowledge to Action.

[h] PTSD: posttraumatic stress disorder.

[i] EU: European Union.

[j] AYC: adolescent young carers.

[k] ACT: acceptance and commitment therapy.

[l] CBT: cognitive behavioral therapy.

[m] LGBTQ: lesbian, gay, bisexual, transgender, and queer.

[n] AFFIRM: Manualised Affirmative Cognitive Behavioral Therapy.

[o] DTC: Direct to Consumer.

[p] ICRA: Independent Children’s Rights Impact Assessment.

[q] TRAILS: Transforming Research Into Action to Improve Lives of Students.

[r] iCBT: internet-based cognitive behavioral therapy.

[s] PCLP: pediatric liaison psychiatric consultation provider.

[t] ED: emergency department.

[u] ASD: autism spectrum disorder.

Stakeholders

Most programs engaged stakeholders, including politicians, not-for-profit organizations, schools, teachers, parents, youth with lived experience, health professionals including general practitioners, psychiatrists, psychologists, social workers, and the criminal justice system [20,25,29,30,35,37,46,79]. A study in Europe used the Knowledge to Action framework [80], with stakeholders involved in each stage of the research process from the development and implementation stages to the evaluation stage, including focus groups, surveys, and interviews [37].

COVID-19 Context

Most of the articles explicitly described that the study was implemented during the COVID-19 pandemic in their titles [9,19-22,24,26-28,30,32-42,44]. Others discussed their study relevance in relation to the COVID-19 pandemic in the abstract or main text [9,23,29,31,38,39]. Several articles described that they were undertaken during the COVID-19 pandemic in both the abstract and title as well as in the main text [48-74]. A few were undertaken before the pandemic but continued throughout the pandemic and had to adjust their implementation strategies, including transitioning from face-to-face programs to adapting to digital health or COVID-19–specific needs [43,45-47].

KT Media

Several but not all the programs delivered mental health KT interventions through diverse media to their various stakeholders [23,26,29,37,39,41,46]. Diverse media included combinations of fact sheets, webinars, Zoom meetings, videos, modules, infographics, and toolkits. For example, Orygen in Australia provided primary, secondary, and tertiary mental health services and education to mental health professionals both on the web and in person along with outreach visits to patients. Their KT media included fact sheets, webinars, videos, web-based modules, and games to increase engagement. Another large study across Europe integrated face-to-face KT using digital tools, including Zoom and a KT app [29]. Several studies used a hybrid method involving face-to-face and digital KT media [22,25,29,30,33,37,46]. However, most focused on implementing e–mental health programs exclusively on the web, usually through virtual mental health or telehealth [9,19,20,22,24,25,28,32,34-36,42,44]. One study focused on using 1 KT medium for translating information on self-care during the pandemic to young cancer survivors to promote their mental well-being using an infographic [30].

KT Theories

A few of the programs applied specific KT theoretical models and frameworks that informed their program implementation [9,31,37,46]. For example, the study by Zbukvic et al [46] in Australia used the Integrated Promoting Action on Research Implementation in Health Services model. The model is founded on usability, the context of the KT intervention, facilitation, and the recipients [46]. In addition, the DREAM KT program in Canada adopted the Knowledge Transitional Integration Framework. The framework is based on 4 pillars, namely, sustainability, credibility, accessibility, and feasibility.

In addition to established KT models, a few positive health psychology theories or models derived from this field were used [23,28,29,37,39,41,43]. For example, a large study across Europe by Hanson et al [29] was informed by positive psychology using acceptance and commitment therapy that informed the Discoverer, Noticer, Advisor model. The study by Zbukvic et al [46] in Australia also integrated the behavior change theory model into the KT program. The program in Canada also focused on developing resilience through emotions, attitudes, and meaning in their youth KT mental health program, whereby they sought to maximize positive experiences in youth with a beginner's mind and creative expression using means such as art, music, and gratitude [37]. They also integrated logotherapy through emotion identification into their program. Grounded theory further informed the first stage of their research at the stakeholder interview stage [37].

Barriers to and Facilitators of Digital and Face-to-Face Mental Health Service Program Delivery and Implementation for Youth During the Pandemic

Digital and Tele–Mental Health Implementation

Several studies reported barriers associated with technology and privacy [19,20,24,25,32,34-36,42,54,61,66,72,73]. Zoom was preferred for privacy reasons when conducting tele–mental health consultations in one study [20]. Accessibility issues included access to technological devices and adequate internet connection [9,25,33,36,54,57,61,63,65,66,68,72-74]. The studies recommended that parents should have adequate training and an orientation on the technology as well as increased accessibility to the internet. Technological support was also needed for the preliminary tele–mental health sessions [32], and technological issues were identified in 31% of users in one study [35].

Space was identified as a critical feature for the successful implementation and delivery of virtual mental health services and programs to children and teenagers [9,24,25,50,51]. For example, the study by Doan et al [24] at the Hospital for Sick Children in Canada, which adopted the 6 Pillars framework in their development of a framework for mental health practitioners, emphasized that the space needed to be clean and private for medical providers.

Body language or nonverbal communication cues were also identified as barriers in some studies [9,22,34,45]. One study found that it was difficult to motivate patients and that work was needed to build the therapeutic relationship when mental health consultations were virtual as opposed to face-to-face [45]. In addition to body language, there were challenges with implementing certain digital mental health interventions, including art therapy programs on the internet during the pandemic [21].

A few studies also found that tele–mental health service implementation was more challenging in younger children [9,19,22,34,36,40,54]. Children preferred face-to-face mental health consultations over virtual ones [40]. In addition, one qualitative study in France by Carretier et al [22] found that teenagers preferred phone calls over video consultations. "Zoom fatigue," feeling tired from using web-based technology for mental health care, was identified as an obstacle in one study in children. In total, 3% (2/59) of the studies made play or art kits for children to keep them engaged. One study recommended offering "play kits" to keep children interested and engaged with the technology [9]. Similarly, "art kits" were mailed out to children undergoing mental health therapy, including dialectical behavior therapy in adjunct to virtual telehealth appointments [26]. Thus, it seems that sending hands-on engaging resources to children may assist with their participation during web-based mental health sessions.

There were also challenges with managing and adapting to using the digital technology. For example, the case study by Zbukvic et al [46] on KT in workforce development (Orygen) involving 4400 mental health workers found that it was challenging to deliver digital mental health care during the pandemic and that there is a need for a framework with clear guidance on how to best deliver e–mental health care using digital media. They found that levels of readiness and adaptability varied across different stakeholder organizations [46]. Physician-level factors included the need for adequate training in tele–mental health [36,40,42,43] as well as readiness to partake in it [24].

A few studies found that physicians needed to be sufficiently trained in the technology when dealing with young patients with mental health problems. The study by Skar et al [43] found that there was higher patient attendance when they had adequately trained physicians. For example, this included leadership training [43] and learning how to undertake virtual interviews [40].

Actual hands-on training in using tele-psychiatry technology and the virtual platform was also emphasized in one study [42]. The study by Doan et al [24] also found that there is a need for a safety plan, with adequate preparation during emergencies or unforeseen events. The qualitative focus group study by Parrot et al [37] found that stakeholders who were not previously supportive of web-based mental health platforms found them to be acceptable after they had tried them, indicating that perceptions of digital mental health are more positive and willingness to try it increases if users learn how to apply it. The qualitative study by Goddard et al [26] involving the "Listening and Learning" platform for school alliances found that most providers adapted to using telehealth and virtual meetings on Zoom, Skype, and FaceTime. The study by Craig et al [23] found that there is a need for medical providers to be familiar with navigating digital technology, including screen sharing, implementing Microsoft PowerPoint for greater engagement and knowledge dissemination, and learning how to break social awkwardness on the web through things such as "icebreaker questions” when implementing cognitive behavioral therapy. They also found that there is a need to implement social apps for social networking [23]. Therefore, adequate knowledge dissemination on the use of digital health technology and its successful implementation through gaining interviewing skills and providing sufficient engagement for children and youth across diverse service providers is needed.

Overall, most of the studies that assessed acceptability and feasibility found that digital health and tele–mental health were viewed positively and there was a high uptake by youth during the pandemic [20,24,32,34,41,77]. The cross-sectional survey involving a needs assessment from the Transforming Research Into Action to Improve the Lives of Students implementation study (N=982 school-based health professionals who were trained) found that school-based mental health professionals were satisfied with the web-based manual that disseminated knowledge on youth coping skills [41]. Only one study found that medical providers experienced burnout from implementing telehealth [9]. The study by Moorman [34] that analyzed practice data from 40 health professionals and 60 families found that tele–mental health increased accessibility to mental health care for children and teenagers and resulted in a higher attendance.

School-Based and Nondigital Mental Health Approaches

A couple of studies examined the challenges with implementing mental health programs in face-to-face settings such as in schools and clinics. A large study in the United States with 29,000 stakeholders that analyzed data from 400 participants who undertook training in trauma-informed practices found that trauma-informed classroom practices could be successfully implemented through joint efforts between school-based professionals and mental health care providers [47]. The mixed methods qualitative interview study with 12 gatekeepers (with longitudinal data from 216 teenagers) by Podar et al [38] in Germany found that there is a need for an integrated mental health care system in schools and that inequities in accessibility exist among young refugees who experience stigma. They emphasized that there should be strong antidiscrimination policies when it comes to youth mental health in schools [38]. Thus, implementing programs in schools should maximize accessibility for all students. A case study analysis in the United Kingdom of youth in wards (N=36) found that it was challenging to implement a youth mental health ward in a pediatric setting, which required setting up a new ward and combining physical health with mental health [27]. They also found that it required joint efforts in a multidisciplinary team setting involving nurses and pediatric psychiatrists, which led to adopting new leadership and managerial approaches as well as tailoring treatments to individual patients [27].

Hybrid Mental Health Approaches

Some of the studies opted for hybrid approaches when implementing mental health services and programs for children and teenagers [22,25,29,30,33,37,46,76]. The case analysis by McMellon and MacLachlan [33] in Scotland recommended a hybrid program with enhanced access to digital mental health services and technology in schools combined with face-to-face in-person support through greater staff training. The lexical analysis study by Eapen et al [25] in Australia also made recommendations for a hybrid mental health care service delivery for youth in clinics and at home to increase accessibility, ensuring clinical assessment in person combined with web-based support. Another study in Australia (case study) by Zbukvic et al [46] found that diverse stakeholders, including mental health care providers, required web-based training and outreach in-person clinic visits, with KT and dissemination strategies involving videos, fact sheets, modules, and webinars to meet the mental health needs of youths. In addition, a large mental health mixed methods KT implementation study in Europe (ME to WE) involving 8000 stakeholders evaluated KT and dissemination strategies to meet the needs of youth who cared for someone [29]. Through extensive knowledge syntheses and a participatory design, they found that youth should receive support from both peers and family in addition to mental health supportive services and respite. They also made recommendations for a mental health app that would support young caregivers [29]. Raising awareness of the mental health needs of young carers was also brought up as a theme [29]. The focus group study by Parrot et al [37] recommended a hybrid model for in-class and web-based KT for youth mental health by ensuring that teachers offered both the in-class learning version and the web-based one. Behavior change techniques such as reminders to enhance memory were also recommended, including things such as games, booklets, and memory aids. They also found that students preferred a range of lyrics with music as part of a meaningful program [37]. To enhance accessibility and engagement, they also recommended more teachers who could offer the program on the web [37]. The study by Hou et al [30] found that an infographic, while informative, was only one medium for KT and dissemination for youth mental health and resilience and that other KT media should be explored in the future along with personally tailored interventions.

In addition, one study combined passive KT with active KT, a type of hybrid approach for disseminating knowledge. The study by Power et al [39] involved a KT leaflet for resilience building in children and teenagers combined with a happiness toolkit that required children to build a physical box, emphasizing the importance of real-life relevance for children in addition to a passive leaflet when it comes to participation and engagement. However, this was an early developmental study on a new model of care rather than an implementation study evaluating its barriers and acceptability.

Overall, support services should include a range of resources, including in-person social support and an app. All these studies with hybrid approaches found that accessibility to mental health supportive services or engagement was enhanced when diverse options were offered through in-person support, web-based support, digital applications, and support from family and friends in addition to professional help to accommodate diverse learning needs and preferences. As barriers were noted for digital delivery, hybrid methods were also recommended for accessibility from this perspective. It also appears that active versus passive methods may enhance participatory engagement; however, more research is needed to confirm these findings.

Mental Health First Aid

A couple of studies implemented mental health first aid through virtual platforms and found that knowledge improved [67,75]. The study by Olson et al [67] found that participation in suicide prevention training increased when they transitioned to a web-based delivery system due to COVID-19.

Summary of Findings

In summary, it seems that the successful implementation of mental health programs requires hybrid approaches involving both in-person (face-to-face) and web-based sessions. Digital mental health may be successfully implemented if barriers are minimized, such as providing children, teenagers, and their families with adequate access to the internet or providing them with stable Wi-Fi, maximizing privacy using encrypted servers, and finding a suitable space for these meetings. Ensuring adequate engagement by keeping younger children interested through sending them hands-on material to engage with during web-based sessions seems desirable. In addition, medical providers require adequate training with sufficient space and knowledge of web-based learning tools. Finally, a couple of studies noted racial inequities in accessibility to mental health programs [48,51,52,74], highlighting that this needs to be addressed to ensure successful and equitable mental health program and service implementation.

Discussion

Principal Findings

The objective of this literature review was to broadly gain a better understanding of the types of programs that were implemented during the pandemic for child and youth mental health along with a better understanding of implementation challenges and knowledge dissemination strategies, including KT theoretical models for program implementation. This included clinical programs in health care settings and community-based programs in schools. It also included individual- and family-level preventive strategies for early identification and referral through knowledge dissemination in mental health training programs. The implications of the results of each aim will be discussed in this section.

First, we aimed to better understand the key barriers and challenges regarding implementing child and youth mental health programs during the pandemic. Certain factors need to be taken into account, including internet accessibility, to ensure that everyone has equitable access and that there are no technological barriers to timely mental health care for youth. Privacy was also raised as an important barrier in e–mental health among youth, highlighting that secure digital media need to be used. There were issues with Wi-Fi accessibility, emphasizing that a stable internet connection is vital for implementing these programs for youth. Policies could consider funding Wi-Fi for families who may struggle financially with respect to purchasing high-speed, stable internet plans. In addition, having a secure and private space is important for both the practitioners and the patients. However, it is challenging for patients to make room for meetings if they do not have adequate space at home. Nevertheless, from a program implementation stance, it appears that mental health services via telehealth are acceptable for young adults overall. However, it seems that younger teenagers and children may require additional strategies to avoid “Zoom fatigue” and keep them interested and engaged. For these reasons, the programs opted for offering hybrid care to youth or combined media such as apps along with family supportive services, whereas children received art kits or play kits to enhance participatory engagement.

Second, we aimed to better understand what types of mental health programs were implemented during the pandemic by key stakeholders and what KT theoretical models and strategies were adopted during the implementation of these programs. We identified a few initiatives, particularly in Canada and Australia, that worked toward providing mental health care to young adults while engaging with critical stakeholders. Important stakeholders included schools, medical doctors, psychologists, the criminal justice system, families, young adults with lived experience, social workers, charities, and politicians, among others. Some offered training to the stakeholders, and others provided direct mental health support to those with lived experience.

We identified several programs that were implemented for youth during the pandemic, with most being telehealth and digital based, followed by hybrid (mixed face-to-face with digital) and in-person face-to-face programs. However, overall, many programs recommended a hybrid method for delivering youth mental health services, including the use of digital media and face-to-face sessions to increase accessibility and meet the learning pretenses of stakeholders. The digital media included apps, the use of Zoom, and other web-based tools or websites.

Some the initiatives used clear KT theories to inform their programs, and 7 of them had used psychological theoretical models. There is a need for more implementation programs to use KT models when training practitioners to use evidence-based methods. Some programs also used theories of behavior change and psychological theories to inform their interventions, such as facilitating positive experiences through meaningful expression and engagement [37].

The use of diverse media for KT rather than one medium appears to be important. In their review of KT interventions for parental knowledge of all childhood health problems published until 2015, Albrecht et al [81] found that most studies used one medium. Thus, the use of digital media in an increasingly digitalized world appears to be an important move toward enhancing accessibility for youth mental health. The pandemic has especially highlighted the urgent need for the transition to web-based methods to enhance accessibility despite different levels of stakeholder acceptability. However, more research is needed to better understand whether the programs and hybrid models are actually effective in improving youth mental health as this was not evaluated in the implementation studies.

Another aim was to understand what mental health first aid training interventions were developed for increasing knowledge of mental health support and understanding any challenges regarding their implementation or adoption. We did not identify many such studies that were undertaken during this period. Initially, we identified 6 studies that were published during the pandemic period, with many finding increased perceived self-efficacy for providing mental health first aid, but not all led to changes in behavior, including the actual provision of mental health support to someone in distress [82-87]. However, after following up and closer examination, the studies were not actually undertaken during the pandemic period itself.

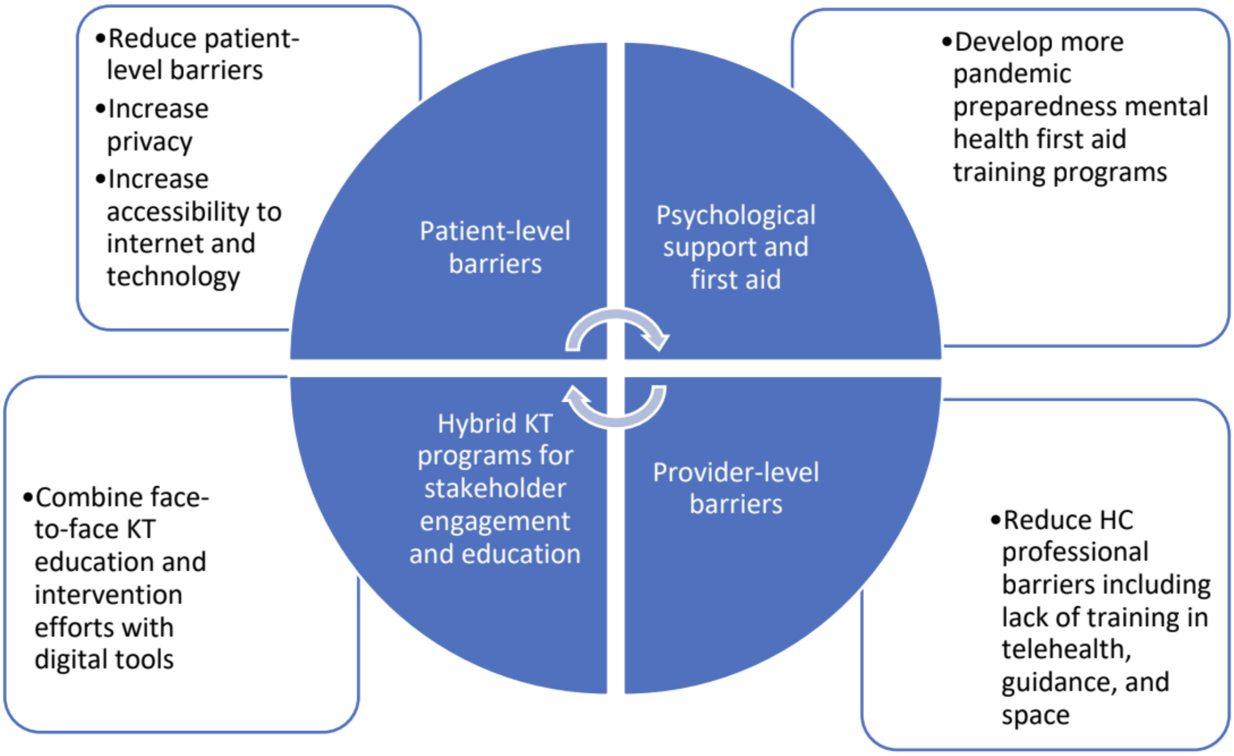
Recommendations

On the basis of the knowledge synthesized from this literature review, several recommendations can be made for youth mental health promotion in the postpandemic era and for future pandemic preparedness. A future youth mental health KT tool may also be developed based on these recommendations.

1. Evaluate more hybrid models of mental health for KT among various stakeholders.
2. Reduce the barriers to implementing tele–mental health in youth by providing adequate technological access, Wi-Fi and stationary internet connectivity, and privacy protection.
3. Enhance staff training and preparedness for a future pandemic by having the equipment, knowledge, and skills in place.
4. Undertake more research on youth mental health for future pandemic preparedness and first aid training, including the barriers to and facilitators of effective KT and implementation.

Figure 2 illustrates 4 levels of steps that could be taken for future child and youth mental health and pandemic preparedness.

Figure 2. Future pandemic preparedness regarding pediatric and youth mental health. HC: health care; KT: knowledge translation.



Limitations

One limitation of this review is that we undertook more of a narrative literature review as, ideally, we would have required 2 screeners for a full scoping review, which was not possible due to resource limitations. We included publicly accessible free articles due to resource limitations. We also did not search gray literature, which could have provided more data on rapidly implemented studies that were not published. There is a possibility that there were more studies on this topic given the breadth of the COVID-19 literature.

However, our overarching aim was to gain a better understanding of the common implementation challenges and KT strategies that were developed in general during the pandemic, and we broadly covered the literature in several key areas spanning KT; implementation; school-based programs; and health care, including telehealth programs. A strength of this review is that we structured our analysis around KT and provided practical “hands on” recommendations for implementation and policy that may be applicable to many future studies, especially when planning for a future pandemic.

We note that there were wide variations in terms of countries and policies during the pandemic, but the overarching implementation issues were common across the studies despite this. In addition, although the studies are generalizable to pre- and postpandemic times, the focus was on the pandemic period to ensure that we understood what the challenges were during times of uncertainty and crisis, when swift decisions had to be made regarding new implementation issues.

Conclusions

In summary, we aimed to better understand the implementation experiences, challenges, and facilitators of child and youth mental health program services during the pandemic. We found that, while many benefited from digital implementation strategies, hybrid in-person combined support was preferred.

Provider-related challenges were also identified with transitioning to telehealth and learning how to use the technology. Barriers for patients were mainly privacy related and technological, including access to the internet and devices and the ability to communicate efficiently through a screen.

We also aimed to gain a better understanding of the KT intervention strategies, programs, and positive psychology interventions that were developed to promote youth mental health during the pandemic period. We identified KT programs that engaged with a wide range of stakeholders during the pandemic, and a few were KT theory informed. Future studies should focus on hybrid systems of KT and youth mental health program delivery and address technological and privacy barriers linked to the implementation stage of youth mental health e-services.

Data Availability

Data sharing is not applicable to this paper as no data sets were generated or analyzed during this study.

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) checklist.
[DOCX File , 31 KB - pediatrics_v7i1e55100_app1.docx]

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Abbreviations

KT: knowledge translation

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Original Paper

Effectiveness of Unguided Internet-Based Cognitive Behavioral Therapy for Subthreshold Social Anxiety Disorder in Adolescents and Young Adults: Multicenter Randomized Controlled Trial

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Abstract

Background: Social anxiety disorder (SAD) is a common mental disorder in adolescents and young adults. Early intervention and support could help prevent the development of full-blown SAD. Considering that adolescents with social anxiety symptoms do not prefer face-to-face sessions due to their fear of communicating with therapists, internet-based cognitive behavioral therapy (ICBT) was implemented.

Objective: This study aimed to examine the effectiveness of complete self-help ICBT for subthreshold SAD in high school and college students with no history of mental disorders.

Methods: A multicenter randomized controlled trial designed to demonstrate the objective was conducted from December 2022 to October 2023. Participants were students enrolled at 6 universities and 1 high school. The intervention was a complete self-help ICBT and consisted of 10 text-based sessions that taught cognitive behavioral therapy techniques for social anxiety in youths and young adults. The comparison was a no-treatment condition (control group), which was randomly assigned in a 1:1 ratio by a computer program. A total of 2 psychological scales were used to assess the severity of social anxiety, and 1 psychological scale each was used to measure symptoms of depression, general anxiety, and quality of life.

Results: In total, 77 students were enrolled as study participants. Through the randomization procedure, 38 participants were included in the intervention group, and 39 patients were included in the control group. Results from the analysis of covariance with depression as covariates showed that the participants in the intervention group had significantly reduced symptoms of social anxiety, depression, and general anxiety compared to the control group. The response rate was 61% (19/31) in the intervention group and 24% (9/38) in the control group: odds ratio (OR) 4.97 (95% CI 1.61-16.53; *P*=.003) in the Fisher exact test. The recovery rate was 68% (21/31) in the intervention group and 34% (13/38) in the control group: OR 3.95 (95% CI 1.32-12.56; *P*=.008). The OR for the remission ratio was 2.01 (95% CI 0.64-6.60; *P*=.20) and for the risk of worsening was 0.23 (95% CI 0.002-1.33; *P*=.10), but no significant difference was observed.

Conclusions: The results of this randomized controlled trial show that fully unguided ICBT improves subthreshold SAD in adolescents and young adults. Interpretation of the effectiveness in preventing SAD that meets the diagnostic criteria is limited by sample size and the follow-up period. Future studies should include more extended observations and larger sample sizes in high-risk populations.

Trial Registration: UMIN-CTR UMIN000050064; https://center6.umin.ac.jp/cgi-open-bin/ctr/ctr_view.cgi?recptno=R000057035

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KEYWORDS

adolescent; social anxiety disorder; general anxiety; adolescents; teens; social anxiety; teenagers; internet-based cognitive behavioral therapy; self-help; randomized controlled trials; young adults; cognitive behavioral therapy; anxiety; mental health; students; colleges; universities; social socialize; anxious; fear; mobile phone

Introduction

Background

Social anxiety disorder (SAD) is a mental disorder characterized by excessive anxiety and embarrassment in social situations and fear of being negatively evaluated [1]. The lifetime prevalence of SAD is 4% [2], with a prevalence of 2.1% in adolescents and young adults [3]. Anxiety disorders, including SAD, are the most common psychiatric disorders [4], and mild (subthreshold) forms are common and cause significant disability [5]. The onset of SAD often occurs in the early to midadolescent years [6], with most of the patients having the disorder before their 20s [7]. The adolescent years represent a life stage where interpersonal relationships become more complex, leading to a heightened susceptibility to anxiety in social situations. Quite a few young individuals, even those who do not meet the diagnostic criteria, are aware of experiencing social anxiety at levels below the threshold for diagnosis. For example, a previous study reported 280 high school students in Japan found that approximately 20% experienced moderate social anxiety over a period of 3 years [8]. Another research focused on social fears and SAD among Portuguese youth, and 26% reported with intense self-reported social fear [9]. The presence of subthreshold anxiety disorders increases the risk of full-blown anxiety disorders by more than 3-fold [10]. Treating subthreshold anxiety disorders in a timely manner may prevent the onset of full-blown anxiety disorders [11]. When adolescents develop SAD, it can negatively affect their interpersonal relationships, academic achievement, and career development [12]. Intervention for subthreshold SAD is crucial, as it holds the potential to prevent these issues from arising in the first place.

Cognitive Behavioral Therapy for SAD

Cognitive behavioral therapy (CBT) is one of the most effective treatment approaches for SAD [13]. By modifying the cognitive behavioral cycle that sustains social anxiety [14], a strong therapeutic effect can be achieved [15]. The effectiveness of face-to-face individual CBT has been established not only for adults but also for children and adolescents [16]. However, low rates of in-person CBT and poor access make it challenging to provide long-term treatment [17]. The low prevalence of CBT in Japan (6.2%) can be attributed to a shortage of cognitive behavioral therapists and its high costs in terms of time and finances [18]. Barriers to mental health treatment have been identified via interviews of patients with SAD. These barriers include a lack of awareness of available treatment facilities, fear of self-disclosure, and financial constraints due to a lack of insurance coverage [19]. Additionally, approximately 80% of adults with SAD developed the condition during adolescence [20]. Adolescence is a period of establishing autonomy, and as the scope of social responsibilities expands, young people tend to hesitate to seek support from others [21]. Access to appropriate treatment remains limited, as many youth do not seek help [22]; this problem is further exacerbated by the shortage of mental health services available worldwide [23]. In resource-limited situations, therapeutic approaches must be refined to improve access to treatment. An early intervention to address the mental health needs of youth could lead to rapid recovery or prevent relapse of mental health problems [24].

Internet-Based CBT for SAD

Internet-based CBT (ICBT) is a promising solution that can overcome physical barriers and time constraints. Many ICBT programs have been implemented, and recently, countries with high smartphone penetration and internet use have begun to validate the effectiveness of self-help ICBT [25,26]. Self-help programs usually have high dropout rates, but the feature of not having to interact with the therapist has been reported to help reduce the dropout rate of patients with SAD and lead to satisfactory treatment completion rates [27,28]. A previous study including individuals with nonclinical anxiety disorders has also confirmed a significant reduction in anxiety symptoms through complete self-help ICBT: 50 cases underwent a web-based ICBT for SAD [29]. Furthermore, conducting ICBT through mobile devices such as smartphones or tablet PCs, as opposed to desktop computers, may enhance therapeutic effects. Social situations eliciting social anxiety are often present outside the home or private spaces, and intervention through mobile devices facilitates the immediate recall and implementation of CBT techniques when confronted with these situations. Unguided ICBT for individuals with SAD using mobile devices has demonstrated a high effect size with a range of Cohen *d*=0.81 when compared to a waitlist group using the Leibowitz Social Anxiety Scale (LSAS) total score [28,30].

ICBT for Subthreshold SAD

However, there is currently no study examining the effectiveness of unguided ICBT for subthreshold SAD treatment providers. Due to not meeting the diagnostic criteria, individuals with subthreshold SAD may have lower motivation and potentially higher dropout rates in self-help treatment. Moreover, adolescents with mild to moderate symptoms of social anxiety may show a small or limited treatment response. On the contrary, subthreshold SAD may exhibit a higher average treatment response rate, potentially surpassing the 53.6% observed in diagnosed SAD [31], as it lacks the functional impairments such as depression and avoidance frequently observed in patients with SAD [32]. Due to these remaining areas of uncertainty, it is inappropriate to simply extrapolate evidence from diagnosed SAD when considering the applicability of unguided ICBT to subthreshold SAD.

Objective

The aim of this study was to assess the effectiveness of intervening in widespread subthreshold SAD during adolescence and evaluate the acceptance of unguided, completely self-help ICBT, taking into consideration dropout.

Methods

Ethical Considerations

The research protocol underwent review and was approved by the ethics review board of the Clinical Research Management Center at Kagoshima University Hospital (ID 220196). Participants received both oral and written explanations of the study and were enrolled upon expressing their voluntary written consent. For high school participants, written consent was obtained from both the participants and their guardians. The data collected in this study were anonymized and required a code to identify specific individuals.

Study Design

This study reports based on the CONSORT (Consolidated Standards of Reporting Trials) Statement for Randomized Trials of Nonpharmacologic Treatments [33]. The CONSORT eHEALTH checklist is presented in Multimedia Appendix 1. A multicenter randomized controlled trial (RCT) was conducted from November 2022 to October 2023 in Japan. A research team (KM, MN, and SH) at Kagoshima University Hospital and the University of Fukui designed this RCT. A total of 6 universities and 1 high school were registered as implementation sites in this study. This clinical trial is registered in the University Hospital Medical Information Network Center, and an overview of the research protocol is publicly available (UMIN000050064).

Participants and Recruitment

Participants were recruited from 6 universities and 1 high school in Japan. In total, 89 students gave informed consent, and the eligibility criteria were confirmed. Of them, 77 students met the eligibility criteria, and they were enrolled in this clinical trial. The participants were randomly assigned to an intervention group (ICBT) and a control group (no treatment). Participants received coupons worth JP ¥5000 (equivalent to US $31.30) as compensation for each of the 2 data submissions. Participants assigned to the intervention group received compensation at baseline and at the start of the intervention. Those assigned to the control group received compensation at baseline and at 10 weeks. High school participants did not receive remuneration, in accordance with their school’s educational policy.

Eligibility and Exclusion Criteria

High school or college students between the ages of 15 to 25 years, with a total LSAS score≥30 or higher [27], and with their own smartphone were eligible. The exclusion criteria were diagnosis of psychiatric disorders such as depression, history of CBT within 2 years, IQ<85, imminent suicidal risk, and the presence of advanced diseases such as cancer.

Intervention

Participants assigned to the intervention group were instructed to complete a specific ICBT program entirely through self-help, using their own smartphones. Participants could contact the research team if they had any specific questions. It was recommended to complete 1 module per week, with automatic email reminders sent every Monday morning, prompting participants to engage in the program. If a module was not completed by Friday, participants received an automatic email reminder on Saturday at noon. The first author (KM) developed an unguided ICBT program for subthreshold SAD in adolescents and young adults. The ICBT program was built on an e-learning platform (learningBOX; learningBOX Inc). The ICBT program is based on the Clark and Wells [14] model. The ICBT program consists of 10 sessions of training on effective CBT components for social anxiety. Table 1 shows the treatment modules. The participants in the control group received no treatment; they also were asked to refrain from accessing information about CBT.

Table 1. The modules and tasks of the treatment course.

	Module	Task
1	Psychoeducation and case-formulation	Developing an idiosyncratic version of the formulation
2	Examine the function of safety behaviors and self-focused attention	Manipulating safety behaviors and self-focused attention with behavioral experiments
3	Video feedback to correct negative self-image	Updating negative distorted self-images by video feedback in participant's smartphone
4	Attention training in photographic social situations	Shifting the focus of attention to external information during a conversation or communication
5	Behavioral experiments to test negative predictions and assumptions	Observing the reactions of others immediately after behavioral experiments
6	Opinion survey to follow-up behavioral experiments	Updating negative assumptions about failures in social situations
7	Handling anticipatory worry and postevent rumination	Exploring the advantages and disadvantages of worry and rumination
8	Image description	Updating negative self-images and impressions
9	Schema work	Addressing dysfunctional negative beliefs and assumptions
10	Prevent relapse	Summarizing coping strategies for social anxiety and reflecting on the progress of the treatment course

Outcomes

Primary Outcome

The primary outcome was the severity of social anxiety, as per the self-rated LSAS score. The LSAS was developed to measure social anxiety [27]. The LSAS contains 24 social situations related to "fear or anxiety" and "avoidance" that the participants are asked to rank on a 4-point scale, with 0=never and 4=severe. The Japanese version of the LSAS has demonstrated reliability and validity and is widely used in clinical and research settings in Japan [34]. Response to the ICBT was defined as a decrease in the LSAS by 28% or more [35]. Remission was defined as an LSAS total score<35, as specified in a previous ICBT study of SAD conducted in Hong Kong [36]. Conversely, to assess the risk of exacerbating social anxiety, we defined worsening as an increase in LSAS of 28% or more.

Secondary Outcomes

The secondary outcomes were the scores on 4 self-administered scales: the Social Phobia Inventory (SPIN) is a self-rating scale that measures 3 characteristic aspects of SAD: fear, avoidance, and physiological arousal [37]. In the Japanese version of the SPIN, 17 questions are answered on a 5-point scale, with 0=not applicable at all and 4=strongly applicable [38]. The Patient Health Questionnaire-9 (PHQ-9) was developed to measure depressive symptoms [39,40]. The first 9 items of the PHQ-9 assess how often various depressive symptoms have occurred in the last 2 weeks. The Generalized Anxiety Disorder-7 (GAD-7) scale was developed to measure anxiety levels [40,41]. The first 7 items of the GAD-7 assess how often various anxiety symptoms have occurred in the last 2 weeks. The EQ-5D-5L measures the quality of life (QOL) values for calculating quality-adjusted life years (QALYs) in the economic evaluation of medical technologies [42,43]. In the EQ-5D-5L, the responder answers questions on 5 dimensions directly related to QOL (mobility, self-care, usual sensitivity, pain or discomfort, and anxiety or depression). Each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. The QALY ranges from 0 to 1.0, with 0=dead and 1.0=in perfect health. We also calculated the recovery rates of the Improved Access to Psychotherapy program and improvement (recovery) rates considering total scores in SPIN<19 and PHQ-9<10, simultaneously for comparison with a UK sample [44].

Sample Size

The sample size was calculated to be 78 using G*Power (version 3.1.9.7; The G*Power Team), which is a free statistical analysis software [45,46]. The required sample size of this RCT was estimated to be 52, considering a 2-tailed significance level of .05, a power of 80%, and an estimated effect size of 0.8 [30]. The required sample size above was calculated considering the 50% dropout rate of previous studies with unguided ICBT [47].

Randomization

Randomized allocation was conducted by the minimization method with a randomization generator [48]. In randomization, LSAS total score <50 or ≥50, sex (male or female), and facilities were used as adjustment factors.

Blinding

Blinding was not implemented.

Statistical Analyses

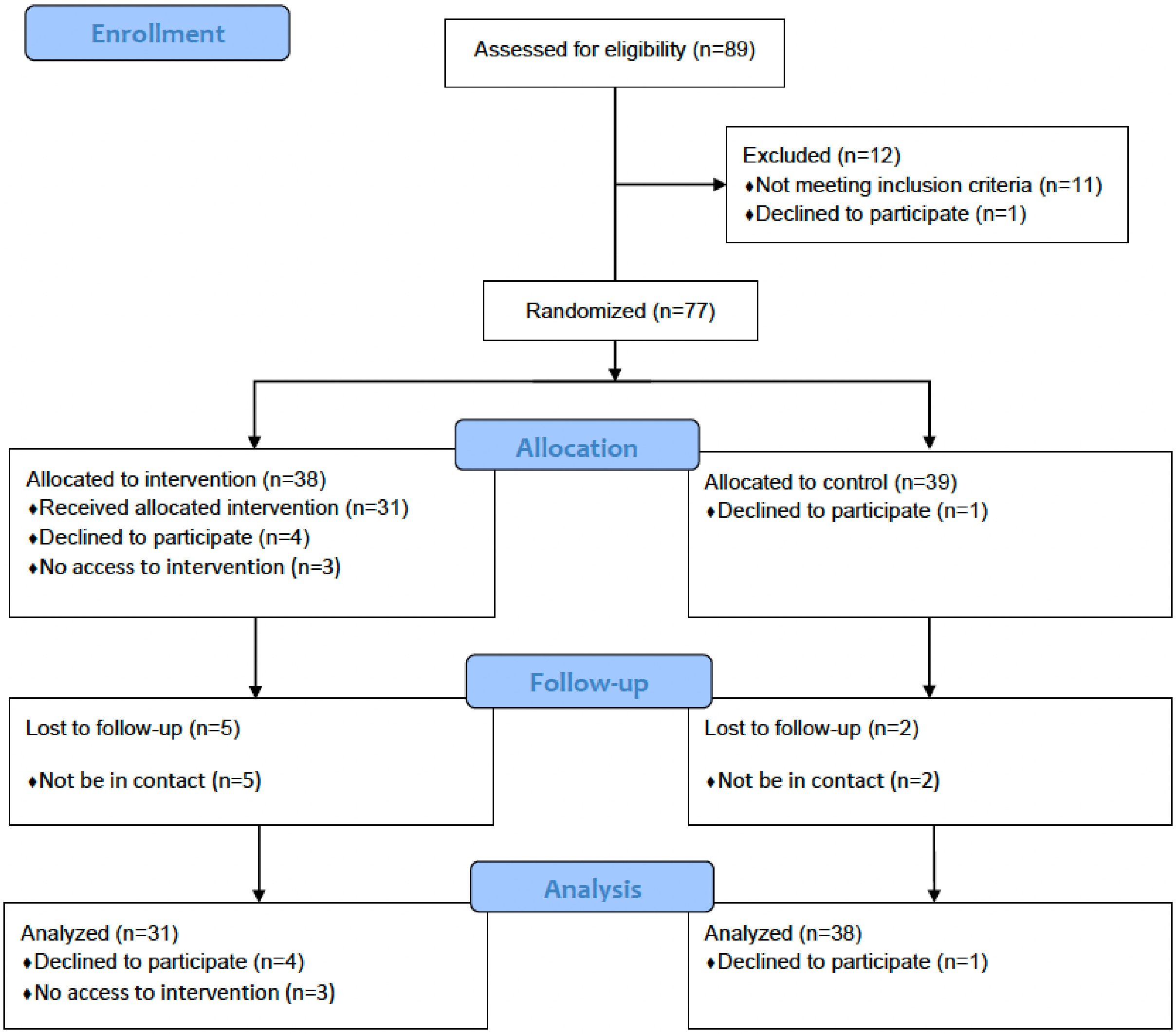
Missing values were imputed using the *mice* package in R (version 4.3.2; R Foundation for Statistical Computing), a free statistical software package [49]. Demographic data at baseline were described, and between-group characteristics were analyzed using independent sample 2-tailed *t* tests. To investigate significant differences in the change of scores between groups for both the primary and the secondary outcome measures, an analysis of covariance (ANCOVA) was conducted. A covariate factor was the severity of depression determined by measuring the PHQ-9 total score at baseline. For treatment response ratio, remission ratio, and recovery ratio, Fisher exact test was performed, and odds ratios (ORs) with 95% CIs were calculated. Analyzing the risk of worsening social anxiety measured in LSAS involved the calculation of risk ratio, relative risk reduction (RRR), absolute risk reduction (ARR), and number needed to treat (NNT). Statistical analyses were implemented by using R (version 4.3.2). A significance level of .05 was used for all analyses.

Results

Recruitment

Among the 38 participants assigned to the intervention group, 4 declined research participation after the preintervention assessment. A total of 31 participants completed the ICBT program at least once, while 3 did not access the intervention program at all. Therefore, the dropout rate from this ICBT program was 9% (3/34), the implementation rate of ICBT was 91% (31/34), and the completion rate was 65% (22/34). Of the 39 participants assigned to the control group, 1 declined research participation, and data on outcomes could not be obtained for 2 students due to unavailability. Following the predetermined analysis plan, the statistical analysis included data from 31 participants in the intervention group and 38 in the control group. Figure 1 shows the participant flow diagram.

Figure 1. CONSORT (Consolidated Standards of Reporting Trials) flow diagram.



Demographical and Characteristic Data

Table 2 shows the demographics, clinical characteristics, and baseline outcomes of the participants included in the analyses. The level of depression, measured by the PHQ-9, in the control group, was significantly higher than the intervention group at baseline; however, clinically, both groups fell within the range of “mild depressive symptoms” (total score 5-9) [50]. No significant differences were observed in other outcomes.

Table 2. Demographical and characteristic data, and the total scores of outcomes at baseline.

Demographical and characteristic data	ICBT[a] group (n=31)	Control group (n=38)	*P* value (unpaired *t* test)
Sex (female), n (%)	20 (65)	25 (66)	N/A[b]
Age, mean (SD)	21.61 (2.06)	21.39 (2.32)	.68
LSAS[c], mean (SD)	58.38 (19.17)	59.08 (20.77)	.88
SPIN[d], mean (SD)	25.39 (10.27)	27.42 (12.50)	.47
PHQ-9[e], mean (SD)	4.87 (4.38)	6.16 (4.29)	.05
GAD-7[f], mean (SD)	4.13 (4.52)	4.21 (3.30)	.31
EQ-5D-5L, mean (SD)	0.9160 (0.079)	0.889 (0.114)	.28

[a] ICBT: internet-based cognitive behavioral therapy.

[b] N/A: not applicable.

[c] LSAS: Liebowitz Social Anxiety Scale.

[d] SPIN: Social Phobia Inventory.

[e] PHQ-9: Patient Health Questionnaire -9.

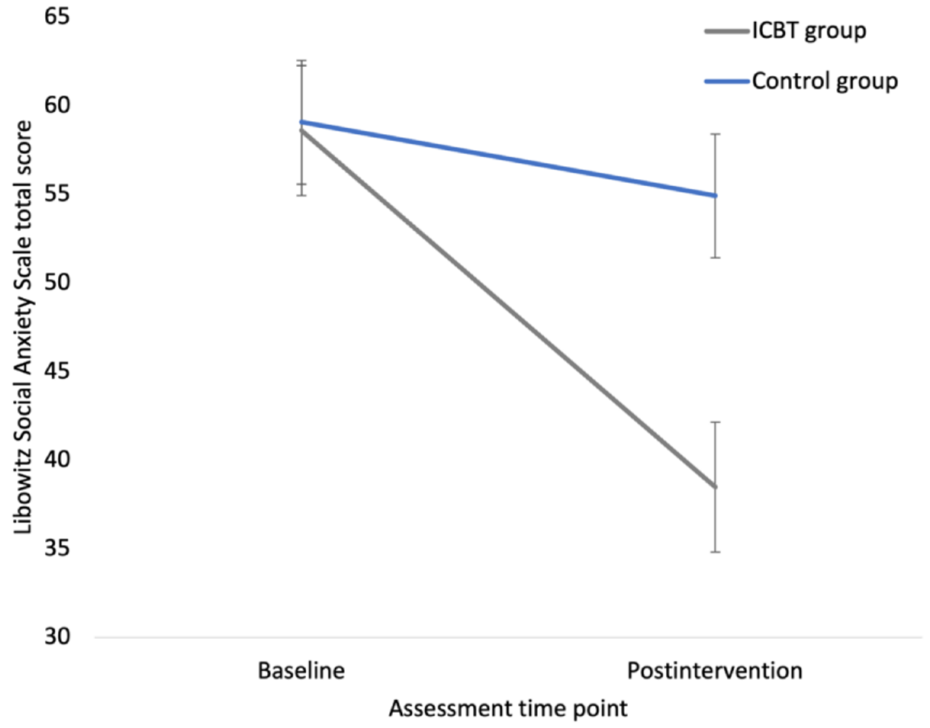
[f] GAD-7: Generalized Anxiety Disorder-7.

Outcomes and Estimation

Primary Outcome

The reduction in LSAS total score from baseline to postintervention assessment was significantly greater in the intervention group compared to the control group by 11.62 (95% CI 1.67-21.56; $F_{1,66}$=3.91; *P*=.02). Figure 2 presents the change in LSAS total score from baseline to postintervention assessment. The change in LSAS total score from preintervention to postintervention assessment in the intervention group was significantly larger than that in the control group by 9.39 (95% CI 1.31-17.48; $F_{1,66}$=4.65; *P*=.01).

Figure 2. Liebowitz Social Anxiety Scale total score. The graphic presents mean and 95% CI. ICBT: internet-based cognitive behavioral therapy.



Secondary Outcome

Table 3 shows the analyses for primary and secondary outcomes in ANCOVA.

Table 3. Difference of score in outcomes, *P* value, and effect size.

Outcome and evaluation point	ICBT[a] group, mean change (SD)	Control, mean change (SD)	*F* test (*df*=2, 66; ANCOVA[b])	*P* value (ANCOVA)	Effect size (Hedge *g*)
LSAS[c]					
Baseline to postintervention assessment	16.90 (22.63)	4.16 (17.38)	3.91	.02	0.64
Preintervention to postintervention assessment	14.90 (14.86)	N/A[d]	4.65	.01	0.66
SPIN[e]					
Baseline to postintervention assessment	10.87 (11.40)	2.87 (8.69)	5.39	.007	0.80
Preintervention to postintervention assessment	11.19 (9.33)	N/A	7.23	.01	0.93
PHQ-9[f]					
Baseline to postintervention assessment	0.68 (3.36)	–0.32 (2.85)	1.19	.31	0.22
Preintervention to postintervention assessment	1.42 (2.98)	N/A	2.96	.06	0.49
GAD-7[g]					
Baseline to postintervention assessment	0.29 (2.98)	–1.03 (3.17)	1.61	.21	0.09
Preintervention to postintervention assessment	0.97 (2.83)	N/A	4.15	.02	0.32
EQ-5D-5L					
Baseline to postintervention assessment	–0.0299 (0.09)	0.0079 (0.09)	1.61	.21	0.003
Preintervention to postintervention assessment	–0.0301 (0.11)	N/A	1.41	.25	0.0004

[a] ICBT: internet-based cognitive behavioral therapy.

[b] ANCOVA: analysis of covariance.

[c] LSAS: Liebowitz Social Anxiety Scale.

[d] N/A: not applicable.

[e] SPIN: Social Phobia Inventory.

[f] PHQ-9: Patient Health Questionnaire-9.

[g] GAD-7: Generalized Anxiety Disorder-7.

The reduction in SPIN total score from baseline to postintervention assessment was significantly greater in the intervention group compared to the control group by 8.05 (95% CI 3.02-13.08; $F_{1,66}$=5.39; *P*=.007). The change in SPIN total score from preintervention to postintervention assessment in the intervention group was significantly larger than that in the control group by 8.26 (95% CI 3.75-12.78; $F_{1,66}$=7.23; *P*=.01).

The reduction in PHQ-9 total score from baseline to postintervention assessment was greater in the intervention group compared to the control group by 1.15 (95% CI 0.41-2.70; $F_{1,66}$=1.19; *P*=.31), not significantly. The change in PHQ-9 total score from preintervention to postintervention assessment in the intervention group was larger than that in the control group by 1.75 (95% CI 0.28-3.23; $F_{1,66}$=2.96; *P*=.06), not significantly.

The reduction in GAD-7 total score from baseline to postintervention assessment was greater in the intervention group compared to the control group by 1.24 (95% CI –3.05 to 2.79; $F_{1,66}$=1.66; *P*=.21), not significantly. The change in GAD-7 total score from preintervention to postintervention assessment in the intervention group was significantly larger than that in the control group by 1.81 (95% CI 0.31-3.33; $F_{1,66}$=4.15; *P*=.02).

The reduction in QALY measured by EQ-5D-5L from baseline to postintervention assessment was greater in the intervention group compared to the control group by –0.0388 (95% CI –0.09 to 0.008; $F_{1,66}$=1.41; *P*=.25), not significantly. The change in QALY measured by EQ-5D-5L from preintervention to postintervention assessment in the intervention group was larger than that in the control group by 0.0366 (95% CI –0.0120 to 0.0852; $F_{1,66}$=1.31; *P*=.28), not significantly.

Ancillary Analyses

Table 4 presents Fisher exact test results for treatment response rate, remission rate, recovery rate, and risk ratio. The treatment response rate in the intervention group was significantly higher at 61% (19/31) compared to the control group at 24% (9/38; *P*=.003; OR 4.97, 95% CI 1.61-16.53). The recovery rate in the intervention group was substantially higher at 68% (21/31) compared to the control group at 34% (13/38; *P*=.008; OR 3.95, 95% CI 1.32-12.56). Regarding the risk of deterioration, the intervention group had a higher but nonsignificant rate of 6% (2/31) compared to the control group 24% (9/38; *P*=.10).

Table 4. Results of Fisher exact test[a].

Result	ICBT[b] group (n=31), n (%)	Control group (n=38), n (%)	OR[c] (95% CI)	*P* value
Response	19 (61)	9 (24)	4.97 (1.61-16.53)	.003
Remission	12 (39)	9 (24)	2.01 (0.64-6.60)	.20
Recovery	21 (68)	13 (34)	3.95 (1.32-12.56)	.008
Worse	2 (6)	9 (24)	0.23 (0.02-1.23)	.10

[a] Definition of clinically significant change: response: a decrease in the Liebowitz Social Anxiety Scale (LSAS) by 28% or more; remission: an LSAS total score<35; recovery: total scores in Social Phobia Inventory<19 and Patient Health Questionnaire-9<10; and worse: an increase in LSAS of 28% or more.

[b] ICBT: internet-based cognitive behavioral therapy.

[c] OR: odds ratio.

Adverse Events and Harms

No severe adverse events were reported for this study period. Table 5 presents the relative risk, RRR, ARR, and NNT. The results of the RRR imply that ICBT reduces the occurrence of deterioration events by 73% compared to no treatment in the control group. The results of the ARR imply that ICBT can save 17% more adolescents and young adults from deterioration events of social anxiety compared to no treatment. The results of the NNT suggest that unguided ICBT could be required for 5.8 individuals with subthreshold SAD in adolescents and young adults to prevent deterioration in symptoms for 1 individual.

Table 5. Results of worse risk analyses[a].

Result	ICBT[b] group (worse=6%) and control group (worse=24%) (%)
RR[c]	26
RRR[d]	73
ARR[e]	17
NNT[f]	6

[a] Formula: RR=percentage of worse event ICBT group/control group; RRR=1–RR; ARR=percentage of worse event in control group–ICBT group; and NNT=1/ARR.

[b] ICBT: internet-based cognitive behavioral therapy.

[c] RR: relative risk.

[d] RRR: relative risk reduction.

[e] ARR: absolute risk reduction.

[f] NNT: number needed to treat.

Discussion

Principal Findings

This study evaluated the effectiveness of unguided ICBT for adolescents and young adults with subthreshold SAD through a multicenter RCT. The dropout rate in the intervention group was 9% (3/34), with an ICBT implementation rate of 91% (31/34) and a completion rate of 65% (22/34). The participants who conducted ICBT showed a significant reduction in social anxiety symptoms compared to those who did not receive treatment. Key indicators representing substantial symptom improvement, namely, treatment response rate (ICBT: 19/31, 61% vs control: 9/38, 24%; *P*=.003) and recovery rate (ICBT: 21/31, 68% vs control: 13/38, 34%; *P*=.008), demonstrated significant differences between the groups, with the intervention group showing better outcomes. No serious adverse events were observed in either group. Regarding deterioration events in social anxiety symptoms, there were 2 (6%) out of 31 cases in the intervention group and 9 (24%) out of 38 cases in the control group, but the difference was not statistically significant (*P*=.10). In summary, this study indicates that ICBT is an effective intervention approach for improving social anxiety symptoms in adolescents and young adults with subthreshold SAD.

Comparison With Prior Work

A systematic review and meta-analysis of outcomes from 20 RCTs on SAD meeting clinical diagnostic criteria demonstrated that ICBT is effective in improving social anxiety symptoms, with a moderate effect size (Hedge *g*=0.55) [51]. In this study, unguided ICBT was shown to be sufficiently effective for subthreshold SAD in adolescents and young adults. This expands the evidence on CBT studies for SAD from several perspectives. The first perspective is the absence of therapist guidance. Many conventional ICBT studies for SAD have included therapist guidance [26,30]. Our results suggest that providing unguided ICBT to students with subthreshold SAD significantly reduces social anxiety symptoms measured by LSAS compared to the untreated group with a moderate effect size (Hedge *g*=0.66-0.66). The moderate effect size calculated in this RCT was comparable to a meta-analysis of 10 RCTs on face-to-face CBT for SAD [15]. Most of the participants assigned to the intervention group in this RCT achieved the treatment course of the Clark and Wells [14] model. Therefore, it appears that, even without guidance, significant improvements in social anxiety symptoms can be achieved with sufficient engagement.

Another perspective is related to the acceptance of ICBT for adolescents and young adults who do not meet the diagnostic criteria of SAD but are at high risk. As an application in clinical psychiatric care, a longitudinal cohort study has reported that ICBT enhances treatment adherence and reduces social anxiety symptoms in adults at risk for the onset of SAD [52]. Since SAD tends to manifest in adolescence [6], similar effects for subthreshold SAD may be observed in student support services in high schools and universities. Given the high likelihood of anxiety disorders persisting into adolescence [53], preventing the onset of mental disorders through early intervention in high-risk individuals is an important endeavor. Therefore, future research on subthreshold SAD in adolescents should consider conducting longitudinal cohort studies within the context of ICBT studies. Additionally, 23.3% of adolescents and young adults experience some form of anxiety, and among them, 39.1% use some form of health care service [54]. Only 108 (39.1%) of the 277 individuals sought medical help for their mental health issues, while the remaining 169 (60.9%) did not access healthcare. Since young individuals with social anxiety tend to avoid seeking help and contacting others [55], unguided ICBT may have the potential to meet their needs.

A previous preliminary study involving 17 adolescents with SAD who underwent ICBT reported high satisfaction with unguided ICBT through web-based questionnaires and semistructured interviews [56]. Participants who received guided ICBT in this preliminary investigation particularly appreciated the ability to access the ICBT program multiple times, allowing for repeated self-help. In this RCT, among the 34 participants in the intervention group, the majority (n=31, 91%) performed an ICBT module at least once. While 65% (n=31) completed the full ICBT course, those who completed the entire treatment course—up to module 9, corresponding to the Clark and Wells [14] model—accounted for 82% (n=28). According to these results, unguided ICBT is probably more acceptable for adolescents and young adults with subthreshold SAD.

Preliminary findings from our results also indicate that receiving complete self-help ICBT reduced the worsening of SAD by 73%. In addition to its short-term efficacy, unguided self-help ICBT may potentially prevent deterioration—that is, inhibiting the onset of SAD—in youths with subthreshold SAD. Even in the absence of guidance from CBT therapists, implementing ICBT based on the Clark and Wells [14] model may be beneficial for young adults and adolescents with SAD symptoms.

Limitations

This study has several limitations that may increase the risk of bias. First, the primary outcome, the self-reported LSAS, was not blinded. The participants assigned to the intervention group may have positive expectations regarding the intervention, which could potentially affect the outcome. In the future, RCTs with blinded assessors should be conducted. Second, the control condition in this study was a no-treatment condition. To control for biases introduced by receiving the intervention or no treatment, future RCTs should consider using sham applications as psychological placebos to ensure blinding. Third, the evidence obtained in this RCT pertains to short-term effectiveness and cannot speak to the medium- to long-term effects. Particularly, to assess the effects on preventing the deterioration of social anxiety symptoms and preventing the onset of SAD, future intervention studies for subthreshold SAD should include a randomized cohort study with an observation period of several years.

Conclusions

This multicenter RCT, conducted in Japan, has demonstrated that unguided ICBT can reduce social anxiety symptoms in adolescents and young adults with subthreshold SAD. Unguided ICBT appears to be a user-friendly intervention approach for supporting subthreshold SAD. Complete self-help ICBT may be a practical treatment approach that prevents deterioration in adolescents and young adults at high risk of developing SAD. Future research should incorporate study designs measuring long-term outcomes and focus on conducting cohort studies aimed at assessing the risk of clinically diagnosed SAD.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
CONSORT-eHEALTH (V 1.6.1).
[PDF File (Adobe PDF File), 290 KB - pediatrics_v7i1e55786_app1.pdf]

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Abbreviations

ANCOVA: analysis of covariance
ARR: absolute risk reduction
CBT: cognitive behavioral therapy
CONSORT: Consolidated Standards of Reporting Trials
GAD-7: Generalized Anxiety Disorder-7
ICBT: internet-based cognitive behavioral therapy
LSAS: Leibovitz Social Anxiety Scale
NNT: number needed to treat
OR: odds ratio
PHQ-9: Patient Health Questionnaire-9
QALY: quality-adjusted life years
QoL: quality of life
RCT: randomized controlled trial
RRR: relative risk reduction
SAD: social anxiety disorder
SPIN: Social Phobia Inventory

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Original Paper

Development and Implementation of Postdischarge Text Messages to Adolescents With Suicidal Thoughts and Behaviors Through Caring Contacts: Implementation Study

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Abstract

Background: Youth suicide is a pressing public health concern, and transitions in care after a suicidal crisis represent a period of elevated risk. Disruptions in continuity of care and emotional support occur frequently. “Caring contacts” validating messages post discharge have the potential to enhance connections with patients and have been shown to improve outcomes. More recently, positive outcomes have been noted using caring contact text messages (SMS and MMS), which hold promise for engaging patients in a pediatric setting, but there are few studies describing the large-scale implementation of such an approach.

Objective: This study aims to describe the process of developing and implementing automated caring contacts within a quality improvement framework, using a standardized series of supportive texts and images, for adolescents discharged from high-acuity programs at a large midwestern pediatric hospital. We describe lessons learned, including challenges and factors contributing to success.

Methods: We implemented the caring contacts intervention in 3 phases. Phase 1 entailed developing supportive statements and images designed to promote hope, inclusivity, and connection in order to create 2 sets of 8 text messages and corresponding images. Phase 2 included piloting caring contacts manually in the hospital’s Psychiatric Crisis Department and Inpatient Psychiatry Unit and assessing the feasibility of implementation in other services, as well as developing workflows and addressing legal considerations. Phase 3 consisted of implementing an automated process to scale within 4 participating hospital services and integrating enrollment into the hospital’s electronic medical records. Process outcome measures included staff compliance with approaching and enrolling eligible patients and results from an optional posttext survey completed by participants.

Results: Compliance data are presented for 4062 adolescent patients eligible for caring contacts. Overall, 88.65% (3601/4062) of eligible patients were approached, of whom 52.43% (1888/3601) were enrolled. In total, 94.92% (1792/1888) of enrolled participants completed the program. Comparisons of the patients eligible, approached, enrolled, and completed are presented. Primary reasons for eligible patients declining include not having access to a mobile phone (686/1705, 40.23%) and caregivers preferring to discuss the intervention at a later time (754/1705, 44.22%). The majority of patients responding to the optional posttext survey reported that the texts made them feel moderately to very hopeful (219/264, 83%), supported (232/264, 87.9%), that peers would be helped by these texts (243/264, 92%), and that they would like to keep receiving texts given the option (227/264, 86%).

Conclusions: This study describes the successful implementation of automated postdischarge caring contacts texts to scale with an innovative use of images and demonstrates how a quality improvement methodology resulted in a more effective and efficient process. This paper also highlights the potential for technology to enhance care for at-risk youth and create more accessible, inclusive, and sustainable prevention strategies.

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KEYWORDS

mental health; suicide prevention; adolescent; caring contacts; mHealth; Zero Suicide; quality improvement; care transitions; safety plan; behavioral health; mobile phone

Introduction

Context

Youth suicide is a pressing public health concern and the third leading cause of death for individuals aged 10 to 19 years in the United States [1]. Suicide deaths among US youth increased during the COVID-19 emergency, with significantly more suicides than expected among male participants, non-Hispanic American Indian or Alaskan Native, and Black youth [2]. Regarding nonfatal suicidal behaviors, the percentage of youth presenting to pediatric hospitals for suicidal thoughts and attempts more than doubled between 2008 and 2015 [3]. A recent national study of emergency department (ED) visits in adolescents aged between 12 and 17 years reported significant increases in suicide attempts beginning in May 2020 and extending through March 2021, compared to corresponding periods in 2019 [4], with increases particularly elevated in females.

To address the needs of pediatric patients at risk of suicide more effectively, the behavioral health (BH) service line at our large Midwestern pediatric hospital adopted the Zero Suicide model, a comprehensive framework using a quality improvement (QI) approach to combine best practice tools and strategies to improve suicide care across health care systems with demonstrated reductions in patient suicides and suicidal behaviors [5-7]. Although identification and treatment of high-risk youth are core to Zero Suicide, transitions in care are also prioritized as vital points for system improvement. One potential means of improving outcomes for adolescents during care transitions is the use of caring contacts, now considered a best practice for transitions in care [8].

In this paper, we describe our hospital's process of developing and implementing an automated and scalable universal caring contacts texting system for adolescents being discharged from the Psychiatric Crisis Department (PCD), Youth Crisis Stabilization Unit (YCSU), Inpatient Psychiatry Unit (IP), and Consult Liaison Service (CL) using an iterative QI approach to improve efficiency and enrollment of eligible patients and enhance health care equity with respect to age, sex, gender identity, race, and ethnicity.

Problem Statement

While hospitalization or crisis care is often accessible for youth at imminent risk for suicide, the days and months after hospital discharge remain a high-risk period [9]. However, many youths receive limited (or no) follow-up mental health care [8,10-12], which is particularly concerning as follow-up care within 7 days of discharge is associated with a decreased risk for suicide [13]. Indeed, studies suggest that 42% of adolescents who attempt suicide do not attend their first scheduled appointment posthospitalization, and 25% do not attend even one follow-up session [10]. These concerning statistics underscore the need to maintain connections with high-risk patients as they transition levels of care, often across multiple, fragmented health care systems.

Similar Interventions

Conceptualized by Motto [14] as validating, nondemand communications following a suicidal crisis, caring contacts are intended to enhance a patient's inherent sense of self-worth and connectedness to ongoing supports [15]. Caring contacts originally took the form of personalized letters expressing concern without placing demands on the recipients (eg, no requests to engage in services or self-care). Working with a high-risk population of adult patients who refused, or did not follow through with, ongoing treatment upon discharge from a psychiatric facility, Motto and Bostrom [15] found significant reductions in suicide for those receiving caring contacts during the first 2 years post discharge. Of note, this reduction was no longer significant after 5 years, and the suicide rates for the intervention and control groups converged by year 14. The first year post discharge is the highest risk period for suicide and also saw the highest frequency of caring contact letters. Although effects may be time-limited, implementation of caring contacts has since been shown to reduce suicidal behaviors and readmissions across communication modalities (eg, letters, postcards, and phone calls), clinical populations, and cultures [16-25]. A recent meta-analysis [26] found that caring contacts reduced self-reported suicide attempts at 1 year but did not find significantly reduced suicide rates or ED visits and hospitalizations. However, the number of studies included in the analysis was small due to the limited number of available randomized controlled trials.

More recently, the feasibility and acceptability of texting as a means of communicating with caring contacts have been demonstrated in adults [19,27,28] and adolescents [29,30]. Furthermore, a randomized controlled trial demonstrated that a brief contact intervention delivered through text messages significantly reduced hospital-related self-harm visits over a 24-month period [31]. Using text messages has significant benefits: texts are nonintrusive, easily accessible, can be stored for later viewing, and the receiver has control over whether to remain involved. However, the existing literature exclusively features text-based caring contacts without the use of images. In considering the pediatric population served by our hospital, we decided to implement caring contact text messages paired with hopeful images to support adolescents during transitions of care as most youth have a high comfort level with receiving text messages [23]. The nearly ubiquitous use of smartphones by adolescents, even in households earning less than US $30,000 a year [32], and the high overall retention rate for youth involved in digital health interventions [33] presented an opportunity to text hopeful and engaging images along with supportive language in a confidential, nonstigmatizing format to all eligible patients without significant concern that access to a smartphone might be a barrier to equitable care.

Methods

Aims and Objectives

The main goal of this paper is to describe the development and implementation of a scalable automated text-based caring contacts intervention using a QI methodology to support eligible youth aged 13 to 18 years being discharged from acute services at our hospital following acute BH interventions related to a suicidal crisis. As a secondary objective, this implementation included a posttext survey to evaluate the extent to which patients found the texts hopeful and supportive.

Blueprint Summary

Overview

In this study, caring contacts texts are supportive messages paired with hopeful images that include local and national youth crisis resources. Messages are unidirectional and do not serve as a text or chat service, although links are provided to youth who would like to access crisis support at any time.

There were three phases for this initiative: (1) phase 1: development and refinement of text messages (November 2018 to January 2019); (2) phase 2: piloting text messages and creating local workflows (February 2019 to February 2020); and (3) phase 3: full implementation with data collection across all 4 service areas (March 2020 to September 2021).

Phase 1: Development (November 2018 to January 2019)

The development of caring contacts message content began with the creation of validating, supportive statements and images aimed at promoting hope and a sense of inclusivity and connection to others while avoiding demanding or potentially emotionally intense or triggering content (Multimedia Appendix 1). An initial set of 16 images with supportive statements and information about crisis resources was developed by the hospital content experts in consultation with an adult former patient and member of the Zero Suicide implementation team, representing lived experience as a suicide attempt survivor. Messages were then reviewed by patient focus groups, representing diversity across race and gender, whose presenting concerns included suicidal ideation or behavior across inpatient and outpatient programs. Feedback from the focus groups indicated that the proposed texts were overwhelmingly viewed as positive and encouraging, were not emotionally triggering, and contained appropriate content. Feedback obtained from parent advocates, therapists, and suicide prevention experts also informed the development of 2 series of 8 caring contacts texts. Each text series was designed to be sent to individual patients over a 4-month period, starting the day after discharge, then weekly for 4 weeks, and monthly for the remaining 3 months. The second set of 8 texts was used for patients readmitted to the hospital.

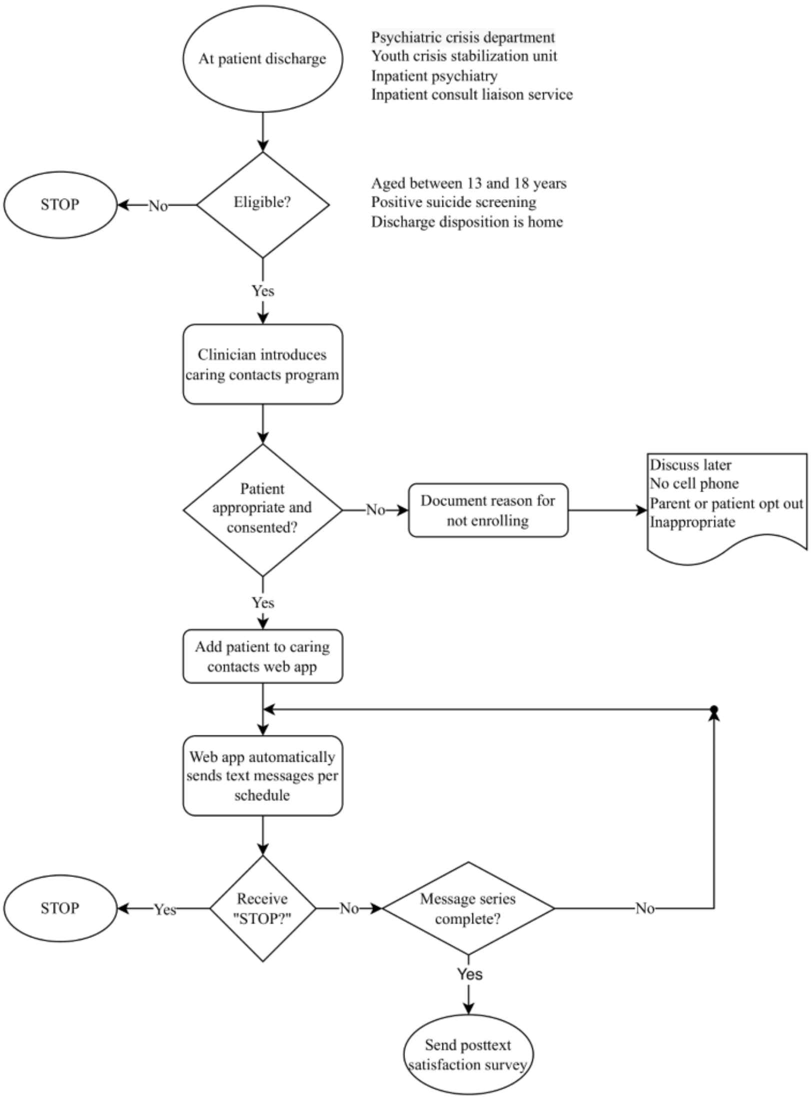
Phase 2: Pilots (February 2019 to February 2020)

As part of our continuous QI efforts, each of the participating services collaboratively developed workflows to identify, consent or assent to receive texts, obtain contact information, and enroll eligible participants. Staff were then trained in these processes, and the first pilots were held, which consisted of multiple plan-do-study-act cycles [34] initially focusing on a small number of clinicians (between 1 and 5) enrolling between 1 and 4 patients each. Barriers to enrollment proved to be using a paper workflow rather than electronic medical records (EMRs), clinicians inconsistently approaching families for consent, failing to provide resources and enrollment forms, and forgetting eligibility criteria.

In response to these barriers, changes were made to the patient enrollment process, which was built directly into the EMR (completed in March 2020). We consulted with hospital legal services, and, given that caring contacts was now the standard care for youth with suicidal thoughts and behaviors, the hospital amended the general consent to allow for texting directly to adolescents aged 13 years and older, consistent with the Children’s Online Privacy Act.

Early in phase 2, we hypothesized that the PCD would be the most effective site to enroll patients, as it serves as the point of entry for most hospital inpatient admissions to our system of care. However, low compliance rates and concerns that the discussion of care transition and caring contacts would fit better into the safety planning and discharge process led to the decision that each of the participating services would be responsible for enrollment at the time of a patient’s discharge. Toward the end of phase 2, all participating services were retrained in the new enrollment workflows. Figure 1 illustrates the final workflow.

Figure 1. Process flow for the caring contacts program.



Phase 3: Full-Scale Implementation With Data Collection (March 2020 to September 2021)

In March 2020, the responsibility for enrollment at the time of discharge was expanded to all participating services. A digital caring contacts enrollment form was implemented in the EMR, and we initiated automatic texting of the caring contacts through a web app. New participants were entered into the site as they were discharged from participating services, and their text sequence was initiated and scheduled automatically. In July 2020, the addition of a flag in the EMR reminding clinicians to enroll patients further increased the percentage of eligible patients approached.

Process Measures

A QI approach for implementation places significant focus on compliance with established protocol to iteratively drive system changes to achieve its aims. One of the goals of this initiative was to maximize the enrollment of youth being discharged from the 4 participating services, making it imperative to identify and approach all eligible patients. Initially, eligible participants were identified through a visit diagnosis, billing diagnosis, or discharge diagnosis. However, in July 2019 during phase 2, BH implemented the Zero Suicide framework, including the use of a well-validated suicide screener at first contact for all patients with the Asking Suicide-Screening Questions [35] and, where appropriate, further risk assessment with the Columbia Suicide Severity Rating Scale [36]. Eligible participants were then identified based on a positive suicide risk endorsement on either measure.

A monthly compliance report was generated to assess adherence to the process, with two metrics, that were (1) percentage of eligible patients approached by staff to enroll and (2) percentage of eligible patients enrolled. Eligible participants were identified based on a positive suicide risk endorsement on the Ask Suicide-Screening Questions [35] and Columbia Suicide Severity Rating Scale [36] tools. For patients declining, 1 of 4 reasons was indicated by the clinician: no mobile phone, patient or family preferring to discuss enrollment at a later time, parent declined, and patient is developmentally inappropriate to enroll (comprehension challenges, autism spectrum, or nonverbal). The compliance data reported in this study were collected in phase 3, for which all participating services enrolled participants. In phase 3, due to the automation of the entire identification, approach, and enrollment process, accurate data could be obtained to determine compliance (compliance data are not reported for phase 2 due to the challenges in accurately determining the number of eligible patients for each plan-do-study-act, but actual numbers of the first texts sent in phase 2 are displayed in Multimedia Appendix 2). Summary compliance data were sent to the clinical leaders of the participating services to review and resolve program barriers to enrollment.

Posttext Survey

Although focus groups suggested that automated texts and images were acceptable and affirming to patients, it was important to establish that this format was not problematic for participants and that they experienced a level of support and hopefulness by receiving them. A 4-question survey was sent to participants through a URL link in the final text. The survey used a Likert scale for the first two questions and yes or no for the last two questions: (1) On a scale of 1-5, how hopeful did these text messages make you feel? (2) On a scale of 1-5, how supported did these text messages make you feel? (3) Do you think other kids like you would be helped by these text messages? (4) If given the option, would you like to keep receiving text messages in the future?

Data and Analysis

Data were extracted from 2 key sources—the EMR (ie, Epic) and the caring contacts web-based app database. Statistical process control methods were used to monitor compliance and analyze improvements over time. Specifically, c-charts allowed the study team to track the percentage of eligible patients approached and the percentage enrolled in caring contacts on a monthly basis for any special cause variation. Standard statistical process control rules were used to establish the control limits and identify special cause variation using the c-chart [37]. Tracking caring contacts enrollment compliance by unit was important as it allowed managers to provide feedback to individual clinicians and identify potential implementation barriers, which facilitated process improvement.

Psychiatric service areas and demographic factors (race, ethnicity, gender, and age) were retrospectively retrieved for all eligible patients based on the daily discharge list. Descriptive statistics of the demographic data and service areas for patients eligible for the program, patients approached about the program, patients enrolled in the program, and patients who completed the program, were generated. The approach rate is defined as the proportion of eligible patients who the clinical team approached to introduce the program. Enrollment rate is defined as the proportion of patients enrolled among patients approached, while completion rate is defined as the proportion of enrolled patients who completed the caring contact program fully. Point estimates of these rates were calculated for each demographic factor value and psychiatric service area, together with their corresponding 95% CIs. These data were examined in a pairwise fashion within each demographic factor or service area to see whether there were statistically significant differences in introduction, enrollment, and program completion rates. When the CIs of rates are nonoverlapping for a pair of factor values within the same category, such as 2 age groups or 2 different race values, then we can conclude the 2 factor values have statistically significant differences.

Technical Design

In phase 2, all caring contacts texts were sent manually through a dedicated mobile phone. However, the large volume of texts per patient over time necessitated the development of an automated process through a web-based app. This required upfront investment but ensured scalability to additional hospital services, reduced the chances of human error, and reduced the administrative burden of a manual process, resulting in long-term savings.

The web-based app was developed to track patient enrollment, automatically send the programmed series of texts to participants, and update enrollees' program progress and status. The app was built on an internal machine server behind the hospital firewall to maximize controls over security and privacy protection. Only patient phone numbers and nonpatient-specific message contents are passed to the messaging service provider, which stores the phone numbers for a limited time to ensure delivery. In turn, the hospital only receives the time of the message sent, the delivery status, and whether patients choose to opt out. Only hospital staff enroll patients to eliminate the inclusion of unnecessary details in the EMR. Youth attempting to reply to the text messages receive an auto-generated response validating their outreach and providing reminders of the different crisis options and links available around the clock.

Target

This QI initiative addressed the use of caring contacts with high-risk adolescents between the ages of 13 and 18 years discharged from our highest acuity BH services at Nationwide Children's Hospital, which serves as a regional hub for pediatric services in Ohio.

Interoperability

The web-based app for caring contacts and the EMR system were designed to not communicate to protect patient health information and minimize risk.

Participating Entities

A brief description of participating services is provided as follows: (1) PCD: a walk-in psychiatric ED for youth and families that serves as an entry point to higher levels of hospital-based care. (2) YCSU: crisis stabilization unit for voluntary admissions with a strong emphasis on individual and family therapy. (3) IP: inpatient psychiatry service with psychiatric unit milieu. (4) CL: psychiatric consult-liaison services provided to youth admitted for medical reasons who present with BH challenges during their admission.

Budget Planning

Although grant-funded, startup costs for this initiative and resources were required to develop process flows and integrate these processes into the EMR. Some ongoing resources are also required to maintain the system. The overall budget for the development and maintenance of the caring contacts program was approximately US $102,560 across the 31-month study time frame. The research and development costs of US $27,720 included the technical design, creation of wireframes, application programming interface integration, testing, implementation, and maintenance to support the startup of automated caring contacts. Vendor fees were US $285 per month (US $3420 per year) throughout the study period. The cost of educational materials provided to families and staff was approximately US $300 per year. In addition, the management of caring contacts typically involves a percentage of the time of a bachelor's-level staff member corresponding to program volume. Given the very high volume of acute care at this pediatric hospital, 50% of the effort was dedicated to personnel costs, equating to approximately US $25,250 per year and US $65,230 over the study period. Costs were covered by grant funding from the Ohio Suicide Prevention Foundation. In terms of replication, it is important to note that costs for new sites would be lower as startup and monthly fees are significantly lower due to a collaboration with a new vendor who offers startup to new sites using our design for US $2500 and a monthly text service fee of US $99 per month.

Sustainability

Nationwide Children's Hospital has made a significant commitment to reducing the pediatric suicide rate in the region and has significant resources devoted to data management and QI. Once grant funding for this initiative ends, we will allocate resources to support and sustain it.

Ethical Considerations

The hospital's Institutional Review Board (IRB) reviewed our proposal to implement caring contacts as a QI initiative and determined that this initiative did not constitute human subjects research under 45 Code of Federal Regulations part 46 or 21 Code of Federal Regulations part 50. Participants were not offered or provided with any form of compensation.

Results

Coverage

This initiative was implemented at Nationwide Children's Hospital, the second-largest children's hospital in the United States, which provides 38 licensed inpatient psychiatric beds and an additional 16 beds in the YCSU. Annually, it facilitates over 2000 discharges from these units. The PCD manages approximately 8000 visits each year. Furthermore, over 240,000 BH outpatient visits occur annually, underscoring its substantial regional role in pediatric mental health care.

Outcomes

From March 2019 to September 2021, a total of 4062 adolescent patients were eligible to receive caring contacts text messages. The total number of youths approached for the caring contact program (n=3601), total number enrolled (n=1888), and total number of youths having completed the program (n=1792) are listed in Table 1, together with summary statistics breakdowns by demographic factors and psychiatric service areas for these patient cohorts.

While compliance data for phase 2 could not be calculated, Multimedia Appendix 2 displays the actual number of texts sent by month during the pilots before automation. Once phase 3 began in March 2020, it took 3 months to consistently achieve an approach rate of over 90% (Multimedia Appendix 3). The enrollment rate by month is reflected in Multimedia Appendix 4. The overall patient approach rate for the 19-month period was 89% (95% CI 88-90), with an enrollment rate of 53% (95% CI 51-54), and a completion rate of 95% (95% CI 94-96; Figure 2). The table on the left of each panel in Figure 2 shows the total number of patients eligible, approached, enrolled, and completed, stratified by demographic factors and psychiatry service areas. The point estimates of approach rates, enrollment rates, and completion rates are listed, along with the associated CIs. Point estimates and 95% CIs of these rates are also visually represented on the right of each panel in Figure 2.

We assessed differences in age, gender, and race or ethnicity in an initial effort to identify whether approach rates were conducted equitably. There were no significant differences in approach rates between male and female patients. However, the approach rate for the White patient group (513/1189, 89.67%) was significantly higher than for the Black patient group (647/756, 85.6%). The approach rate for the patient group with another or unknown ethnicity was significantly lower than the other patient groups. The approach rate for the 13-year-old patient group was significantly lower than all other age groups, while the approach rate for the 18-years-old patient group was significantly higher than the other age groups. The pairwise approach rates were all statistically different between any 2 service areas in CL, PCD, IP, and YCSU, ordering from the lowest to the highest. The program enrollment data show that females enrolled in the caring contact program at a significantly higher rate than males (54% vs 48%). There were no significant differences in enrollment by race or ethnicity. The 13-year-old patient group had a significantly lower enrollment rate than older groups. YCSU had a significantly higher enrollment rate than the other service areas.

The reasons for declining the caring contact program are summarized in Table 2. The "no cell phone" option was chosen at a significantly higher rate for females (513/1189, 43.15%) than for males (173/516, 33.5%), while "inappropriate" was chosen at a significantly higher rate for males (55/516, 10.7%) than for females (65/1189, 5.5%). "No cell phone" was selected at a significantly higher rate for 13-year-olds (91/168, 54.2%) than for 16- (142/377, 37.7%), 17- (101/299, 33.8%), and 18-year-olds (71/210, 33.8%). "Inappropriate" was selected at the significantly highest rate for inpatient consultation or liaison, while "inappropriate" was selected at the significantly lowest rate for YCSU among all service areas. "Discuss at a later time" was selected at a significantly higher rate in the PCD (442/947, 46.7%) than the CL (30/93, 32%) and inpatient (79/217, 36.4%).

Program completion data indicated that females also completed the caring contact program at a significantly higher rate than males (1360/1418, 95.9% vs 432/470, 91.9%). There were no significant differences in program completion by race, ethnicity, age group, or service area.

Table 1. Patient cohort descriptive statistics.

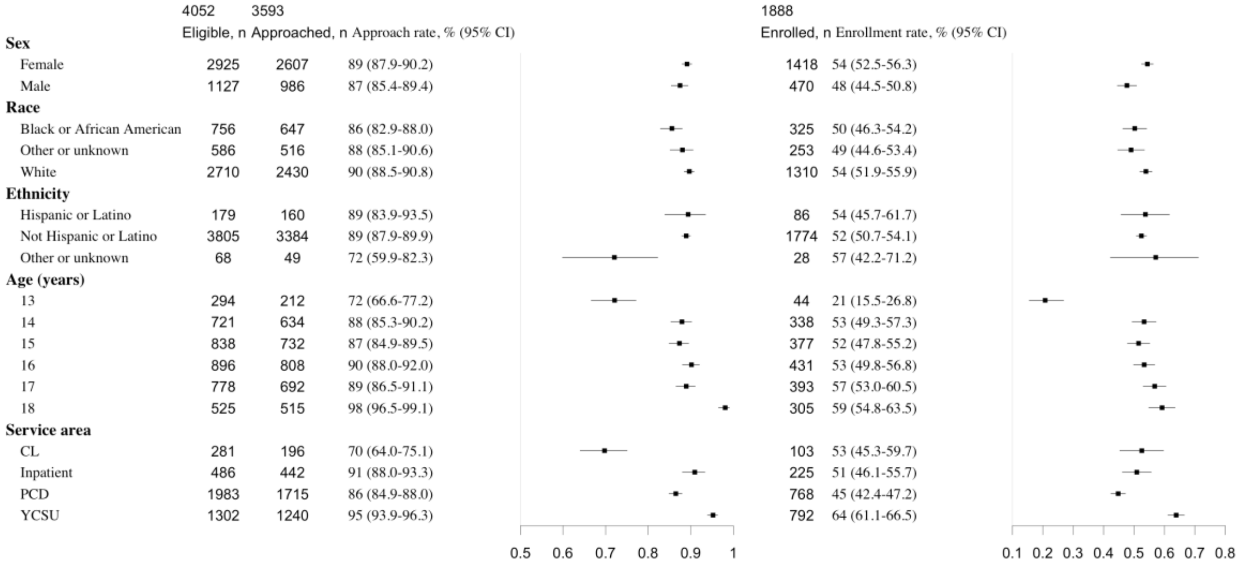
Values	Eligible, n (%)	Approached, n (%)	Enrolled, n (%)	Completed, n (%)
Sex				
Female	2925 (72)	2607 (73)	1418 (75)	1360 (76)
Male	1127 (28)	987 (27)	470 (25)	432 (24)
Race				
Black or African American	756 (19)	647 (18)	325 (17)	310 (17)
Other or unknown	586 (14)	516 (14)	253 (13)	238 (13)
White	2710 (67)	2430 (68)	1310 (69)	1244 (69)
Ethnicity				
Hispano or Latino	179 (4)	160 (4)	85 (5)	79 (4)
Not Hispanic or Latino	3805 (94)	3384 (94)	1774 (94)	1687 (94)
Other or unknown	68 (2)	49 (1)	28 (1)	26 (1)
Age (years)				
13	294 (7)	212 (6)	44 (2)	44 (2)
14	721 (18)	634 (18)	338 (18)	326 (18)
15	838 (21)	732 (20)	377 (20)	359 (20)
16	896 (22)	808 (22)	431 (23)	405 (23)
17	778 (19)	692 (19)	393 (21)	371 (21)
18	525 (13)	515 (14)	305 (16)	287 (16)
Service area				
CL[a]	281 (7)	196 (5)	103 (5)	96 (5)
Inpatient	486 (12)	442 (12)	225 (12)	212 (12)
PCD[b]	1983 (49)	1715 (48)	768 (41)	722 (40)
YCSU[c]	1302 (32)	1240 (35)	792 (42)	762 (43)

[a] CL: Consult Liaison Service.

[b] PCD: Psychiatric Crisis Department.

[c] YCSU: Youth Crisis Stabilization Unit.

Figure 2. Comparison of patients eligible, approached, and enrolled. CL: Consult Liaison Service; PCD: Psychiatric Crisis Department; YCSU: Youth Crisis Stabilization Unit.



	4052 Eligible, n	3593 Approached, n	Approach rate, % (95% CI)	1888 Enrolled, n	Enrollment rate, % (95% CI)
Sex					
Female	2925	2607	89 (87.9-90.2)	1418	54 (52.5-56.3)
Male	1127	986	87 (85.4-89.4)	470	48 (44.5-50.8)
Race					
Black or African American	756	647	86 (82.9-88.0)	325	50 (46.3-54.2)
Other or unknown	586	516	88 (85.1-90.6)	253	49 (44.6-53.4)
White	2710	2430	90 (88.5-90.8)	1310	54 (51.9-55.9)
Ethnicity					
Hispanic or Latino	179	160	89 (83.9-93.5)	86	54 (45.7-61.7)
Not Hispanic or Latino	3805	3384	89 (87.9-89.9)	1774	52 (50.7-54.1)
Other or unknown	68	49	72 (59.9-82.3)	28	57 (42.2-71.2)
Age (years)					
13	294	212	72 (66.6-77.2)	44	21 (15.5-26.8)
14	721	634	88 (85.3-90.2)	338	53 (49.3-57.3)
15	838	732	87 (84.9-89.5)	377	52 (47.8-55.2)
16	896	808	90 (88.0-92.0)	431	53 (49.8-56.8)
17	778	692	89 (86.5-91.1)	393	57 (53.0-60.5)
18	525	515	98 (96.5-99.1)	305	59 (54.8-63.5)
Service area					
CL	281	196	70 (64.0-75.1)	103	53 (45.3-59.7)
Inpatient	486	442	91 (88.0-93.3)	225	51 (46.1-55.7)
PCD	1983	1715	86 (84.9-88.0)	768	45 (42.4-47.2)
YCSU	1302	1240	95 (93.9-96.3)	792	64 (61.1-66.5)

Table 2. Reasons for declining caring contacts.

Category		No cell phone		Inappropriate		Parent opt out		Discuss at a later time	
	Total, N	n (%)	95% CI	n (%)	95% CI	n (%)	95% CI	n (%)	95% CI
Sex									
Female	1189	513 (43)[a]	40-46[a]	65 (5)[a]	4-7[a]	98 (8)	7-10	513 (43)	40-46
Male	516	173 (34)[a]	29-38[a]	55 (11)[a]	8-14[a]	47 (9)	7-12	241 (47)	42-51
Race									
Black or African American	322	140 (43)	38-49	22 (7)	4-10	25 (8)	5-11	135 (42)	36-47
Other or unknown	263	96 (37)	31-43	20 (8)	5-12	27 (10)	7-15	120 (46)	39-52
White	1120	450 (40)	37-43	78 (7)	6-9	93 (8)	7-10	499 (44)	41-47
Ethnicity									
Hispanic or Latino	74	25 (34)	23-46	—[b]	—	—	—	—	—
Not Hispanic or Latino	1610	650 (40)	38-43	—	—	—	—	—	—
Other or unknown	21	11 (52)	30-74	—	—	—	—	—	—
Age (years)									
13	168	91 (54)[a]	46-62[a]	—	—	—	—	58 (35)	27-42
14	296	128 (43)	38-49	20 (7)	4-10	18 (6)	4-9	130 (44)	38-50
15	355	153 (43)	38-48	26 (7)	5-11	23 (6)	4-10	153 (43)	38-48
16	377	142 (38)[a]	33-43[a]	23 (6)	4-9	36 (9)	7-13	176 (46)	41-51
17	299	101 (34)[a]	28-39[a]	22 (7)	5-11	35 (12)	8-16	141 (47)	41-53
18	210	71 (34)[a]	27-41[a]	—	—	—	—	96 (45)	39-52
Service area									
CL[c]	93	32 (34)	24-44	—	—	—	—	30 (32)[a]	22-42[a]
Inpatient	217	99 (46)	39-53	21 (10)	6-14	18 (8)	5-13	79 (36)[a]	30-43.2[a]
PCD[d]	947	366 (39)	35-42	69 (7)	6-9	72 (8)	6-9	442 (47)[a]	43.3-50[a]
YCSU[e]	448	195 (43)	39-48	—	—	—	—	203 (45)	40-50
Total	1705	686 (40)	38-43	120 (7)	6-8	145 (8)	7-10	754 (44)	42-46

[a] The proportion is statistically significantly different than at least another value in the demographic category, for example, proportions of “no cell phone” among females and males are statistically significantly different.

[b] Cell value of “—” is used to avoid the disclosure of cell counts less than 11.

[c] CL: Consult Liaison Service.

[d] PCD: Psychiatric Crisis Department.

[e] YCSU: Youth Crisis Stabilization Unit.

A total of 1961 optional posttext satisfaction surveys were sent, of which 264 (13.46%) were completed. A total of 219 (83%) respondents reported that the texts made them feel moderately to very hopeful, 232 (87.9%) respondents reported feeling moderately to very supported, 243 (92%) respondents reported that peers would be helped by these text messages, and 227 (86%) respondents reported they would like to keep receiving texts in the future if given the option.

Lessons Learned

Success Factors

As expected for any large-scale implementation initiative, engaging staff across disciplines and hierarchy was a critical factor in successful implementation. Service areas with actively engaged leaders and champions facilitated smooth integration of the initiative into existing workflows and demonstrated greater adaptability and flexibility throughout the process. Embedding these new procedures seamlessly into the EMR and daily workflows of clinicians also contributed significantly to successful implementation.

Challenges

High volume periods, especially when combined with low staffing levels, negatively impacted compliance and may have contributed to clinicians checking the "discuss later" reason for declining the intervention instead of taking the time to educate and enroll families. Staff turnover and program workflow changes led to a need for regular updated training. Furthermore, the data suggest implicit bias may have impacted approach rates.

Discussion

Overview

This paper describes the process of developing and implementing automated caring contacts, containing both text and images, for adolescents receiving acute services in a large BH service line using a QI methodology, with the ultimate goal of decreasing suicide risk during transitions in care. We were able to demonstrate that an automated system can be delivered at scale and that data obtained from the system can be leveraged to provide rapid improvement in adherence to established protocols. Moreover, the addition of images to the texts appears to be acceptable to an adolescent population. Consistent with the initial implementation of caring contacts letters by Dr Jerome Motto, these texts and hopeful images were expressions of care and validation. However, using a pre-established series of texts for all patients deviates from the original concept of sending personalized letters. The low dropout rate and posttext survey results suggest this was not a barrier to our patients. Youths receiving caring contacts reported that they felt supported and hopeful and that they thought this intervention would help others. Not personalizing the content of texts ensured that communication minimized the potential for exposure to protected health information and allowed us to significantly expand capacity. This has improved efficiency and, arguably, the cost-benefit ratio of this initiative. Further analyses will examine whether there has been a reduction in return visits to the PCD and psychiatric readmissions and whether this varies by participating service unit.

Our intent was to scale up this initiative through an iterative QI process. This approach enabled us to refine enrollment procedures, seamlessly integrate the initiative into the EMR, and enhance recruitment strategies. As a result, we relatively quickly achieved over 90% of eligible patients being approached monthly, with a consistent enrollment rate exceeding 50%. The potential benefits of implementing caring contacts to scale are significant—decreased loss to suicide, decreased suicide contagion, improved hospital readmission rates, decreased costs, and decreased pressure on an already overburdened mental health system.

Our process outcomes reflected some significant differences by age group in approach, enrollment, and completion rates. The 13-year-old patient group was less likely to be approached and had a lower enrollment rate than the other age groups, which may be due to a lower rate of mobile phone access. The lower approach rate is also potentially a reflection of lower perceived autonomy and clinician perceptions of lower risk in younger patients. In general, the enrollment rate increased with age, and the 18-year-old group had a significantly higher enrollment rate than the younger age groups. In addition, females were more likely than males to enroll in and complete this initiative, possibly reflecting an increased openness to accessing mental health support and to emotional information processing.

Approach rates differed by service type. Specifically, the approach rate was higher for the YCSU than for other service areas, and their patients were also more likely to enroll than patients in the other services. The YCSU was also less likely to endorse the "discuss at a later time" reason for declining the intervention. These differences may reflect the unit's relatively high acuity, focus on intensive therapy, including family therapy, favorable clinician-to-patient staffing ratios, and patient population (older youth admitted voluntarily and without significant disruptive behaviors). The CL service had a significantly lower approach rate than the other participating services and also had the highest use of the "inappropriate" decline reason. This likely reflects the nature of the CL service, which is spread across medical units rather than being on a single unit, and possibly lower engagement with the CL clinicians. As might be expected with a real-world QI implementation, there were external pressures that impacted staff compliance over time, such as high-volume periods that decreased the likelihood eligible patients would be approached.

We posited that a large-scale suicide prevention intervention made available to a broad population would increase health care equity as all eligible participants would be identified and approached. However, Black youth were less likely to be approached to participate than their White peers (647/756, 85.6% vs 2430/2710, 89.67%), possibly reflecting implicit bias on the part of clinicians. To further examine this difference by race, we analyzed the approach rates by race for each service area separately but found no statistically significant differences, which could be due to smaller cell sizes. There were no differences in enrollment or completion by race or ethnicity. The percentage of patients without access to a smartphone was higher than expected, but there were no statistically significant differences by race.

A limitation of this study is that demographic data were not collected for the focus groups, and it is unclear whether feedback was obtained at similar rates from youth of color as from White youth. However, the data reflect no significant differences in completion rates based on race or ethnicity. There were also no follow-up data collected for families who declined because they preferred to discuss the initiative at a later time. Another limitation was the relatively low rate of response to the survey and the potential for selection bias; our results may not be representative of all youth enrolled. As this implementation was a QI initiative rather than a research study, all data were aggregated, and there was no control group.

Based on the literature suggesting the year after discharge is a high-risk period, we moved to sending a set of 19 texts over the course of a year, starting in September 2021. Future enhancements include implementing caring contacts in other languages (Spanish, Somali, Arabic, and Nepali) to ensure cultural inclusivity. In addition, as the hospital expands the larger Zero Suicide framework across departments beyond the BH service line, we have also expanded caring contacts, starting with primary care and several intensive outpatient programs. We have begun the dissemination of our caring contacts content and processes to other health care systems in Ohio as well. Through this effort, we have standardized our processes and workflows, which will ultimately make implementation easier and more cost-efficient for our health care partners. Notably, during the initial manual phase, caregivers frequently expressed interest in receiving caring contacts and additional resources. This highlights the potential value of additional support for those caring for at-risk youth. Therefore, we are developing a set of caring contacts specifically tailored to support caregivers.

Future research could focus on identifying an optimal number and duration of texts and whether the addition of images impacts outcomes. As we plan to expand the program to include multilingual support and adapt to broader health care contexts, subsequent research will be essential in evaluating these adaptations' effectiveness, the stability of outcomes across diverse groups, and ensuring that the interventions remain culturally sensitive and equitable. There is preliminary support suggesting that cultural adaptations to caring contacts are acceptable across diverse populations [38]. Furthermore, this study lays the groundwork for future studies to explore the long-term impacts of automated messaging on suicide prevention outcomes for youth, the nuances of its acceptability across different demographic groups, and its integration into various health care settings.

Conclusions

In summary, this study describes the implementation of a scalable, automated caring contacts intervention integrated into a larger suicide prevention QI framework, in our case the Zero Suicide model, within a large health care system that is sustainable over time. An innovative component of our implementation was the use of images to engage participants. Consistent with other studies, our data suggest that this is an acceptable approach to intervening with adolescents at risk for suicide. The scalability and acceptability emphasize the potential for implementing automated supportive interventions on a broader scale, offering a viable pathway to enhancing postdischarge care for at-risk youth. This study highlights the growing potential for leveraging technology in mental health interventions and shifting toward more accessible, inclusive, and sustainable suicide prevention strategies.

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Data Availability

The data sets generated and analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

GVT, EC, FAM, YH, and JPA made substantial contributions to conception and design, drafted the paper, and revised it critically. JAB and JV made substantial contributions to conception and design. All authors granted final approval of the version submitted.

Conflicts of Interest

JAB receives research grant support from the National Institute of Mental, the Centers for Disease Control and Prevention, and the Patient-Centered Outcomes Research Institute; he is also a member of the Scientific Council of the American Foundation for Suicide Prevention and a member of the Scientific Advisory Board of Clarigent Health.

Multimedia Appendix 1
Example of a Caring Contact text.
[DOCX File , 1405 KB - pediatrics_v7i1e51570_app1.docx]

Multimedia Appendix 2
Number of first texts sent in phase 2 before automation.
[DOCX File , 57 KB - pediatrics_v7i1e51570_app2.docx]

Multimedia Appendix 3
Patients approached for caring contacts enrollment in phase 3.
[DOCX File , 48 KB - pediatrics_v7i1e51570_app3.docx]

Multimedia Appendix 4
Patients enrolled in caring contacts in phase 3.
[DOCX File , 52 KB - pediatrics_v7i1e51570_app4.docx]

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Abbreviations

BH: Behavioral Health
CL: Consult Liaison Service
ED: emergency department
EMR: electronic medical records
IP: Inpatient Psychiatry Unit
PCD: Psychiatric Crisis Department
QI: quality improvement
YCSU: Youth Crisis Stabilization Unit

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Original Paper

Videoconference-Delivered Cognitive Behavioral Therapy for Parents of Adolescents With Internet Addiction: Pilot Randomized Controlled Trial

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Abstract

Background: The rise in internet addiction, including web-based gaming and social networking services, is a serious concern. Even with access to medical institutions and counseling services, individuals with internet addiction, particularly adolescents, often refuse medical treatment or counseling. Parent-focused psychological intervention may lead to positive outcomes by improving the parent-adolescent relationship and helping parents identify and modify their adolescent’s problematic behaviors, including internet addiction.

Objective: This study was a pilot randomized controlled trial to test the feasibility of remote cognitive behavioral therapy via videoconferencing for parents of adolescents with internet addiction.

Methods: A total of 13 parents of adolescents aged 12-20 years with internet addiction were recruited and randomly assigned to either 12 sessions of the videoconference-delivered cognitive behavioral therapy (vCBT) group (n=6, 46%) or the waitlist control group (n=7, 54%). The study period was from March 1, 2018, to March 31, 2022. The primary outcome was the scores of the Young Internet Addiction Test reported by the adolescents. The secondary outcomes were adolescents’ hours of internet use per day (Internet Addiction Test), reported by the adolescents and by their parents; the Young Diagnostic Questionnaire, completed by the parents; and the quality of life of the adolescents and the parents, measured by the EQ-5D-5L. These were evaluated at weeks 0 and 13.

Results: As the primary outcome, the mean total Internet Addiction Test score decreased from 67.7 (SD 18.3; 6/13, 46%) at week 0 to 56.2 (SD 25.1; 5/9, 56%) at week 13 in the vCBT group, compared to an increase from 66.9 (SD 21.9; 7/13, 54%) to 68.0 (SD 18.7; 4/9, 44%) in the control group. For all outcomes, no significant differences were found between the 2 groups (all $P>.05$).

Conclusions: This study suggested the practical feasibility of vCBT for parents of adolescents with internet addiction. Further large-scale, multicenter randomized controlled trials are necessary to examine the effectiveness.

Trial Registration: UMIN Clinical Trials Registry UMIN000032483; https://tinyurl.com/yuhen6c9

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KEYWORDS

internet addiction; adolescents; parents; cognitive behavioral therapy; digital health

Introduction

The invention of the internet changed the world in unimaginable ways. With the internet, instantaneous and comprehensive exchange of large amounts of information with the rest of the world is possible. In the information age, the internet directly and indirectly impacts various aspects of people's lives; it is used, among other things, for information gathering, entertainment, communication, and buying and selling products and services [1]. However, with its continual development, its negative aspects, such as fraud, crime, cyberbullying, and wasteful spending, have come to the front; the problem of internet addiction is one such issue that has received considerable scholarly attention [2-5].

Research on internet addiction has been ongoing since the 1990s; studies have aimed to address the serious consequences associated with growing internet use, such as low grades, withdrawal, disordered eating habits, and lack of sleep [6-8]. Internet addiction can lead to depression, aggression, exacerbation of general psychiatric symptoms, and a decline in self-esteem, which can affect a person's career prospects and social support [9-15]. However, while studies have highlighted the importance of providing ongoing support for individuals with internet addiction, the number of medical and educational institutions that provide support remains limited [16-18]. In addition, even when a parent or guardian (hereafter referred to as a parent) of a person with internet addiction has access to medical institutions and counseling services to overcome the same, individuals with the addiction often refuse treatment, leaving them struggling with the addiction. In many cases, parents lack continuous access to medical institutions and counseling services; thus, the entire family is unable to receive the necessary support.

Parental factors have a significant impact on their children's risk of developing internet addiction [19,20]. In addition, many adolescents with internet addiction may be reluctant to receive treatment or have difficulty attending the intervention sessions. Therefore, researchers recommend designing interventions focusing on parents. Such parent-focused interventions can lead to positive outcomes for the entire family by improving the parent-child relationship and helping parents identify and modify their child's problematic behaviors using evidence-based methods.

Cognitive behavioral therapy (CBT) is a psychotherapy that helps thoughts and behaviors that have become rigid and narrow due to emotional stress to be more flexible and open. It is effective in treating a wide range of mental disorders, including depression and anxiety, and also in helping prevent recurrence [21]. In addition to face-to-face CBT, videoconference-delivered CBT (vCBT) is known to be effective in treating many mental disorders. Videoconferencing systems transmit audio and video signals over the internet and are used in treating mental health problems [22-24]. Research has demonstrated the effectiveness of vCBT for anxiety disorders [25] and chronic pain [26].

In this study, we administered CBT to the parents of adolescents with internet addiction, based on Community Reinforcement and Family Training (CRAFT) [27-29], a cognitive-behavioral program designed to get individuals who abuse substances and refuse treatment to enter treatment by teaching family members how to support a clean or sober lifestyle [30-33]. In Japan, CRAFT has also been used for families of youth in withdrawal [34].

This study aimed to conduct a pilot randomized controlled trial (RCT) to examine the feasibility of vCBT for parents of adolescents with internet addiction. Questionnaires and other surveys were administered to adolescents with internet addiction; however, the adolescents themselves did not receive any direct interventions in the form of vCBT.

Methods

Participants

The inclusion criteria of adolescents with internet addiction and their parents were as follows: (1) parents of adolescents with internet addiction (aged 12-20 years at the time of the survey) who provided consent; (2) parents who were aged at least 20 years and living with the adolescent with internet addiction at the time of providing consent; (3) adolescents and parents who were adequately informed, fully understood, and had given their free and voluntary written consent to participate in this study; (4) adolescents who were able to complete the self-administered questionnaire; (5) adolescents with internet addiction who scored 40 or higher on the self-administered Internet Addiction Test (IAT); and parents who were healthy enough to receive continuous CBT counseling support once a week for 12 weeks at home, using a videoconferencing system, and who had no physical or mental illness or disability that would interfere with counseling support.

Exclusion criteria for adolescents with internet addiction and their parents were as follows: (1) those who had difficulty obtaining ongoing counseling support due to problem behaviors, such as severe self-injurious behaviors, including cutting wrists or experiencing domestic violence; (2) those who had complications, such as a severe psychotic disorder, bipolar disorder, drug dependence, or alcohol-dependence, that are likely to interrupt CBT due to worsening of these symptoms; (3) those who were at an imminent risk of suicide, exhibited repeated antisocial behavior, or had progressive illness, thereby consequently discontinuing CBT; (4) those who had difficulty contacting the investigator; and (5) those deemed by the principal investigator or subinvestigator to be unfit for the safe conduct of this study.

Participants were recruited through posters on the Chiba University website; the Chiba University Hospital and its affiliated hospitals; and educational institutions in the Chiba Prefecture in Japan. During enrollment, adequate written and oral explanations were provided to the adolescents and their guardians. Only those who provided written and oral consent of their own free will were enrolled. However, if it were difficult for the participants to visit Chiba University (eg, because of COVID-19), an initial diagnostic evaluation was conducted remotely via videoconferencing.

Randomization

Parents of adolescents with internet addiction who agreed to the study design were asked to come to the hospital once—for the diagnostic evaluation; they were examined directly by the physician, and then divided, by random assignment, into a vCBT group (research treatment intervention group) and a waitlist control group. Participants who were unable to visit Chiba University Hospital due to COVID-19 restrictions were offered the option of completing the web-based initial diagnostic assessment for this study (to determine their eligibility to receive CBT counseling), so that they could participate in the clinical trial as soon as possible.

The case registration system was centrally administered at the Clinical Research Data Center (Department of Clinical Trials, Chiba University Hospital). The case registration was performed by issuing subject identification codes in the electronic medical record using the clinical trial system, creating a correspondence table, and performing linkable anonymization. For case registration, subject identification codes were issued, correspondence tables were created, and linkable anonymization was performed. The screening period was no longer than 8 weeks.

Sample Size

Considering this was a pilot study, the target number was calculated to ensure that the safety and feasibility of conducting a large-scale RCT in the future could be verified. Subsequently, 20 patients were targeted for analysis (CBT group: n=10, 50%; waiting list group: n=10, 50%). The main hypothesis of this study was to verify the superiority of the symptom-improving effect of the combined CBT group on patients with internet addiction.

Study Design

This study was an RCT (2 parallel groups) and a prospective intervention study. As mentioned above, parents were randomly assigned to either the vCBT group (the intervention group) or the control group.

In the vCBT group, for each parent, sessions were held weekly for 50 minutes each, over 12 weeks, either remotely or in person. The primary efficacy and safety outcomes were assessed before the intervention began (week 0), at the end of the intervention (week 13), and during the follow-up period (week 24).

In the control group, the parents and adolescents waited without intervention. The primary efficacy and safety outcomes were assessed only before the start of the intervention (week 0) and at the end of the intervention (week 13), but not during the follow-up period (week 24).

Intervention: vCBT for Parents

As mentioned above, CBT was administered to the parents of adolescents with internet addiction, based on CRAFT [23,24]. The program was designed to reduce the burden on family members of addicted individuals, improve family relationships, and promote the use of medical treatment services for individuals with addiction. The content and objectives of all 12 sessions are listed in Table 1 [27,29-33].

Sessions were held weekly for 50 minutes each over 12 weeks focusing on a specific theme. Parents completed the homework presented after the session and aimed to solve their communication problems with their adolescents. In the waiting list control group, parents and adolescents waited without receiving any intervention. Tests related to the primary outcome for evaluating efficacy and safety were to be conducted only before the start of the intervention (week 0) and at the end of the intervention (week 13), but not during the follow-up period (week 24). The waiting list control group then received CBT similar to the vCBT group.

Table 1. Content of each session.

Times	Contents	Purpose
1	Assessment interview	Conduct specific interviews with the adolescent with internet addiction about their daily life and set treatment goals.
2	What is internet dependence? (psychoeducation)	Parents gain a better understanding of internet addiction and cognitive behavioral therapy.
3	Understanding problematic behaviors	Categorize the adolescent’s desirable and undesirable behaviors in daily life.
4	Case formulation (functional analysis)	Parents learn how to conduct a functional analysis of problem behaviors and recognize external and internal triggers.
5	CRAFT[a] (problem solving)	Parents understand the CRAFT problem-solving method. They also practice the RIBEYE[b] and score evaluation methods. RIBEYE is one of the problem-solving techniques in CRAFT.
6	CRAFT (assertion)	Encourage parents to acquire positive communication skills. Additionally, parents undergo assertion training.
7	Effective praise	Parents learn strategies to encourage positive behaviors in adolescents with internet addiction, while also addressing their own actions and taking a proactive approach to reduce negative behaviors.
8	What the family does first?	In order to enrich the lives of the whole family, parents reconsider their roles and rebuild their relationships with their children.
9	How to treat children?	Parents understand “6 ways to protect adolescents from internet addiction.”
10	Stability of the whole family	Parents understand ways to prevent violent behavior and learn the importance of improving the whole family's overall stability to help address the problem of their adolescent’s internet addiction.
11	Treatment of internet addiction	Review and generalize previous treatment sessions.
12	Relapse prevention	Approach appropriate counseling institutions.

[a] CRAFT: Community Reinforcement and Family Training.

[b] RIBEYE: relax, identify, brainstorm, evaluate, yes to one, encourage yourself. This is a method in which the therapist (supporter) helps the client solve the problems they are facing. It is said that by mastering this method, the range of thinking will be broadened, and the client will be able to respond calmly and flexibly.

Outcomes

Primary Outcome: Young IAT

The primary outcome was the scores of the Young IAT [34] reported by the adolescents. The 20 items were rated on a 5-point Likert scale, ranging from 1=not at all to 5=frequently, to indicate the extent to which internet use interfered with their daily life, family relationships, social life, personal health, and state of mind. The score ranged from 20 to 100, with higher scores indicating greater problems caused by internet use. Young IAT defines a score between 20 and 49 as an average user who is in control of their internet use, a score of 50 to 79 as an addicted user with occasional or frequent problems with their internet use, and a score of 80 to 100 as an addicted user with major problems with their internet use.

For adolescents with internet addiction, the primary outcome was the change in IAT scores at week 13, compared to week 0 (baseline).

Secondary Outcomes

For adolescents with internet addiction, the following secondary outcomes were included to measure the effectiveness of the intervention: (1) daily hours of internet use as reported by adolescents; and (2) the Japanese version of the EQ-5D-5L [35-39] questionnaire, a self-reported quality-of-life index.

EQ-5D-5L Questionnaire

The EQ-5D-5L is a self-management questionnaire and rating system comprising 5 dimensions (mobility, self-care, usual activities, pain or discomfort, and anxiety or depression), each with 5 levels of severity (no problems, mild problems, moderate problems, severe problems, and extreme problems). The 5 dimensions of responses can be combined into a 5-digit number describing the health status of the respondent (11111=no problem at all and 55555=extreme problems). This defines a total of 3125 possible health states, which can be converted into a single health index by applying a formula that assigns a value to each response. To obtain the EQ-5D-5L index, the Japanese version of the EQ-5D-5L was used.

For the parents, the secondary outcomes included: (1) daily hours of internet use by adolescents as reported by parents; (2) parent-administered Japanese version of the EQ-5D-5L; and (3) Young Diagnostic Questionnaire (YDQ).

YDQ Instrument

To assess problematic internet use, the parents answered the YDQ [40,41]. The YDQ consists of 8 items (binary response format: 0=no, 1=yes). By summing up the values of all 8 items of the questionnaire, a YDQ sum score (range 0-8) was calculated with a higher sum indicating a higher risk of problematic internet use among adolescents.

Ethical Considerations

The Research Ethics Committee of Chiba University Hospital approved this study (IRB: 607). Written informed consent was obtained from all participants. Data were anonymized and participants in this study were not compensated. The study registration is UMIN000032483. This study was funded by Grants-in-Aid for Scientific Research (C) 20K10350.

Statistical Analysis

The distribution and summary statistics of subject background data were calculated in each analysis. For nominal variables, the frequency and proportion of categories are shown for each group. For continuous variables, summary statistics (number of cases, mean, SD, minimum, median, and maximum) were calculated for each group. Comparisons between groups were performed using the Pearson chi-square test for nominal variables, the Fisher exact probability test when more than 20% of cells had expected frequencies fewer than 5, and 2-tailed *t* tests for continuous variables. The significance level was set at 5%.

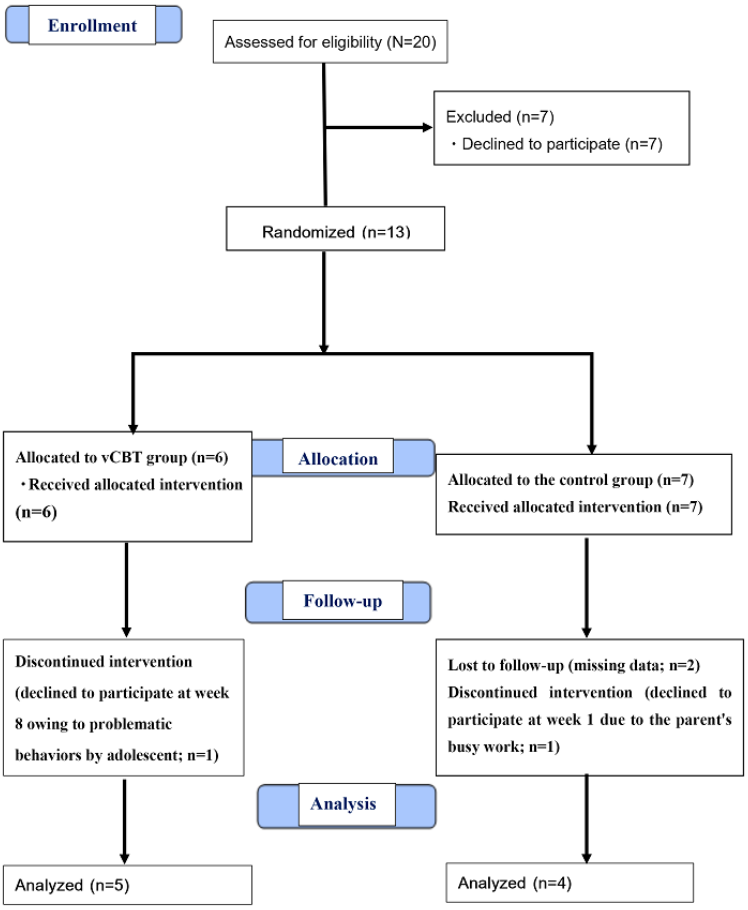
For the primary outcome, the adolescents' IAT score at the start of the study was used as the baseline value, and statistical analyses were performed to determine the change at the end of treatment. The 2-sided significance level for hypothesis testing was set at the 5% level, and the 2-sided 95% CIs were calculated. The primary objective of the study was to determine whether the vCBT group showed significant improvement over the control group at week 13, based on the adolescents' IAT scores. The null hypothesis posited no significant difference in the changes of IAT scores between the 2 groups in the primary analysis, which was tested using analysis of covariance. The covariates included in this analysis were factors used for allocation adjustment: sex, age less than 16 years, and age 16 years and older [34]. To complement the results of the primary analysis, secondary outcomes, briefly described here, were analyzed using both analysis of covariance and linear mixed-effects models, without adjustment for multiplicity. The significance level for hypothesis testing was set at a 2-sided 5%, and corresponding 2-sided 95% CIs were calculated. All statistical analyses were executed using R (version 4.2.1, R Foundation for Statistical Computing), with a significance level set at *P*<.05.

Results

Participants

The study period was from March 1, 2018, to March 31, 2022. Figure 1 shows the characteristics of the participants. Of the 20 participants who were assessed for eligibility, 7 declined to participate. Finally, 13 participants and their adolescents (vCBT group: n=6, 46%; control group: n=7, 54%) provided informed consent, and were randomized to receive the intervention (Multimedia Appendix 1).

Figure 1. Flow diagram of the participant selection process based on Consolidated Standards of Reporting Trials (CONSORT) guidelines. vCBT: videoconference-delivered cognitive behavioral therapy.



During the follow-up, 1 patient in the vCBT group discontinued the intervention. This youth withdrew from participation in week 8 due to behavioral problems. In the control group, 2 patients were lost to follow-up due to missing data, and 1 patient discontinued the intervention because their parents refused to participate in the first week due to work reasons. Finally, 5 patients in the vCBT group and 4 in the control group were analyzed.

Adverse Events

One of the participants in the intervention group declined to participate in this study at week 8 due to her adolescent's problematic behaviors. After that, the problem behavior disappeared. Table 2 shows the characteristics of participants. There were 0 male and 6 female participants in the vCBT group and 1 male and 6 female participants in the control group. The mean age of the participants was 47.33 (SD 4.6) years in the vCBT group and 50.29 (SD 5.2) years in the control group. As for adolescents, 5 were male and 1 was female in the vCBT group and 6 were male and 1 was female in the control group. The mean age of the adolescents was 15.00 (SD 2.2) years in the vCBT group and 15.57 (SD 2.1) years in the control group.

Table 2. Characteristics of the participants.

Participant and characteristics	vCBT[a] group (n=6)	Control group (n=7)	*P* value[b]
Parent			
Sex, n (%)			
Male	0 (0)	1 (14)	≥.99
Female	6 (100)	6 (86)	≥.99
Age (years), mean (SD)	47.33 (4.6)	50.29 (5.2)	.30
Adolescent			
Sex, n (%)			
Male	5 (83)	6 (86)	≥.99
Female	1 (17)	1 (14)	≥.99
Age (years), mean (SD)	15.00 (2.2)	15.57 (2.1)	.64

[a] vCBT: videoconference-delivered cognitive behavioral therapy.

[b] 2-tailed *t* test.

Primary Outcome

The primary outcomes are shown in Table 3. As assessed by the IAT for youths, the vCBT group scored 67.7 (SD 18.3; 6/13, 46%) points and the control group 66.9 (SD 21.9; 7/13, 54%) points at week 0. At week 13, the vCBT group scored 56.2 (SD 25.1; 5/9, 56%) points and the control group scored 68.0 (SD 18.7; 4/9, 44%) points. The change from baseline was –7.80 (SD 17.3) points in the vCBT group and 1.75 (SD 16.6) points in the control group. There was no significant change of IAT between the 2 groups (*P*=.43; Table 3).

Table 3. Primary outcome.

Time point and outcome	vCBT[a] group	Control group	*P* value[b]	*P* value[c]
Week 0 (n=13)			.94	N/A[d]
Participants, n (%)	6 (46)	7 (54)		
Internet Addiction Test score, mean (SD)	67.7 (18.3)	66.9 (21.9)		
Week 13 (n=9)			.46	N/A
Participants, n (%)	5 (56)	4 (44)		
Internet Addiction Test score, mean (SD)	56.2 (25.1)	68.0 (18.7)		
Change from baseline			.43	.57
Participants, n (%)	5 (56)	4 (44)		
Internet Addiction Test score, mean (SD)	–7.80 (17.3)	1.75 (16.6)		

[a] vCBT: videoconference-delivered cognitive behavioral therapy.

[b] 2-tailed *t* test.

[c] ANCOVA.

[d] N/A: not applicable.

Secondary Outcomes

As shown in Table 4, the change from baseline in adolescents' hours of internet use per day was –2.30 (SD 1.86) hours for the vCBT group and –0.50 (SD 1.00) hours for the control group. There was no significant difference of change in internet use time reported by the adolescents between the 2 groups (*P*=.33).

Table 4. Secondary outcomes.

Change from baseline	vCBT[a] group (n=5)	Control group (n=4)	*P* value[b]	*P* value[c]
Internet usage time (hours) reported by adolescents, mean (SD)	–2.30 (1.86)	–0.50 (1.00)	.33	.71
Adolescent's EQ-5D-5L index score (QOL[d]), mean (SD)	0.04 (0.28)	0.06 (0.18)	.45	.38
Internet usage time (hours) reported by parent, mean (SD)	–2.00 (3.81)	0.25 (1.26)	.14	.84
Parent's EQ-5D-5L index score (QOL), mean (SD)	0.20 (0.30)	–0.06 (0.18)	.01	.84
Parent's Young Diagnostic Questionnaire scores, mean (SD)	–0.20 (1.30)	0.50 (1.73)	.70	.09

[a] vCBT: videoconference-delivered cognitive behavioral therapy.

[b] 2-tailed *t* test.

[c] ANCOVA.

[d] QOL: quality of life.

For the EQ-5D-5L in adolescents, the change from baseline was 0.04 (SD 0.28) points for the vCBT group and 0.06 (SD 0.18) points for the control group. There was no significant change in the QOL of the adolescents between the 2 groups (*P*=.45).

The parent-reported change from baseline in the adolescents' daily internet use time was –2.00 (SD 3.81) hours for the vCBT group and 0.25 (SD 1.26) hours for the control group. There was no significant difference of internet use time reported by the parents between the 2 groups (*P*=.14).

For the EQ-5D-5L, a parent QOL index, the change from baseline was 0.20 (SD 0.30) points for the vCBT group and –0.06 (SD 0.18) points for the control group. The change of QOL of the parents in the vCBT group was significantly higher than that in the control group (*P*=.01).

For the YDQ, the change from baseline was –0.20 (SD 1.30) points for the vCBT group and 0.50 (SD 1.73) points for the control group. There was no significant difference in change of YDQ between the 2 groups (*P*=.70).

Discussion

Overview

We conducted vCBT for parents of adolescents with internet addiction and tested its effectiveness in improving the symptoms of internet addiction in adolescents. In this study, the change in the IAT from the start of intervention week 0 to the end of intervention week 13 was –11.5, from 67.7 (6/13, 46%) to 56.2 (5/9, 56%) in the vCBT group, and 1.1, from 66.9 (7/13, 54%) to 68.0 (4/9, 44%) in the control group. We did not find a statistically significant difference between the vCBT group and the control group in this study. In the completed analysis, the change in the IAT in the vCBT group was –7.8, from 64.0 (5/9, 56%) to 56.2 (5/9, 56%), and the change in the IAT in the control group was 1.75, from 66.3 (4/9, 44%) to 68.0 (4/9, 44%).

A systematic review of meta-analyses of treatments for internet addiction shows that CBT is generally effective [42,43]. For the primary outcome, Bernstein et al [44] conducted a 2-arm RCT of a digital health intervention in 130 people with internet use disorders. An intervention group of 65 participants received 7 of their CBT-based sessions and were compared to a waitlist control group of 65. The results showed the IAT of the intervention group decreased by 7.99, from 63.46 to 55.47, and the waitlist control group decreased by 3.09, from 63.89 to 60.8. This was statistically significant (*d*=0.54, 95% CI 0.19-0.89).

Similarly, Yang et al [45] conducted an RCT comparing an intervention group and a control group to examine the effects of a short-term intensive CBT intervention on internet addiction among Chinese university students. Intensive CBT comprised 5 sessions of 90 minutes each, totaling 7.5 hours. The intervention group received an intervention program in addition to an internet addiction training course. By contrast, the control group received only an internet addiction training course. Consequently, from baseline to posttreatment assessment, the IAT decreased by 7.3 from 59.6 to 52.3 in the intervention group, and by 1.1 from 59.9 to 58.8 in the control group.

Compared to the studies by Bernstein et al [44] and Yang et al [45], our study showed similar reductions in the CBT intervention group. However, these studies directly intervened with individual internet addicts, whereas our study differed in that the target of intervention was the parents of adolescents with internet addiction.

For the secondary outcomes, regarding the amount of time adolescents use the internet per day, Wölfling et al [46] conducted a 2-arm RCT of a CBT called short-term treatment for internet and computer game addiction; it consisted of 15 weekly group and up to eight 2-week individual sessions in 143 people with internet addiction, compared to a waitlist control group of 71. As a result, the amount of time spent on the internet a weekday decreased by 3.1 hours for the intervention group, from 6.5 to 3.4 hours and remained unchanged for the waitlist control group at 5.8 hours. The amount of time spent on the internet on weekends decreased for the intervention group by 4.3 hours, from 8.4 to 4.1 hours, and for the waitlist control group by 2.0 hours, from 7.6 to 5.6 hours. They showed that the intervention group was statistically significant on both weekdays and weekends ($P \leq .001$).

In this study, the amount of change in youth-reported internet usage time in the intervention group decreased by 2.30 hours, from 11.4 to 9.1 hours, and that in the control group by 0.50 hours, from 9.25 to 8.75 hours (*P*=.33). Although our study did not distinguish between weekdays and weekends, the values in Wölfling et al [46] study and ours were similar. Taken together, these results suggest that CBT may help patients with internet addiction reduce internet usage time.

Zhu et al [47] conducted a systematic review of 3538 internet addicts and a total of 57 RCTs to examine the effectiveness, benefits, and drawbacks of various treatments used alone or in combination. Their network meta-analysis of 13 interventions showed that the top 4 were repetitive transcranial magnetic stimulation+CBT, drugs+other, repetitive transcranial magnetic stimulation, and electroacupuncture+CBT. Cañas and Estévez [48] conducted a systematic review of intervention or prevention programs for excessive internet use among adolescents and considered 14 programs that met inclusion criteria. Both systematic review studies were regarding interventions for internet-addicted adolescents themselves; no study about CBT for parents of adolescents with internet addiction was identified.

Concerning family therapy as the intervention, Liu et al [49] conducted multifamily group therapy for each family with an adolescent with internet addiction (aged 12-18 years) and a parent (aged 35-46 years). They showed that the intervention group was significantly better than the control group on the adolescent pathological internet use scale, the internet use time, the parent-child communication scale, and the parent-child intimacy scale.

In addition to the previous studies about CBT for adolescents with internet addiction themselves or family therapy, this study suggested the feasibility of vCBT for parents of adolescents with internet addiction.

Limitations

A few limitations of this study must be acknowledged. First, although the implementation plan called for 20 participants (vCBT group: n=10, 50%; control group: n=10, 50%), the final analysis included a smaller number of 9 respondents (vCBT group: n=5, 56%); control group: n=4, 44%). The sample size for this study was examined to determine what sample size would be needed to show a significant difference; based on the results of this exploratory RCT, statistical analysis indicated that the ideal sample size would be 108 cases for vCBT (n=54) and control group (n=54) combined. This was substantially larger than the current sample size.

Second, the waiting list group was used as a control group because of ethical reasons. As the waitlist control may be inappropriate for evaluating treatment outcomes, alternative treatments should be used as a control group in future large-scale RCTs. Third, this was a single-center RCT and not a multicenter study, which affects its generalizability. Fourth, since there are no data on follow-up after the vCBT intervention in this study, future efforts should focus on collecting follow-up data and implementing efficient strategies to ensure a higher response rate. Fifth, for the primary outcome, we used the Young IAT. In the systematic review by meta-analysis, the IAT was the most used measure of internet addiction; however, other measures should be considered as well. Specifically, data should be collected by objective machines, such as tablets, on the time spent on the internet by addicts. Additionally, other evaluation measures that have emerged since the IAT, such as the Compulsive Internet Use Scale, should be examined [50,51].

Conclusions

This study suggested the practical feasibility of vCBT for parents of adolescents with internet addiction. Further large-scale, multicenter RCT is necessary to examine the effectiveness.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Analysis results by subject background.
[PNG File , 283 KB - pediatrics_v7i1e60604_app1.png]

Multimedia Appendix 2
CONSORT‐eHEALTH checklist (V.1.6.1).
[PDF File (Adobe PDF File), 359 KB - pediatrics_v7i1e60604_app2.pdf]

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Abbreviations

CBT: cognitive behavioral therapy
CRAFT: Community Reinforcement and Family Training
IAT: Internet Addiction Test
QOL: quality of life
RCT: randomized controlled trial
vCBT: videoconference-delivered cognitive behavioral therapy
YDQ: Young Diagnostic Questionnaire

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Original Paper

Disclosure Patterns of Opioid Use Disorders in Perinatal Care During the Opioid Epidemic on X From 2019 to 2021: Thematic Analysis

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Abstract

Background: In 2021, the United States experienced a 14% rise in fatal drug overdoses totaling 106,699 deaths, driven by harmful opioid use, particularly among individuals in the perinatal period who face increased risks associated with opioid use disorders (OUDs). Increased concerns about the impacts of escalating harmful opioid use among pregnant and postpartum persons are rising. Most of the current limited perinatal OUD studies were conducted using traditional methods, such as interviews and randomized controlled trials to understand OUD treatment, risk factors, and associated adverse effects. However, little is known about how social media data, such as X, formerly known as Twitter, can be leveraged to explore and identify broad perinatal OUD trends, disclosure and communication patterns, and public health surveillance about OUD in the perinatal period.

Objective: The objective is 3-fold: first, we aim to identify key themes and trends in perinatal OUD discussions on platform X. Second, we explore user engagement patterns, including replying and retweeting behaviors. Third, we investigate computational methods that could potentially streamline and scale the labor-intensive manual annotation effort.

Methods: We extracted 6 million raw perinatal-themed tweets posted by global X users during the opioid epidemic from May 2019 to October 2021. After data cleaning and sampling, we used 500 tweets related to OUD in the perinatal period by US X users for a thematic analysis using NVivo (Lumivero) software.

Results: Seven major themes emerged from our thematic analysis: (1) political views related to harmful opioid and other substance use, (2) perceptions of others' substance use, (3) lived experiences of opioid and other substance use, (4) news reports or papers related to opioid and other substance use, (5) health care initiatives, (6) adverse effects on children's health due to parental substance use, and (7) topics related to nonopioid substance use. Among these 7 themes, our user engagement analysis revealed that themes 4 and 5 received the highest average retweet counts, and theme 3 received the highest average tweet reply count. We further found that different computational methods excel in analyzing different themes.

Conclusions: Social media platforms such as X can serve as a valuable tool for analyzing real-time discourse and exploring public perceptions, opinions, and behaviors related to maternal substance use, particularly, harmful opioid use in the perinatal period. More health promotion strategies can be carried out on social media platforms to provide educational support for the OUD perinatal population.

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KEYWORDS

X; Twitter; opioid use disorder; thematic analysis; pregnancy; perinatal care; women and child health; maternal health; COVID-19; opioid epidemic

Introduction

In 2021, it was reported that fatal drug overdoses accounted for 106,699 deaths in the United States, which marks a 14% increase in fatal drug overdose rates compared to the rates in the previous year [1]. Notably, harmful opioid use was a major contributor, implicated in 75.36% of these drug overdose fatalities [1,2]. The ongoing opioid epidemic persists as a significant public health challenge in the United States, particularly affecting individuals of reproductive age. It is estimated that 70% to 80% of women with substance use disorder (SUD) have concurrently endured physical abuse, sexual harassment, and severe mental health conditions—factors that exacerbate morbidity and mortality rates in this demographic [3]. Moreover, in 2019, about 20% of birthing individuals reported their opioid misuse during pregnancy based on their self-reported data [4]. According to self-reported data from 2019, disseminated by the Centers for Disease Control and Prevention [4], approximately 7% of surveyed individuals indicated they used prescription opioid pain relievers while pregnant, with one-fifth of them reporting opioid misuse. These findings underscore the prevalence and detrimental impact of opioid use disorders (OUDs) among pregnant and postpartum individuals, making it one of the most prevalent and pernicious forms of SUD in the United States.

In the context of perinatal care, opioid medications are often prescribed for pain relief (analgesia). Nonetheless, the prolonged use of these prescription opioids can cause dependency, tolerance, and addiction, collectively characterized under OUD. Data from 2017 to 2018 indicate that approximately 42.5% of opioid overdose fatalities among women in the United States were associated with prescription opioids [3]. Given their efficacy in pain management, a significant proportion of women diagnosed with OUD are more inclined to persist in their opioid consumption throughout pregnancy. The excessive prescription of opioids during this critical period not only heightens the susceptibility to OUD in new mothers but also escalates the likelihood of postpartum depression [5]. Furthermore, the deleterious impacts of opioid use extend to fetuses, notably increasing the risk of neonatal opioid withdrawal syndrome [6], seizures, and respiratory complications in neonates [5]. Despite the progress in medication-assisted treatments designed to enhance maternal and fetal health outcomes by mitigating the fetal stress associated with OUD, the ramifications of opioid use during prenatal and postpartum phases persist as a significant societal concern [5].

The ubiquity of social media plays a key role in facilitating public discourse and fostering connections, thereby making these platforms invaluable for real-time public data collection and capturing public sentiment, increasingly recognized as vital for public surveillance. X, formerly known as Twitter, emerged as a preeminent social media platform for its expansive global reach, enriched by its user engagement features and capabilities for users to rapidly disseminate information through retweets. By 2023, X had attracted more than 450 million active users monthly [7], highlighting its significance in global digital communication. In addition, research also reveals that X is among the foremost platforms used by individuals for stress management through constructive and detrimental practices, as well as expressing views, concerns, and insights about diverse health issues [8]. Furthermore, X represents a cost-effective and efficient medium for the dissemination of public health communications, providing a rich vein for researchers to identify consumer health interests and concerns [8-10]. Its user engagement functions, such as retweets, likes, and user follow-up conversations, enable the dynamic assessment of public sentiment, facilitate the real-time exchange of personal health perspectives, and enhance public education through the accessible presentation of scientific findings [9,11,12].

The exploration of linguistic patterns within X conversations related to opioids unravels intricate insights into harmful opioid use trends and societal perceptions of this substance. Graves et al [13] analyzed 84,023 opioid-related tweets in the United States, delineating discussions on opioid issues across diverse geographic regions. Their analysis indicated that ongoing monitoring of X data could facilitate the detection of emerging opioid trends. Moreover, this study highlighted that linguistic analyses may yield valuable insights into public reactions to dynamic opioid markets and identify intervention opportunities for targeted high-risk populations and areas [13].

Existing literature, primarily using qualitative methodologies and randomized controlled trials with limited samples, has predominantly focused on risk factors associated with opioid use during pregnancy, perceptions of treatment for OUD, and health care–seeking experiences of women with OUDs [14-16]. Scarce studies used X data to explore widespread perception related to OUD, its treatments, and naloxone [16]. To the best of our knowledge, there is a void in social media research examining perinatal OUD to gauge public sentiment. As such, in this study, we address this gap by analyzing tweet content on opioid use in the perinatal period during the opioid epidemic from 2019 to 2021. Through classical thematic analysis, a methodology extensively used in qualitative research for identifying, analyzing, and reporting data patterns [17] along with the latest machine learning models for initial testing the feasibility of scaling up the annotations and improving labeling accuracy, we aim to uncover emerging perinatal OUD trends and user engagement reflected in social media discourse [18-20]. More specifically, the objective of this study was to unravel X users' disclosure and communication patterns concerning public opinions, personal experiences, and challenges associated with OUD and OUD care during pregnancy and postpartum periods, with a view of enhancing health promotion strategies for this vulnerable population on social media platforms. Consequently, this study provides a more detailed overview and insightful implications on public health policy and services, aiming to enhance OUD treatment options for women in the perinatal period. As such, our three primary research questions (RQs) to guide this study are as follows:

- RQ1: What are key themes and trends in perinatal OUD discussions on X from 2019 to 2021?
- RQ2: What user engagement patterns, including disclosure frequency, retweeting and replying tweet behaviors, emerged in perinatal OUD–related discourse on X?
- RQ3: Considering the labor-intensive process of manually coding qualitative data, even for a small sample of tweets, are there any computational methods to streamline and scale this annotation effort?

Methods

Ethical Considerations

The University of South Carolina's Institutional Review Board (Pro00113240) has reviewed this study's data collection and analysis approach. Since we extracted public data from X, this study was deemed as nonhuman participant research and exempted from review. Furthermore, we also cleaned and de-identified anonymous tweets before our data analysis process.

Data Collection

We gathered 6 million raw tweets from X related to general perinatal OUD guided by a set of keywords provided by our clinical team, spanning from May 2019 to October 2021. This data set underwent a refinement process using English keywords pertinent to OUD in English, encompassing terms such as "opioid," "heroin," "codeine," "oxycodone," "Vicodin," "fentanyl," and "Percocet," among others. The full list of these keywords is listed in Multimedia Appendix 1. Additionally, we applied a geolocation filter to narrow down the data to tweets within the United States. This filtering process yielded a narrowed pool of 3290 perinatal opioid use–related tweets. Then, we further identified and removed 85 duplicate tweets to 3205 unique tweets. A random sample of 500 was then extracted for thematic analysis, a sample size aligned with prior qualitative research methods that have analyzed Twitter data sets of similar scope [21,22]. Figure 1 outlines the sequential steps of data collection, cleaning, and sampling processes used in this study.

Figure 2 illustrates the trends of the number of monthly perinatal OUD-related tweets from May 2019 to October 2021. The highest volume of tweets was recorded in July 2019. Subsequently, from August 2019 to February 2020, there was a significant decline in the number of tweets. In March 2020, coinciding with the COVID-19 period, the tweet volume surged nearly 7-fold.

Figure 1. Flowchart of data collection, cleaning, and sampling process. OUD: opioid use disorder.

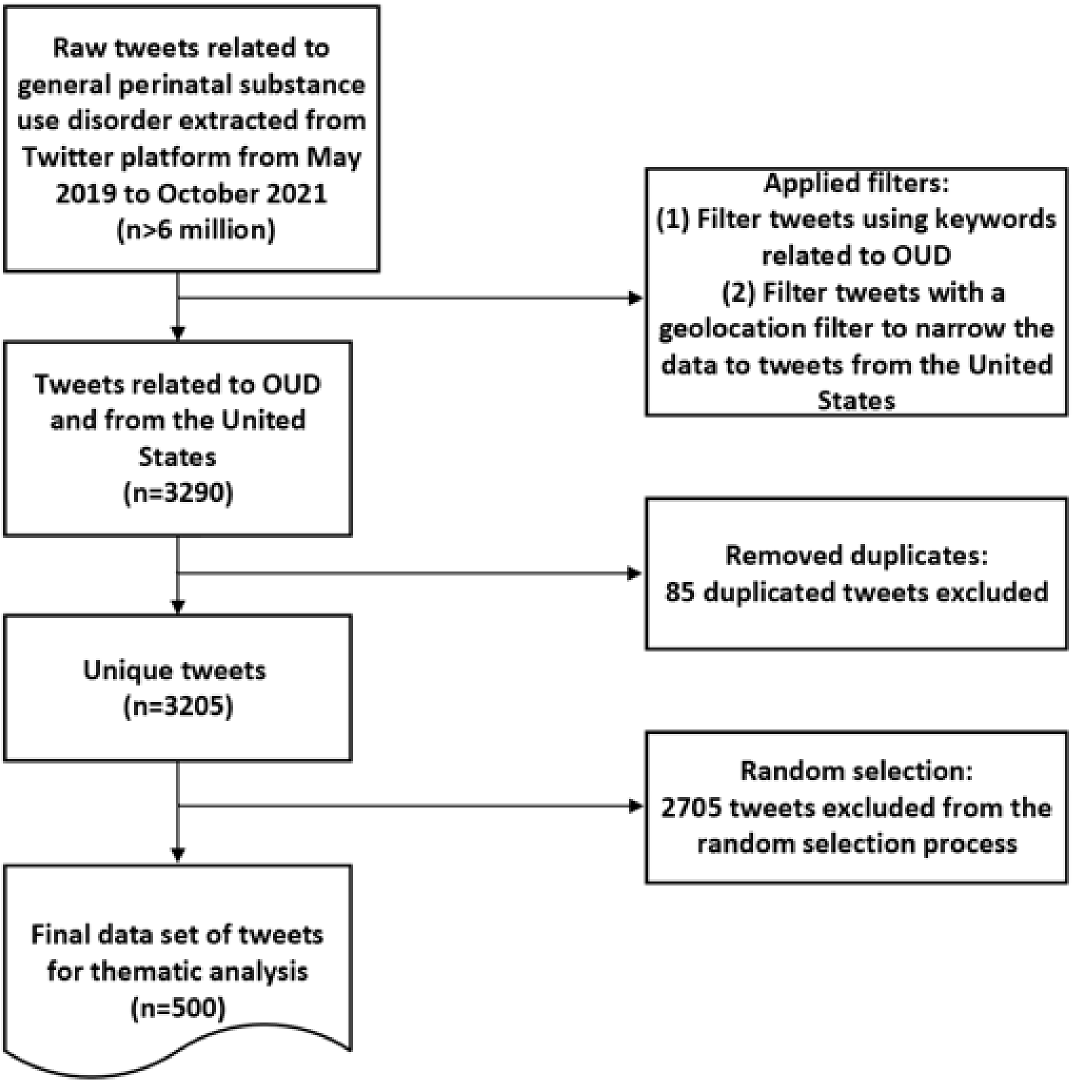
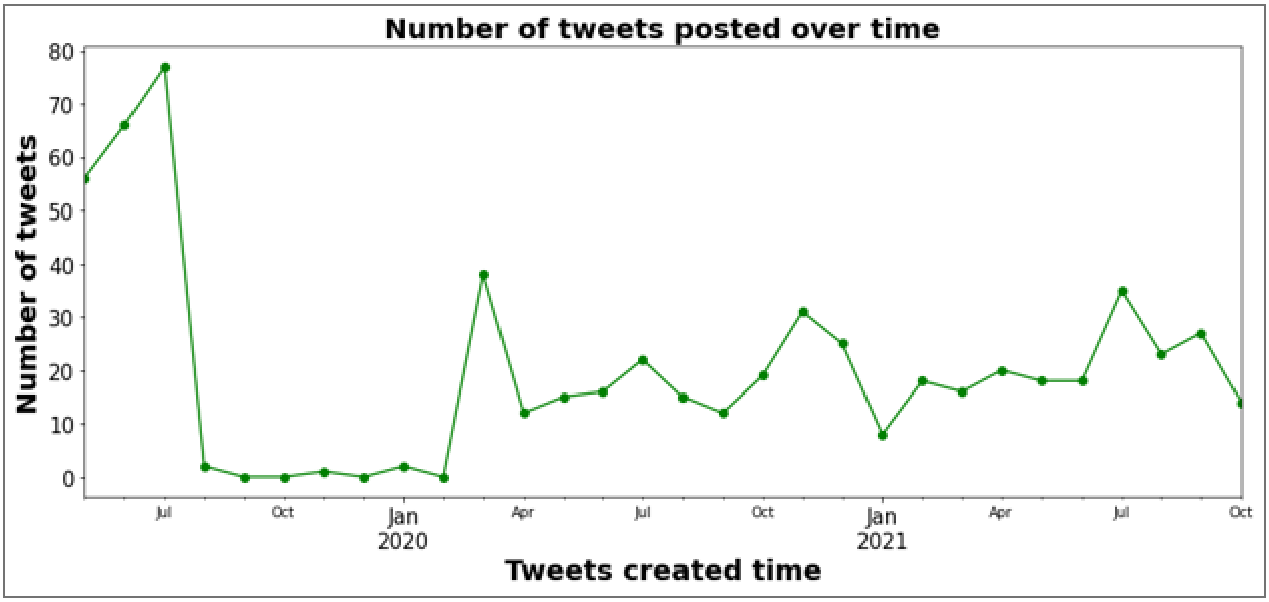


Figure 2. Number of monthly perinatal opioid use disorder–related tweets from May 2019 to October 2021.



Thematic Analysis

Two trained researchers independently conducted the thematic analysis on the 500 randomly selected tweets, achieving a satisfying κ score of 0.82. NVivo (version 12; Lumivero) software was used in analyzing the tweet data set through a manual coding process, such as labeling and categorizing specific sections [23]. Using open-coding techniques, the researchers identified themes in the X discourse on opioid use and labeled codes based on the content and context of the tweet. Each tweet was coded independently, and the main themes identified were further divided into subthemes. These subthemes provided specificity and helped address the tweet's context and information. The occurrence of thematic overlap was notable, necessitating multiple categorizations per tweet to encapsulate the breadth and complexity of themes articulated [24]. In total, the analysis of the 500 tweets resulted in the identification of 7 main themes. The researchers deployed 174 unique codes throughout this process, accounting for 1307 references across the selected tweets.

Results

Identified Themes of Perinatal OUD

Table 1 provides a brief description of the 7 main themes, the number of references for each theme, and their sample tweets. The number of references in NVivo refers to the number of times a passage of text was coded to each theme and subtheme. The seven primary themes we identified include (1) political views related to harmful opioid and other substance use, (2) perceptions of others' substance use, (3) lived experiences of opioid and other substance use, (4) news reports or papers related to opioid and other substance use, (5) health care initiatives, (6) adverse effects on children's health due to parental substance use, and (7) topics related to nonopioid substance use. We described each main theme and its subthemes in the following subsections.

Table 1. Seven main themes identified with opioid use disorder in the perinatal period.

Main themes	Description	Sample tweet	References (n=457), n (%)
Political views related to harmful opioid and other substance use	Opinions or perceptions on the influence of politics and other governmental structures on substance use	• "@***a@real*** @*** @*** was born in Detroit! ***, you need to go back to Pennsylvania and, those suburban Opioid addicts in your old neighborhood."	101 (22.1)
Perceptions of others' substance use	Opinions or perceptions on other people's use of substances	• "@***a @***a @***a @***a @***a Can we talk seriously about opioid addiction in pregnant mothers? How We the PEople can write law to PROactively PROtect our women & children? @***a @***a @***a Get to the core"	91 (19.9)
Lived experiences of opioid and other substance use	Personal substance user's experiences including individual's experience or an individual's family or friends	• "I Am: An Un-apologetic Opioid Patient – National Pain Report ..." • "Chronic pain is a disease. Do we have to start a mea culpa for every disease? Cancer, MS, polio, broken bones, DDD, dystonia, strokes, Parkinsons, IBS, kidney stones, childbirth w/o a spina"	70 (15.3)
News reports or papers related to opioid and other substance use	Published information regarding a recent event, change, or situation related to substance use	• "Rate of women addicted to opioids during pregnancy quadrupled in 15 years, CDC says"	48 (10.5)
Health care initiatives	Information and methods for either educational purposes or to address current health needs	• "Opioid exposure following vaginal delivery appears to be a trigger for future persistent opioid use and misuse, independent of confounding factors #***a #SOAPAM2019 #BestPaper #OBAnes #OpioidCrisis #OpioidEpidemic"	37 (8.1)
Adverse effects on children's health due to parental substance use	The consequences that children face due to their parents ' use of substances	• "Not to be stupid but does that go for heroin crack marijuana ok to put as much in your body as you want. My wife had an abortion we regret it now you have to live with it"	24 (5.3)
Topics related to nonopioid substance use	Tweets comparing other substances or ideas to opioids or about nonopioid drugs	• "Booking holidays and city breaks - that's my heroin. Edinburgh, Brussels, Manchester & Berlin done! Roll on Vegas, Portugal & Spain! See the world, have great fun with great friends and family! Get her booked! #***"	86 (18.8)

[a] ***: Reaction from a private Twitter user account.

Political Views Related to Harmful Opioid and Other Substance Use

Tweets were categorized under the theme "political views or criminalization of behaviors related to opioid and other substance use" if the content referred to an individual's beliefs or opinions on a political or governmental topic related to opioids or other substances. Within this theme, the researchers identified 2 major subthemes, as shown in Table 2, with "opioid epidemic" being the most common (n=68). Under the "opioid epidemic" subtheme, tweets frequently referenced opioid addiction (n=11), followed by illegal drug importation (n=10), and companies that manufacture opioids (n=8). Meanwhile, tweets categorized under the "multifactorial perspectives" subtheme mentioned the topic of abortion most often (n=7), followed by drug addiction (n=4) and human trafficking (n=4).

Table 2. Subthemes of political views related to opioid and other substance use.

Subthemes	Description	Sample tweet	References (n=89), n (%)
Opioid epidemic	Political opinions regarding the opioid crisis	"Why don't we look at maternal health disparities the way we do the opioid epidemic? We don't blame that community for addiction, we look at other factors and causes (prescribing, etc). What are risk factors in the community leading to maternal disparities?"	68 (76)
Multifactorial perspectives (abortion, child abuse, drug addiction, homelessness, human trafficking, and imprisonment)	Tweets that contain multiple components within one tweet in relation to politics	"@***[a] @*** NYC is becoming a #[obscenity] $15 coffee, gangs running some neighborhoods, illegals [obscenity] taxpayers money dry, reduction in services for residents, homelessness, drug addiction, human trafficking, child abuse #ToxicLiberals advocating 4 everything but values integrity and Americans"	21 (24)

[a] ***: Reaction from a private Twitter user account.

The 21 tweets categorized under the "multifactorial perspectives" subtheme were further categorized into 4 sublevels: individual, general public, health care provider, and policy. The result is presented in Table 3. The analysis revealed policy-level tweets as the most frequently occurring with a count of 14, followed by general public-level tweets (n=7). However, no tweets were at the health care provider (n=0) or individual (n=0) levels. Policy-level tweets were defined as tweets referring to specific governmental regulations or policies, with most tweets about abortion and domestic terrorism. General public tweets were defined as tweets on the general public, with no particular attention on governmental policies. Within this category, most tweets were about drug addiction and homelessness. Coding for the general public tweets that target no specific audience is important, as it facilitates researchers in comprehending the perspectives and beliefs on current issues, thereby suggesting potential solutions.

Table 3. Sublevels of multifactorial perspectives.

Levels	Description	Sample tweet	References (n=21), n (%)
Policy level	Tweets referring to specific governmental regulations or policies	"i can't believe this people haven't been prosecuted for domestic terrorism yet. what a [obscenity] corrupted [obscenity] system. a child molester walking amongst the children and a [obscenity] heroin addict/porn star acting as a journalist. [obscenity] white people"	14 (67)
General public level	Tweets on the general public, with no particular attention on governmental policies	"this is their concern when homeless line streets of major cities, when illegals flood our country, when infrastructure needs repair, when babies left to die after birth if unwanted, when illegal voting plagues the system, when hundreds die from opioid addiction, etc. really?!"	7 (33)

Perceptions of Others' Substance Use

Tweets were classified under the "perceptions of others' substance use" theme when their content demonstrated an individual's opinions regarding another person's substance use or general use in the larger population. The researchers identified 5 major subthemes. The most common subtheme was "opioid use" (n=34), followed by "children exposure" (n=21), "substance use during pregnancy" (n=20), "polysubstance use" (n=8), and "religious beliefs" (n=6), as shown in Table 4.

Table 4. Subthemes of perceptions of others' substance use.

Subthemes	Description	Sample tweet	References (n=89), n (%)
Opioid use	The use of opioids, prescribed or illicit use	• "@***a is surprised by the prevalence of Opioid prescribing after a vaginal delivery: 30%; 87% after C Section. Most patients rate pain at 0 at D/C and do not use all the opioids they are prescribed."	34 (38)
Children exposure	Children being exposed to substances, intentional or unintentional	• "First, how dare you even think of giving a baby Morphine?!! I'm beyond [obscenity]."	21 (24)
Substance use during pregnancy	The use of substances during which a fetus is developing in the mother's womb	• "@***'d rather have 95% of your profits..." • "Momma's got baby number seven on the way and has an opioid craving she needs to take care of ..."	20 (22)
Polysubstance use	The use of more than one substance simultaneously	• "Forgot to mention: his default state is 'vapes maximum strength THC 24/7' recovering opioid addict still on prescription opioids, also 'occassionally' does coke" • "His drug problem is clearly SKY HIGH atm so yeah, baby intervention tonight"	8 (9)
Religious beliefs	Tweets regarding an individual's religious views or beliefs	• "PRAYER REQUEST: 100 percent disabled vet in his last moments from mesothelioma (service related-asbestos exposure.) He is a warrior born/bred." • "He's in great pain; being kept on morphine to keep him comfortable. He can't speak, eat or move." • "Pray for a peaceful transition. Amen"	6 (7)

[a]***: Reaction from a private Twitter user account.

Lived Experiences of Opioid and Other Substance Use

Tweets that described an individual's experience or experience of family and friends related to opioid and other substance use fell under the main theme of "lived experiences of opioid and other substance use." There were 2 main subthemes, "opioid use" (n=65) and "polysubstance use" (n=5), identified under this category, as shown in Table 5.

Table 5. Subthemes of lived experiences of opioid and other substance use.

Subthemes	Description	Sample tweet	References (n=67), n (%)
Opioid use	The use of opioids, prescribed or illicit use	"It's been a year since I lost my baby brother to dumb ass heroin and my heart still hurts just the same. I miss you so much"	62 (92)
Polysubstance use	The use of more than one substance simultaneously	"What'chu want? I got ketamine, MDMA, Adderall, Bromo-Dragonfly, heroin, coke, crack, codeine, oxys, percs, vikes, PCP, LSD, Dilaudid, mescaline, mushrooms, bath salts, cortisone, Toradol. I got molly. I got her sister Sandra. I got big Frank. I got birth control, I got Plan B."	5 (8)

Most of the tweets under "opioid use" were related to the loss of loved ones, predominantly due to harmful opioid use leading to fatal overdose (n=24), followed by opioid use for pain management (n=17). When further stratified by opioid type mentioned under both subthemes combined, heroin was the most common (n=17), followed by morphine (n=10), codeine (n=10), fentanyl (n=9), oxycodone (n=5), and hydrocodone (n=2).

News Reports or Papers Related to Opioid and Other Substance Use

Tweets that referred to published news reports or papers concerning opioid and other substance use were placed under "news reports or papers related to opioid and other substance use" theme. Five subthemes were identified, as shown in Table 6, with "opioid use" being the most common (n=30), followed by "substance use during pregnancy" (n=11), "unintentional drug exposure" (n=2), "child neglect" (n=2), and "concurrent use of alcohol and opioids" (n=2).

Table 6. Subthemes of news reports or papers related to opioid and other substance use.

Subthemes	Description	Sample tweet	References (n=47), n (%)
Opioid use	The use of opioids, prescribed or illicit use	"***[a] hospital shut down as revelations emerge that a dangerous dose of morphine killed 7-month-old baby Ethan. We tell you more on #K24EveningEdition"	30 (64)
Substance use during pregnancy	Prenatal substance use during fetus development	"The opioid crisis comes to the classroom as soaring numbers of children born in drug withdrawal reach school age | The Seattle Times"	11 (23)
Unintentional drug exposure	Accidental exposure of children to substances	"highlights problems: Baby was exposed to 87 micrograms, 4% of the therapeutic dose. Codeine level tho was 'stratospherically high': 50x higher than would be expected. Opioid poisoning could not be the cause of death. Neonatal opiod toxicity hard to envision."	2 (4)
Child neglect	A form of abuse in which the caregiver fails to meet the child's basic need	"Police arrested Edwardo Zepeda after he lost his daughter when he went on a late-night alcohol run. The 4-year-old was later found sleeping in between two power boxes. He is now charged with child abuse @KTNV"	2 (4)
Concurrent use of alcohol and opioids	The use of opioids and alcohol simultaneously	"Radle was born in Tulsa, Oklahoma, and died in May 1980 from a kidney infection, exacerbated by the effects of alcohol and narcotics; he was 37."	2 (4)

[a] ***: Reaction from a private Twitter user account.

Tweets were also stratified by the news media outlets in which they were published and categorized by national outlet, state outlet, community, health news, international, and unknown source. News reports or papers generated at the national level included CNN, USA Today, New York Times, Fox News, and ABC News, which provide information and reports on the United States overall. State-level news outlets included Oklahoma News, Seattle Times, Tennessean, and San Antonio Express-News. Community-level news outlets, such as Vox News, are privately owned, publish opinionated journals and cover American news. Tweets listed under health news are news outlets that specifically publish medically related information and reports, such as *Science Daily*, *Medical Press*, and *JAMA Network*. International-level news is international news outlets, which include Irish News, Irish Times, and United Press International. Finally, tweets were coded as "unknown" if the user-generated content referred to a news report or paper but did not specify its source. Among these 6 categories, national-level news and unknown were the most common (n=13), followed by state-level news (n=9), international-level (n=5), health news (n=5), and community-level news (n=2).

Health Care Initiatives

Tweets were categorized under "health care initiatives" theme if they contained information to educate the public and address current societal health needs. Four main subthemes were identified under this category as shown in Table 7. The most common subtheme was "speaker presentations" (n=20), followed by "government initiatives" (n=6), "research" (n=6), and "addiction treatment services" (n=3).

Table 7. Subthemes of health care initiatives.

Subthemes	Description	Sample tweet	References (n=35), n (%)
Speaker presentations	Individuals or a group of individuals who educate others and raise awareness based on current data and information	"Important #***[a] findings by @*** on the risk of persistent opioid use after childbirth, especially after c-sections and when getting prescriptions before delivery."	20 (57)
Government initiatives	Government-funded programs or policies to assist with substance use	"During Health, Welfare Family Services cmte, Senate Committee Chairman @***Senate discusses @*** HEAL opioid research grant working in 16 counties, two of them in his district."	6 (17)
Research	Ongoing investigation or discoveries regarding substance use	"PROMISE and MOTHER studies debunked lots of myths—dose of #buprenorphine and #methadone not related to neonatal withdrawal severity and methadone was associated with more #opioid need than bup Hendree Jones #CPDD19"	6 (17)
Addiction treatment services	Treatment programs with the objective to assist people with drug addiction	"Great tour and presentation from the staff at *** Addiction and Family Services. We were impressed with the organizations no wait time screening and triage as well as the Rapid Access Opioid Treatment program. Providing services to those when they need it most is crucial"	3 (9)

[a] ***: Reaction from a private Twitter user account.

Tweets placed under "speaker presentations" were further divided into national, state, and clinician levels. National presentations were cited most frequently (n=10), followed by clinician speaker presentations (n=5), and finally, state-level presentations (n=3).

All sample tweets coded under "health care initiatives" were also stratified in relation to opioid use during prenatal care, pregnancy period or delivery, postpartum or breastfeeding, and childcare or maternal health to determine the prevalence of perceptions and opinions about opioid use across the different stages of pregnancy. The results showed tweets were most commonly about childcare and maternal health (n=11), followed by the quality of care received during pregnancy and delivery period (n=7), care quality postpartum and during the breastfeeding period (n=4), and finally, prenatal period (n=1).

Adverse Effects on Children's Health due to Parental Substance Use

Tweets that described the outcomes of children's health due to parental use of opioids and other substances were listed under "adverse effects on children's health due to parental substance use" theme. Table 8 indicates the most common subtheme under this category was "multifactorial perspectives" (n=22), followed by opioid orphans (n=1).

Table 8. Subthemes of adverse effects on children's health due to parental substance use.

Subthemes	Description	Sample tweet	References (n=23), n (%)
Multifactorial perspectives (neonatal abstinence syndrome, abortion, miscarriage, foster care, and deaf)	Tweets that contain multiple components within one tweet in relation to adverse effects on children	"Was born in withdrawal to heroin. Had 2 ab, tubes tied after 3rd child. Have company spons ins, still can't afford to go to dr even though have afib, so went strict vegan, quit weed, liquor, etc. Have been on welfare b4, but now help family, but I'm happy and grateful!"	22 (96)
Opioid orphans	Children who became parentless due to parental opioid use	"15-year-old ***[a] calls himself an opioid orphan, which is a child who has lost one or both parents to the opioid crisis whether it's to rehab prison or death. Part of Steven's path to healing is his plan to help other kids."	1 (4)

[a] ***: Reaction from a private Twitter user account.

Under "multifactorial perspectives," tweets related to neonatal abstinence syndrome were the most frequent (n=9), followed by abortion (n=5), foster care (n=2), miscarriage (n=1), and deaf (n=1). There was 1 specific tweet about opioid orphans, which is a term describing children who become parentless due to parent's use of opioid (n=1).

Topics Related to Nonopioid Substance Use

Tweets were coded as “topics related to nonopioid substance use” if the content was not related to opioid use. There were references to other drugs, abstract ideas about opioids, and mentions of opioids in pop culture, music, and television. There were 3 major subthemes under this category, with the most common being nonopioid drugs (n=43), followed by pop culture (n=28), and Norco, California (n=6), as listed in Table 9.

Table 9. Subthemes of topics related to nonopioid substance use.

Subthemes	Description	Sample tweet	References (n=77), n (%)
Pop culture	Entertainment that is enjoyed by the general public	• “Book your tickets to see our Grad Show ‘Darknet’ . 10/13July at The Union Theater.” • “Computer hacking, Heroin overdosing, Methadone Selling, The rise of Robots and Artificial Intelligence, Family conflict and Big tech ... ”	28 (36)
Nonopioid drugs	In relation to drugs that are not opioids	• “A few people have asked about the #surgery I had.” • “It was a #laparoscopic #hysterectomy with a #chemo flush. I have three incisions in my #stomach and they took my #cervix #FallopianTubes and #uterus out through my #vagina. #no #narcotics #cannabis only!”	43 (56)
Norco, California	In relation to the city in California with the same name as the brand name of hydrocodone or acetaminophen	• “***a going away party. It [obscenity] that one of my best friends is moving so far away. But I wish nothing but the best for him and his family. I owe a lot to him. A real to friend! @ Norco, California”	6 (8)

[a]***: Reaction from a private Twitter user account.

Table 10 presents the distribution of various identified topics or themes across 3 time periods: before COVID-19 in 2019, during the COVID-19 pandemic period without COVID-19 vaccination (year 2020), and during the COVID-19 pandemic period with COVID-19 vaccination (year 2021). Notably, in the pre–COVID-19 era, the predominant theme among tweets pertained to “political views related to substance use.” Throughout the duration of the COVID-19 pandemic, “lived experiences of opioid and other substance use” emerged as the theme with the highest frequency of tweets, closely followed by “political views related to substance use.” In the COVID-19 pandemic period after launching the COVID-19 vaccination in 2021, “lived experiences of opioid and other substance use” continued to dominate the thematic landscape of the tweets.

Table 10. Comparison of various theme distributions during 3 time periods of before and during the COVID-19 pandemic with and without COVID-19 vaccination.

Themes	Time period (n=600)		
	Pre–COVID-19 tweets, n (%)	COVID-19 without vaccination tweets, n (%)	COVID-19 with vaccination tweets, n (%)
Political views related to opioid and other substance use	63 (10.5)	54 (9)	46 (7.8)
Perceptions of others’ use	28 (4.7)	26 (4.3)	22 (3.7)
Lived experiences of opioid and other substance use	30 (5)	71 (11.8)	72 (12)
News reports or papers related to opioid and other substance use	19 (3.2)	14 (2.3)	24 (4)
Health care initiatives	13 (2.2)	13 (2.2)	10 (1.6)
Adverse effects on children’s health due to parental	17 (2.8)	14 (2.3)	14 (2.3)
Topics related to nonopioid substance use	30 (5)	8 (1.3)	12 (2)

To understand user engagement dynamics on X, we further analyzed additional users' retweet and reply tweets to examine user interaction behaviors. Table 11 summarizes the mean counts and percentages of retweets and replies associated with tweets across the identified thematic categories. Analysis of user engagement in terms of retweeting behavior reveals that "health care initiatives" emerges as the preeminent theme, recording the highest mean retweet count, closely followed by "news reports or papers related to opioid and other substance use." In terms of tweet replies, "lived experiences of opioid and other substance use" was ranked the highest replied theme, with other thematic categories lagging significantly.

Table 11. Average retweet and reply count based on themes.

Themes	Theme retweet count, mean (SD)	Tweet reply count, mean (SD)
Adverse effects on children's health due to parental substance use	0.98 (3.26)	0.51 (0.99)
Health care initiatives	1.61 (2.28)	0.31 (0.47)
Lived experiences of opioid and other substance use	0.47 (1.83)	1.72 (5.05)
News reports or papers related to opioid and other substance use	1.47 (4.68)	0.40 (0.96)
Topics related to nonopioid substance use	0.32 (0.77)	0.34 (0.89)
Perceptions of others' substance use	0.26 (0.79)	0.53 (0.92)
Political views related to harmful opioid and other substance use	0.62 (2.81)	0.46 (1.16)

Table 12 presents the distribution of tweets across various themes as percentages. Importantly, the themes "lived experiences of opioid and other substance use" and "political views related to harmful opioid and other substance use" were ranked a higher percentage of the perinatal OUD tweet data set compared to the others.

Table 12. Thematic breakdowns of perinatal opioid use disorder tweets in percentages.

Themes	Tweet count (n=600), n (%)
Political views related to harmful opioid and other substance use	163 (27.2)
Perceptions of others' substance use	76 (12.7)
Lived experiences of opioid and other substance use	173 (28.8)
News reports or papers related to opioid and other substance use	57 (9.5)
Health care initiatives	36 (6)
Adverse effects on children's health due to parental use of substances	45 (7.5)
Topics related to nonopioid substance use	50 (8.3)

Discussion

Principal Findings

Overall, public health researchers and public health authorities can potentially use these social media platforms as a communication and monitoring tool to promote public health awareness and positively influence public health behavioral changes in all pregnancy stages [25,26]. This study leveraged the expansive reach of X with a set of tweets pertinent to perinatal SUD as informed by relevant keywords curated by our clinical team, ranging from May 2019 to October 2021. This corpus underwent a rigorous refinement procedure to result in a set of 3205 unique perinatal OUD-related tweets in the United States, among which we randomly selected 500 tweets for in-depth thematic analysis, forming the foundation for our data analysis.

Our thematic analysis unveiled several key trends: the consequences of harmful opioid use in the perinatal period, shared experiences and published newspapers on opioid use, perspectives on the opioid epidemic, and current protocols and practices that are put in place to combat the opioid epidemic. As one of the first such studies to explore perinatal OUD disclosure patterns on social media, we identified seven major themes from 500 random tweets related to OUD in the perinatal period: (1) political views related to harmful opioid and other substance use, (2) perceptions of others' substance use, (3) lived experiences of opioid and other substance use, (4) news reports or papers related to opioid and other substance use, (5) health care initiatives, (6) the adverse effects on children's health due to parental substance use, and (7) topics related to nonopioid substance use.

This study also revealed the potential of social media platforms such as X for public health surveillance. For example, before the COVID-19 pandemic, the dominant theme about OUD in the perinatal period was "political views on substance use." However, during the prevaccination period in the pandemic, tweets about "lived experiences of opioid and other substance use" and "political views related harmful opioid and other to substance use" surged among tweets related to OUD in the perinatal period, and they remained prominent even after COVID-19 vaccinations became available. This study further provides support that social media data can provide valuable insights and trends regarding public concerns and opinions during public health crises. Policy makers can leverage these insights and trends emerged from social media platforms to understand evolving public concerns and opinions and further develop public health policies and interventions accordingly.

Overall, these themes collectively identified socioecological factors at the individual, interpersonal, environmental, community, and national levels (including policies and structures that can promote or hinder treatment), underscoring the multifaceted nature of OUDs and their treatment within the perinatal population. Addressing 3 issues necessitates a multitiered treatment strategy that fosters substantial and sustainable changes, advocating a systematic approach for collective action among key stakeholders. Notably, the analysis highlighted the prominence of "health initiatives" conducted by health welfare, family services, senate committees, local addiction treatment services, and other legislative bodies. The health promotion strategies funded by government health programs can be used to increase public awareness on social platforms about adverse effects caused by OUD and disseminate information on safe nonpunitive networks where pregnant and postpartum women can safely access treatment. There are also opportunities to disseminate targeted research discoveries, especially to and for families and children. This study underscores the potential of government-initiated health promotion strategies through social media platforms, such as X, particularly for families and children impacted by OUD to enhance the quality of OUD care during the perinatal period.

Given the labor-intensive nature of the human manual annotation process, to elevate the scalability and precision of thematic analysis within perinatal opioid–related tweets, we also initially explored support vector machine (SVM), random forest (RF), and extreme gradient boosting (XGBoost) algorithms in tandem with the Word2Vec model, creating binary weak labeling models for each identified theme. These models were trained on 80% (n=400) of the manually annotated tweet data, using the derived themes as labels, and their performance was evaluated on the remaining 20% (n=100). The comparative analysis across 7 thematic categories revealed distinct strengths among the models: XGBoost demonstrated superior accuracy in themes concerning adverse effects on children's health due to parental substance use, SVM excelled in analyzing health care initiatives and lived experiences of opioid and other substance use, and RF was significantly effective in interpreting politically charged content. This machine learning approach is promising to facilitate the processing of a larger data set but also enabling nuanced analysis across various dimensions, underscoring the potential of enhancing text analysis efficiency.

Limitations

This research study had several limitations and challenges. First, key term ambiguity sometimes led to the inclusion of irrelevant data, such as tweets referring to Norco, California, coincidentally captured as the brand name of hydrocodone or acetaminophen. We had to manually exclude these irrelevant terms for our content analysis. Second, the anonymous nature of X posed challenges in consistently delineating the demographic and geographical details of users. Finally, the user-generated content provided limited insights into ethnic and racial disparities and maternal disparities in our small sample, which could be expanded with a much larger tweet sample in future studies.

Discussions and Future Research

Addressing harmful opioid use in the perinatal period remains a public health imperative in the United States. Researchers have turned toward using X, a popular social media platform, to dissect health perceptions and behaviors, offering a lens on the opioid epidemic's evolving discourse. Our study findings suggest a universal opioid screening in perinatal care, destigmatization, enhanced care access, and a preference for treatment over penalization to combat the epidemic effectively, especially among pregnant individuals. Using X as a valuable social media platform, we were able to analyze real-time public perceptions and behavior as well as current trends on the opioid epidemic and opioid use during the perinatal period. As such, this study provides important implications on perinatal OUD treatment policies, services, and potential ways of using social media as a platform to facilitate and promote healthy and impactful initiatives and community support to the vulnerable perinatal OUD population at large.

With many more identified relevant and touching themes, we significantly enriched the overall understanding of the complexity of OUD use in the perinatal care domain and associated pressing issues in a much broader way, calling for more research and services in this specific domain. First, this study highlights the need to establish more comprehensive initiatives and universal screening, as they were recommended by the American College of Obstetricians and Gynecologists and Centers for Disease Control and Prevention. Universal screening and assessment of all pregnant individuals for substance use are crucial during pregnancy, and targeted support for child welfare and maternal health, especially given that there are fewer initiatives on postpartum or breastfeeding and prenatal period, and thus there is room for expanding this area of care services, health promotion initiatives, and research. Second, we advocate for a collaborative and resource-adequate approach to mitigate OUD's impacts on maternal and child health [4,27,28]. Likely, social media platforms can be used as a medium to promote such universal screening, reduce stigma, and increase assisted treatment programs for these disadvantaged vulnerable populations through government agencies, public health–related organizations, and communities. Third, more government initiatives and services to address the health concerns of pregnant individuals with OUD delay in health seeking, an emphasis might need to be placed on treatment rather than criminalization of child abuse and loss of child custody [10]. Fourth, additional studies assessing racial and ethnic maternal disparities and maternal disparities are needed due to significant racial and ethnic disparities with reported higher maternal morbidity and mortality rates for Black women compared to non-White Hispanic women due to pregnancy-related causes [29] and postpartum depression driven by increased substance use of alcohol and illicit drug use during pregnancy [30]. As a result, further research is essential to address racial and ethnic disparities, emphasizing more the important role of social media platforms in broadening outreach and support for vulnerable populations, guiding policy changes, and fostering stakeholder engagement for systematic solutions in OUD-related perinatal care.

Moreover, to improve the labeling accuracy and scalability, our future research will also aim to integrate large language models to refine the labeling technique, leveraging large language models' advanced text comprehension for improved feature extraction and more accurate predictions, thereby streamlining the analysis of complex thematic data within social media discourse.

Overall, as topics related to perinatal OUD discussed on social media platforms evolve, more systematic investigation is needed to capture the full spectrum of perinatal opioid misuse and disparities. Larger samples in different geolocations from more diverse social media platforms may provide greater insights on current health perceptions and public response on opioid use in perinatal care for practical public health policy implications.

Conclusions

Given the prevalence and detrimental impact of OUD among pregnant and postpartum individuals, this study aims to enhance our understanding of opioid use patterns during the perinatal period by analyzing related tweets on the X platform. We randomly sampled 500 tweets from May 2019 to October 2021 and conducted a thematic analysis.

Our analysis, thematic analysis, identified 7 key themes in perinatal OUD discussions, with "lived experiences of opioid and other substance use" and "political views related to harmful opioid and other substance use" among the most frequently discussed on X. Our user engagement analysis revealed that "health care initiatives" and "news reports or papers related to opioid and other substance use" received the highest average retweet count, and "lived experiences of opioid and other substance use" received the highest average tweet reply count. Given the labor-intensive nature of manual annotation, we investigated machine learning models to improve the scalability and precision of thematic analysis. We found that different computational methods excel in analyzing different themes: XGBoost for identifying adverse effects on children's health due to parental substance use, SVM for analyzing health care initiatives and lived experiences of substance use, and RF for interpreting politically charged content.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Keyword list.
[DOCX File , 14 KB - pediatrics_v7i1e52735_app1.docx]

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Abbreviations

OUD: opioid use disorder
RF: random forest
RQ: research question
SUD: substance use disorder
SVM: support vector machine
XGBoost: extreme gradient boosting

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Original Paper

Experiences and Views of Young People and Health Care Professionals of Using Social Media to Self-Manage Type 1 Diabetes Mellitus: Thematic Synthesis of Qualitative Studies

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Abstract

Background: Social media have shown the potential to support type 1 diabetes self-management by providing informational, emotional, and peer-to-peer support. However, the perceptions of young people and health care professionals' (HCPs) toward the use of social media for type 1 diabetes self-management have not been systematically reviewed.

Objective: The aim of this study is to explore and summarize the experiences and views of young people with type 1 diabetes and their HCPs on using social media for self-management across qualitative findings.

Methods: We searched MEDLINE, Embase, PsycINFO, and CINAHL from 2012 to 2023 using Medical Subject Heading terms and text words related to type 1 diabetes and social media. We screened and selected the studies according to the inclusion and exclusion criteria. We quality appraised and characterized the included studies and conducted a thematic synthesis.

Results: We included 11 studies in our synthesis. A total of 9 of them were qualitative and 2 were mixed methods studies. Ten focused on young people with type 1 diabetes and 1 on HCPs. All used content analysis and were of moderate to high quality. Thirteen descriptive themes were yielded by our thematic synthesis, contributing to five analytic themes: (1) differences in how young people interact with social media, (2) characteristics of social media platforms that influence their use and uptake for type 1 diabetes self-management, (3) social media as a source of information, (4) impact on young people's coping and emotional well-being, and (5) impact on support from and relationships with HCPs and services.

Conclusions: The synthesis suggests that we should consider leveraging social media's peer support capabilities to augment the traditional services for young people with type 1 diabetes. However, the patients may have privacy concerns about HCPs' involvement in their online activities. This warrants an update of existing guidelines to help young people use social media safely for self-managing their diabetes.

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KEYWORDS

adolescents; health care professionals; social media; thematic synthesis; type 1 diabetes; type 1 diabetes mellitus; T1DM; young people

Introduction

Type 1 diabetes mellitus (T1DM) is the most common form of diabetes diagnosed in children and young adults, with a global prevalence of 5.9 per 10,000 people per year [1,2]. Children with T1DM have a 12-year reduced average life expectancy, mainly as a result of acute and chronic complications (eg, hypoglycemia, as well as cardiovascular and cerebrovascular diseases) [3-5].

Reducing the incidence of complications and improving diabetes-related quality of life relies on effective self-management [6,7]. This includes psychosocial acceptance of living with T1DM and tasks such as home blood glucose monitoring and adhering to complicated medical regimens [8]. Yet, many young people struggle to self-manage effectively and find it overwhelming [9], while also often enduring depression, anxiety, stigma, discrimination, and inadequate support [10-13]. Moreover, traditional health care services may not fully meet their needs because of long waiting hours, scheduling problems, and a fear of being judged [14].

Social media platforms have shown potential to support self-management for several long-term conditions, including T1DM [15-19]. For example, Meade et al [20] suggested that social media could help build diabetes-related skills and knowledge by providing patients and health care professionals (HCPs) access to information and means to interact with each other. In addition, social media platforms can be a source of emotional support [14] by facilitating contact with peers for validation and sympathy, which can increase their sense of normality and belonging [21,22]. Finally, the anonymity offered by social media (eg, use of pseudonyms) can enable young people to discuss sensitive topics with less fear of embarrassment or judgment [23-25].

At the same time, however, information shared on social media can be inaccurate, inappropriate, or misrepresented [8,26], and there are concerns about privacy and security when sharing personal health information online [27,28]. Given the presence of both potential benefits and risks, it is important to further understand young people's and HCPs' experiences, views, and concerns about using social media to self-manage T1DM. Previous qualitative studies explored this [14,25,28] but were limited to a particular time, geography, demographic group, and context [29]. A review and summary of findings across qualitative studies is still lacking.

We, therefore, aimed to address this gap by (1) identifying and characterizing the studies that examined young people's and HCPs' experiences and views of using social media to self-manage T1DM and (2) exploring and synthesizing these experiences and views, as well as the reasons for young people to use or not to use, or for HCPs to recommend or to not recommend social media for self-managing T1DM.

Methods

Thematic Synthesis

Thematic synthesis is a way of integrating findings from multiple qualitative studies and providing a wide range of perceptions of people in different time, space, population groups, and contexts [30] by synthesizing quotations and findings from each study. We used a thematic synthesis approach for summarizing young people's and HCPs' experiences and perceptions of using social media to self-manage T1DM as reported in previous qualitative studies. With this, we aimed to produce a new, higher-level understanding of this phenomenon beyond the original findings of individual studies.

The design of this review was informed by Thomas and Harden's [29] guidelines and reported in line with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines [31], where relevant. We registered this review on PROSPERO [32], which is an international prospective register platform for systematic reviews.

Identifying Relevant Studies

Search Strategy

We searched MEDLINE, Embase, and PsycINFO via Ovid, as well as CINAHL on February 16, 2023, using Medical Subject Heading terms and text words related to T1DM and social media (see Multimedia Appendix 1). We selected search terms based on previous reviews on related topics (eg, Elnaggar et al [8] and Faulds et al [26]) and refined them with the support of a librarian. The search was restricted to studies published in English since 2012, which was when social media became more mainstream. To complement our electronic search strategy, we manually searched reference lists of included studies.

Inclusion and Exclusion Criteria

Our criteria for selecting papers, structured according to population, phenomenon of interest, and context [33] are mentioned in Table 1.

Table 1. Inclusion and exclusion criteria.

Inclusion criteria
Population
People aged 10-24 years diagnosed with T1DM[a]
This age range aligns with the definition of young people by the World Health Organization [34]
Studies with mixed age or disease groups were included if we were able to check if quotes were from people who met our criteria
HCPs[b], ie, doctors, nurses, and allied HCPs, providing care for young people with T1DM
Phenomenon of interest
Studies that addressed experiences and views of young people with T1DM and HCPs of using social media platforms for self-management. As social media platforms, we considered messaging platforms (eg, WhatsApp), mainstream social networks (eg, Facebook, Instagram, Twitter, and Reddit), and disease-specific web portals and online communities (eg, diabetes.uk [35])
Studies or data from young people and their HCPs were included if they shared their views and perceptions about social media platforms for T1DM self-management regardless of whether they had personal experience of using it as such
Context
Any health care context
This will include self-management activities that young people undertook outside of clinic settings in the context of their daily lives
Study type
Any study with qualitative data
For example, studies reporting findings from interviews or ethnographic research, survey studies reporting free-text comments from questionnaires, studies qualitatively analyzing posts from social media platforms, and mixed methods studies presenting qualitative data or findings (eg, a randomized controlled trial with a nested qualitative process evaluation)
Publication type
Original research published in peer-reviewed journals
Language
English
Time of publication
2012-current
Exclusion criteria
Population
People outside the 10-24–year age range or without a diagnosis of T1DM
Informal caregivers or parents; HCPs providing T1DM care solely for adults
Phenomenon of interest
Experiences and views about self-management of T1DM but without references to the role of social media within that, or about social media in general but not in relation to T1DM self-management
Context
None
Study type
Study only reporting quantitative data (eg, survey studies without analysis of free text comments)
Publication type
Reviews, books, conference papers, opinion pieces, commentaries, and gray literature
Language
Other languages
Time of publication
<2012

[a] Type 1 diabetes mellitus.

[b] Health care professional.

Screening

At least 2 reviewers independently conducted 2 rounds of screening (round 1: title or abstract [YM, LH, and KL]; round 2: full text [YM and KL]) to assess papers against the criteria in Table 1. Discrepancies between reviewers were solved through discussion.

Quality Assessment

We used the Critical Appraisal Skills Programme Qualitative Studies Checklist [36] to assess the quality of included qualitative studies (consisting of 10 criteria) and the Mixed Methods Appraisal Tool (MMAT; 17 relevant criteria) [37] for mixed methods studies. Each study was assessed independently by 2 researchers (YM and KL), with disagreement resolved through discussion. We reported how many criteria each study met as an indicator of their quality. In line with methodological guidance [36,37], we did not remove or assign lower importance to quotations from lower-quality studies, but left it to readers to judge the accuracy of the quotations in reflecting the participants' viewpoints and perceptions.

Data Extraction and Synthesis

For objective 1, we extracted information on publication (authors, year of publication, and country), study method (study design, recruitment setting, and data collection), study population (sample size, age, gender, ethnicity, and social media experience), and social media platform (name and type, target users, and purpose). We synthesized information using counts and percentages.

For objective 2, we extracted and thematically synthesized all text labeled as "findings" or "results," as well as related participants' quotes [29]. We also extracted participants' sex and age, if reported at quote level. One researcher (YM) extracted data for all studies, with another (KL) doing this in duplicate for a random 20% (n=3) of studies. Data were exported to NVivo (Lumivero) for further thematic synthesis in 3 steps [29]. First, line-by-line coding in duplicate by 2 researchers (YM and KL) using an inductive approach—the researchers extracted and tabulated all quotes and applied codes that reflected the meaning of the quote. The researchers met regularly to discuss and compare codes, solving disagreements through discussion and with input from another researcher (SvdV) where needed.

Second, developing descriptive themes—once no new codes were identified and data saturation was achieved, 2 researchers (YM, and KL) grouped the final codes into descriptive themes based on their differences or similarities and underlying relationships.

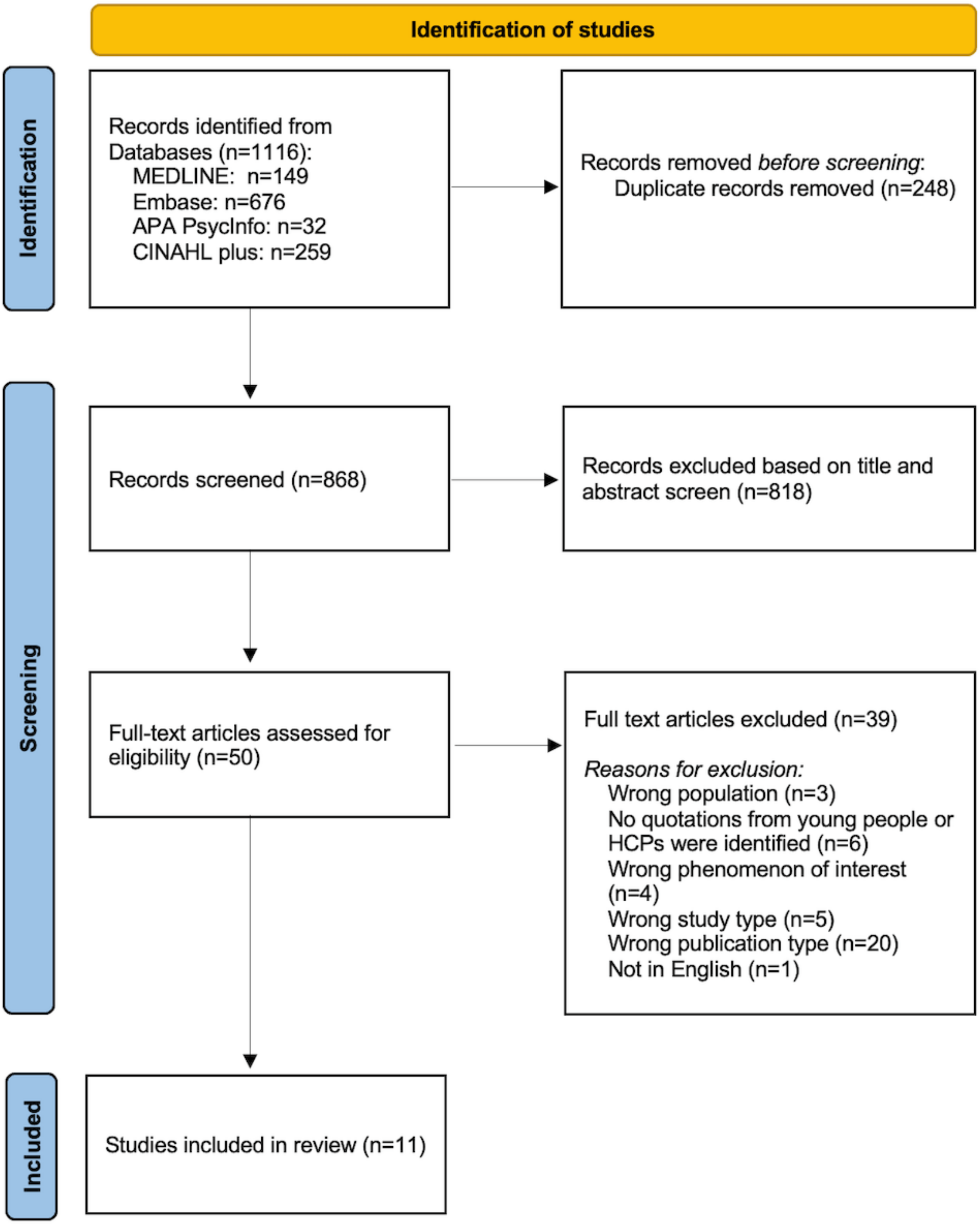
Third, generating analytical themes through a series of discussions within the team to explore how the descriptive themes related to our research aim and objectives, while endeavoring a novel interpretation and insights that expanded beyond simply summarizing the findings of individual-included studies.

Results

Overview

Figure 1 shows our search yielded 1116 studies, of which we ultimately included 11 [22,23,38-46]. The main reason for excluding papers based on full text was "wrong publication type" (n=20).

Figure 1. PRISMA flow diagram of the study selection process. HCP: health care professional; PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses.



Study Characteristics

The characteristics, aim, and main results of the included studies were summarized in Multimedia Appendix 2. Of the 11 included studies, the majority were qualitative studies [22,23,38-40,43-46] and conducted in the United States [22,39,41,45,46]. All used content analysis. Most studies focused on young people with T1DM, with only 1 focusing on HCPs [43]. A total of 4 studies used moderated platforms [41-43,46]. All studies met most quality criteria, except 1 that failed to meet 3 out of 10 criteria [38]; Multimedia Appendix 3 contains our detailed quality assessment for each study.

Synthesis

Table 2 shows how we identified 13 descriptive themes that contributed to 5 analytic themes, with Figure 2 showing to what extent studies contributed to each of the themes (see Multimedia Appendix 4 for the underlying study-level information).

Table 2. Analytic and descriptive themes with additional illustrative quotations.

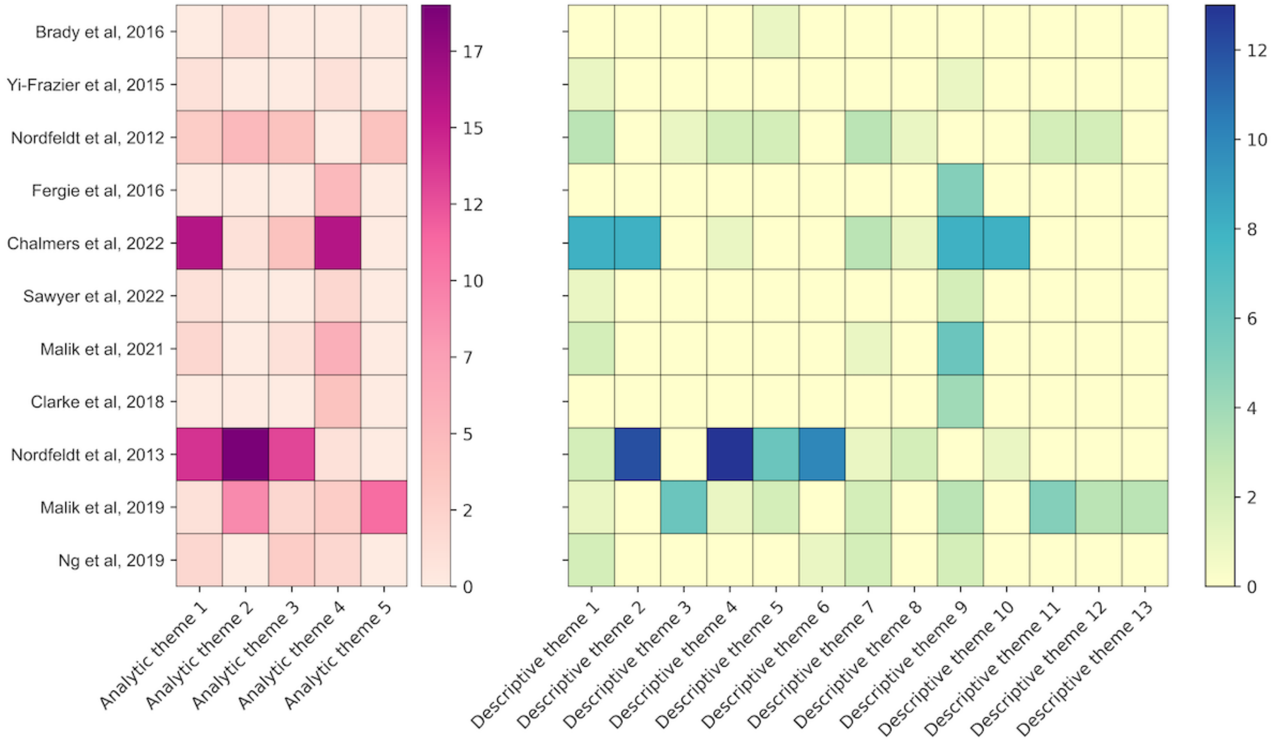
Analytic and descriptive themes	Additional illustrative quotations
Analytic theme 1: differences in how young people interact with social media (differences in how young people with T1DM[a] interacted with social media, including different levels of engagement and willingness to disclose information about their condition).	
Descriptive theme 1: passive versus active user engagement	• "I also read blogs, but don't post anything myself." [HCPs[b]], [43] • "I've made posts about going to camp with other diabetics or that I'm with my 'dia-besties.'" [Female participant aged 16 years], [39]
Descriptive theme 2: levels of T1DM disclosure	• "A girl I went to middle school with has [information about the fact that she has diabetes in] her Instagram handle. some people have their handles as their real names and then have type 1 in their bio." [Female participant aged 18 years], [39] • "[Y]ou see most websites, if you're creating a website which you don't want everybody to see...only just friends, then you can arrange it with passwords" [44] • "People don't understand. Most people think you have to be overweight to have diabetes and they're like, 'How do you have diabetes? You're not fat'" [Female participant aged 14 years], [39]
Analytic theme 2: characteristics of social media platforms that influence their use and uptake for T1DM self-management (characteristics of social media that influenced their use and uptake for T1DM self-management, including easier access to information and peer support, platform design, and trustworthiness).	
Descriptive theme 3: easier access to information and peer support	• "The advantages are that it is handy if you need to look something up, accessible information, and that it is easy to search" [HCPs], [43] • "I get a lot of emails and it's really hard to distinguish what is spam and what is not [since] sometimes it doesn't go into the spam box" [22]
Descriptive theme 4: platform design	• "I feel like a social media page would be a lot better because depending on how it would be set up, it would be organized" [22] • "I want like...I want it to be colourful and funny..." [Girls, 10-11 years], [44]
Descriptive theme 5: trustworthiness	• "The website here looks serious, if it should be some strange person, or for instance a paedophile, I don't think that he would enter a diabetes website and look there. I rather think that those who enters a diabetes website are those interested in diabetes as a subject" [Girls, 14-15 years], [44] • "If it comes across as reasonable and educational, you know, you kind of trust in it. rather than someone who types 'lyk dis'" [18-25 years], [38] • "If you feel certain about what kind of website it is, who's behind it, then you can trust that there's no false things there" [Girls, 12-13 years], [44]
Analytic theme 3: social media as a source of information (social media had the potential to cater to diverse information needs and provided an avenue to learn from peers and educate others).	
Descriptive theme 6: catering for diverse information needs	• "And there is news, what happens in the body, sexuality, and lots of different things...about insulin and medical devices, and about food and how you're affected by things...what you ought to think about, not to smoke, and with diabetes, don't drink and such stuff" [Girls, 14-15 years], [44]
Descriptive theme 7: learning from peers' experience	• "It was so helpful to be able to ask questions and see the questions asked by others to learn from their experiences and gain knowledge of how others manage their diabetes" [Female participant aged 23 years old], [42]
Descriptive theme 8: educating others	• "School and preschool staff can visit the site to prepare themselves prior to our visits" [HCPs], [43]
Analytic theme 4: impact on young people's coping and emotional well-being (positive and negative effects social media could have on young people's coping and emotional well-being).	
Descriptive theme 9: emotional support from peers	• "Have friends who you know are also going through the same problems and who you know understand what you are feeling" [Female participant aged age 22], [23] • "I think if you have something as big as diabetes in common then like you could probably bond really fast" [22]
Descriptive theme 10: humor and hope	• "I just post like jokes and relatable stuff for diabetics...When it comes to my diabetic page, I just hope it makes someone laugh...It's just a bunch of memes." [Female participant aged 14 years], [39] • "It would be fun to know just, yes, that there will be the remedy for diabetes within 15 years and...it is...they have been talking a lot about finding a certain remedy to regain your insulin production" [Boys, 14-15 years], [44]
Analytic theme 5: Impact on support from and relationship with HCPs[b] and the health care service (how social media might affect the support from and relationship with HCPs and the health care service) support from and relationship with HCPs and the health care service.	

Analytic and descriptive themes	Additional illustrative quotations
Descriptive theme 11: more direct support from HCPs	- "If it's a question that affects your care during those three months [between clinic visits], or it does something to help what you're doing within diabetes, then that could be helpful because you get the answer then and not have to wait" [22]
Descriptive theme 12: better HCP-patient relationships	- "By doing so I learn how the patients think, which can be useful in working with them (HCPs) [43], [Through social media] they would know more about me, and what I like and what kind of foods I like, so that could also factor into insulin pump settings" [22]
Descriptive theme 13: potential privacy concerns	- "In a DM [conversation] it's only going to me...[but] I feel like if it was me and [care team member] in a DM, I could add anyone at any time, or [the care team member] could add anyone at any time, and then it's no longer private" [22] - "I think it would be a little weird [engaging over social media] at first" [22]

[a] T1DM: type 1 diabetes mellitus.

[b] HCP: health care professional.

Figure 2. Heat map visualizing the extent to which studies contributed to analytic and descriptive themes. Darker colors indicate more substantial contributions and the numbers beside the color bars refer to the number of quotations coded under each theme [22,23,38-46].



Analytic Theme 1: Differences in How Young People Interact With Social Media

Descriptive Theme 1: Passive Versus Active User Engagement

Young people exhibited different levels of engagement on social media. Some could be categorized as "content consumers" or "lurkers" who tended to be more passive observers [39,43]. They might consume content, such as reading blogs and following forums, to stay informed about the others' experiences, but they rarely contributed content or engaged with the other users [39,43]. This might be due to a lack of time, having other priorities, or not being interested in posting [41,42,44]. For example [39],

> *There's nothing for me to like post about, I don't do like blood sugar updates on my story or anything.* [Male participant aged 13 years]

On the other hand, there were "active participants" who actively contributed to the social media community. They regularly shared content related to their diabetes journey, interacted with T1DM peers, offered insights to raise awareness, and fostered connections within the diabetes community [39]. Some "active participants" also worked as "role models" to motivate fellow users by showing a positive attitude toward T1DM management and sharing how they combatted their condition [44,45]. For example [39],

> *[I]t's second nature. That's the mood I would want [my followers] to get out of [my posts]. Show it who's boss.* [Male participant aged 16 years]

Descriptive Theme 2: Levels of T1DM Disclosure

Young people expressed different opinions toward diabetes disclosure on social media. Some were comfortable being open and outspoken about having T1DM, freely disclosing their condition in their posts and even profile descriptions on public-facing platforms such as Instagram (Meta Platforms) and Twitter (Twitter, Inc), thus appearing to consider it part of their online identity [39]. For example [39],

> *When you have an Instagram [account], you set your profile...and I put that I'm diabetic on there.* [Female participant aged 18 years]

Others selectively shared their T1DM-related activities in more inclusive platforms such as Facebook (Meta Platforms) group and Snapchat (Snap Inc), appreciating the features that allowed them to choose audiences or block unwanted viewers to keep themselves safe and protected from unwanted strangers accessing personal information [39,44]. For example [39],

> *Snapchat has a feature where you can block people from seeing your story and stuff, so I am comfortable [discussing T1D] because I can control who sees what.*

Additionally, some young people chose not to share their T1DM-related activities possibly due to previous bad experiences or concerns about potential misunderstanding or judgment from others [39]. For example, one female participant aged 18 years explained [39],

> *I have always gotten bullied for it (T1D), so I keep it on the down low on social media.*

Analytic Theme 2: Characteristics of Social Media Platforms That Influence Their Use and Uptake for T1DM Self-Management

Descriptive Theme 3: Easier Access to Information and Peer Support

Social media were perceived by young people of T1DM and HCPs to be easier and more timely means of communication and to have quicker access to information compared with traditional methods such as email and phone calls [22,43]. For example, unlike the complexities of searching through emails and distinguishing spam, it was "just at the tip of your fingers" [22] to flip through information and communicate with others.

Social media also provided an alternative online channel for seeking peer support compared with in-person interactions. This online support complemented face-to-face interactions, offering individuals a sense of autonomy to access social support whenever they felt ready and comfortable [41]. At the same time, however, others felt in-person meetings could offer a chance to better understand personalities and foster deeper connections [41].

Descriptive Theme 4: Platform Design

The platform's user interface design and how content was presented influenced young people's and HCPs' choice of using social media in T1DM self-management [22,43,44]. Young people and HCPs expressed a preference for well-organized platforms that simplified the process of finding specific information [22]. Platforms that appeared messy and overwhelming with excessive information might deter users' exploration and engagement [43,44]. Additionally, young people preferred regularly updated content that aligned with their needs—they found it difficult to feel engaged or interested if platforms did not offer anything new or relevant to their experiences [39,44]. Younger participants further expressed a preference for colorful platforms that provided age-specific information on a wide range of topics [39,44].

Descriptive Theme 5: Trustworthiness

Trustworthiness was another important part that affected young people's use and HCPs' recommendation of social media for T1DM self-management.

First, young people with T1DM and HCPs tended to trust platforms with well-presented facts [44], using formal and professional language rather than casual language such as "lyk dis" (18-25 years) [38].

Second, young people were more likely to use platforms that were recommended by sources they perceived as reliable, such as HCPs and peers [22,43], while HCPs felt more comfortable offering information via sites that were developed with or moderated by HCPs to ensure accurate information was given [43]. One HCP explained [43],

> *What feels safe for me...is that the information they can read here is the information we have provided. We know that we have critically reviewed it together.*

Third, young people trusted transparent platforms where they knew who was allowed to join and use the platforms as users. Otherwise, they might feel unsafe or concerned about interacting with malicious or deceptive individuals [44].

Analytic Theme 3: Social Media as a Source of Information

Descriptive Theme 6: Catering for Diverse Information Needs

Social media could provide diverse diabetes-related information, such as food and sports tips, insulin and pump instructions, information about drugs and medicine, advice on healthy habits (eg, abstaining from smoking or drinking alcohol), and insights on long-term complications and future expectations about life quality [39,44]. Moreover, social media provided information tailored to different groups of people, such as age-specific information for children and young people and diabetes management guidance tailored to the needs of caregivers and school staff [44].

Descriptive Theme 7: Learning From Peers' Experience

Social media also served as a valuable platform for young people with T1DM to learn from the experiences of their peers who openly discussed different treatment options and gave advice based on their experience [39,43]. This real-life experience complemented the more standardized advice from HCPs and clinical services [39,44], bringing pros and cons of treatment to life. As such, it better informed young people's understanding of different treatment options [22,40,41,44]. One female participant aged 18 years explained [42],

> *...through the website and seeing how other people manage their health to see what could work better for me.*

Descriptive Theme 8: Educating Others

Social media offered opportunities for others to learn and stay up-to-date about T1DM. For example, caregivers and school staff could equip themselves with knowledge involving T1DM management to provide more appropriate and informed support to young people with T1DM [43]. Additionally, the knowledge shared on certain types of public-facing social media (eg, YouTube videos and hashtag campaigns on Instagram and Twitter) played a vital role in raising public awareness and reducing misunderstandings [44], such as the misconception that T1DM was associated with being overweight as shown in the quote "...Most people think you have to be overweight to have diabetes." (female participant aged 14 years) [39].

Analytic Theme 4: Impact on Young People's Coping and Emotional Well-Being

Descriptive Theme 9: Emotional Support From Peers

T1DM self-management has the potential to be an overwhelming process, often leading to mental health issues, such as anxiety and depression [10,48]. While social media could be a source of emotional support to help them manage these [22,40,42,46], there were examples in the literature of it being associated with negative feelings, for example, diabetes-related stigma [39] and sometimes increasing feelings of loneliness [42].

First, social media provided a platform for young people with T1DM to openly share their feelings and seek comfort and understanding from other users [23]. When they did so, it was very common to receive positive and encouraging responses [39]. These positive responses from their peers could validate their condition and uplift their spirits, making them realize they were not alone in the journey of managing T1DM and gradually accepting the condition as "second nature" [39]. For example [41],

> *Just feeling like you're not the only one going through it...and that you can still lead like a normal life and still have diabetes.*

At the same time, however, others felt that despite the positive feedback they received, those without T1DM could not fully comprehend their challenges [39]. This sense of disconnection further intensified their feelings of isolation [39]. One female participant aged 17 years explained [39],

> *[Other social media users] would be like, "Do your best" or "You're doing wonderful!" But a lot of people don't know, and I feel like that makes you feel a little bit more alone.* [Female participant aged 16 years]

The conflicting views above highlighted the importance of emotional support from peers with shared experiences and who truly understood the challenges. This shared understanding could give young people a sense of belonging and normalization, creating a safe space where they could freely express their emotions and struggles. Furthermore, shared experiences could easily foster strong bonds and friendships with others [22]. For example, young people tended to use social media to reconnect with peers after attending a face-to-face diabetes camp [45]. This was particularly important for young people who lacked family support, as it could provide supplementary information and emotional help [40,44].

Descriptive Theme 10: Humor and Hope

Humor and hope were 2 important strategies that young people used to cope with T1DM [39,44]. By joking about their condition on social media, they could reduce the stress associated with it and treat it as "less of a big deal and kinda normalize it" (male participant aged 15 years) [39]. Additionally, some young people used humor to defend themselves against potential bullying and negative comments. For example, 1 person explained, "I just have to eliminate that chance [of bullying] by like making fun of me before they do" [39]. Moreover, some young people posted jokes and humor and had a positive outlook on social media to inspire their peers to take on a more optimistic approach to deal with their long-term conditions [39]. Finally, young people also expressed hopes of a cure for T1DM on social media [44]. This outlook could fill them with hope and excitement, igniting a sense of optimism for the future.

Analytic Theme 5: Impact on Support From and Relationship With HCPs and the Health Care Service

Descriptive Theme 11: More Direct Support From HCPs

Social media changed the way how young people with T1DM received support from HCPs [22,43]. In some cases [22], young people reported that their parents communicated with HCPs about their diabetes and felt their parents were not fully informed about their condition. Social media enabled young people with T1DM to communicate directly with their HCPs, promoting greater engagement in self-management and empowering them to take control of their condition [22]. For example [22],

> *My parents are normally the ones who would talk with the doctors and stuff. and so with social media it would be like I'm taking more control over what's happening.*

Young people also valued the timeliness of communication via social media in between clinic visits. For example, when wanting to contact HCPs, young people with T1DM could send direct messages to their HCPs, rather than going to clinics, sending emails that were lost or never replied to, or trying to get in contact through a phone [22,43].

Descriptive Theme 12: Better HCP-Patient Relationships

Engaging with HCPs through social media offered the potential to cultivate a more personalized HCP-patient relationship [22,43]. By sharing insights with HCPs about their lifestyle and preferences, HCPs could better understand young people's conditions and adopt a more patient-centered approach to care. Young people with T1DM and HCPs believed this resulted in better and more tailored support [22,43]. For example, "you would probably get to know each other a bit more and you would be more knowledgeable about things going on" [22].

Descriptive Theme 13: Privacy Concerns

Despite the benefits mentioned above, some young people felt awkward when they engaged with their HCPs through social media [22]. They expressed privacy concerns about the potential inspection and judgment if their HCPs were a part of their personal social media platforms or if their HCPs inadvertently invited someone they did not know into their private conversation, potentially leaking their personal information to others [22]. For example [22],

> *...it might be awkward at the same time, like, if your doctor's following you on Instagram and they can see everything you're posting and all that stuff.*

Discussion

Summary of Findings

This synthesis systematically reviewed the qualitative data on experiences and views of young people with T1DM and their HCPs regarding the use of social media for self-management. We included 11 studies in our synthesis, 10 of which focused on young people with T1DM. All used content analysis and met most quality criteria.

A total of 5 analytical themes and 13 descriptive themes were yielded by the synthesis. It revealed varying levels of engagement and comfort among young people with T1DM in using social media for self-management, with greater levels of trustworthiness given to professionally designed platforms recommended by HCPs or peers. Social media facilitated young people's access to a wide range of information and peer support and enabled easier and more direct communication with HCPs. Privacy and safety concerns were the main barriers preventing the use of social media for T1DM self-management.

Relation to Other Studies

Several of our findings were in accordance with previous research on the role of social media for self-managing T1DM in young people. For example, consistent with other reviews [8,14,27,49,50], we identified that young people with T1DM used social media to enhance their diabetes management knowledge and skills and to provide and receive emotional peer support. Similarly, we confirmed that social media could complement traditional health care services by providing direct communication with HCPs, complemented with tailored insights from online peers. Beyond these studies, we additionally identified the supplementary role of social media in complementing family and face-to-face support [41]. Overall, our findings reinforced the established understanding of the supplementary supportive potential of social media for T1DM self-management.

In contrast to previous research [8,27,49], we did not find many concerns related to misinformation. This may be explained by young people's trust in the experiences and tips shared by their online peers [22,43]. However, these individualized experiences may not be a suitable source for everyone and may contain information that is not necessarily accurate [22,37]. Furthermore, privacy and safety concerns were the main risks identified in the synthesis, often preventing young people from using social media [22,39]. These risks were linked to disclosing excessive personal information online, which in turn might lead to things such as online bullying, harassment, and encountering malicious individuals [22,27,44]; these risks and issues are common in any online activity and can be minimized by using social media safely [27].

Finally, our synthesis revealed novel insights into HCPs' role in using social media for T1DM self-management. We found that HCPs encouraged patients to connect with peers on social media to gain diverse perspectives on T1DM treatment and to use HCP-moderated online platforms, while other research found that HCPs might advise against patients' social media use [50,51]. Also, where previous reviews and studies indicated HCP involvement in self-management could improve HCP-patient relationships and health care delivery more generally [8,50-52], our synthesis found more diverse patient attitudes, ranging from beliefs that HCP involvement would enable tailored support to worries about potential scrutiny of their social media posts.

Implications for Practice and Research

Implications for Social Media Platforms and HCPs

The supplementary role of online peers' experiences identified in our synthesis, which was confirmed by other studies [8,14,27,49,50], implies that HCPs should consider integrating customized peer-to-peer mechanisms into traditional services to provide better health care. For example, moderated social media online forums and Facebook groups such as Diabetes UK [35] and Diabetes Yes [42] have created online communities that provide professional-reviewed knowledge and real-life experiences from peers that complement medical care. HCPs could recommend that their patients access these platforms to get information and peer support between clinic visits. Meanwhile, they could participate in moderated online groups to communicate with and support their patients.

However, the reliability and applicability of information and experiences exchanged online cannot be assured [22,37], social media platforms and HCPs should educate young people on how to identify credible online health information about their T1DM, for example by providing evidence-based knowledge and contrasting it against misleading content [22,43].

Furthermore, our synthesis showed that young people have different comfort and engagement levels in sharing their T1DM-related content online. This may warrant further refinement of available functionality within social media platforms to give users more control over what they share with whom, such as features allowing selective audiences or restricted profile access.

Implications for Health Policy Makers

Our synthesis identified that young people had privacy and safety concerns about using social media and involving HCPs for T1DM self-management [22,39,44]. Existing guidelines [27,53,54] provided a broad and comprehensive framework for safe social media use and appropriate HCP involvement, but these did not incorporate patient and HCP input, and may be outdated given the rapidly evolving social media landscape.

Furthermore, protections for patients regarding inappropriate HCPs' involvement were insufficiently addressed.

Recommendations could be enhanced by developing updated and evidence-based guidelines that incorporate input from patients and HCPs. Informed consent procedures could be added to existing guidelines to protect patients by (1) informing patients on the risks and best practices of using social media for T1DM self-management; (2) emphasizing patients can opt out of HCPs' involvement in their social media T1DM self-management; (3) providing clear conduct guidelines for HCPs; and (4) establishing formal reporting channels for patients' concerns over uncomfortable interactions, boundary violations, or privacy issues.

Implications for Future Research

The participants in the included studies were mostly social media users; only 1 study in our synthesis [22] included a small proportion of participants who did not have social media experience. This may have introduced a potential bias toward more positive views, especially as several studies interviewed young people involved in developing a social media platform. To gain a more holistic perspective and inform platforms and guidance suitable for a broad range of young people with T1DM, future research could include input from nonsocial media users.

The first-order qualitative data included in our synthesis consisted of participants' quotations about their experiences and opinions. Future studies could analyze young people's social media posts to gain additional insights into their actual (instead of reported) online behaviors, attitudes, and topics of interest.

Limitations

One limitation of our synthesis came from the exclusion of non-English studies, which means we may have missed insights from non-English studies on this topic. Widening the scope beyond English could enrich our findings by uncovering different cultural perspectives from non-English speaking contexts that were not captured in our synthesis.

Another limitation arose from solely analyzing qualitative data from original studies published in peer-reviewed journals. This excluded potentially valuable inputs from gray literature and text from social media platforms that may have provided additional real-world practices, patient experiences, and emerging trends relevant to this topic. Incorporating these wider sources in future analyses could lead to a more comprehensive synthesis of diverse qualitative evidence.

Conclusions

Our synthesis identified the experiences and views of young people and HCPs using social media for T1DM self-management. It reinforced social media's role in providing peer support, supplementary information, and emotional support. In addition, privacy and safety concerns were identified as key barriers preventing young people from engaging with social media for support and information.

The synthesis suggests we should consider leveraging social media's peer support capabilities to augment traditional services for young people with T1DM. However, patients may have privacy concerns about the HCPs' involvement in their online activities. This warrants an update of existing guidelines to help young people use social media safely for self-managing their diabetes.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy.
[DOCX File , 19 KB - pediatrics_v7i1e56919_app1.docx]

Multimedia Appendix 2
Characteristics, aim, and main results of included studies.
[DOCX File , 23 KB - pediatrics_v7i1e56919_app2.docx]

Multimedia Appendix 3
Quality assessment.
[DOCX File , 22 KB - pediatrics_v7i1e56919_app3.docx]

Multimedia Appendix 4
Themes identified in each study.
[DOCX File , 17 KB - pediatrics_v7i1e56919_app4.docx]

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Abbreviations

HCP: health care professional
MMAT: Mixed Methods Appraisal Tool
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
T1DM: type 1 diabetes mellitus

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Development and Delivery of an Integrated Digital Health Care Approach for Children With Juvenile Idiopathic Arthritis: Usability Study

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Abstract

Background: Juvenile idiopathic arthritis (JIA) is a chronic inflammatory disorder with no cure. Most children are prescribed several medications aimed at controlling disease activity, managing symptoms, and reducing pain. Physical activity is also encouraged to retain musculoskeletal function. The primary determinants of treatment success are maintaining long-term adherence, ongoing monitoring by a pediatric rheumatologist, and involvement of an interdisciplinary team. To support these goals, a new digital intervention was developed, InteractiveClinics, which aimed to prompt children to take their medications, report pain levels, and increase their physical activity.

Objective: This study aims to evaluate the usability of InteractiveClinics among children with JIA.

Methods: As part of this pediatric cross-sectional study, 12 children were asked to wear a smartwatch for 2 weeks, which was synchronized to the InteractiveClinics phone app and web-based platform. Personalized notifications were sent daily to the watch and phone, to prompt and record medication adherence and pain level assessment. Physical activity was automatically recorded by the watch. At the end of the study, all children and parents completed a postintervention survey. Written comments were also encouraged to gain further feedback. Descriptive statistics were used to summarize the survey results, and all qualitative data underwent thematic analysis.

Results: Twelve children aged 10 to 18 years (mean 14.2, SD 3.1 years; female: n=8, 66.7%) and 1 parent for each child (n=12; female: n=8, 66.7%) were enrolled in the study. Based on the highest and lowest agreement areas of the survey, most children and parents liked the smartwatch and web-based platform; they found it easy to learn and simple to use. They were also satisfied with the pain and physical activity module. However, usability and acceptability barriers that hindered uptake were identified in the phone app and medication module. Children required a unique in-app experience, and their suggestive improvements included more personalization within the app; simplification by removing all links not relevant to antirheumatic medications; flexibility in response times; improved conferment through gamification; additional comment fields for the input of more data, such as medication side effects or pain-related symptoms; more detailed graphical illustrations of the physical activity module, including a breakdown of metrics; and importantly, interconnections between modules, because medication adherence, pain levels, and physical activity can each influence the other. They were, overall, improving usefulness for children and parents.

Conclusions: The usability of InteractiveClinics was positive. Children and parents liked the watch and web-based platform and were satisfied with the pain and physical activity module. However, children wanted a unique in-app experience through more personalization, simplification, flexibility, conferment, comment fields, graphical illustrations, a breakdown of metrics, and interconnections. Certainly, inclusions are needed to promote user adoption and advancement of new validated digital health interventions in pediatric rheumatology, to support the delivery of integrated care.

Trial Registration: ANZCTR ACTRN12616000665437; https://tinyurl.com/mwwfje8r

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KEYWORDS

phone app; smart watch; juvenile idiopathic arthritis; pain; medication adherence; physical activity; integrated care; medication; development; usability study; chronic inflammatory disorder; children; child; usability; survey; thematic analysis; gamification; modules; web-based platform; support

Introduction

Overview

Globally, more than 3 million children are currently living with the autoimmune disorder juvenile idiopathic arthritis (JIA) [1,2]. JIA is the broad term used to describe a heterogeneous group of 7 inflammatory disorders, all of which have an unknown origin that begins in children younger than 18 years [3,4]. The commonality between these disorders is joint inflammation and pain [5,6]. Prolonged exposure to this inflammation can cause serious widespread complications for a child, such as impaired growth [7,8], delayed pubertal development [8,9], premature cardiovascular disease [10], and organ damage [11]. Ongoing exposure to pain can induce permanent changes in the nervous system, increasing pain sensitivity and the continuance of persistent pain in adulthood [6,12]. Regrettably, there is no cure. Instead, a "treat to target" approach is used to induce clinical remission or lower disease activity [13]. The aim is to normalize and preserve joint function, prevent growth retardation, maintain physical function, and avoid permanent disability [7,14], ultimately improving the child's quality of life [15].

Background

Medications

For most children, the first line of treatment includes the aggressive use of medications, for a prolonged period of time, because the therapeutic response to gain disease control and symptom relief is slow [16,17]. Typically, these medications include disease-modifying antirheumatic medications (such as methotrexate, sulphasalazine, and leflunomide) in combination with corticosteroids to target inflammation. In addition, ibuprofen and naproxen can ease the pain and further calm the swelling [14,16,18]. However, adhering to a strict medication schedule can be difficult for many children due to the need to take multiple medications of varying doses, by different routes of administration (oral, intravenous, and intra-articular) [14,16,19] and on different days at different times, to limit the medications' side effects on well-being [20]. An example is administering disease-modifying antirheumatic medications on a Friday night, to ensure the associated nausea and brain fog do not interfere with school performance. Therefore, reliable monitoring of a child's medication adherence by a pediatric rheumatologist is crucial to ensure they are gaining the full therapeutic response and alleviating any side effects they may experience [21].

Pain Level Monitoring

Pain is often one of the first JIA-related symptoms experienced by a child. Pain begins at an early stage of the disease trajectory when a child's joints begin to swell and become restricted. It is at this early stage that a child's pain perception can be permanently altered [6,12] because pain activates changes in the central and peripheral neural pathways, decreasing a child's pain threshold [22] and increasing sensitization [12]. This means pain can persist despite good disease control [6,23] and become widespread throughout the body, such as in both the affected and unaffected knee [24]. Understandably, it is essential that pain fluctuations for JIA are meticulously monitored, and appropriate treatments quickly initiated to achieve pain-free remission [12,15].

Physical Activity

Exercise is prescribed for children with JIA because of the abundant health benefits [25]. Exercise helps to retain musculoskeletal function and muscle strength [26], cardio-respiratory health, a healthy weight, and good mental health [27]. Yet, children are often not motivated to exercise because of their symptoms, such as chronic synovial joint inflammation, erythema, pain, stiffness, limited range of movement, and fatigue [28]. However, this motivation does not change when there is no pain and good disease control [29]. Perhaps this is because many children and parents are under the belief that exercise will exacerbate symptoms [25], when the reverse is true, exercise can promote alleviation. In fact, a recent systematic review reported no adverse events related to exercise [25].

Importantly, there are also many non–JIA-related reasons why children do not exercise. They simply do not enjoy it, have too little time, or need parental support to attend exercise programs [30] or pay for the ongoing costs associated with attending [31]. Undeniably, in order to improve the current low adherence rates for children with JIA (40% - 47%) [32,33], a new, cost-effective way is needed to promote and maintain a regular exercise regime.

Interdisciplinary Team

To achieve the best possible outcomes for children with JIA, children need access to a diverse interdisciplinary team that works in conjunction with the pediatric rheumatologist, child, and parents [34-36]. Services from allied health can include physiotherapy, occupational therapy, and podiatry to support physical function and pain [36-38], while nursing can support medication adherence through education and demonstration of injection techniques [36]. Importantly, this support also needs to be maintained for an extended period of time [39], and ongoing monitoring of the child is needed to ensure treatment success [37].

Digital Health

Recent advances in smart technology have the potential to support chronic disease management [40,41] by improving treatment adherence, recording symptoms, and monitoring health behaviors [42]. For JIA, digital health innovations could be adopted to prompt medication adherence, record pain levels, and improve physical activity. These are 3 key areas that can lead to poor outcomes. Research to date on eHealth and mobile health (mHealth) interventions for JIA has predominantly focused on electronic pain diaries and web-based programs [43]. These electronic pain diaries have used personal digital assistants [44], Apple iPods, and computers [45], while web-based programs have focused on providing education and skills to promote chronic disease management, cognitive behavior [46], physical activity [47], peer support [48], and improved quality of life [49]. Overall, feasibility and usability studies have revealed that these forms of interventions are readily accepted by children [45,46]. They find this technology easy to use and navigate [50] and need little training because they are already using the internet and mobile technology in their day-to-day life [51,52]. In fact, in Australia, 81% of children over 14 years and 55% between 10 and 13 years own a mobile phone [53,54]. Internationally, 18% - 43% of children aged between 13 and 17 years and 7% - 45% of children aged 6 - 12 years own a smartwatch [55], with a predicted rate that will substantially increase over the next few years [56].

InteractiveClinics

InteractiveClinics is an innovative digital health web-based platform aimed at supporting digital health research. It was developed by academics from the University of Newcastle, Australia, and the University of Manresa (Catalonia) Spain, with IT support from BitGenoma Ltd Digital Solutions. For JIA, InteractiveClinics was used to prompt and monitor the 3 modifiable risk factors associated with poor JIA-related outcomes—medication adherence, pain levels, and physical activity—by using a commercially available smartwatch, a customized phone app, and a password-protected Australian web server. To further address the ethical and privacy issues related to data safety, all data collected by the app and web-based platform was managed in accordance with the University of Newcastle's Information Security Data Classification and Handling Manual, and the Privacy Management Plan. The cost of development for the platform, app, and important server protection was approximately Aus $75,000 (US $48,000).

Objectives

The aim of this study is to evaluate the usability and acceptability of InteractiveClinics among children (aged 10 - 18 years) by determining if the intervention is (1) easy to use, (2) acceptable, and (3) useful [57,58].

Methods

Study Overview

This study was part of a cross-sectional study, following the World Health Organization's 6-stage step-up approach to develop a digital health intervention. These steps start from monitoring the intervention's functionality and fidelity through to evaluating feasibility, usability, efficacy, and effectiveness [58], allowing improvements to be put into place after each stage of testing and improving the quality of the intervention [59].

This study focuses on evaluating InteractiveClinics' usability to support the development of a user-centered design, because the success of an intervention is dependent on whether intended end users engage with the intervention [58]. For 2 weeks, children and parents gained hands-on experience using InteractiveClinics and then completed a postintervention survey. To ensure detailed analysis, survey questions were based on a quantitative descriptive and qualitative design, to invite participants to answer questions in their own words [60].

Recruitment of Participants

As part of this pediatric cross-sectional study, children were recruited through 2 pediatric rheumatology outpatient clinics within 2 tertiary children's hospitals in Australia. The eligibility criteria included an age range of 10 to 18 years, a diagnosis of JIA, and good comprehension of the English language. The exclusion criteria included a cognitive impairment, physical disability, or visual impairment that would affect the child's ability to understand or use smart technology.

Ethical Considerations

Ethics approval for this study was granted by the Hunter New England Research Ethics Committee (approval no: 2019/ETH01035). To ensure informed consent, all potential participants were provided with an information sheet, explaining the study's purpose, expectations, and how all data collected will be deidentified. Additionally, all study participants were informed that they could withdraw from the study at any time, without discrimination, by simply not completing the survey. In total, 12 children and 12 parents agreed to participate in the study, provided signed consent, and completed the anonymous survey between September and November 2022 (Table 1).

Table . Participants' demographics.

Demographics		Values
JIA subtype [a] , n (%)		
	Polyarthritis (rheumatoid factor [Rh] negative)	5 (41.7)
	Oligoarthritis	4 (33.3)
	Enthesitis related	1 (8.3)
	Polyarthritis (Rh positive)	1 (8.3)
	Psoriatic	1 (8.3)
Medications, n (%)		
	DMARDs[b]	5 (41.7)[c]
	bDMARDs[d]	2 (16.7)
	NSAIDs[e]	5 (41.7)
	Corticosteroids	3 (25)
	Pain relievers	7 (58)
	Folic acid	1 (8.3)
Disease duration (years), mean (range)		4.9 (5 months to 10 years)

[a] Juvenile idiopathic arthritis (JIA) subtypes based on the International League of Associations for Rheumatology criteria [3].

[b] DMARD: disease-modifying antirheumatic drug.

[c] One participant was prescribed both DMARDs and bDMARDs.

[d] bDMARD: biological disease-modifying antirheumatic drug.

[e] NSAID: nonsteroidal anti-inflammatory drug.

Intervention

InteractiveClinics aims to motivate children to take their medication, record their pain, and increase their participation in physical activity. Personalized notifications were sent daily to the smartwatch and phone, to prompt and record medication adherence (Figure 1) and complete a pain level assessment within the app (Figure 2). Physical activity was automatically recorded by simply wearing the watch.

InteractiveClinics presents these 3 key areas of monitoring as 3 modules—medication adherence, pain level, and physical activity level—which can be monitored daily, weekly, or monthly by the child within the app (Figures 1 and 3) or on a secure, password-locked, web-based platform by the child, parents/caregiver, pediatric rheumatologist, and health care team (Figure 4).

Pain levels were recorded on the validated electronic visual analog scale (eVas) module [61-63]. eVas uses a simple horizontal line with defined pain limits. The left end point indicates "without pain," and the right end point indicates "worst possible pain" (Figure 2). This reporting scale has been found to be highly reliable and consistent with the original paper-based visual analog scale [61-63].

Figure 1. Weekly example of medication adherence responses.

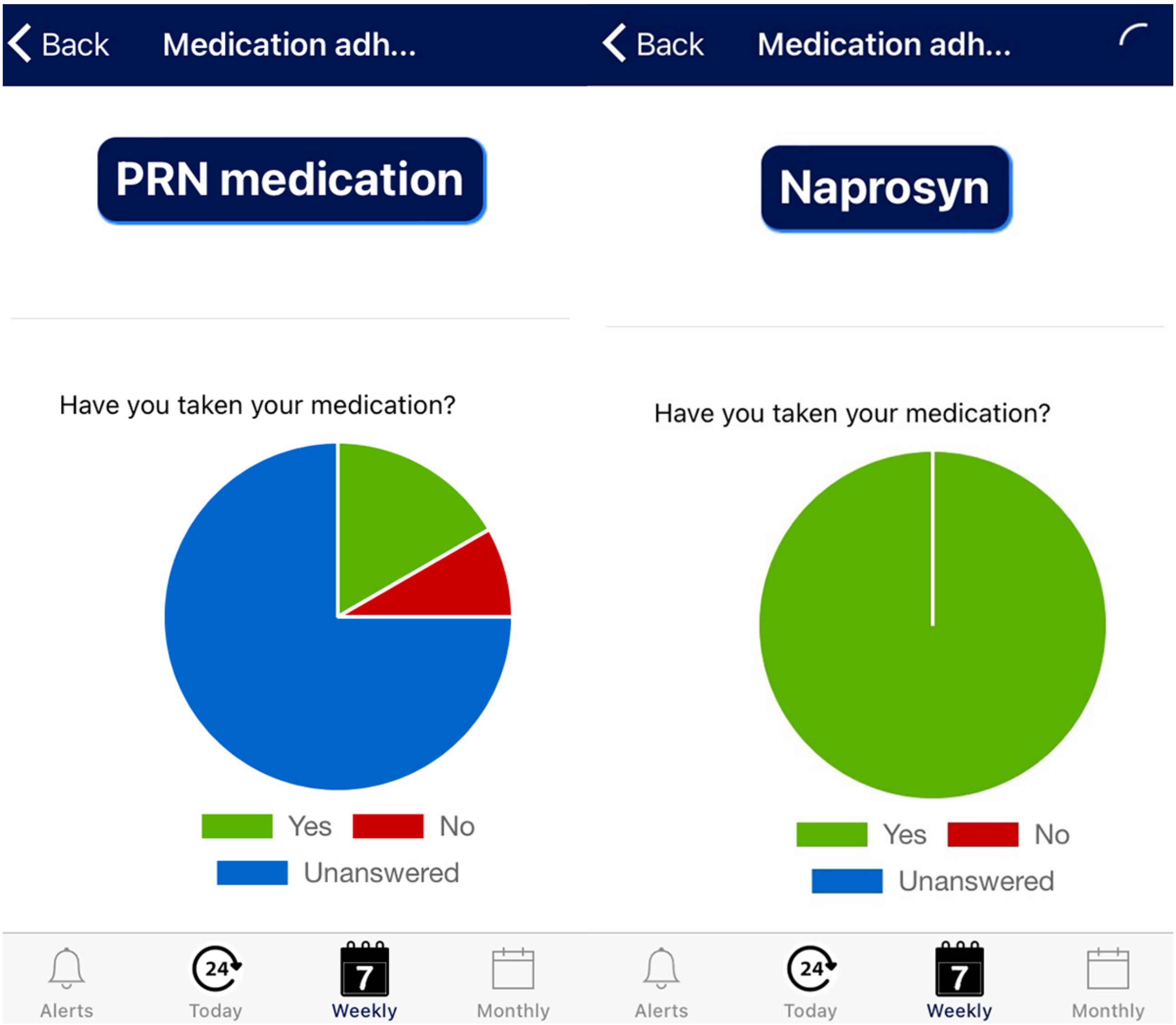
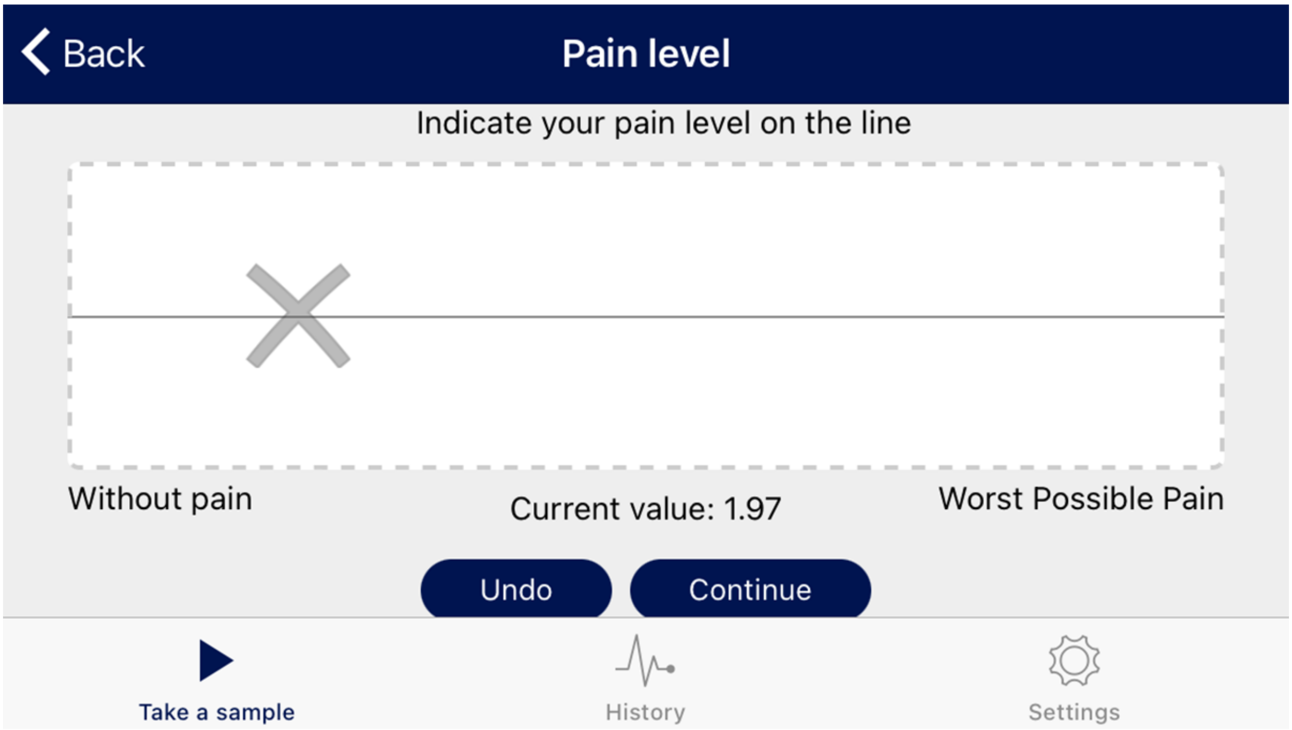


Figure 2. Recording pain level on the electronic visual analogue scale module.

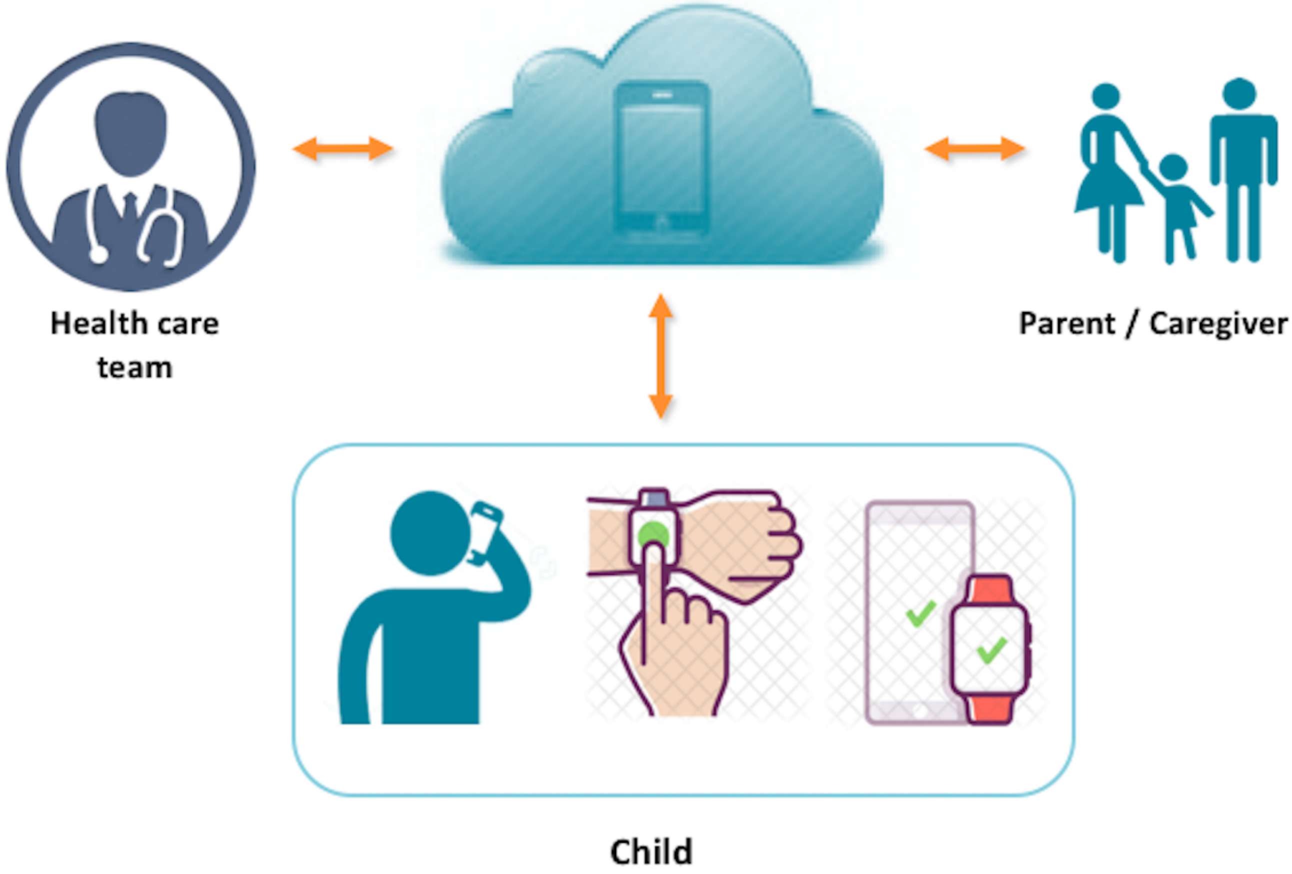


Indicate your pain level on the line

Current value: 1.97

Figure 3. Weekly example of real-time pain levels.

Figure 4. Data communication supporting an integrative model of care for juvenile idiopathic arthritis.



Materials

The materials supplied to support participation in the intervention were as follows: a smartwatch (Apple Watch series 3, with a water-resistance rating of 50 meters, to support low-intensity activities such as swimming [64]), a smartphone (Apple iPhone, SE, 2016, loaded with Aus $30 [US $20.01] worth of pre-paid credit), the InteractiveClinics app (preset on the iPhone), and a personal password (to access the data collected on the secure web-based platform).

The persuasive influences used to promote the adoption of the intervention were as follows [43]: training (for 15 minutes on how to use the smartwatch, InteractiveClinics app, and web-based platform), an instruction manual, ongoing technical support, ongoing human communication (researcher contact details [SB] were placed in the phone), goals set by the user (for the physical activity module), personal reminders (daily personal notification sent to the watch and phone, at a time preselected by child, to prompt and record medication administration and pain level assessment), and a reactive feedback loop (for the physical activity module).

A more detailed description of InteractiveClinics has been provided in an earlier feasibility study [59].

Data Collection

InteractiveClinics' usability and acceptability were measured through a postintervention survey. Two surveys were developed to collect feedback from children and their parents after they used the digital intervention for 2 weeks. Survey questions were adapted from the System Usability Scale [65,66], to ensure the survey questions encompassed the unique multimodal approach being used by InteractiveClinics. Further, to enable younger children to complete the survey without help from their parents, age-appropriate language was used.

For the parents, survey responses were based on the 1-to-5 Likert scale (1=strongly disagree, 2=disagree, 3=unsure, 4=agree, and 5=strongly agree). For children, survey responses were based on the visual face scale [66].

Written comments were also encouraged by children and parents throughout the survey, in a free-text format, to identify any unmet inclusions; to illustrate important points; and, importantly, to facilitate a user-friendly design.

Data Analysis

Quantitative Data Analysis

Descriptive statistics were used to summarize participants' demographic characteristics. For the survey results, a percentage agreement was used to place the data into 2 independent judgments, to allow the examination of either agreement or disagreement [67]. Commonly agreed included the responses "strongly agree" and "agree," and commonly disagreed included the responses "unsure," "disagree," and "strongly disagree." This form of data analysis focuses on reporting the proportion of answers that agree, by calculating them as a percentage [68]. These percentages can then be easily compared because there is a common denominator.

Qualitative Data Analysis

For all the qualitative data, this study used thematic analysis. This is an inductive approach used to examine themes and patterns within the data [69]. Coding began by clustering together small descriptive segments to expose both the strengths and weaknesses of InteractiveClinics. Then collectively, mutual patterns emerged forming latent themes, allowing the child's and their parent's experience to be heard.

To ensure rigor at all stages of interpretation, codes were continually checked to ensure they retained their original meaning, and trustworthiness and clinical relevance were enhanced by all members of our research team. Final results were internally reviewed, and data saturation was reached, drawing no more conclusions.

Results

Child Survey Feedback

The response rate to the survey among children was 100% (12/12). Most children (9/12, 75%) also completed the survey without any help from their parents. The results of the quantitative section of the survey are presented in Table 2.

Table . Quantitative survey results: child version (n=12).

Child survey questions		Smartwatch, n (%) agree	App, n (%) agree	Web-based platform, n (%) agree
Usability				
	Easy to learn	12 (100)	6 (50)	7 (58.3)
	Simple to use	12 (100)	8 (66.7)	9 (75)
	Felt comfortable using the…	11 (92)	8 (66.7)	8 (66.7)
	Quick to use	9 (75)	9 (75)	10 (83.3)
	Information clear and well organized	8 (67)	6 (50)	7 (58.3)
Acceptability				
	I liked the…	9 (75)	3 (25)	8 (66.7)
	Was fun	9 (75)	0 (0)	2 (16.7)
	Was useful	10 (83)	5 (41.7)	6 (50)
	Satisfied with…	9 (75)	6 (50)	6 (50)
	Would recommend to other young people with arthritis	10 (83)	5 (41.7)	5 (41.7)

Smartwatch

Based on the highest and lowest agreement areas of the survey, the results support using a smartwatch as part of the intervention. The watch was easy to learn (12/12, 100%) and simple to use (12/12, 100%), and the information was useful (10/12, 83%). However, only 8 children reported the information was clear and organized (8/12, 67%). Written feedback also identified children were "expecting the App to open in the watch." Instead they "could not answer anything on the watch." Children wanted an expandable notification with a reply action, to allow their medication administration and pain levels to be directly recorded from the watch.

Phone App

In comparison to the smartwatch, problems were identified within the phone app.

Although the perceived usability of the app was reported as simple (8/12, 66.7%) and quick (9/12, 75%), only half of the participants found learning to use the app easy (6/12, 50%). Furthermore, only a small number of children liked the app (3/12, 25%), and none described the app as fun (0/12, 0%), impairing acceptability. Written feedback revealed participants were seeking a unique in-app experience through demographic "personalisation."

Web-Based Platform

The usability of the web-based platform was reported as simple (9/12, 75%) and quick (10/12, 83.3%). However, only 7 participants reported it was easy to learn (7/12, 58.3%). Similar to the app, only half of the participants reported the platform as useful (6/12, 50%) or were satisfied (6/12, 50%). Further, only 2 participants reported the platform to be fun (2/10, 16.7%). Written feedback resulted in the following theme: interconnections. Participants wanted to see a comparison between the 3 modules, medication adherence, pain levels, and physical activity, to explore if any relationships exist. A participant explained the following: "has the potential to be helpful if I could access the physical activity [and medication adherence] results in line with my pain" (child 7).

Parent Survey Feedback

The response rate to the survey among parents was 100% (12/12). The results of the quantitative section of the survey are presented in Table 3.

Table . Quantitative survey results: parent version (n=12).

Parents survey questions	Smartwatch, n (%) agree	App, n (%) agree	Web-based platform, n (%) agree
Easy to learn	11 (91.7)	8 (66.7)	7 (58.3)
Simple to use	11 (91.7)	9 (75)	8 (66.7)
Comfortable in supporting my child	11 (91.7)	11 (91.7)	10 (83.3)
Supporting my child was quick	10 (83.3)	8 (66.7)	8 (66.7)
I did not need to prompt my child	7 (58.3)	5 (41.7)	3 (25)
My child was independent	9 (75)	8 (66.7)	5 (41.7)
Information is clear and well organized	10 (83.3)	8 (66.7)	7 (58.3)
The system is error-free	10 (83.3)	3 (25)	10 (83.3)

Smartwatch

Most parents' responses supported the usability and acceptability of the smartwatch. Parents reported the watch was easy to learn (11/12, 91.7%) and simple to use (11/12, 91.7%). However, only 9 parents reported children could independently use the watch (9/12, 75%), and 7 parents did not need any prompting (7/12, 58.3%). No written feedback for improvement was recorded.

Phone App

Most parents felt comfortable supporting their child (11/12, 91.7%) and agreed using the app was simple (9/12, 75%). However, only a small number of parents did not need to prompt their child to use the app (5/12, 41.7%), or found the system error-free (3/12, 25%).

> *I don't think the app is working properly. [parent 5]*

To improve the app, written feedback suggested simplification, to ensure the app directly aligned with their child's needs. A parent explained the following: "simplified interface by removal of unnecessary buttons" (parent 6).

Web-Based Platform

Parents reported that they were comfortable in supporting their child when using the platform (10/12, 83.3%), and found the system to be error-free (10/12, 83.3%). However, less than half reported that their child could independently use the platform (5/12, 41.7%), and only 3 parents did not need to prompt their child (3/12, 25%). Suggested improvements included "improving the activity rings [for the physical activity module]" (parent 3).

Modules Within the App

Medication Adherence Module

Child Usability

Half of the participants agreed medication reminders were helpful (6/12, 50%), sent at the right time (6/12, 50%), and not bothersome (7/12, 58.3%). There were also no reported adverse events (12/12, 100%).

Child Acceptability

Less than half of the participants were satisfied with the medication module (5/12, 41.7%). Even less agreed that the response list was clear (2/12, 16.7%). Only 3 children would continue to use the medication module (3/12, 25%). Suggestions for improvement included flexibility. Rather than asking the research team to update their medications, children wanted to "self-change medication times [within the app]" (child 2) and "add or remove medications [within the app]" (child 12).

Parent Satisfaction

Parents were also not satisfied with the medication module (5/12, 41.7%), resulting in the following theme: comment fields. They wanted to see a broader range of data collected that aligned with their child's needs. For example:

> *add comment fields to record medication symptoms such as nausea from Methotrexate, headaches from Humira, exhaustion and brain fog. [parent 9]*

Pain Level Module

Overview

Children agreed recording pain was helpful (8/12, 66.7%), how to record their pain was clear (10/12, 83.3%), and responding to the pain reminders was not bothersome (7/12, 58.3%). There were also no adverse events reported (12/12, 100%). However, less than half were satisfied (4/12, 33.3%) and would continue using the pain module (6/12, 50%). Children were underwhelmed by the eVas response to their pain. When they entered their pain level on the numerical line and pressed confirm, only the numerical value between 0 and 10 emerged, describing their pain.

> *When you put your pain in nothing happens. [child 1]*

This resulted in the following theme: conferment. Children suggested that the pain score should include gamification or the use of "visual aids, which may be of benefit."

Similar to the feedback from the medication module, children also wanted flexibility. Although pain scores could be added at any time in the app, children wanted to be able to self-adjust their pain-reporting notification time within the app.

> *I wanted to change my pain time. [child 5]*

Parent Satisfaction

Most parents were satisfied with the pain module (8/12, 66.7%). However, parents expressed, again, wanting to "record" additional information. Further supporting the comment fields theme, this would allow them to document “joint/s the pain is in” (parent 3) and “potential contributing factors for pain such as weather, over-exertion” (parent 9).

Physical Activity Module

Child Usability

Children were overall satisfied with the physical activity module (9/12, 75%). Most followed (8/12, 66.7%) and understood their physical activity levels (8/12, 66.7%) and agreed that the module increased their physical activity (7/12, 58.3%).

Child Acceptability

Half the children agreed that recording their physical activity was helpful (6/12, 50%) and would like to continue using the physical activity intervention (6/12, 50%). No adverse events were reported (12/12, 100%).

Written feedback suggesting how to improve this module included a graphical illustration. Children reported they needed more graphical representation of their daily and weekly physical activity levels.

> *Have the physical activity show more details [child 1]*

Parent Satisfaction

More than half of the parents were satisfied with the physical activity module (7/12, 58.3%), and their feedback on improvements aligned with children, suggesting more details, such as “a break-down of metrics” (parent 7).

Overall Satisfaction With InteractiveClinics

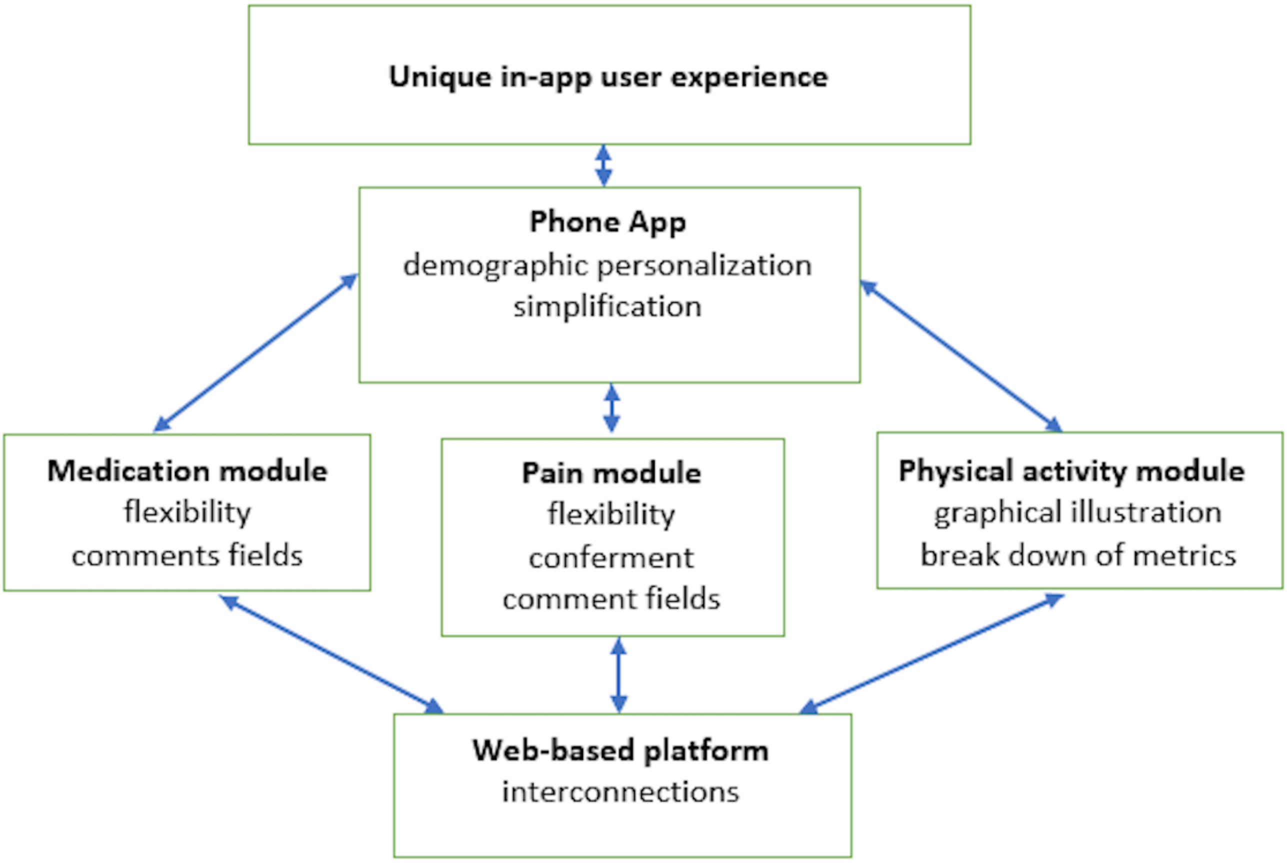
Overall, most children found all the information on InteractiveClinics easy to understand (9/12, 75%). However, only 5 children reported that the information collected met their needs (5/12, 41.7%), and 4 children reported that it would support their doctor with their care (4/12, 33.3%).

In contrast, most parents felt InteractiveClinics was appropriate to address their child’s needs (10/12, 83.3%). They found the information useful (8/12, 66.7%) in supporting their understanding of the effects JIA had on their child (8/12, 66.7%) and would use InteractiveClinics again (6/12, 50%). Importantly, 7 parents reported that InteractiveClinics would support their child in their next pediatric rheumatology consultation (7/10, 58.3%).

> *We found the App very useful. My child required no prompting to record her pain levels and it was good for me to understand her level of pain.* [parent 6]
>
> *I think it will be very useful in the future.* [parent 4]

Summing up the feedback on all key areas in InteractiveClinics, participants wanted a unique in-app experience (Figure 5).

Figure 5. Coding tree representing the analyzed content.



Discussion

Principal Findings

This study sought to evaluate the usability and acceptability of InteractiveClinics for children (aged 10 to 18 years) living with JIA. A unique feature of InteractiveClinics is the multimodal approach it uses to support the 3 key management areas in JIA treatment: medication adherence, pain, and the retention of physical activity. InteractiveClinics was supported through a commercial smartwatch, customized phone app, and web-based platform.

This study exposed both the strengths and weaknesses of InteractiveClinics. Most children and their parents liked the watch and web-based platform, finding it easy to learn and simple to use. They were satisfied with the pain and physical activity module, and no adverse events were reported. However, there was also the need for improvements. Children identified usability and acceptability barriers that hindered uptake, particularly in the phone app. This finding is important because user feedback can be vastly different from how the intervention was planned to be used [70]. To improve InteractiveClinics, children wanted a unique in-app experience through more personalization, simplification, flexibility, conferment, comment fields, graphical illustrations, a breakdown of metrics, and interconnections.

Suggestive Improvements

The importance of personalization is that it provides children with choice, autonomy, and ownership when using technology [71]. This is achieved by enabling children to customize the app features to suit their needs [72] and providing more feedback, on an individual level [73].

Parents also requested more simplification by removing all the buttons that were not relevant to their child. Other studies have also requested removing any complexities. DeForte et al [74], for example, reported children only wanted simple buttons. This would also support a child with a disability or low level of literacy, improving their ability to navigate the app [75].

In addition, the app needed to be more flexible. Children wanted to be able to change their medication response times within the app, earlier or later than the previously selected notification times given to the research team (SB). Rather than being reliant on the research team to update their medications, they wanted to adjust the response times to work around their activities. Interestingly, a systematic review of medication apps for adults, reported that the main components that foster medication adherence were reminders and importantly, medication-tracking histories [76]. Therefore, future changes will be made to InteractiveClinics to provide users control over their notification reminders, to ensure an accurate medication history is recorded.

Further, children wanted more from the pain module; instead of the numerical scale confirming their pain recording, they wanted more exciting conferment. In contrast, children with cancer pain in a phone app study requested the numerical scale instead of the pediatric face scale using smiley faces [77]. Therefore, it was not surprising then when children suggested more engaging gamification. Yet, very few studies have considered gamification mechanics as part of their pain assessment, despite the evidence suggesting they are liked and can increase motivation [78]. Indeed, this is certainly an area in need of further research.

There was also an overwhelming response from parents to include comment fields to record additional information such as medication-induced side effects. This is important because a recent study identified that two-thirds of children with JIA, within 1 year of diagnosis, experience side effects that have an impact on their life [79]. Understandably, concerns about these side effects can result in the termination of their treatment, posing the risk of increasing disease activity [80]. Therefore, it is imperative for InteractiveClinics to collect detailed input from children on what occurs between pediatric rheumatology appointments, to gain a more comprehensive overview of disease activity and adverse events [81], enabling timely re-evaluation and mitigation strategies to be put into place, rather than merely relying on the assessment of pain and active joint count at each visit [82]. Permitting suitable changes to treatment such as prescribing folate to reduce methotrexate-induced nausea [17,83,84] or brain fog [85], changing the route of administration [17,84], splitting doses, or altering the rate of absorbency [20] can reduce the risk of disease burden and further polypharmacy in adulthood [19].

For the physical activity module, children reported wanting more graphical illustrations representing their physical activity. According to the World Health Organization, children between the ages of 10 to 18 years are in a phase of life between childhood and adulthood where health behavior can be greatly influenced. Therefore, they are in need of age-appropriate comprehensive information [86], as they are active agents in their own development [87]. A similar study that used an activity tracker, app, and web-based profile also reported the need for more detailed feedback. Children, instead of a similar traffic light system, wanted the see the actual step count [88] (in other words, the breakdown of metrics).

To improve the app and web-based platforms' usefulness, children also wanted to see interconnections between the medication adherence module, pain level module, and physical activity module to, for example, determine the impact pain or medications may have on physical activity levels. This is important because each of these modifiable risk factors can affect another [15,49]. Demonstrating a correlation between this information could also be useful for the pediatric rheumatology team to better understand disease progression or remission, therefore facilitating adjustments to treatment accordingly, and also to avoid the impact JIA can have on development, physical function, and health-related quality of life [15,49].

Clinical Importance

An important clinical finding in this study was parental endorsement. Parents, in contrast to children, felt InteractiveClinics was useful in addressing their child's problems by helping them understand the effects JIA had on their children. This is an important finding because parents' narratives of their child's condition often remain unmet [89]. By gaining self-awareness, the parent may gain a more insightful understanding of their child's status on treatment that may be interfering with their progress [89]. In addition, parents then examine their own views and behaviors that can also contribute either positively or negatively to their child's health outcomes, because children are observational learners [90]. For example, a parent's fear and catastrophizing can result in protective behaviors and avoidance of treatments, therefore impairing their child's functional ability [90], suggesting the importance of digital health care in educating and empowering parents.

Overall, the children and parents included in this study, through their own lived experience, were incredible collaborators in improving the usability of InteractiveClinics, greatly extending our understanding of the unique needs of children with JIA. This is important, as there is criticism toward the current "treat to target" approach used in JIA management. Children and their parents are often not included when formulating treatment plans [82]. Yet, their goals of treatment are often different from those of the Pediatric Rheumatology teams because they are focused more on the present, rather than the long impact of the disease [82], emphasizing the importance digital health care can have in supporting child-centered and family-centered care [91].

Limitations

There are several limitations that need to be considered when interpreting this study's findings. First, this study only recruited a small convenience sample of 12 children and 12 parents, limiting generalizability. Although a small sample size (>10 participants) is typically used for usability testing[58], the suggestive inclusion to improve InteractiveClinics may not be representative of all children with JIA. Therefore, to overcome sampling bias, a larger, more diverse participant sample is needed across different demographic and geographical locations in the next stage of testing.

Also, due to the nature of this usability and acceptability study, consenting participants were actively prompted to be critical and provide written feedback on how the proposed digital health intervention could be improved. This may have limited the provision of any positive attributes.

In addition, the written feedback they provided may have not been as detailed as expected for thematic analysis. Patterns did emerge, and data saturation was reached; however, there was still a risk of research bias [69], so all authors internally reviewed and rereviewed emerging codes and themes against the original text during all stages of analysis.

Further Research

Further research is now needed to examine the potential challenges and limitations of incorporating InteractiveClinics into clinical practice. First, this research needs to focus on device access and digital literacy, because this study supplied all the equipment needed to participate and provided ongoing technical support. Second, the level of engagement and length of adherence among participants using the intervention needs to be considered, to clearly understand whether digital health care is an effective and sustainable intervention to support chronic disease management for children and their families.

A comparative analysis is also needed to compare InteractiveClinics to other digital health interventions targeting pediatric chronic disease. This would help with positioning the intervention within the broader digital health landscape and identifying any unique benefits that may be offered over existing tools, in order to find supportive and effective digital health solutions.

Interestingly, for JIA, 2 recent systematic reviews identified no similar digital health interventions that have used a multimodal approach to support chronic disease management [43,92]. In fact, most interventions were still at an early stage of development [43], and heterogeneity exists, making it difficult to compare their effectiveness [92]. Instead, the findings of these reviews helped to identify 3 specific areas that are needed in JIA management—symptom monitoring, physical activity promotion, and self-management development [92]—which were used to support the development of the 3 modules included in InteractiveClinics: pain level, physical activity level, and medication adherence. It is also important to note that no studies directly targeted medication adherence [43,92], yet early aggressive pharmacological treatment and the monitoring of side effects are keystones in JIA treatment [91].

Now, the future direction of InteractiveClinics is to use the feedback gained from the children and parents within this study to improve the usability of the intervention. The World Health Organization clearly reinforces the importance of doing this before commencing costly trials [58]. Then, the next step is to test the intervention's efficacy and effectiveness [58]. This will be achieved through conducting a pilot randomized controlled trial, which will remove the sampling bias identified in this study and determine the intervention's effectiveness on health outcomes for children with JIA and children living with other chronic conditions.

Conclusion

Most children and their parents liked using the smartwatch and web-based platform; they found it easy to learn and simple to use. They were also satisfied with the pain and physical activity modules. However, usability and acceptability barriers that hindered uptake were identified in the phone app and medication module. Children sought a unique in-app experience, and their suggestive improvements included more personalization within the app; simplification by removing all nonrelevant links; flexibility in response times; improved conferment through gamification; additional comment fields for the input of more data, such as medication side effects or pain-related symptoms; more detailed graphical illustrations of the physical activity module, including a breakdown of metrics; and importantly, interconnections between the modules, because medication adherence, pain levels, and physical activity can each influence the other. Further research is now needed to ensure these inclusions are combined with standardized comprehensive assessments and evidence-based behavior change strategies to promote user adoption and advancement of new, validated digital health interventions in pediatric rheumatology clinical care.

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Conflicts of Interest

None declared.

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Abbreviations

eVas: electronic visual analog scale
JIA: juvenile idiopathic arthritis
mHealth: mobile health

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Original Paper

A Web-Based Peer-Patient Navigation Program (Compassionate Online Navigation to Enhance Care Transitions) for Youth Living With Childhood-Acquired Disabilities Transitioning From Pediatric to Adult Care: Qualitative Descriptive Study

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Abstract

Background: Studies have highlighted significant challenges associated with the transition from pediatric to adult health and social care services for youth living with childhood-acquired disabilities and their caregivers. Patient navigation has been proposed as an effective transitional care intervention. Better understanding of how patient navigation may support youth and their families during pediatric to adult care transitions is warranted.

Objective: This study aims to describe the preferred adaptations of an existing web-based platform from the perspectives of youth with childhood-onset disabilities and their family caregivers to develop a web-based peer-patient navigation program, Compassionate Online Navigation to Enhance Care Transitions (CONNECT).

Methods: A qualitative descriptive design was used. Participants included youth living with childhood-acquired disabilities (16/23, 70%) and their caregivers (7/23, 30%). Semistructured interviews and focus groups were conducted, digitally recorded, and transcribed. Thematic analysis was used to analyze the data and was facilitated through NVivo software (Lumivero).

Results: Participants desired a program that incorporated (1) self-directed learning, (2) a library of reliable health and community resources, and (3) emotional and social supports. On the basis of participants' feedback, CONNECT was deemed satisfactory, as it was believed that the program would help support appropriate transition care through the provision of trusted health-related information. Participants highlighted the need for options to optimize confidentiality in their health and social care and the choice to remain anonymous to other participants.

Conclusions: Web-based patient navigation programs such as CONNECT may deliver peer support that can improve the quality and experience of care for youth, and their caregivers, transitioning from pediatric to adult care through personalized support, health care monitoring, and health and social care resources. Future studies are needed to test the feasibility, acceptability, usability, use, and effectiveness of CONNECT among youth with childhood-onset disabilities.

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KEYWORDS

youth; patient navigation; web-based intervention; peer support; transition; childhood disability; caregiver; transitional care intervention; social support; usability; program; children; pediatric; disability; digital health; eHealth; web-based support; web-based health

Introduction

Background

Young people with childhood-onset disabilities (eg, acquired brain injury and cerebral palsy) are living longer than previous generations owing to advances in medical knowledge and clinical management [1,2]. Research and advocacy efforts have focused on ensuring continuous access to health, education, and social services for youth transitioning from pediatric to age-appropriate and developmentally appropriate adult health care services, to support autonomy and maximize independence in society for capable youth [3-7]. Many youths who age out of pediatric services experience a gap in services designed to meet their adult health and social needs [6,8-12]. Furthermore, finding and accessing the appropriate adult care providers and services is often challenging [8,12,13]. Adult health care providers often lack training related to aging with a childhood-onset disability and supporting the unique health and psychosocial needs of young adults [7,14-16].

Youth and young adults living with disabilities acquired in childhood often have chronic health issues that require frequent health care visits, and yet, few receive the comprehensive services and support they need [8,12,17]. Without seamless, accessible, and appropriate services, health concerns may remain poorly managed or undetected, increasing the risk of preventable secondary health complications and comorbidities in young adulthood [18-21], which may lead, in turn, to increased or inappropriate reliance on acute health services (eg, hospitalizations) [7,13,22]. For example, young adults with disabilities aged between 19 and 27 years, including cerebral palsy, spina bifida, and acquired brain injuries, visit physicians and are admitted to the hospital, on average, 9 times more than that among the general population [17,23]. Results from studies conducted in Alberta, Canada, indicate that individuals providing care for children or adolescents with complex care requirements frequently experience feelings of being overwhelmed, fearful, and isolated [24]. Collectively, this evidence highlights gaps in appropriate care for a growing population of transition-age young adults with disabilities (eg, aged 18-30 y) and their caregivers [7]. Closing this gap and ensuring the successful transition from pediatric to adult services is vital to improve the health and well-being of youth and young adults living with disabilities.

Despite the critical importance of successful transition, there is limited evidence about effective transitional care interventions for young adults with childhood-onset disabilities. Most evaluation studies have been descriptive in nature [7], lack rigor in design [25], and often do not use instruments that are valid and reliable for meaningful evaluation [26]. Furthermore, high variability across practice settings and the siloed nature of health and social services have led to issues with transferability to practice settings and community contexts [7]. Previous evidence syntheses in this area, including a systematic review [25], and clinical guidelines [27] have focused mainly on managing chronic medical diagnoses and failed to address the specific and additional needs of the youth with disabilities. It is important to address this gap, as young adults with disabilities may have diverse requirements as they prepare to transition to adult care settings [28,29]. Thus, there exists a pressing need to develop and implement culturally sensitive, accessible, effective, and fiscally sustainable approaches to youth transition. Cost-effective transitions for young adults with childhood-onset disabilities can be expected to have positive, far-reaching impacts on health and social care systems [30].

Although case navigation is a recognized effective transition intervention [31], a recent systematic review found no studies of peer navigation for transition-age youth with childhood-acquired disabilities [7]. Patient navigation emerged in the 1990s as a model of transitional support across health care settings [32,33]. Patient navigation has been defined as a partnership among the patient; family; members of the care team; and patient navigator, who facilitates timely access to health or community resources and fosters self-management and autonomy through education and emotional support [34]. Patient navigators can be peer (lay) navigators (eg, peers with lived experience) or professional navigators (eg, nurses) [32]. Although patient navigation has historically been implemented in the context of adults with cancer, recent programs have focused on children and youth with complex, chronic conditions [35,36]. Patient navigation has been posited as an intervention for youth and young adults with disabilities by reducing barriers to access and integrating various services in a timely, coordinated manner, thus facilitating seamless transitions in care [37]. For example, NaviCare/SoinsNavi is a professional patient navigation center in Canada that is specifically designed to provide support and assistance to children, youth, and their families who are dealing with complex care needs [38]. Patient navigation centers such as NaviCare/SoinsNavi play a crucial role in helping individuals and families navigate the complex health care system by offering guidance, information, and coordination of care [38]. Peer navigation is generally defined as an advantageous interaction between a peer navigator and a patient and traditionally involves a trained peer who provides education and support to a patient to promote recommended health care use behaviors (eg, health screening, attending the recommended care events, and adhering to treatment or follow-up care) with the goal of optimizing care [39,40]. Specifically, through the provision of emotional, informational, and appraisal support, peer navigators can increase patient self-efficacy and, consequently, promote the achievement of recommended health behaviors. However, so far, it is not well known whether and how peer navigation can contribute to the delivery of integrated care for youth with childhood-acquired disabilities transitioning to the adult health care system and community services. Thus, studies of the role that patient navigators may have in assisting during these transitions and specific components of such an intervention are needed.

The NexJ Health Wellness Platform is a web-based platform that has been previously used to build peer navigation programs for adults with chronic illness (eg, cancer [41]). The profile and dashboard display users' personal information that they wish to share with their circle of care members (eg, peer navigators, health care providers, and families). The profile also includes contact information such that the youth or care team can connect with one another via the platform. The dashboard is adaptable, such that the youth can personalize it with their own background or goals. Points are assigned as individuals meet their goals. The care plan is also where navigators can note any action item that youth should be taking to manage their health (eg, medications to take). Related to this aspect, there is a scheduling feature on the program, which is very similar to a digital calendar, where the clients can set up an appointment with their care team members, who will receive this request and schedule the appointment. Reminders of appointments will be facilitated through the scheduling feature. The health library contains resources provided by the study team that are verified by health care professionals and organized into different categories according to conditions, disabilities, mental health, socialization, mindfulness, and health needs. In phase 1, we received initial ideas about how the platform should be modified to build the Compassionate Online Navigation to Enhance Care Transitions (CONNECT) platform, which are presented as part of phase 2, as described in the following sections.

Objective

This study aimed to describe the preferred adaptations of this existing web-based platform from the perspectives of youth with childhood-onset disabilities and their family caregivers to develop a web-based peer-patient navigation program called CONNECT. CONNECT aims to be a web-based tool in peer-patient navigation for youth with childhood-acquired disabilities transitioning to adult health care and community services. The development of an evidence-based, patient and family–informed, web-based peer navigation intervention for young adults with childhood-onset disabilities holds the potential to improve transitional care experiences and outcomes [42].

Methods

Study Design

We conducted a qualitative descriptive study using semistructured interviews and web-based focus groups [43,44]. Qualitative description is a commonly used methodology in health care research, whereby the primary goal is to describe a complex construct by staying close to the data elicited from the perspectives and in the words of participants with lived experiences [45]. A qualitative descriptive approach is based on individuals' experiences and points of view—in this case, on peer navigation [38]. We have reported our methods as per the COREQ (Consolidated Criteria for Reporting Qualitative Research) [46].

Ethical Considerations

The protocol for this study was approved by the (University Health Network Research Ethics Board REB 22-5023). Informed verbal and written consent were obtained from all participants.

Setting

The study was conducted in Ontario, Canada, where peer navigation has recently emerged as a novel model of pediatric care provincially [47] but where little is known about patient navigation in the context of transition-age youth with disabilities.

Sampling and Recruitment

A convenience sampling strategy that combined criterion and snowball sampling was used to recruit English-speaking youth, aged between 19 and 30 years with cerebral palsy, intellectual disabilities, or acquired brain injury, and their caregivers [48]. Individuals who were unable to communicate in English were excluded from the study. The recruitment process primarily involved 2 health care organizations that maintain email lists of clients interested in research projects related to youth living with disabilities. The research coordinator used the email list to send invitations to individuals, and in addition, administrators at these organizations verbally promoted the study during group support sessions. Furthermore, social media advertisements were used to reach a wide audience of eligible participants. As part of the snowball sampling approach, at the end of the interview, participants were encouraged to actively inform their peers about the study, facilitating the expansion of our participant network. Eligible participants were subsequently contacted by a study coordinator to obtain informed verbal and written consent. It is important to note that none of the participants had previous affiliations or associations with the research team, ensuring impartiality in data collection.

We initially set a predetermined sample size goal of 15 to 25 participants, which was informed by existing guidance for qualitative research, where the aim is to reach a point of saturation at which new data no longer significantly contribute to the emergence of additional themes or insights [49,50].

Data Collection and Analysis

Overview

Data collection and analysis occurred in 2 phases. Phase 1 aimed to obtain insight about the initial, desired characteristics of a web-based patient navigation program. Before phase 2, we incorporated the findings from phase 1 into the CONNECT program. Phase 2 aimed to obtain feedback about the preferred adaptations of an existing web-based platform to further develop the CONNECT intervention. We also collected information about sociodemographic characteristics to help contextualize the interview data.

Phase 1

Semistructured interviews were conducted using an interview guide developed by the research team (refer to Textbox 1 for a sample interview guide). Before the interview, participants were provided with a definition of patient navigation to help orient them to the topic area. Then, 2 experienced qualitative researchers (KMK and TSJL) conducted all interviews over the phone. Each participant completed a single interview ranging between 30 and 75 minutes. Interview were audio recorded and professionally transcribed verbatim. Immediately following each interview, the interviewer wrote reflexive memos about the interview. In total, 61% (11/18) of youths and 39% (7/18) of caregivers participated in the interviews (phase 1).

Textbox 1. Sample interview questions.

If money/resources were no object, what would the "ideal" patient navigation intervention look like to you?

- Not applicable

Thinking about your experience as you transitioned from pediatric to adult health and social care services, how might a patient navigation program have been helpful when you/your family member transitioned (ie, to adult healthcare, community resources/services)?

- What benefits do you think such a program would provide to patients and family caregivers that current support, training, resources, programs, services, etc. you receive do not?

From your perspective, what are the ideal components of a patient navigation intervention?

- In what ways, specifically, do you think a patient navigator could help provide education and support?
- What can/should the navigator do?
- What information can/should the navigator provide?
- What information about the program is needed to inform people who are taking part in the intervention?
- What kind of training is needed for the navigators?

Interview data were thematically analyzed, whereby preliminary themes were derived from ongoing data collection and analysis through a coding process [51,52]. First, all transcripts were reviewed for accuracy by author, KMK, who compared the audio files with the transcript. During this process, any preliminary thoughts about the data were recorded. Next, all transcripts were reviewed independently by 3 investigators (KMK, TSJL, and SEPM) and coded using open coding procedures. Discussions around key ideas and codes in the data occurred through a series of weekly meetings to reach consensus on a codebook [51]. This codebook was then applied to the transcripts by 2 researchers (KMK and TSJL), under the guidance of the senior author (SEPM). The coded data were reviewed by the research team, who met at least once weekly to discuss similarities and differences across and within the coded data. This process occurred until preliminary themes were identified. Full-team meetings helped to refine the themes and their content [51]. The full research team comprised content and methodological experts (ie, experts in disabilities, health care transition research, health system research, and qualitative methods). Interviews were stopped when theme saturation was believed to have been achieved, as consistent redundancy was evident in the themes derived from participant experiences [51,53,54]. Data from these interviews were shared with technology developers of the NexJ Health Wellness program to inform the customization of the existing program. An existing web-based program, NexJ Health Wellness, was previously designed to support the monitoring and coaching of chronic diseases in adults.

Phase 2

Web-based focus groups were conducted where participants were introduced to the initial features of CONNECT that had been incorporated based on the feedback provided in the interviews (ie, phase 1). However, owing to scheduling difficulties (ie, unable to gather participants on the same day), we also offered participants individual interviews if they preferred. Of the 18 participants who were interviewed and had consented to be contacted for focus groups, 3 (17%) participated in the focus groups and 2 (11%) participated in individual interviews. Some participants who participated in the initial interviews did not participate in the follow-up focus groups or interviews; reasons included the following: their phone or email was not working, and thus, they were unreachable by the research coordinator, and time constraints (eg, work schedules and family obligations). Then, 6 new participants (ie, individuals who did not participate in the original interviews; n=1, 17% caregivers and n=5, 83% youths) were also recruited. Of these 6 participants, 3 (50%) participated in a focus group and 3 (50%) were interviewed individually. These individuals also completed the sociodemographic questionnaires. Overall, 2 focus groups, with 3 participants per focus group, and 5 individual interviews were conducted.

The focus groups lasted approximately 90 minutes and were facilitated by 2 experienced qualitative investigators (KMK and SEPM). A focus group guide (Textbox 2), informed by the preliminary analysis of and reflexive memos from the interviews, was developed by the first and senior authors. During the focus groups, the qualitative investigators strived to ensure that participants had equal opportunity to share their thoughts by using probes to ask individuals their own thoughts. A research assistant took field notes and memos during and after the focus groups [55]. As in phase 1, the research team explored the emergence of new themes as we conducted additional interviews and focus groups. When we reached a point where new interviews did not yield substantially new insights or themes and, instead, reinforced the existing ones, we made the informed decision to conclude the data collection phase.

Textbox 2. Sample focus group guide.

From your perspective, what qualities make an effective peer navigator (especially with the view to promoting quality of life and increased participation/integration in the community)? We are defining effective as a program that would help you in promoting quality of life and increased participation/integration in the community.

- What training should a peer navigator have to be effective?
- How often should the touch-points with peer navigators be?

Now thinking about the platform you've just seen/reviewed, what components/features here would you like/be helpful in your peer navigator program (or the program for your family member)? Why?

- What components would you dislike/not be helpful (and be helpful to you as a family member)? Why?
- Has the platform captured the issues that are important to you (ie, that you described before)?
- Are there any components not included that you would like to see?

We are interested in building an online peer navigation program that focuses on compassionate care. Do the features presented here promote the description of compassionate care you hold? Why or why not?

- If not, what could be added/amplified?

Is the platform easy to use and understand in terms of its eg, wording and the interface? Why or why?

- Are there ways that we could improve on these areas?

The individual interviews were conducted by the same 2 interviewers who led the focus groups, using the same guide. All focus groups and interviews were audio recorded and transcribed verbatim. Phase-2 data (ie, interviews and focus groups) were analyzed using the same thematic analysis process as the interviews [51,52]. Following this process, a more critical review of both the interview themes and focus group themes was conducted. Similarly, the coded data from both data sets were combined. Once completed, a side-by-side comparison of the individually coded transcripts was conducted during a team meeting. To help identify the major themes across the data, 3 research team members (KMK, TSJL, and SEPM) led the analysis by individually reviewing the coded transcripts, meeting minutes, and memos. The full investigation team then reviewed the preliminary major themes to reflect about salient ideas, which resulted in full-team discussion and subsequent follow-up discussions to clarify ideas. Hence, investigator and data triangulation were used to ensure the trustworthiness of the data [56,57].

Positionality of the Research Team

Qualitative researchers are urged to consider how their background and position affect the design, analysis, and reporting of their study [58]. The research team consisted of Canadian researchers with various backgrounds (eg, cultural) and education (eg, trainees, health care professionals, and researchers). Throughout the data collection and analysis process, the research team had frequent discussions to remain cognizant of their own positions and reflect about how these could influence the design of the intervention and the findings. This was the first time the research team had worked with the technology partner. None of the investigators experienced living with cerebral palsy. Throughout the data collection process, we upheld reflexivity by consistently engaging in critical self-reflection and modifying our interview and focus group guides accordingly. This iterative approach empowered us to enhance our questioning techniques and remain responsive to the emergence of new themes and valuable insights.

Results

Overview

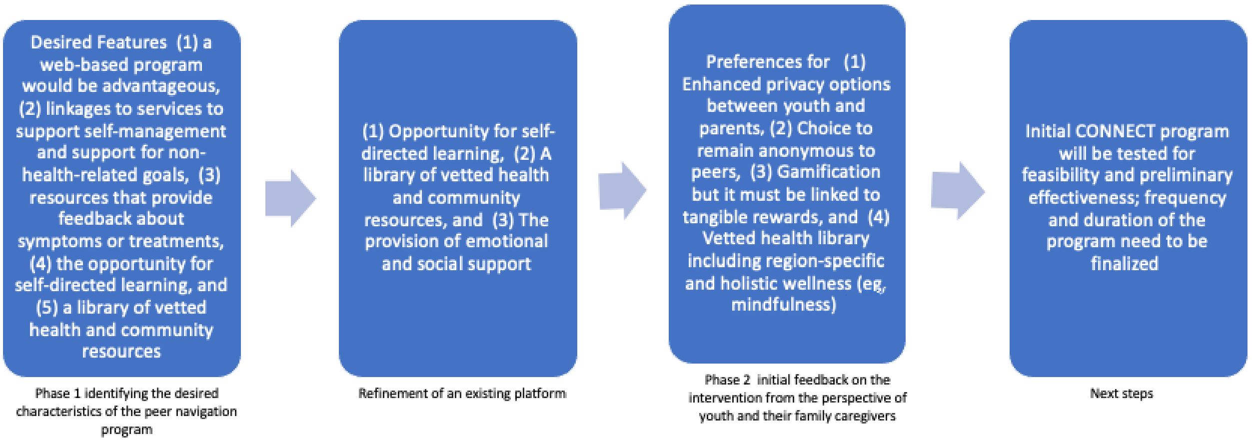
In total, 24 participants participated in this study, with 5 (21%) participating in both phase 1 and phase 2. Of these 24 unique participants, 8 (33%) were caregivers (all women) and 16 (67%) were youths (n=11, 69% young women; n=5, 31% young men). Most of the caregivers (7/8, 88%) were mothers to a youth with a childhood-onset disability, and a participant was an aunt. Characteristics of the youths and caregivers are reported in Table 1. To secure anonymity, quotations include only the participants' group (ie, youth or caregiver), sex, diagnosis, and participant ID number. We have synthesized the findings from phase 1 and phase 2 in Figure 1 and Table 2.

Table 1. Characteristics of the participants (N=24).

Characteristics	Youths (n=16), n (%)	Family caregivers (n=8), n (%)
Sex		
Female	11 (69)	8 (100)
Male	5 (31)	0 (0)
Age (y)	3 (23)	7 (58)
Living environment		
Urban	15 (94)	8 (100)
Rural	1 (6)	0 (0)
Highest level of education		
Obtained high school	9 (56)	4 (50)
Obtained college or university	7 (44)	4 (50)
Ethnicity		
Asian	4 (25)	2 (25)
White	11 (69)	4 (50)
South Asian	1 (6)	0 (0)
Southeast Asian	0 (0)	2 (25)
Primary diagnosis		
Intellectual disability	8 (50)	N/A[a]
Cerebral palsy	5 (31)	N/A
Acquired brain injury	3 (19)	N/A
Primary diagnosis of care recipient		
Cerebral palsy	N/A	6 (75)
Acquired brain injury	N/A	1 (13)
Intellectual disability	N/A	1 (13)

[a] N/A: not applicable.

Figure 1. Summary of key findings categorized based on the phase. CONNECT: Compassionate Online Navigation to Enhance Care Transitions.



Desired Features (1) a web-based program would be advantageous, (2) linkages to services to support self-management and support for non-health-related goals, (3) resources that provide feedback about symptoms or treatments, (4) the opportunity for self-directed learning, and (5) a library of vetted health and community resources

Phase 1 identifying the desired characteristics of the peer navigation program

(1) Opportunity for self-directed learning, (2) A library of vetted health and community resources, and (3) The provision of emotional and social support

Refinement of an existing platform

Preferences for (1) Enhanced privacy options between youth and parents, (2) Choice to remain anonymous to peers, (3) Gamification but it must be linked to tangible rewards, and (4) Vetted health library including region-specific and holistic wellness (eg, mindfulness)

Phase 2 initial feedback on the intervention from the perspective of youth and their family caregivers

Initial CONNECT program will be tested for feasibility and preliminary effectiveness; frequency and duration of the program need to be finalized

Next steps

Table 2. Summary of themes.

Phases and themes	Description
Phase 1	
Advantages of web-based programs	• In this theme, participants expressed the advantages of a web-based program over in-person support, citing time-saving benefits and independence in navigating web-based resources. Some participants, especially caregivers, acknowledged limited technology knowledge and concerns but saw the potential for enhanced accessibility, particularly for non–health-related goals, through a web-based program.
Benefits of peer support	• Participants highlighted the benefits of peer support within the proposed program. They emphasized the importance of the peer navigator being trained in individualized, client-centered care and possessing knowledge about regional health and social services. Furthermore, participants stressed the significance of training the navigator in mental health support to aid in transitions from pediatric to adult services.
Core components of a navigation program	• Participants expressed their desires for several core components of a navigation program: • Patient education: Participants emphasized the importance of patient education to enhance their understanding of their condition and treatment options. They believed that this knowledge would empower them with the confidence to actively engage in shared decision-making regarding their health care. • Care coordination: Participants stressed the need for care coordination to enable collaborative, patient-centered, and team-based care across various health care settings. This aspect was seen as essential for ensuring seamless transitions in care. • Monitoring and coaching: Participants desired remote and mobile support for self-management of their health conditions. They expressed the need for ongoing monitoring and coaching from the research team to help them navigate their health care effectively.
Phase 2	
Logistical considerations for CONNECT[a]	• Participants discussed various logistical considerations for the CONNECT program. They emphasized the importance of specific aspects: • Navigator characteristics: Participants expressed a preference for peer navigators with similar life experiences and disabilities. • Value of appraisal support: Participants highlighted the need for the navigator to provide appraisal support, including feedback and evaluation. They suggested regular opportunities for participants to provide feedback and suggestions, with input reviewed by trained health care professionals to enhance the program. • Necessary infrastructure for accessibility: Participants discussed the importance of accommodating the differences in abilities when using CONNECT.
Balancing youth confidentiality with caregiver involvement	• Both youth and caregivers highlighted the importance of personalized control over the information shared via CONNECT. Participants believed that navigators could help facilitate discussions with caregivers. Caregivers also wanted control over specific platform functions to prevent unintended actions, suggesting additional confirmation steps for certain actions owing to concerns about unintentional changes.
Value of multimodal communication	• Participants valued the program's multimodal communication options, including phone calls, instant messaging, email, and video calls, with the ability to initiate contact themselves. Digital text-based communication was seen as providing fast access to psychosocial support and enhanced privacy for sensitive discussions.

Holistic and developmentally appropriate care needs	• Participants emphasized the importance of holistic and developmentally appropriate care within the CONNECT program:
	  • Developmentally appropriate care: Participants believed that receiving care through CONNECT should consider their unique developmental stages, life events, and personal goals, making their participation in the program meaningful.
	  • Point system: Many youth participants did not find value in the point system incorporated into the generic program, especially if points were not linked to tangible outcomes or rewards.
	  • Health library: Participants responded positively to the health library, viewing it as a trusted and credible source of health information and comparing it with a more reliable version of a Google search.
	  • Forums: Regarding the community forum, participants discussed the issue of anonymity and its impact on their ability to connect with peers. They believed that not remaining anonymous could lead to the potential for meaningful peer connections, providing additional opportunities for mentorship during transitions in care.

[a] CONNECT: Compassionate Online Navigation to Enhance Care Transitions.

Phase 1: Development

Overview

During the phase-1 interviews, participants described their desires for a web-based patient navigation program. The research team worked with participants during the interviews to identify features for the first iteration of the novel, web-based CONNECT program. Phase 1 consequently identified themes related to the advantages of a web-based patient navigation program facilitated by peer support and the core categories desired in a web-based peer navigation program.

Phase 1—Theme 1: Advantages of Web-Based Programs

Several participants explained that a web-based program would be advantageous in comparison with in-person support owing to time-saving benefits related to not needing to travel. Many participants indicated that they would feel comfortable in navigating the web-based navigation program, whereas some caregiver participants highlighted having limited knowledge about technology and associated worries of being unable to support their care recipient:

> *I think if you can, implement the program using technology as best as you can because that way, I can do it on my own time without finding a drive and I can do all the things that I need to do online independently without assistance. If I do need help, then it's okay, but I always do it independently when tech. issues come up.* [Youth 10; female; cerebral palsy]
>
> *I guess, not too many families struggle with technology I have, but I don't know how to fix things. Like, as a single mom, working full-time, I have a child with very, very severe disabilities, not really able to use technology like this. So, I'll need to learn how to use it to help him.* [Caregiver 2; female; cerebral palsy]

Although participants reported working with various care providers to support and maintain their health during transitions in care, many were unfamiliar with opportunities for self-management and support for non–health-related goals. Youth believed that that a web-based program would make such services more accessible:

> *I wish the services, specifically life skills and things like that were more easily accessible, because they're only in a couple of places right now and you have to have the time available to go to certain sessions wherever they're happening. And I wish they were more frequent or accessible maybe online and just to be able to talk to people even just for five minutes if you have a question about a goal rather than having to book an appointment a year in advance to see five different people at the same time. It's not always the best way to get the help that you need, so the program should help with that by being online with one peer.* [Youth 8; female; cerebral palsy]

Phase 1—Theme 2: Benefits of Peer Support

Participants noted that, in addition to being a peer, the navigator should be someone who is trained in individualized, client-centered care with knowledge about the existing health and social services in the region, if possible. Participants also highlighted the importance of training the navigator in mental health support to facilitate the transitions from pediatric to adult services.

Participants highlighted numerous components to be considered for the program. Considerations included resources that provided feedback about disability-related symptoms or treatments; opportunity for self-directed learning; library of vetted health and community resources; and ability to allow for human connection including ongoing communication, compassion, and understanding. Participants validated the notion of peer navigators as being ideal to provide compassionate, appropriate care because they can provide information and emotional support and facilitate health care navigation from a lived experience perspective. Participants also highlighted a general need for support from their navigator with managing personal goals of care and nonmedical transitions (eg, desire to find employment).

Despite consensus on these preferences, participants highlighted that a degree of personalization would be required in the navigator's approach. Participants believed that the peer navigator is uniquely positioned to provide this individualized support. There was no consensus among participants about the duration for or frequency in which an individual would want to interact with their peer navigator or use the CONNECT program. Thus, participants highlighted that the program should be available for as long as the individual felt that they needed to be enrolled, as transitions can range in time. A participant shared the following:

> *But maybe 6-12 months or 12-18 months for 2 hours. The reason I say two hours is because there are a lot of things that you have to learn and express, right? If people get the hang of it somewhere, I guess they can go on their own. But if they still have problems with it, or like accessing it even, they can stay longer. Every individual is different, so I would like to see it tailored to their own individual needs.* [Youth 2; male; cerebral palsy]

Phase 1—Theme 3: Core Components of a Navigation Program

Participants described desiring the following: education to improve the understanding of their condition and treatment options for confidence in shared decision-making; care coordination to enable collaborative, patient-centered, team-based care across multiple care settings; and monitoring and coaching to provide remote and mobile support to help self-management, until they were built into a functioning prototype. Participants also described desiring multiple channels and modes of communication to support participants in achieving their health and wellness goals, whereby the peer navigator is the first point of contact for participants.

Phase 2: Feedback About the Features of the Initial CONNECT Program

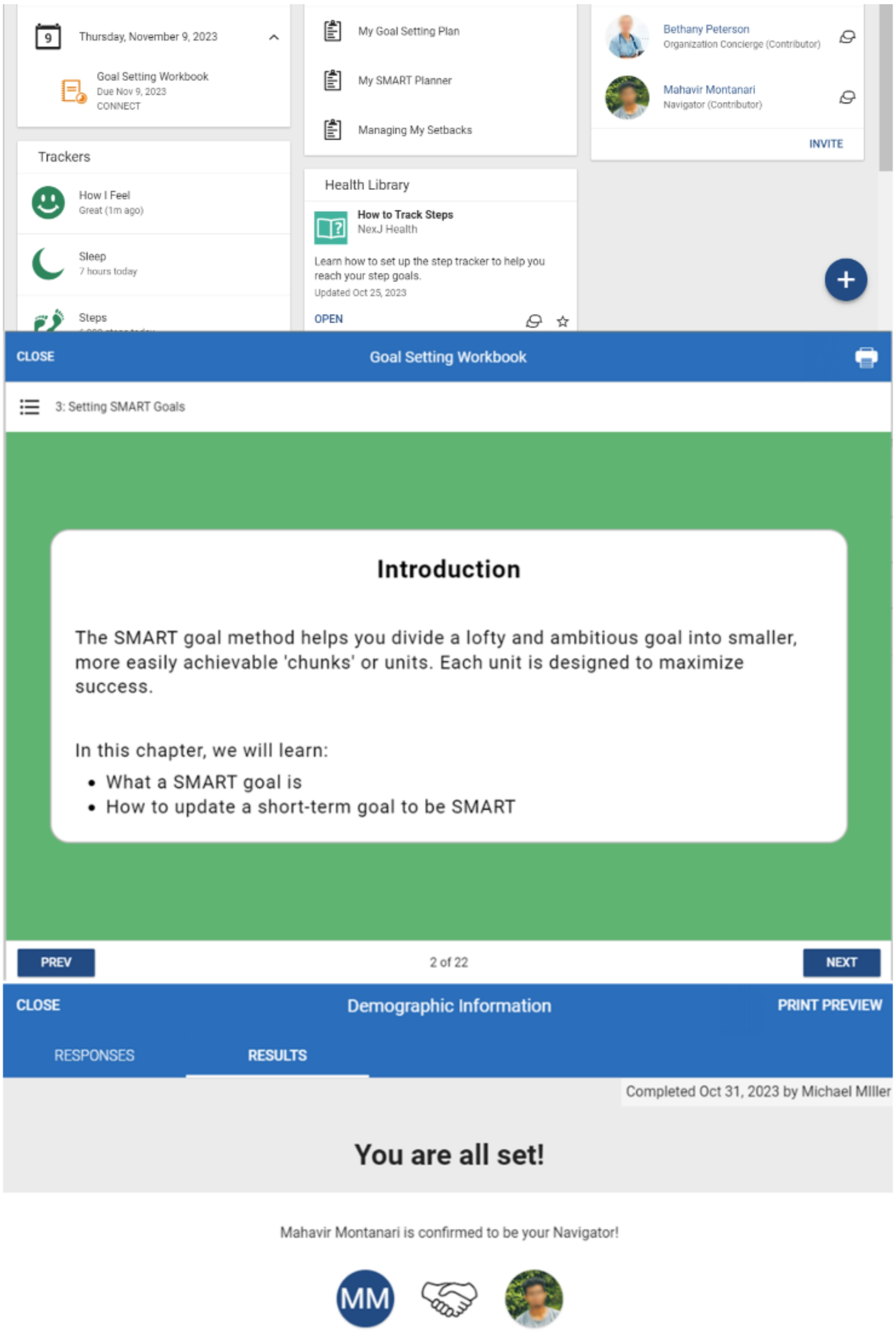
In this section, we have outlined the key themes related to the logistics, parental control, multimodal communication, and varied needs for support regarding the use of CONNECT. Figure 1 presents the collective learnings across phase 1 and phase 2.

Phase 2—Theme 1: Logistical Considerations for CONNECT

Overview

Participants described a wide range of logistical considerations related to the CONNECT program. These included the training of the patient navigator, value of appraisal support, and infrastructure needed for CONNECT. We have illustrated these changes in an updated image of the CONNECT system in Figure 2.

Figure 2. Updated Compassionate Online Navigation to Enhance Care Transitions platform.



Learn how to set up the step tracker to help you reach your step goals.

Introduction

The SMART goal method helps you divide a lofty and ambitious goal into smaller, more easily achievable 'chunks' or units. Each unit is designed to maximize success.

In this chapter, we will learn:

- What a SMART goal is
- How to update a short-term goal to be SMART

Completed Oct 31, 2023 by Michael Miller

You are all set!

Mahavir Montanari is confirmed to be your Navigator!

Subtheme 1: Navigator Characteristics

Participants described their ideal peer navigator as someone with similar life experiences and disabilities. Participants described that they would prioritize someone with these similar experiences over someone of the same age or sex. An individual shared the following:

> *As a person of colour, and as a self-identifying woman, I would feel more comfortable if someone my age and my demographic were to provide me information, compared to, let's say just purely an example, of a cis white man.* [Youth 19; female; intellectual disability]

Another youth participant described this by sharing the following:

> *It's just nice to have a person who lived through that experience, and know that somebody has been through it. Actual lived experience is very good versus just a doctor telling you some theoretical things, versus a real person.* [Youth 14; male; acquired brain injury]

Another caregiver shared the following:

> *I prefer my son connect with a person who has the same condition. Especially in my son's case, it's a little bit different because he's underweight, he is suffering from dysphasia and he has a G-Tube inserted in his stomach....So, when you have these resources and connect with other persons who have the same condition, it would be very helpful for me and my son both in critical and non-critical situations.* [Caregiver 7; female; cerebral palsy]

Having time to meet the navigator before receiving care or advice from them was reported as an important facilitator to developing a trusting relationship.

Subtheme 2: Value of Appraisal Support

Participants also highlighted the importance of and need for the navigator to assist with appraisal support (ie, evaluation and feedback), particularly in providing feedback to the navigator and other health care providers. A participant shared the following:

> *I think also maybe just giving them the option to provide feedback and suggestions as needed so maybe having it once a week, or two weeks, or something where a form goes out for them to provide feedback or if they would provide any suggestions. I guess that would be helpful on your side as well when creating it and making the program a bit better so having that going out once every month or so, just so that they know that their suggestions are being heard.* [Youth 5; female; intellectual disability]

Participants shared that this feedback could be reviewed with trained health care professionals who could provide the navigator with strategies for improvement. Many youths suggested that these strategies should be provided by someone who is trained in mental health care. A youth shared the following:

> *I think counsellors and therapists, for example, are a very good role model to draw upon these professional qualities from. I think people who are trained in mental health aspects do hold the qualities it takes to create an environment where the participant would feel safe talking about their issues.* [Youth 19; female; intellectual disability]

Subtheme 3: Necessary Infrastructure for Accessibility

Upon reviewing the existing platform, participants highlighted that owing to accessibility concerns, different hardware may be needed to accommodate the differences in abilities when using CONNECT. Examples of hardware mentioned included laptops, desktops, iPads or tablets, and cellular phones. A caregiver described the following:

> *[My son] cannot use a computer because both of his are closed. Even now, he uses the computer, but I have to open it and set everything up and put the camera in front of him. But also, the iPad, yeah, sometimes is much better because he has hand control movement, so yeah, the iPad is much better for my son, but it's different for other people.* [Caregiver 1; female; has a son with cerebral palsy]

Regardless of the technology, almost all participants noted that the device should allow for features such as control over the size of font, brightness, and speech-to-text functions. To serve the multicultural population of Canada, participants emphasized that the program had to be available in English, French, and other languages that may be spoken by users.

Some participants identified the barriers to the use of CONNECT for individuals who may not have access to internet. A participant said the following:

> *I would say that perhaps having the program in an online program might not work for everyone. They might not be able to access a computer or access the internet. But I think it's really important to figure out a way to make sure that these individuals are still included in the program and are still able to be supported through the program.* [Youth 13; female; acquired brain injury]

Phase 2—Theme 2: Balancing Youth Confidentiality With Caregiver Involvement

Many youths raised concerns over their parents accessing the information they shared via CONNECT. Youth described that all aspects of the program (ie, communication among the care team and progress posts) should be personalized such that the youth can control who can view their personal health information. Confidentiality came up as an important factor regarding youth feeling comfortable with using CONNECT, particularly in the context of discussing sexual and reproductive health issues or medical concerns with the navigator (eg, impact of the disability on reproductive health). Moreover, youth thought that the navigator could help them with discussions with their caregivers about their role in their care. A youth shared the following:

> *Thinking of sexual health concerns and like if someone wants their parents to know. Because I know that there are youths who are already basically independent at a very young age, and so they can easily bring up this conversation with their parents because they just have that type of dynamic. Some other youths might have a different dynamic with their parents, such that it's like, they've relied upon them for medical issues and things like that, so they don't really know how to go about bringing conversations other than, hey, I kind of want to do this. I think in that case, having a navigator would definitely help to express next steps to the youth.* [Youth 19; female; intellectual disability]

At the same time, caregivers wanted to be able to control the functions their care recipient could access. A caregiver shared the following:

> *My point is some of the features I don't want him to play with like canceling appointments. I want to prevent him from doing that on his own. All the features we have on the platform will be absolutely necessary. It's like in the bank account you have to have it joint with certain people so you can do it. Because if he makes it, sometimes I can't change it or something, I have to make up the time to make it right back, right? So, that's what I worry about.* [Caregiver 7; female; has a son with cerebral palsy]

Another caregiver described that owing to the nature of some disabilities, many of the features on the program should have "an extra layer of clicks or click/confirm options" such as a need to click a second button or confirm button to make the action happen:

> *My son is 20 years old and he has uncontrolled movement for his hand. Sometimes he pushes the button and makes a mistake. So, what should I do in this case? For my son, he clicks very fast. So, the thing is I want a lock, so both of us to be there, so we can make it available.* [Caregiver 1; female; cerebral palsy]

Phase 2—Theme 3: Value of Multimodal Communication

All participants appreciated that the program allowed for multiple modes of communication. Participants responded favorably to having the option to communicate with the navigator on one's own terms (ie, phone call, instant messaging, email, and video call), with the contact being initiated by the youth. Simultaneously, participants believed that digital communication (ie, SMS text message) could lead to fast access and more prompt management of their psychosocial issues. Some youths found that not having to communicate verbally provided an added sense of privacy, for example, if they were discussing issues that they did not want others to hear (eg, in the community forum or through messaging their patient navigator). Moreover, caregivers noted that this option may help accommodate youth with nonverbal communication abilities.

Moreover, youth believed that being able to contact the navigator when they wanted could help them better access services for a variety of health and nonhealth issues. For example, a participant shared the following:

> *My main goal is to be able to be in a place where I can live in an apartment and go to work every day and not necessarily have to think about how my disability will impact me after I've already troubleshot it for long enough that I have a routine. So I also just want to talk about that and get support with that. Just living life when something comes up.* [Youth 8; female; cerebral palsy]

Participants emphasized that the navigator should be available to the youth, caregivers, and care providers beyond standard business hours (eg, Monday to Friday from 9 AM to 5 PM), through a toll-free number, email, or messenger functions on the platform. Participants described wanting to reach a navigator that they trusted with a specific concern or a general need for emotional support during a crisis. Participants suggested having alternative navigators available to support the provision of 24/7 care. A participant stated the following:

> *Like, because people that will go through health issues, and they need support, but you don't know when they need the support. You can't just have it, have someone that's a registered person be present only from nine to five, or like, I don't know, eight to four, or something like that. Sometimes going through something right now, like my...like, I'm talking fine right now, but at night I'll be like, crying in my bed. So, you need to have people there, and someone to talk to at all times. Even at two in the morning, three in the morning. That's the key, I believe, when you're building something to support someone. Because our struggles happen all the time, not just during the day and sometimes we have no one who understands us to talk to....So, having a main person from nine, from eight, or whatever, and then having a couple of people at night to, just to...you know, just there. Even though people...even if people don't need it, you know, you want to be there in case someone wants it, right?* [Youth 15; female; intellectual disability]

Phase 2—Theme 4: Holistic and Developmentally Appropriate Care Needs

Overview

Participants indicated that the CONNECT program should provide health education and support that is developmentally appropriate. Youth perceived that receiving care through CONNECT should account for their unique developmental needs, life events, and personal goals, therefore making participation in the program meaningful. Participants operationalized developmentally appropriate care as care that could be personalized to their abilities including up-to-date health information that was written in lay terms and care that could promote self-management.

Subtheme 1: Point System

Many youth participants did not value the point system that is a part of the generic program, especially if the points were not linked to outcomes such as a prize. A participant described the following:

> *I don't know, a little reward or something tangible, that is motivational, but just having the points itself might not be worth anything to someone who isn't a child.* [Youth 18; female; intellectual disability]

Subtheme 2: Health Library

Participants responded positively to the health library, often comparing the program with a Google search that was more trusted or credible. A participant described the following:

> *So, if I had someone recommending things to me that would be incredible. When it's on an app for healthcare, it's already you would trust it a lot more as a rule I would think.* [Youth 16; female; intellectual disability]

However, participants noted that the health library should be expanded beyond physical health, to include mental health and information about accessible hobbies (eg, sport centers), restaurants, and transportation options.

Subtheme 3: Forums

Regarding the community forum, participants discussed the issue of anonymity. By not remaining anonymous, participants felt that there would be the potential to meet other peers. The potential to meet more peers with lived experiences was an attractive possibility to many of the youths as it would provide additional opportunities for mentorship through transitions in care. A participant described the following:

> *I feel like people can actually make friends out of this. Because some people might be going through the same thing, and they might be, eventually, buddies down the road. So, I feel like definitely this is something...especially patient-to-patient. There will be a connection. Like, oh, she or he is going through the same thing as I am. And they will feel like they're not alone, in case they want to make a decision. I definitely understand why you guys did anonymous, and it's definitely a good option to still keep anonymous, but there should be...if people want to share their name, it's okay to share their name, so that they can make friends that way.* [Youth 15; female; intellectual disability]

Participants appreciated the information vetting (eg, using peer navigators as moderators) that would occur in the forums, such that the advice provided by peers would likely be considered legitimate and safe.

Discussion

Principal Findings

We have presented the findings from the development process of a web-based patient navigation program that highlighted the preferred adaptations of an existing web-based platform from the perspectives of youth with childhood-onset disabilities and their family caregivers that will be incorporated into a web-based peer-patient navigation program called CONNECT. Participants desired a program that included (1) information about disabilities, (2) self-directed learning, (3) a library of reliable health and community resources, and (4) emotional and social supports. Upon obtaining feedback, we found that participants perceived that CONNECT could help support holistic and developmentally appropriate care needs. Participants also desired a program that was accessible to people with various physical disabilities. Moreover, as with other peer support literature [59-61], we found that for peer navigation to be most meaningful, the navigator should have similar life experiences as the user.

Our findings suggest that youth wanted their personal health information to remain confidential and preferred options of personalized caregiver involvement. Confidentiality is a major factor affecting youth's decision to access health care services [62]. When health care professionals can assure confidentiality and a trusting relationship, youth are more likely to communicate regarding their needs, engage with follow-up, and develop skills to navigate the health care system [62]. Having a navigator with the same disability and similar life circumstances was viewed as important by participants, as it can help foster trusting relationships. A study of an existing web-based peer navigation program for adult cancer care also found that participants wanted to be matched with a peer navigator who shared common characteristics, particularly the same language and sexual orientation [41]. Optimal Matching Theory, a well-cited theory in the peer support literature that informed CONNECT, suggests that living with a disability or illness creates the need for social support across many aspects of care (eg, physical and occasional) [63]. Matching the support desired with the support provided can enhance outcomes including improved friendship formation, reduced social isolation, and improved mental health [63]. Incorporating simple screening questions regarding language, disability, and sexual orientation may be helpful. It may also be helpful to incorporate specific areas where youth are seeking support, such as emotional, informational, or practical support; their preferred mode of communication; specific modes of web-based delivery; and when and how much the intervention should be delivered. Taken together, these considerations or adaptations may serve to enhance the overall benefits of the CONNECT intervention.

Although there are many definitions of patient navigation [64], implicit in most definitions is the notion that a patient navigator works to meet the health needs of individuals and their families [32]. Our study found that patient navigation should address psychosocial, educational, recreational, and vocational considerations and physical health considerations. In addition to health information, participants also desired information that could facilitate their day-to-day lives such as locating restaurants that are accessible for people with disabilities. Moreover, an important finding from this study was that despite the positive views about having peer support offered in various ways (eg, forum and via the navigator), participants also wanted the information shared and discussed to be vetted by a trained professional. Thus, opportunities for peer navigators to routinely work alongside health care professional navigators may be worth considering in future studies and programs, as current interventions often include solely lay or professional navigators, rather than both [65,66]. For example, youth desired emotional support during times of crises, indicating an example of where care can be better facilitated through trained professionals. Future studies should begin to explore navigation programs that include a combination of professional and peer support and programs that have professional oversight of peer navigators to determine whether and how they can be effectively integrated into transitional support interventions to optimize peer navigation delivery for youth with childhood-acquired brain injury, intellectual disabilities, and cerebral palsy and their families. Our findings provide the preferred requirements for a web-based peer navigation program for youth with childhood-acquired disabilities transitioning from pediatric to adult care. Future studies focused on refining the CONNECT program have the potential to improve the transitional experiences and outcomes of youth living with childhood-acquired disabilities and their families. The age and developmental variations among youth with complex care needs complicate the logistics of patient engagement with the intervention, as tailored approaches are essential owing to diverse cognitive and communication abilities [67,68]. Therefore, addressing these logistical challenges while maintaining a patient-centered, coproduced approach is paramount in the refinement of the CONNECT program.

In a meta-analysis of randomized controlled trials to determine the effects of patient navigation on health care use outcomes, Ali-Faisal et al [69] determined that compared with usual care, patients who received patient navigation were significantly more likely to access health screening and attend a recommended follow-up. Peer-patient navigation was also associated with increased adherence to cancer care follow-up treatment and obtaining early diagnoses [69]. Moreover, data from published studies reporting telehealth solutions for people living with illness or disability suggest the delivery of patient-centered care, relationship building between professionals and patients [68], and supporting medication adherence and health system cost savings [70]. Future directions for this program of research will include evaluating the effectiveness and health economic impacts of an optimized CONNECT intervention in a large-scale, pragmatic, randomized controlled trial. Benefits of the CONNECT program could include increasing participants' knowledge, skills, and confidence in managing health care transitions and health-related quality of life. The results of a future randomized controlled trial may help determine the potential of CONNECT for wide dissemination and public health impact, if it demonstrates effectiveness.

We acknowledge that implementing CONNECT in real-world clinical practice entails multifaceted challenges. Successful implementation of patient navigation programs within health care systems necessitates planning, funding, multidisciplinary engagement, workflow establishment, communication mechanisms, knowledge user support, appropriate caseload management, and in-kind resource allocation [71]. Thus, to ensure a fit with existing health and social care systems, careful consideration must be given to how the CONNECT system aligns with established health care workflows, processes, and roles [72,73]. Future implementation studies are required to determine who will provide the initial instructions to both users and administrators and are essential for successful adoption. In addition, addressing the provision of ongoing technological support is vital to resolving any technical issues promptly and ensuring seamless operation of CONNECT in the community setting (ie, home) [74]. Thoughtful planning regarding these aspects will play a pivotal role in the effective implementation and sustainability of the system within the complex landscape of health care practices.

Limitations

This study had some limitations. Most notably, participant selection was biased toward individuals who had high-speed internet and telephone service, as they were more likely to participate in the interviews and focus groups. As such, the needs of individuals living in rural and remote areas, who may be without high-speed internet, and individuals without access to necessary hardware should be considered [75]. Moreover, our study was limited to individuals who could verbally communicate in English, excluding youth with certain communication impairments or disabilities. Moreover, we only recruited individuals with cerebral palsy, acquired brain injury, and intellectual disabilities. All participants in this study were from Ontario, Canada. As such, the preferences and perceptions of the participants may not be transferable to the desires and perceptions of a broad community of youth living with childhood-acquired disabilities [76]. Beginning our intervention development with an existing platform (ie, iterating on an existing platform) may have limited the opportunity to meaningfully co-design the CONNECT program. Finally, our participants explored the existing platform without actual interactions with the peer navigator. By deploying the patient navigation intervention, future studies could also assess its ecological validity [77].

Conclusions

This study describes the development of CONNECT, a web-based peer-patient navigation intervention for youth with childhood-acquired disabilities to support transitions from pediatric to adult care. Our findings reveal that youth desire receiving peer support from an individual with similar life experiences through multimodal communication techniques and with assurance of confidentiality. At the same time, participants highlighted that for web-based patient navigation to be age appropriate and developmentally appropriate, it must involve trusting relationships and vetted information. Future studies are needed to further refine CONNECT before determining its effectiveness in real-life settings. To the best of our knowledge, this study is the first to explore the desires of youth and their caregivers regarding web-based patient navigation and a codeveloped potential technology solution; however, additional studies are needed to expand the knowledge about the benefits of web-based patient navigation for youth with childhood-acquired disabilities to support transitions from pediatric to adult care.

Conflicts of Interest

MP received research funding from Autism Speaks, unrelated to this work, and has done paid consulting work with the Province of Nova Scotia, unrelated to this work. SEPM is the Editor-in-Chief of JMIR Rehabilitation and Assistive Technologies and a Guest Co-Editor of Healthcare Transitions.

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Abbreviations

CONNECT: Compassionate Online Navigation to Enhance Care Transitions
COREQ: Consolidated Criteria for Reporting Qualitative Research

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Original Paper

Guiding Principles for Adolescent Web-Based Portal Access Policies: Interviews With Informatics Administrators

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Abstract

Background: Web-based patient portals are tools that could support adolescents in managing their health and developing autonomy. However, informatics administrators must navigate competing interests when developing portal access policies for adolescents and their parents.

Objective: We aimed to assess the perspectives of informatics administrators on guiding principles for the development of web-based health care portal access policies in adolescent health care.

Methods: We interviewed informatics administrators from US hospitals with ≥50 dedicated pediatric beds. We performed a thematic analysis of guiding principles for developing and implementing adolescent portal access policies.

Results: We interviewed 65 informatics leaders who represented 63 pediatric hospitals, 58 health care systems, 29 states, and 14,379 pediatric hospital beds. Participants described 9 guiding principles related to three overarching themes: (1) balancing confidentiality and other care needs, (2) balancing simplicity and granularity, and (3) collaborating and advocating. Participants described the central importance of prioritizing the health and safety of the adolescent while also complying with state and federal laws. However, there were differing beliefs about how to prioritize health and safety and what role parents should play in supporting the adolescent's health care. Participants also identified areas where clinicians and institutions can advocate for adolescents, especially with electronic health record vendors and legislators.

Conclusions: Informatics administrators provided guiding principles for adolescent portal access policies that aimed to balance the competing needs of adolescent confidentiality and the usefulness of the portal. Portal access policies must prioritize the adolescent's health and safety while complying with state and federal laws. However, institutions must determine how to best enact these principles. Institutions and clinicians should strive for consensus on principles to strengthen advocacy efforts with institutional leadership, electronic health record vendors, and lawmakers.

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KEYWORDS

adolescent; patient portal; electronic health records; policy; ethics; portal; portals; adolescents; youth; health record; health records; EHR; EHRs; perspective; perspectives; policies; administrator; administration; informatics; information system; information systems; guidelines

Introduction

Web-based patient portals are widely available tools that can improve patients' sense of control [1-4], adherence [1], and medical understanding [2,3,5]. Portals represent an opportunity to engage adolescents in health care and support their developing autonomy. However, adolescents could experience emotional distress or frustration when reviewing results or clinical notes through the portal, especially if they receive difficult news such as a cancer diagnosis. These portals also risk divulging confidential information to parents that an adolescent has shared with a clinician [6,7]. Adolescents are less likely to communicate transparently with clinicians if they have concerns about confidentiality [8,9]. These concerns could lead adolescents to forgo sensitive medical care that could result in serious health repercussions, such as sexually transmitted infections, unplanned pregnancies, or poor mental health. However, parents often play an important role in managing the adolescent's health, and US public opinion supports parental access to adolescents' health care records [10]. Additionally, most adolescents rely on their parents' support to manage or comanage their health care, especially if the adolescent has a chronic illness [11]. To provide ethical and effective access to adolescent portals, institutions must strive for ideal strategies that balance confidentiality and usefulness [12-14].

The 21st Century Cures Act mandates that US health care systems allow patients access to their electronic health record (EHR) data, typically through web-based patient portals [15]. We previously found that pediatric institutions have used widely varying policies for adolescent portal access across the United States [16]. Although most studies of adolescent portal use have been performed in the United States [17], other countries are similarly providing portal access to adolescents and their parents [18,19]. Variations in portal policy are driven, in part, by adolescent confidentiality laws that vary by state [20]. Each state has unique confidentiality laws with categories of protected information that generally include information about reproductive health, substance use, sexually transmitted illnesses, and mental health [21,22]. However, even within states, health care systems have interpreted the same laws differently, leading to different access policies [16]. Similarly, regulations vary in other countries. For example, the General Data Protection Regulation of the European Union requires a patient to be 16 years old to provide digital consent. The 21st Century Cures Act mandate for transparency has encouraged institutions to further reevaluate these adolescent portal access policies and their interpretation of laws.

Few studies have engaged administrators to understand their perspectives on guiding principles for developing and implementing adolescent portal access policies following the 21st Century Cures Act. Several professional medical societies have published guidelines and policy statements about adolescent portal policies and focused mainly on preserving confidentiality [13,14,23,24]. However, it is essential to understand the perspectives of administrators who are charged with developing and implementing these policies because they have rich experiential insights into the challenges of administrating adolescent portal access in the US health care system. In the United States, these administrators often work in teams that include technical staff and clinicians with informatics expertise. These groups also collaborate with risk management and legal counsel to develop adolescent portal access policies that they perceive to be compliant with state and federal laws. We interviewed 65 informatics administrators from multiple health systems across the United States. Our prior analysis of these interviews characterized the varying adolescent portal policies across the United States [16], as well as approaches to engaging adolescents in using the portal [25]. In this analysis, we aimed to identify guiding principles to inform the development of these policies in the future.

Methods

Overview

We report these findings following the Standards for Reporting Qualitative Research (SRQR) checklist [26] (Multimedia Appendix 1).

Participants and Recruitment

We performed structured interviews with informatics administrators who oversaw adolescent portal access policies. Informatics administrators were eligible if they were involved in developing or implementing adolescent portal policies and if they oversaw a US children's hospital with ≥50 dedicated pediatric beds. Specialty and rehabilitation hospitals were ineligible. We identified children's hospitals using the Children's Hospital Association (CHA) database in January 2022. Of 232 children's hospitals, we excluded specialty or rehabilitation hospitals (n=37), non-US hospitals (n=7), and hospitals with <50 pediatric beds (n=9), yielding 179 eligible hospitals. We recruited participants through 2 email groups of informatics administrators and simultaneously identified contact information for informatics administrators through publicly available data. These email groups included informatics administrators across the United States who opted into the list to communicate with fellow informatics leaders. After initially sending recruitment materials through these email groups and receiving some responses, we then sent targeted emails to administrators at each remaining children's hospital listed in the CHA database. We emailed administrators at every eligible children's hospital to request interviews. We also included administrators from US hospitals with which the authors were affiliated, given the importance of capturing representative data across the United States.

Data Collection

We identified the number of pediatric beds from the CHA database, supplemented with information from hospital websites. We developed a structured interview guide that explored adolescent portal policies, factors influencing the development and implementation of policies, and approaches to engaging adolescents through portals (Multimedia Appendix 2). We specifically asked for advice from other informatics administrators and guiding principles for developing adolescent portal access policies. This interview guide was developed through a literature review and engagement with informaticists. We revised the interview guide with a stakeholder advisory board and 3 informatics administrators. This advisory board included 4 physicians with expertise in informatics, primary care, adolescent medicine, and endocrinology, as well as an adolescent with chronic illness and their parents. In the interview guide, we indicated which questions were essential and which questions could be skipped if insufficient time. However, we were able to ask each pertinent question for the current analysis in every interview. BAS conducted interviews between February and July 2022 via telephone or videoconferencing software. Interviews were audio-recorded and professionally transcribed. Interviews ranged from 12 to 43 minutes.

Data Analysis

Our overall qualitative analysis adhered to the Total Quality Framework, a comprehensive approach that ensures the accuracy, credibility, analyzability, transparency, and usefulness of qualitative findings [27,28]. We used thematic analysis [29] of guiding principles for developing and implementing adolescent portal policies. BAS and ALA developed the codebook. BAS is a pediatric oncologist, ethicist, and communication researcher with training in qualitative research. ALA is an organizational psychologist and ethics researcher with experience and training in qualitative research. Coding involved multiple iterative steps: (1) read transcripts to familiarize themselves, (2) descriptively coded 5 transcripts to formulate preliminary codes, (3) grouped codes into categories and collapsed categories into representative themes, and (4) refined definitions for themes through 3 cycles of independent coding and consensus meetings. After reviewing 25 transcripts, we reached saturation for representative themes. Using this final codebook, BAS, CB, and ME independently coded all transcripts, using these codebook definitions to ensure consistent and reliable application of codes. These authors then reviewed the other's application of codes, marked disagreements, and resolved disagreements through discussion. We used Dedoose (SocioCultural Research Consultants) qualitative software.

Ethical Considerations

The institutional review board at Washington University determined this study was exempt. We obtained verbal informed consent. All transcripts were deidentified prior to analysis.

Results

Participant and Health Care System Characteristics

We identified 179 eligible pediatric hospitals and contacted an informatics administrator at every eligible center. We interviewed 65 informatics experts representing 63 hospitals across 58 health care systems. Thus, participants represented 35% of all US children's hospitals with more than 50 dedicated pediatric beds. EHRs from all participating health systems had web-based health portals in pediatrics. The number of dedicated pediatric beds in participating hospitals ranged from 51 to 664 (median 189, IQR 107-313) beds. In total, participants represented systems with 14,379 dedicated pediatric beds across 29 states plus Washington, District of Columbia (Table 1). The majority of health care systems used Epic EHR systems.

Table 1. Characteristics of participants and represented health care systems.

Characteristic	Values
Professional role of participant (n=65), n (%)	
Chief medical information officer	34 (52)
Clinical informaticist	15 (23)
Chief information officer[a]	3 (5)
Other[b]	13 (20)
Type of electronic health record (n=58), n (%)	
Epic	41 (70)
Cerner	9 (16)
Multiple	5 (9)
Allscripts	1 (2)
Other	2 (3)
Pediatric-specific informatics team (n=58), n (%)	
Yes	31 (53)
No	27 (47)
Pediatric-specific instance of EHR[c] (n=58), n (%)	
Yes	20 (34)
No	38 (66)
Number of dedicated pediatric hospital beds (n=58)	
Range	51-664
Median (IQR)	189 (107-313)
Age of adolescent access (years; n=58), n (%)	
No access provided	8 (15)
10	1 (2)
11	2 (3)
12	14 (24)
13	21 (36)
14	7 (12)
15	2 (3)
16	1 (2)
Unsure	2 (3)
Are parents permitted proxy access? (n=58), n (%)	
Yes	55 (95)
No	3 (5)
Are adolescents permitted access? (n=58), n (%)	
Yes	43 (74)
No	8 (14)
Unsure	7 (12)

[a] Includes 1 participant who identified as a director of health information systems.

[b] Other roles included pediatric service line lead, director of nursing informatics, director of quality, certified analyst, adolescent physician, director of clinical analytics, medical director of informatics, chief medical officer, and clinician champion.

[c] EHR: electronic health record.

Guiding Principles and Advice for Developing Adolescent Portal Access Policies

Overview

Participants described 9 guiding principles related to three overarching themes: (1) balancing confidentiality and other care needs, (2) balancing simplicity and granularity, and (3) collaborating and advocating. We describe each of these themes and principles in Table 2 and subsequent sections.

Table 2. Subtheme definitions for guiding principles for developing and implementing adolescent portal policies.

Themes and subthemes	Representative excerpts
Balancing confidentiality and other care needs	
Provide appropriate transparency while complying with state and federal laws	Compliance with laws and regulations was noted as an essential requirement for any portal policy. The overarching goal of improving transparency was shared by nearly all administrators, but there were differences in how to achieve this transparency in ethically and legally acceptable ways. Administrators described the vagueness of these laws and several instances with state and federal laws are in conflict. As a result, administrators described the importance of developing a productive, collegial working relationship with the institutional compliance office and legal counsel.
Prioritize adolescent health and safety	Administrators strongly believed that all policies should aim to ensure the health and safety of the adolescent. However, health and safety could sometimes be in conflict. For example, some adolescents might need parental involvement to help them manage complex disease. Other adolescents might be unsafe if their parents see sensitive information, such as drug use, gender identity, or sexual activity.
Preserve clinician-adolescent relationship	Administrators highlighted the importance of ensuring that portal policies support rather than strain the clinician-adolescent relationship. Clinicians especially needed to honor their promises of confidentiality or they would risk losing the adolescent's trust.
Support adolescent's developing autonomy	Although administrators had disagreements about what level of access is appropriate or mandated for parents, most administrators expressed that adolescents should have access to as much of their own information as possible. Not only do adolescents have a right to learn about their own health, but administrators believe that this access could support the adolescent's development into adulthood and self-management.
Balancing simplicity and granularity	
Strive for appropriate granularity in the differential sharing of health information	Administrators generally agreed that some granularity in the ability to determine which information is shared with parents versus adolescents is ideal. Some described an ideal in which adolescents could determine each type of information that is shared with their parents. However, technological limitations created barriers for differential sharing, especially at centers with smaller pediatric populations.
Ensure the end product is useful for families	Administrators urged vendors and institutions to ensure the user interface was user-friendly and provided meaningful information for parents and adolescents. They also described how it was important to make sure information was understandable to families. Simply providing access was not sufficient. Additionally, administrators urged against the view of the portal as a panacea for all communication and information challenges.
Collaborating and advocating	
Engage key stakeholders within the institution	Administrators emphasized the importance of engaging with leadership, informatics workforce, legal or compliance officers, clinicians, frontline staff, parents, and adolescents in developing and implementing access policies. Additionally, they encouraged the ongoing engagement of these parties after implementation to ensure the system continues to meet all parties' needs.
Collaborate with colleagues at other institutions	Given the uncertainty and vagueness of state and federal laws, administrators encouraged other administrators to communicate with colleagues at other institutions to understand the variety of approaches to adolescent portal access. This collaboration was especially important to understand how other hospitals in the same state were interpreting the laws.
Advocate with external parties for adolescent and pediatric issues	Many of the conditions influencing adolescent policies originated outside of the institution, especially state laws, federal policies, and EHR[a] functionality. It is imperative for health care institutions to advocate with these external parties to support safe and transparent sharing of adolescent medical information through portals.

[a] EHR: electronic health record.

Balancing Confidentiality and Other Care Needs

Provide Appropriate Transparency While Complying With State and Federal Laws

State-level confidentiality laws varied widely across states, leading to policies that varied in the amount of authority parents have to access their child's medical information through the portal. The federal mandate against information blocking did not specify how this mandate applied to adolescent health, and the federal law specifically defers to state laws in these matters. Furthermore, federal and state laws were written vaguely, and some perceived the state and federal laws to be in conflict. For a detailed analysis of state-by-state variability, see Sharko et al [22]:

> *It was a lesson learned how really poorly written state laws are. Whether it's state or federal or regulations, you think it would spell out exactly what you need to do, but it's not that way at all. That 1,250-page*

> *behemoth that [Office of the National Coordinator for Health Information Technology] produced only muddied the waters even further. We really don't know what they're really expecting and they're not.* [Participant #181, chief medical information officer]

Participants described how adhering to state laws was a critical foundation for any portal access policy for adolescents:

> *We have an affirmative requirement to protect certain information and not violate the state laws of [our state]. That is, obviously, something we take extremely seriously.* [Participant #176, chief medical information officer]

Given the complexity, variation, and vagueness of state laws, participants expressed the essential role of institutional legal and compliance officials:

> *There are many regulations that are conflicting, and it's really important to ensure that you are looping in your compliance and legal folks...because ultimately, there's just laws that are in conflict.* [Participant #26, chief information officer]

However, the recommended approaches to complying with confidentiality laws varied. While participants described the need to balance transparency and confidentiality, some participants emphasized the importance of prioritizing the adolescent's confidentiality over transparency and limiting access for both parents and adolescents because this was the "path of least resistance" (participant #78, clinical informaticist), technically easier, and satisfied the concerns of legal and compliance administrators. Additionally, some participants expressed their beliefs that state laws provided protection if they opted to restrict information from both parents and adolescents:

> *We have not increased access for adolescents...We would defend it based on state laws about confidentiality. If there's state laws that supersede some of the Cares Act, we can seek protection behind those.* [Participant #78, clinical informaticist]

Conversely, others emphasized the importance of transparency:

> *I think that the default assumption should be that teens can access all their own information, and that parents can access all of their kids' information, except that that's protected by adolescent health laws.* [Participant #153, chief medical information officer]

Some participants also described the "importance of parents knowing what's going on with their [adolescent]" (participant #93, chief medical information officer).

> *We can't disconnect the parents from the non-confidential information. I think it's so important and key for them to be able to continue to meaningfully provide care and safely provide the care that's required for their adolescent. Disconnecting them from that information, I think, is just the wrong thing to do.* [Participant #172, chief medical information officer]

However, this point was discussed less frequently than the importance of preserving transparency. Some participants recommended that adolescents should be empowered to determine this balance of transparency and privacy by determining what level of access their parents are permitted: "I think having it be in the adolescent's hands to determine what their parents have access to and to be the ones in control of that I think is the right approach" (participant #119, chief medical information officer). Participants in other states, however, explained that such an approach might conflict with their state laws that provided parents with rights to access these data.

Prioritize Adolescent Health and Safety

In addition to adhering to the law, participants described how the adolescent's health and safety must be the other central guiding principle for portal access policies: "To me, the guiding principle is always what's the safety of the patient and what's in their best interest" (participant #26, chief information officer). Furthermore, some participants described the need to prioritize the adolescent's health needs over the legal concerns of the institution:

> *Focus on the patient, not on the lawyers. If we can, again, try and stay focused on what is gonna help us take care of the patients, why do we want to be transparent with this information, understand that nobody is out to get us...Frankly, the government doesn't have the resources to do any kind of investigation anyway.* [Participant #112, chief medical information officer]

However, there were differing beliefs about how to prioritize health and safety. For some participants, supporting health requires transparent disclosure of high-quality information to both adolescents and their parents.

> *Information is powerful. Information helps improve communication, helps improve health outcomes, helps improve quality.* [Participant #57, chief medical officer]

Additionally, some participants reiterated the need to incorporate parents in the adolescent's health care, especially for adolescents with serious illness:

> *I do think for other health conditions, we want to be careful not to set barriers to where the parents can be helpful in helping that adolescent manage those conditions. It's very much a balancing act.* [Participant #176, chief medical information officer]

Others, however, described how limiting parental access might be necessary to ensure the adolescent's safety, for example, if they were at risk of abuse from parents following disclosure of sensitive information:

> *At the very top of the pyramid is patient. All of our decisions, we try to keep that in mind. That's where, even though I may get frustrated that sometimes there's access that's decreased for my parents, if it means that it's providing the actual patient a little bit more security and privacy, then I'm able to appreciate that this is really what's best for them.* [Participant #38, chief medical information officer]

Still, others were uncertain about how to determine what portal policy is best for adolescents:

> *Yeah. I think it should be about patient—what's best for the patient. I think that should be—to me, it's pretty simple. Now, that's a complex part, right? How much information do you divulge? What do they keep from their parents? What's the right thing to do? The more ethical issues there, which I don't have an answer to but, I think, at the end of the day, what's gonna promote the best health for child and adult?* [Participant #140, chief medical information officer]

Preserve Clinician-Adolescent Relationship

Participants advised clinicians to recognize that adolescents have a right to their own relationship with their clinician:

> *At the end of the day, we wanna protect their information and their relationship with their provider...I struggle because, as a parent, I want to have access to my child's information, but I also realize it's their relationship as well, so, I guess, just protecting their—I don't know—right to have that relationship with a provider.* [Participant #167, chief medical information officer]

The trust established in this relationship is essential to engaging adolescents in their care and bolstering the long-term clinical relationship: "I think if [trust is] fractured, then it's difficult to have an ongoing good relationship with that teenager" (participant #20, chief medical information officer). This trust relies on clinicians honoring their promises of confidentiality:

> *If we tell them that a conversation is private, it truly is private and that we honor that, and that there is a mechanism for that to truly be information that we do not share without their consent. Otherwise, they're just never going to trust us. They're not gonna trust giving us that information or really feeling comfortable engaging with a portal.* [Participant #172, chief medical information officer]

Support Adolescent's Developing Autonomy

Supporting and developing the adolescent's autonomy were also goals of many participants:

> *Patient access to patient portals has a lot of positives, and I think one that gets overlooked is patients taking ownership of their own health care because the portal allows them to learn about themselves at an earlier age, learn what their diagnoses are, what their medications are, who their providers are...I think it'll help patients understand more about themselves, communicate better with health care professionals, and make them an active participant in their health care.* [Participant #57, chief medical officer]

They viewed portals as a teaching tool to support the independence of the adolescents:

> *The portal, I think for the adolescent group, is a way to increase engagement and to, hopefully, teach some of these skills that are going to be lifelong skills. This is like a really pivotal time, and I think we're missing the opportunity, from that perspective.* [Participant #10, clinical informaticist]

However, the role of the adolescent must be adapted to their level of development and interest:

> *We can't expect a 14-year-old to manage their Type I Diabetes or their own Inflammatory Bowel Disease, but I do think that by giving them access, it does kind of help them take that next step in owning the management of their current diseases.* [Participant #138, clinical informaticist]

In addition, policies should not force responsibilities on the adolescent if they are not ready or willing to manage their health:

> *For adolescents that truly want to manage their own health care and want to be engaged to that degree, then they should be the primary user of the portal, with the parent being in a supporting role. On the flip side, if you have a parent and a child relationship where the parent really is managing everything, then they need to retain that.* [Participant #181, chief medical information officer]

Some participants described the importance of guidance and guardrails to ensure adolescents remain safe. For some participants, the ideal guardrail is comanagement of care between the parent and adolescent, with graduated responsibility for the adolescent over time. Without this support, adolescents might be unable to sufficiently manage their health care:

> *Is a 13-year-old ready to make their own medical decisions? There's probably a handful who are, but there's probably a lot more who struggle with that. I know certainly my kids at 13 wouldn't have been able to manage their own care.* [Participant #133, chief medical information officer]

Balancing Simplicity and Granularity

Strive for Appropriate Granularity in Differential Sharing of Health Information

Many participants described the need for technological advancements that will permit differential sharing of information between the parent and adolescent:

> *Technology needs to evolve so that parents can be engaged, and teens have the ability to actively, through portals, decide what they're gonna share and not share because every relationship between a teen and their parents is different and can change on a moment's notice.* [Participant #176, chief medical information officer]

The adolescent would ideally control this access, perhaps through widgets on their portal that do not require clinician actions:

> *I would put the widgets for access right on the portal for the adolescent to control in addition to reupping having an active process for re-upping. I would also make it more autonomous that they can manage the access independently. They don't have to go through us.* [Participant #60, chief medical information officer]

Some participants believed that adolescents with complex needs might need different or modified privacy settings to ensure that the child's medical problems are sufficiently managed:

> *I think that we try to make it as simple as possible, and this is a rather complex issue. I think that we probably need another type of access for those patients with chronic medical care needs, or if we could pick and choose more easily which things a child was letting their parent see, I think that would make it a little bit easier, and I think I would be more satisfied with it.* [Participant #38, chief medical information officer]

With this granular sharing, however, some participants worried that allowing the adolescent to censor certain health information might be considered information blocking or might conflict with state laws that consider the medical record to be the parent's property: "When you cross over into that world where you're now blocking certain elements from the parent, then you possibly fall into information blocking" (participant #98, clinical informaticist). Another participant further elaborated:

> *I think that to be fully compliant with the Cures Act and the need to prevent information blocking, we should really only be selectively not sharing that information with the proxy, the third party [and adolescents should retain access to this information]. Right now, at least in our system, we only really have the ability to either have it appear in the portal or not appear in the portal [for both the adolescent and proxy]...That seems unfair to adolescents 'cause those may be the things they most care about.* [Participant #119, chief medical information officer]

Conversely, other participants worried that more granular sharing was required to comply with the Cures Act because many health care systems were withholding information from adolescents. To achieve this granularity, a participant encouraged other administrators to "figure out your needs, and then design backwards from that" (participant #52, chief medical information officer).

Ensure End Product Is Useful for Families

In addition to the focus on portal access and privacy issues, participants also emphasized the importance of focusing on the user experience to ensure the portal is useful. Participants noted that registration processes needed to be simplified and streamlined to encourage portal use:

> *Making our consent form electronic. Instead of having to come in and sign a piece of paper, that process is now online. You can sign up for a patient portal account through an electronic form. You can upload a picture of your driver's license, and that has made all the difference in helping people get enrolled with a patient portal account.* [Participant #167, chief medical information officer]

However, many of the barriers to streamlined enrollment were related to identity verification to ensure parents were not registering for their adolescent's account. Furthermore, some participants described the need to engage adolescent end users to ensure the interfaces are user-friendly:

> *In general, I'm not sure if people have set about to do studies from the patient perspective, on how difficult or easy it is to use any of these personal health records or the portals that they have, so there's a lot of improvement that could be done in terms of making these user-friendly.* [Participant #116, chief medical information officer]

Collaborating and Advocating

Engage Key Stakeholders Within the Institution

When developing policies, participants stressed the importance of engaging multiple stakeholders within the health care institution, clinical teams, and families to ensure the policies were responsive to the needs of these parties and as broadly acceptable as possible: "Communication, communication, communication, get everybody involved early and speak to all the people who were involved" (participant #121, clinical informaticist). Stakeholders included teens, parents, legal and compliance teams, clinicians, informaticists, information technology support staff, and other frontline staff involved in registration and enrollment. Participants advised multiple approaches to engaging families, including advisory boards, open forums, and satisfaction surveys:

> *If you don't have a family advisory board or a teen advisory board, that is really key. Then I also think just having open forums to hear what people say because we're not perfect.* [Participant #167, chief medical information officer]

Yet, some participants felt that the adolescent voice was lacking at their institution:

> *I don't think there's any adolescent voices being represented. I think there's a lot of parental voices being represented, but I don't think in our situation, I don't think that there's any—there's ever been a teen at the table in adolescent practices even in creating clinic culture.* [Participant #144, clinician]

Within the clinical team, participants advised administrators to consider differences in practice patterns and patient populations when developing and implementing policies:

> *We had to have a working group with legal, with experts in adolescent care, and really with care providers from different venues. Outpatient versus ED, versus urgent care, versus inpatient are all very different sets of episodes of care, and information types. The needs and perspectives, the providers are also gonna be different.* [Participant #153, chief medical information officer]

One participant described the need to continue tracking the expected and unexpected outcomes of policies after implementation:

> *Put this on your agenda regularly. How are we accomplishing this, and what are our gaps? For our organization, I feel like we—and how are we gonna*

> *continually assess it? We are not successfully doing that.* [Participant #163, chief medical information officer]

Another important aspect was collaborating with hospital administration to understand organizational priorities to most effectively advocate for adolescents:

> *Know what your state laws are but also know what are your guiding principles as an organization with respect to adolescent health. Those might be in conflict. Then you have to determine what is your risk tolerance when it comes to that.* [Participant #20, chief medical information officer]

Collaborate With Colleagues at Other Institutions

Given the multiple challenges inherent in developing and implementing portal policies for adolescents, participants emphasized the importance of collaborating and sharing best practices with colleagues. Additionally, some participants noted how institutions within the same state are implementing very different policies. As such, some participants called for institutions within states to strive toward consensus on a common approach, even though consensus would be difficult to reach:

> *I would say that to the extent you can within your state, come together across institutions and try to at least discuss a common approach...I think some uniformity agreements which is straight in will never get there, but it's great to strive for.* [Participant #180, chief medical information officer]

Furthermore, institutions should share their best practices with other institutions:

> *Then I would encourage institutions to share best practice. If something's working put it out there so that other people that are using the same EHR can see what you're doing and learn from it as well.* [Participant #37, clinical informaticist]

Finally, a participant from an integrated health system advised informatics leaders from major academic pediatric hospitals to consider smaller pediatric centers with fewer resources when recommending standards and policies:

> *The big pediatric institutions in the country, I would ask that they really think about where and how a lot of pediatric care is delivered in the country...How do we help the great work that's happening at some of the big, pediatric centers from that standpoint really get into these other places in the country that are providing lots of pediatric care?* [Participant #36, clinical informaticist]

Advocate With External Parties for Adolescent and Pediatric Issues

Participants described the need to pressure EHR vendors to develop necessary technical functions in the EHR, especially related to granular differential sharing of content between adolescent and proxy portals. Currently, each health system has to modify its EHR instance to meet these unique sharing needs, and the capacity to differentially share information between proxy and adolescent portals is limited:

> *I think the other thing is to continue to pressure the vendors to make this easier to do out of the box, and that's really where the CEOs have the ear of the leads of the vendor, EHR vendors, and so really to push that this is something that needs to be really addressed at the vendor level. It's crazy for us all to be doing our own build on this.* [Participant #155, chief medical information officer]

Additionally, participants described the need to advocate and lobby legislators to improve laws and regulations by adding specificity around the type of sharing required, age of adolescence, and parental and adolescent rights: "Encourage Uncle Sam [United States Government] to write rules that make sense specific to the pediatric population" (participant #109, chief medical information officer). One participant described the importance of engaging with legal counsel that was external to the hospital, to avoid being "stuck in an institutional echo chamber" (participant #158, clinical informaticist). To support these advocacy efforts, 1 participant called for guidance from national organizations:

> *It would be really great if one of our professional organizations would come forward, like the [American Academy of Pediatrics] and say like, "This is what we believe," in the context of information blocking and the Cures Act...If you could refer to some external expert body...I think it would really lend that extra weight.* [Participant #90, chief medical information officer]

Discussion

Informatics administrators described guiding principles that aimed to maximize transparency while complying with laws, respecting parental roles, protecting the adolescent's health and safety, and ensuring that the portal remains a useful tool. These overarching guiding principles align well with prior policy statements from professional organizations, providing an evidence base to support these statements. For example, the American Academy of Pediatrics advised health care institutions to ensure medical teams are "aware of state and federal requirements and to assist them in complying with standards, rules, and regulations" [23]. The Society for Adolescent Health and Medicine described the crucial importance of institutions determining which information will be shared with patients and proxies, as well as ensuring this information sharing complies with the 21st Century Cures Act Final Rule. This organization specifically recommended that clinicians and institutions know and abide by state and federal laws and advocate on behalf of the adolescent with key stakeholders within and outside of the institution [24]. The American College of Obstetrics and Gynecology similarly called for awareness and compliance with pertinent laws, while ensuring adolescents have the ability to have private, confidential communication with their obstetrician-gynecologists. Additionally, they advised clinicians to be aware of their institution's policies and capabilities regarding confidentiality when they are documenting sensitive information [14].

While we observed general agreement on many of these overarching principles, these goals can be conflicting when put into practice. For many adolescents with chronic illness, for example, providing parents with information is essential to support that child's complex care needs. Yet, technological limitations and interpretations of state laws led many institutions to limit parental access to information that is essential to support the adolescent [16]. Furthermore, the usefulness of portals is greatly diminished when institutions limit available information. For example, we previously found that some institutions shut down the portal completely during adolescence for parents and adolescents, and other institutions only provide minimal information such as vaccination status and vital signs [16]. Contrarily, other adolescents might need information withheld from their parents to protect them from abuse or harm. Inadvertent disclosure of sensitive information can subvert the adolescent's right to privacy, diminish trust in clinicians, and decrease the adolescent's transparent engagement with the health care system [6,8,9,30]. Furthermore, some adolescents might forgo sensitive care (ie, sexually transmitted infections, pregnancy, and drug abuse) if they are not guaranteed confidentiality. Some participants described how adolescents should be empowered to decide on this balance between confidentiality and usefulness by determining how much access they will permit their parents. Yet, some institutions considered this practice to be in conflict with their state's laws.

While it is important to ensure adolescent's confidentiality, the role of parents in supporting adolescents must not be ignored. Most adolescents rely on their parents for medical management, insurance and financial support, transportation, assistance in decision-making, emotional support, and consent to treatment [11]. Furthermore, some adolescents have limited interest in using portals, scheduling appointments, filling prescriptions, and managing other aspects of care. For adolescents with serious or debilitating illness, this reliance on parents can be even greater. Depending on each adolescent's unique situation, protecting privacy can either be essential to providing safe and effective health care or a major barrier to health and safety. When developing policies, the beneficial role of parental involvement must be weighed against the potential harms of inadvertent disclosure. To the extent possible, administrators should leverage available technology to minimize these disclosures while also allowing adolescents to involve parents in their health care to the extent desired or required by law.

These data highlight several targets for ongoing advocacy efforts, further supporting prior calls for advocacy in this area [24]. Within each institution, pediatricians can advocate with institutional leaders to ensure policies are informed by the adolescent's best interests and the voices of key stakeholders. To address technological limitations, institutions can advocate with EHR companies to develop tools and workflows to permit differential sharing of information to the adolescent and proxy. Pediatricians and pediatric institutions can also advocate with lawmakers at the state and federal levels to support legislation that is informed by the experiences of adolescents, parents, and clinicians. Future studies should aim to capture the perspectives of adolescents and parents to better inform these advocacy efforts. To strengthen these advocacy efforts, health care institutions within and across states should attempt to align policies and priorities to the extent possible. While many participants described myriad challenges to gaining a national consensus, intrastate consensus should be more feasible, since all institutions are responding to the same state laws.

This study has limitations that should be considered. We limited enrollment to hospitals with at least 50 dedicated pediatric beds, which could underrepresent the challenges of hospitals in integrated health systems with a smaller pediatric presence. Our results could be biased toward larger pediatric hospitals, which could limit the representativeness of our data. Also, participants could have moderated their responses during interviews due to social desirability bias. Furthermore, we did not design this study to evaluate specific characteristics of different EHR platforms, which could have provided additional practical information.

Informatics administrators provided guiding principles for adolescent portal access policies that aimed to balance the competing needs of adolescent confidentiality and the usefulness of the portal. As bedrock principles, these policies must prioritize the adolescent's health and safety while complying with state and federal laws. The main limiting factors in balancing these priorities were technological limitations and institutional interpretations of laws. Although most participants agreed on broad principles, we observed disagreements about how to specify the principles into policies. Institutions and clinicians should strive for consensus on principles to strengthen advocacy efforts with institutional leadership, EHR vendors, and lawmakers.

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Authors' Contributions

BS participated in the conceptualization, design, and implementation of the study; participated in formal analysis; drafted the initial manuscript; and reviewed and revised the manuscript. CB and ME participated in the design of the study, facilitated the acquisition of data, participated in formal data analysis, and critically reviewed and revised the manuscript. ALA, FB, and JD participated in the conceptualization, design, implementation of the study; participated in formal analysis; and reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Standards for Reporting Qualitative Research (SRQR) checklist.
[DOCX File , 21 KB - pediatrics_v7i1e49177_app1.docx]

Multimedia Appendix 2
Interview guide.
[DOCX File , 20 KB - pediatrics_v7i1e49177_app2.docx]

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Abbreviations

CHA: Children’s Hospital Association
EHR: electronic health record
SRQR: Standards for Reporting Qualitative Research

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Original Paper

Chest X-Ray–Based Telemedicine Platform for Pediatric Tuberculosis Diagnosis in Low-Resource Settings: Development and Validation Study

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Abstract

Background: Tuberculosis (TB) remains a major cause of morbidity and death worldwide, with a significant impact on children, especially those under the age of 5 years. The complex diagnosis of pediatric TB, compounded by limited access to more accurate diagnostic tests, underscores the need for improved tools to enhance diagnosis and care in resource-limited settings.

Objective: This study aims to present a telemedicine web platform, BITScreen PTB (Biomedical Image Technologies Screen for Pediatric Tuberculosis), aimed at improving the evaluation of pulmonary TB in children based on digital chest x-ray (CXR) imaging and clinical information in resource-limited settings.

Methods: The platform was evaluated by 3 independent expert readers through a retrospective assessment of a data set with 218 imaging examinations of children under 3 years of age, selected from a previous study performed in Mozambique. The key aspects assessed were the usability through a standardized questionnaire, the time needed to complete the assessment through the platform, the performance of the readers to identify TB cases based on the CXR, the association between the TB features identified in the CXRs and the initial diagnostic classification, and the interreader agreement of the global assessment and the radiological findings.

Results: The platform's usability and user satisfaction were evaluated using a questionnaire, which received an average rating of 4.4 (SD 0.59) out of 5. The average examination completion time ranged from 35 to 110 seconds. In addition, the study on CXR showed low sensitivity (16.3%-28.2%) but high specificity (91.1%-98.2%) in the assessment of the consensus case definition of pediatric TB using the platform. The CXR finding having a stronger association with the initial diagnostic classification was air space opacification (χ21>20.38, *P*<.001). The study found varying levels of interreader agreement, with moderate/substantial agreement for air space opacification (κ=0.54-0.67) and pleural effusion (κ=0.43-0.72).

Conclusions: Our findings support the promising role of telemedicine platforms such as BITScreen PTB in enhancing pediatric TB diagnosis access, particularly in resource-limited settings. Additionally, these platforms could facilitate the multireader and systematic assessment of CXR in pediatric TB clinical studies.

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KEYWORDS

telemedicine; telehealth; pediatric tuberculosis; tuberculosis; screening; chest radiograph; usability; low-resource settings

Introduction

Tuberculosis (TB) is a communicable disease caused by *Mycobacterium tuberculosis*. According to the World Health Organization (WHO), TB remains one of the leading causes of death globally from a single infectious agent, with over 1.6 million TB-related deaths reported in 2021 [1]. Alarmingly, most children who succumb to TB are never diagnosed or treated [2]. The risk of death is notably high (44%) among children under 5 years with untreated TB, while less than 1% of children receiving recommended treatment die [3].

The diagnosis of TB in children is complex, especially in infants and young children, where the risk of rapid disease progression and mortality is higher than in any other age group [4,5]. The paucibacillary nature of TB in this age group and the absence of highly sensitive point-of-care diagnostic tests to microbiologically confirm pediatric TB make diagnosis challenging [4]. Chest x-ray (CXR) remains a valuable diagnostic tool for TB in children, especially when laboratory testing is unavailable, infeasible, or yields negative results. Most children with pulmonary TB exhibit radiographic changes indicative of TB. For children under 5 years, anteroposterior (AP) and lateral (LAT) views are recommended, while posteroanterior (PA) CXRs are preferred for older children and adolescents [6]. The LAT radiograph is particularly useful in children under 5 years for the optimal evaluation of hilar or mediastinal lymphadenopathy [7]. CXR findings in children with pulmonary TB may lack specificity [8], and CXR alone is insufficient to determine the appropriate treatment for the child. Instead, CXR can support the clinical diagnosis of pulmonary TB when TB is presumed and microbiological testing is negative.

Screening tests using symptoms or CXR may be useful in children who are TB contacts or living with HIV [2]. According to Vonasek et al [2], any abnormality identified on CXR appears to be the most accurate screening test for pulmonary TB in children, although this accuracy can be influenced by the quality of the CXR and interreader variability. In a recent study [9] involving a cohort of HIV-negative children, the majority of whom (92%) were under 5 years old, a treatment-decision algorithm was proposed for low-resource countries. In these settings, CXRs are reserved to confirm diagnoses in patients lacking sufficient clinical evidence to initiate treatment. The WHO guidelines underscore the necessity for further research concerning integrated treatment-decision algorithms [6]. This highlights the crucial importance of promoting research aimed at improving and validating these tools within the pediatric context, thus facilitating informed recommendations in this area [9,10].

Assessing disease severity in children is essential for determining their eligibility for the recommended 4-month treatment regimen for nonsevere TB in children and adolescents aged 3 months to 16 years. CXRs serve as a valuable tool for this purpose. Furthermore, recent WHO guidelines [6] emphasize that CXRs can assist in evaluating treatment response and identifying alternative diagnoses in children who do not respond to TB treatment.

The limitations in accessibility and sensitivity of available diagnostic tests for childhood TB are probable reasons for the gap between the estimated 1.17 million annual incident child TB cases, of which less than half are diagnosed or reported to the WHO [6]. This gap is even more pronounced for children under 5 years old. Additionally, the COVID-19 pandemic has decreased access to TB diagnosis and treatment, particularly affecting children and young adolescents, resulting in a significant decrease in notifications for younger age groups. To address these challenges, the End TB Strategy outlined by the WHO emphasizes the importance of leveraging enhanced digital health tools for more efficient delivery, monitoring, and evaluation of TB patient diagnosis, treatment, and care [11,12]. Telemedicine tools could play a crucial role in enhancing accessibility for diagnosis and treatment. Previous studies have shown that telemedicine can be beneficial in optimizing the care of multidrug-resistant TB in resource-limited settings [13]. Moreover, providing specialist expertise directly through telemedicine tools in low-resource settings has not only improved patient management but also provided additional educational value to local physicians, thereby benefiting other patients as well [14].

In this paper, we introduce a novel telemedicine web platform called BITScreen PTB (Biomedical Image Technologies Screen for Pediatric Tuberculosis), designed for the assessment of pediatric TB using digital CXR images and clinical information. The platform aims to facilitate remote interpretation, streamlining, and standardizing the clinical evaluation of pediatric TB cases, particularly in resource-limited settings where access to expert readers may be limited. The platform underwent functional evaluation in a pilot study conducted by 3 independent expert readers (RSJ, JLR, and HSS). This evaluation involved a retrospective assessment of a data set comprising 218 examinations of children under 3 years of age, selected from a previous study conducted in Mozambique [5,10]. Furthermore, based on the results of the evaluations conducted through the platform in the pilot study, we present new insights into its performance, the agreement among evaluators, and the challenges associated with the assessment of pediatric TB using CXR images, considering various radiological findings.

Methods

BITScreen Platform

BITScreen is a store-and-forward telemedicine platform built using a Model-View-Controller (MVC) design pattern, implemented on open-source frameworks and tools by JJGV. The MVC design pattern offers a modular and scalable structure for organizing and building software applications, facilitating efficient development, maintenance, and expansion of the platform. In an MVC application, the "View" is responsible for presenting information to the end user, while the "Controller" manages the user's interaction using the data stored and organized in the "Model." The primary functional requirement of the platform is to facilitate asynchronous medical evaluation of pediatric TB studies. This involves assessing clinical data and CXR images, optionally including corresponding clinical symptoms. The global requirements identified in the design of the system are listed in Textbox 1.

Textbox 1. Global requirements identified in the system design.

- Multistudy

The capacity to perform multiple clinical projects simultaneously.

- Multicenter

The system must allow the participation of multiple medical centers and admit many-to-many relationships between medical centers and projects/studies.

- Multidevice

Web-based access to the views of the platform, which allows its use in different devices through an internet browser.

- Security

The platform must warrant security in terms of authentication, confidentiality, and integrity in compliance with European regulations.

- Cloud Storage

The system must enable the secure storage of images, tests, and reports associated with the project in a remote environment.

Figure 1 illustrates the unified modeling language use case diagram, which delineates the interaction between users and the system. The user roles include the examiner, responsible for patient management and creating new examinations; the evaluator, tasked with assessing studies by identifying potential TB-related findings in CXR images; and the administrator user, responsible for managing user and medical center access. Additionally, the administrator defines examiners (individuals who examine patients) and evaluators (individuals who assess CXRs) and monitors the progress of evaluations.

Figure 1. Use case diagram of the BITScreen PTB (Biomedical Image Technologies Screen for Pediatric Tuberculosis) platform with the 3 roles considered (examiner, evaluator, and administrator) and the operations associated with them. All the “Manage” operations included the suboperations new, edit, and delete.

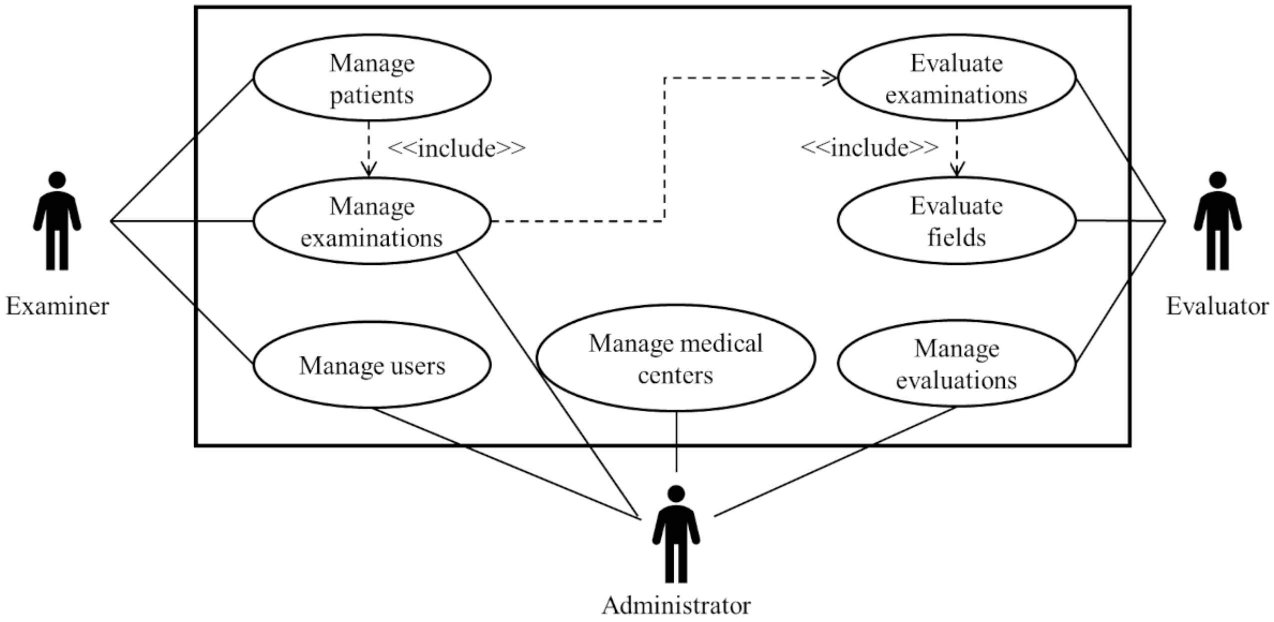
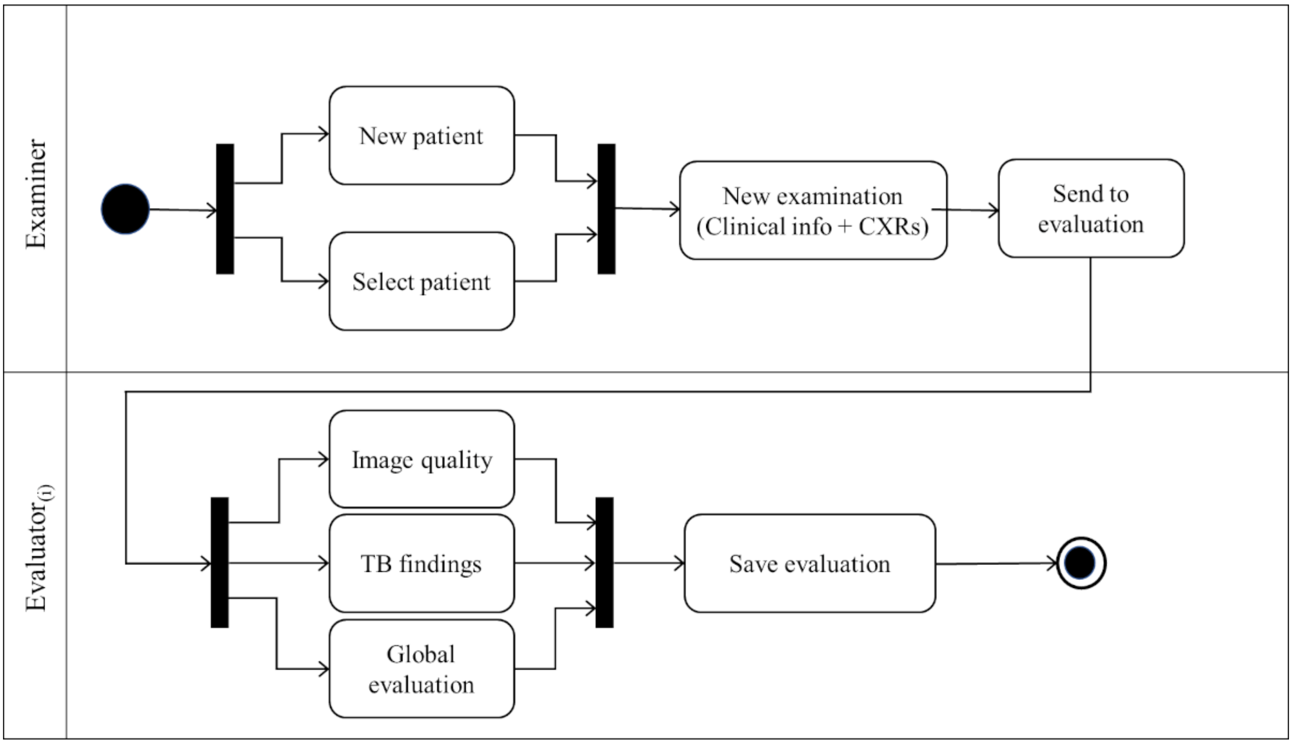


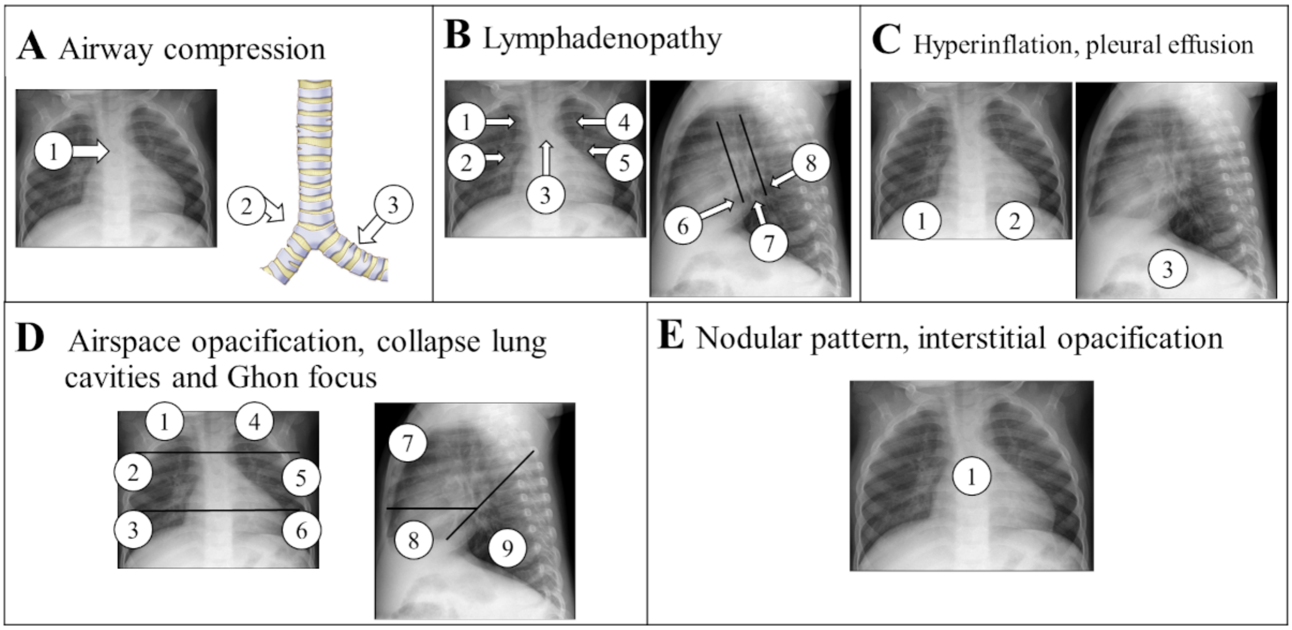
Figure 2 displays the activity diagrams designed to illustrate the process of uploading a new examination to the platform by an examiner, incorporating clinical information and CXR images, as well as the subsequent transmission of the corresponding examination to be evaluated by an evaluator user. The input fields included by the examiner to create a new examination were month and year of birth, date of the examination, cough, fever, malnutrition, HIV status, BCG (Bacillus Calmette-Guérin) vaccine scar, tuberculin skin test, TB diagnosis, TB contact, TB treatment, treatment starting date, and the CXR images (AP or PA and LAT views). In our pilot study, only the CXR images were presented to the evaluators. The patient’s age was determined based on the month and year of birth in relation to the acquisition date of the CXR. The examiner is required to upload at least one AP or PA view CXR image, with the LAT view being optional if available. In this pilot study, only evaluators were granted access to the CXR images. In the evaluation process, the platform was designed to include the assessment of the image quality of the CXR images; the identification of pulmonary TB radiological findings in various regions of the lungs, considering different types of findings; and a global evaluation of the CXR examination. In Figure 2, only 1 evaluation is depicted, but the platform allows for multiple evaluations (in our platform validation, we included 3 evaluations for each examination). If more than 1 evaluation is configured, the evaluation process of the examination will not conclude until all evaluators have completed their assessments within the platform.

Figure 2. Activity diagram of the process for creating and evaluating a new examination including the clinical information about the patient and the chest x-ray (CXR) images (anteroposterior or posteroanterior and lateral views). TB: tuberculosis.



The evaluation of CXR images is pivotal for identifying presumed patients with TB and constitutes a primary focus of the platform’s design. To ensure a comprehensive and rigorous assessment of the CXR images, evaluators are required to indicate “yes” or “no” to assess the presence or absence of various radiological TB findings across different thoracic locations. For this purpose, we divided the assessment into 10 sections corresponding to different types of findings, resulting in a total assessment of 55 independent observations, with 36 from the AP/PA view and 19 from the LAT view. The 10 sections of pediatric CXR TB findings corresponded to airway compression or tracheal displacement, soft tissue density suggestive of lymphadenopathy, hyperinflation, pleural effusion, air space opacification, collapsed lobe or lung, cavities, calcified parenchymal lesions, nodular pattern, and interstitial opacification. Figure 3 depicts the templates provided to the evaluators, highlighting the specific locations of the features to be assessed. These locations and types of findings were determined based on previous recommendations in the literature, including the “Diagnostic CXR Atlas for Tuberculosis in Children” [15] and the CXR review tool developed by Andronikou and the South African Tuberculosis Vaccine Initiative (SATVI) and used in Graham et al [16].

Figure 3. Evaluation templates with the location of the specific findings that should be assessed by the evaluators with "yes" or "no" for each of the 10 sections. (A) Locations for the evaluation of possible airway compression or tracheal displacement. (B) Locations for the assessment of soft tissue density suggestive of lymphadenopathy. (C) Locations for the assessment of hyperinflation and pleural effusion. (D) Locations for the evaluation of air space opacification, collapsed lung, cavities, and calcified parenchyma. (E) Location for the assessment of nodular pattern, either miliary or larger widespread and bilateral nodules, and interstitial opacification. Based on [15,16] and chest x-ray review tool developed by Andronikou and the South African Tuberculosis Vaccine Initiative and used in Graham et al [16].



For the back-end implementation of the platform, we used PHP's Laravel framework (version 6.2; PHP Group). Laravel offers a range of built-in tools and features, which were leveraged in the project, including routing, authentication, authorization, database connection management, and the Blade templating engine. For data storage, we opted for the MariaDB database (version 10.1.38; MariaDB plc/MariaDB Foundation), a fork of the MySQL database management system. We chose MariaDB because of its efficiency, customization options, portability, reliability, open-source nature, cost-effectiveness, and widespread adoption by a large and active community. The front end of the platform was built using the Bootstrap framework (version 4.3.1; Bootstrap Core Team), which offers a plethora of predesigned components that can be seamlessly integrated into a website. Indeed, Bootstrap's responsive design ensures that the application can be easily accessed and used across a wide range of devices and screen sizes. As for the server configuration, it operates on Debian 4.9 (Debian Project) and is equipped with 2 virtual central processing unit cores (Intel Xeon), 4 GB of RAM, and 100 GB of hard disk space. This setup provides a stable and efficient environment for hosting the platform and handling user interactions.

Data Set Pilot Study

The data set used to evaluate the platform in our pilot study was sourced from a previous prospective descriptive study called ITACA [5]. This study focused on young children under 3 years of age presumed to have TB and was conducted at the Manhiça Health Research Center (CISM), situated in Southern Mozambique [5,10]. For our evaluation, we collected a total of 218 examinations. This included all microbiologically confirmed and "probable" cases, as well as a random selection of 113 additional cases from the unlikely TB cases subset. The cases were confirmed using Ziehl-Neelsen staining, rapid tests, and Xpert MTB/RIF, with identification through mycobacterial molecular identification (HAIN GenoType Mycobacterium CM/AS; Hain Lifescience) [5]. Table 1 presents their demographic data. To enhance comparability between studies and encourage the standardization of diagnostic procedures, we adhered to the case definition classification for research reporting based on diagnostic evaluation studies of intrathoracic TB in children proposed by Graham et al [17]. In this update from the previous case definitions presented in 2012 and 2013 [16,18], the authors established 3 case definitions: confirmed TB, unconfirmed TB, and unlikely TB. The collected cases were retrospectively classified [5] according to these definitions, using the information gathered from the previous study [10]. Table 2 displays the TB diagnosis categories identified alongside the corresponding clinical data for each case. The symptom definitions considered were as follows [5]: cough for 14 days or more not responding to a course of antibiotics; fever greater than 38°C for 14 days or more; malnutrition defined as under 60% weight for height, failure to gain weight for more than 2 months, or any loss of weight not responsive to nutritional intervention; and TB contact in the last 12 months.

Table 1. Patient demographic characteristics of the data set of the pilot study.

Demographic characteristics	Male (n=122), n (%)	Female (n=96), n (%)	Total (N=218), n (%)
Age range			
<12 months	18 (14.8)	19 (19.8)	37 (17.0)
12-23 months	54 (44.3)	43 (44.8)	97 (44.5)
24-35 months	50 (41.0)	34 (35.4)	84 (38.5)

Table 2. Diagnostic categories and corresponding clinical characteristics considering the definitions from López-Varela et al [5] and Graham et al [17].

TB[a] category	Confirmed (n=10), n (%)	Unconfirmed TB (n=95), n (%)	Unlikely TB (n=113), n (%)
Sex			
Female	6 (60.0)	44 (46.3)	46 (40.7)
Age range (months)			
<12	3 (30.0)	21 (22.1)	13 (11.5)
13-23	3 (30.0)	42 (44.2)	52 (46.0)
24-35	4 (40.0)	32 (33.7)	48 (42.5)
Cough			
Yes	5 (50.0)	17 (17.9)	14 (12.4)
Fever			
Yes	4 (40.0)	6 (6.3)	5 (4.4)
Malnutrition			
Yes	5 (50.0)	81 (85.3)	104 (92.0)
HIV status			
Positive	2 (20.0)	35 (36.8)	4 (3.5)
BCG[b] scar			
Yes	10 (100.0)	94 (98.9)	113 (100.0)
TB contact			
Yes	2 (20.0)	11 (11.6)	4 (3.5)

[a] TB: tuberculosis.

[b] BCG: Bacillus Calmette-Guérin.

Ethics Approval

The ITACA study protocol received approval from both the Mozambican National Bioethics Committee (15/CNBS) and the Hospital Clinic of Barcelona Ethics Review Committee (HCB/2009/4682). Written informed consent was obtained from the parents/legal guardians of all study participants. Additionally, the substudy focusing on the digital processing of the CXR images was approved by the Mozambican National Bioethics Committee.

Evaluation Protocol

The 218 baseline examinations, conducted at the time of evaluation for presumptive TB, were uploaded by the administrator user using the platform's automatic importing feature. This was done via a CSV file containing the input fields outlined in Table 2, along with the location of the CXR files featuring the AP view (in all participants) and the LAT view (in 207 participants). The platform automatically assigned all cases to 3 pediatric CXR expert readers, each possessing extensive experience in assessing TB imaging in endemic settings of low-income, resource-limited countries [5,19]. These 3 evaluators conducted a blind evaluation of the 218 examinations using the platform, relying solely on the CXR views and reference templates (Figure 3), without any additional information. The evaluation encompassed the following components: (1) assessment of CXR image quality, categorized as "acceptable," "poor but readable," or "not acceptable not readable"; (2) evaluation of 55 observations across 10 sections, with responses marked as "yes" or "no"; and (3) a final global evaluation of the case, categorized as "suggestive of TB," "not suggestive of TB," or "not evaluable."

Performance Metrics

To evaluate the performance of the evaluations, we used the metrics sensitivity, specificity, positive predictive value (PPV), F_1-score, and accuracy. We defined sensitivity or recall as the number of true-positive cases with x-ray findings suggestive of TB divided by the sum of true positives and false negatives.

We defined specificity as the number of true negatives divided by the sum of true negatives and false positives. The PPV is the proportion of true-positive predictions out of all positive predictions (true positives + false positives). It measures how many of the positive predictions are actually correct. The F_1-score serves as a measure of a model’s accuracy by blending both the PPV and recall. It is commonly used to assess the effectiveness of a classification algorithm. Ranging between 0 and 1, an F_1-score of 1 indicates flawless PPV and recall, while a score of 0 signifies the poorest performance achievable. Accuracy, by contrast, is calculated as the sum of true positives and true negatives divided by the sum of true positives, true negatives, false positives, and false negatives. A true-positive case is identified when an evaluator marks a case as “suggestive of TB” in the global evaluation, and the examination is classified as either “confirmed” or “unconfirmed TB.” Conversely, a true-negative case occurs when the evaluator designates “not suggestive of TB,” and the examination is labeled as “unlikely TB.” An examination is considered a false negative if the evaluator indicates “not suggestive of TB,” yet the case is classified as “confirmed” or “unconfirmed TB.” A case is classified as false positive if an evaluator marks it as “suggestive of TB,” while the examination is categorized as “unlikely TB.” Furthermore, we examined the relationship between TB features identified in the CXRs and the global evaluation (“suggestive of TB” and “not suggestive of TB”) concerning the initial diagnostic classification, combining “confirmed” and “unconfirmed TB.” Statistical significance was determined by a chi-square P value <.05. Finally, we used Cohen kappa to assess the interreader agreement across all evaluations conducted by the evaluators, including CXR image quality, TB feature assessments, and TB global evaluations. Kappa scores were categorized as follows: ≤0 for no agreement, 0.01-0.2 for slight agreement, 0.21-0.4 for fair agreement, 0.41-0.6 for moderate agreement, 0.61-0.8 for substantial agreement, and 0.81-1.00 for almost perfect agreement.

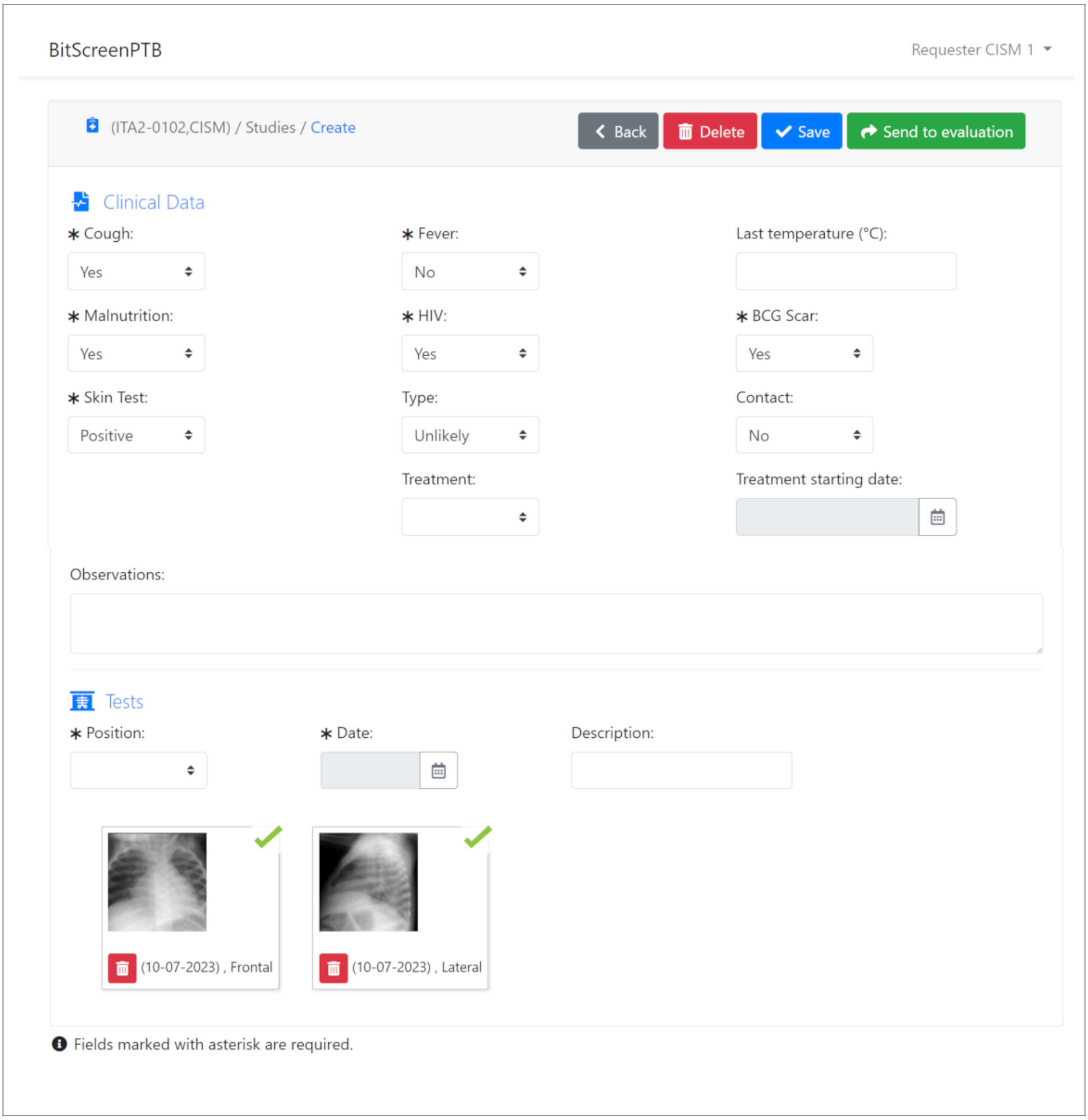
Platform Usability Evaluation

We developed a comprehensive questionnaire comprising 5 sections and 15 items to thoroughly assess the usability of the platform. This questionnaire was adapted from the Telehealth Usability Questionnaire (TUQ) proposed by Parmanto et al [20], a well-established tool for evaluating telemedicine services [21]. Our questionnaire addresses various crucial usability aspects, encompassing usefulness (3 items), ease of use and learnability (2 items), interface quality (4 items), reliability (2 items), and global satisfaction (2 items). A detailed breakdown of the questionnaire components and associated items is presented in Table 3. Additionally, we conducted an analysis to ascertain the duration of the evaluation process for each examination. We precisely measured the duration from the initiation of a new examination request to the submission of the evaluator’s final evaluation into the system. By computing the time difference between these 2 events, we obtained a precise and dependable estimate of the time taken by the expert to conduct a comprehensive evaluation of an examination.

Results

The 2 primary views of the new BITScreen platform are illustrated in Figures 4 and 5: the input form utilized by examiner users and the evaluation form used by evaluator users, respectively. In the top section of the input form (Figure 4), examiners input details such as cough, fever, last temperature, malnutrition, HIV status, BCG scar presence, tuberculin skin test result, TB category, contact with a TB source patient, treatment status, treatment starting date, and any observations. In the bottom section, examiners have the option to upload CXR images for evaluation by the evaluators.

Figure 4. Example of the BITScreen PTB (Biomedical Image Technologies Screen for Pediatric Tuberculosis) examiner user view of a new examination with the 2 different areas: Clinical data and Images.



∗ Cough: Yes
∗ Fever: No
Last temperature (°C):
∗ Malnutrition: Yes
∗ HIV: Yes
∗ BCG Scar: Yes
∗ Skin Test: Positive
Type: Unlikely
Contact: No
Treatment:
Treatment starting date:
Observations:

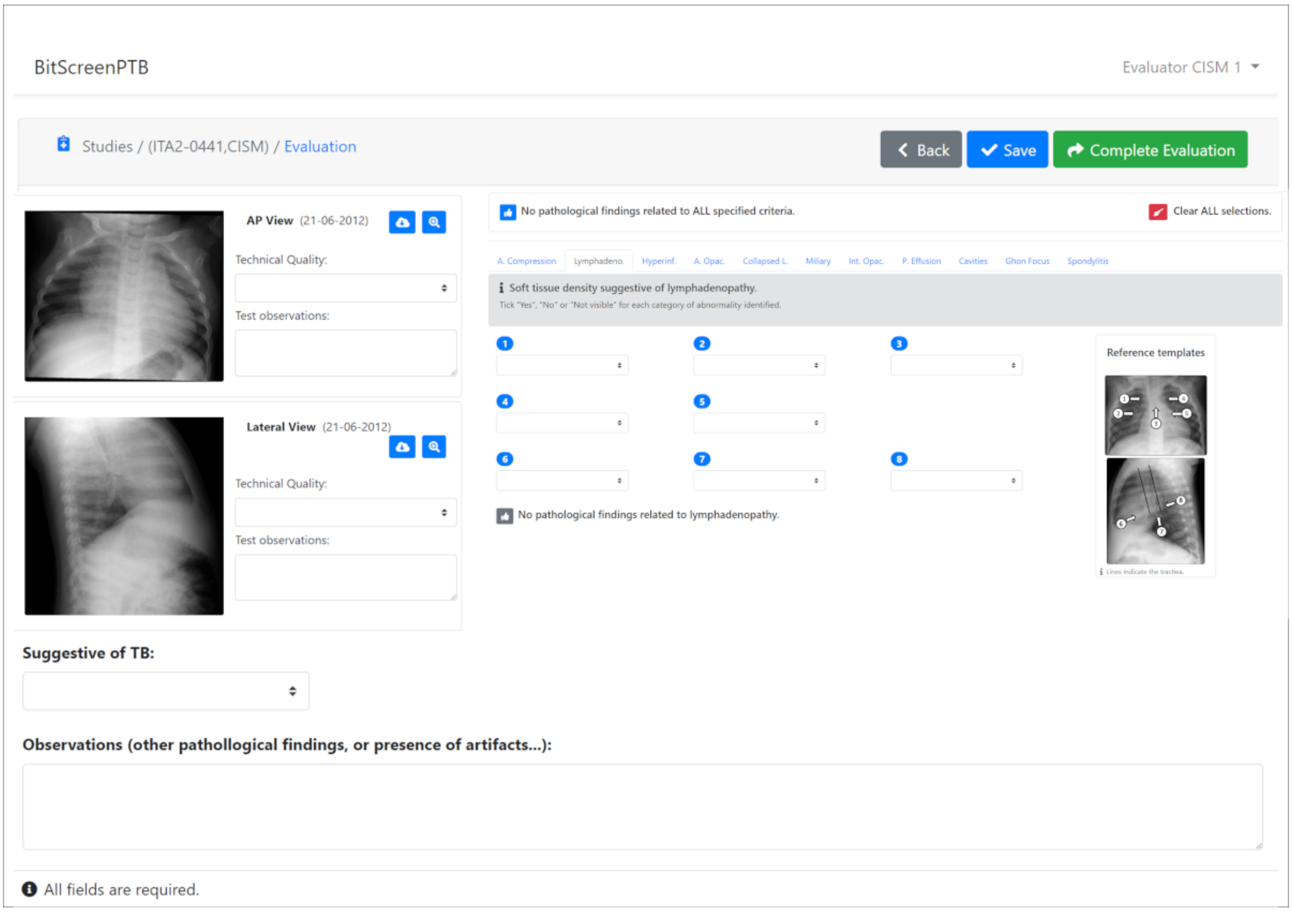
∗ Position:
∗ Date:
Description:

(10-07-2023) , Frontal
(10-07-2023) , Lateral

Fields marked with asterisk are required.

In the case of the evaluation form (Figure 5), the view used by the evaluators displays the CXR images on the left side of the screen, allowing them to download or zoom in on each image for detailed examination. Evaluators are tasked with assessing the quality of each CXR image. On the right side of the screen, the 10 sections described previously are presented as separate tabs. Within these tabs, evaluators are required to assess all 55 different observations. The templates depicted in Figure 3 remain consistently visible in the view to aid evaluators in their tasks. Readers are provided with the option to mark all locations without pathological findings as “no” for all criteria at once or for all locations of a specific criterion, streamlining and expediting the evaluation process. At the bottom of the view, the global evaluation field for the examination is displayed. All fields are mandatory, except in cases where the CXR images are deemed not evaluable.

Figure 5. Example of the BITScreen PTB (Biomedical Image Technologies Screen for Pediatric Tuberculosis) evaluator user view with 3 different areas: quality image assessment, identification of the presence of findings in the different locations presented in the templates, and a global evaluation of the case.



No pathological findings related to ALL specified criteria.

Soft tissue density suggestive of lymphadenopathy.

Tick "Yes", "No" or "Not visible" for each category of abnormality identified.

No pathological findings related to lymphadenopathy.

Lines indicate the trachea.

All fields are required.

The results of the usability questionnaire administered on the telemedicine platform are outlined in Table 3. The overall score for all questions averaged 4.4 (SD 0.59) out of 5. Users rated the platform positively in terms of usefulness, with an average rating of 4.42 out of 5; ease of use and learnability, receiving an average rating of 4.47 out of 5; and interface quality, which garnered positive feedback with an average rating of 4.13 out of 5. The platform was also perceived as reliable, with an average rating of 4.26 out of 5 and a high level of variability (SD 0.82). Additionally, all 3 evaluators expressed a high level of satisfaction with the platform, giving it an average rating of 5.0 out of 5.

Some specific questions received lower ratings, particularly item 4 in the interface quality dimension (The system is able to do everything I would want it to be able to do) and item 1 in the reliability dimension (Whenever I made a mistake using the system, I could recover easily and quickly). Conversely, items with higher feedback included item 1 in the ease of use and learnability section (It was simple to use this system), as well as questions related to global satisfaction and future use, where “I would use the platform again” and “Overall, I am satisfied with the platform” received maximum feedback from all evaluators.

Table 3. Results of the Usability Questionnaire (1=strongly disagree to 5=strongly agree).

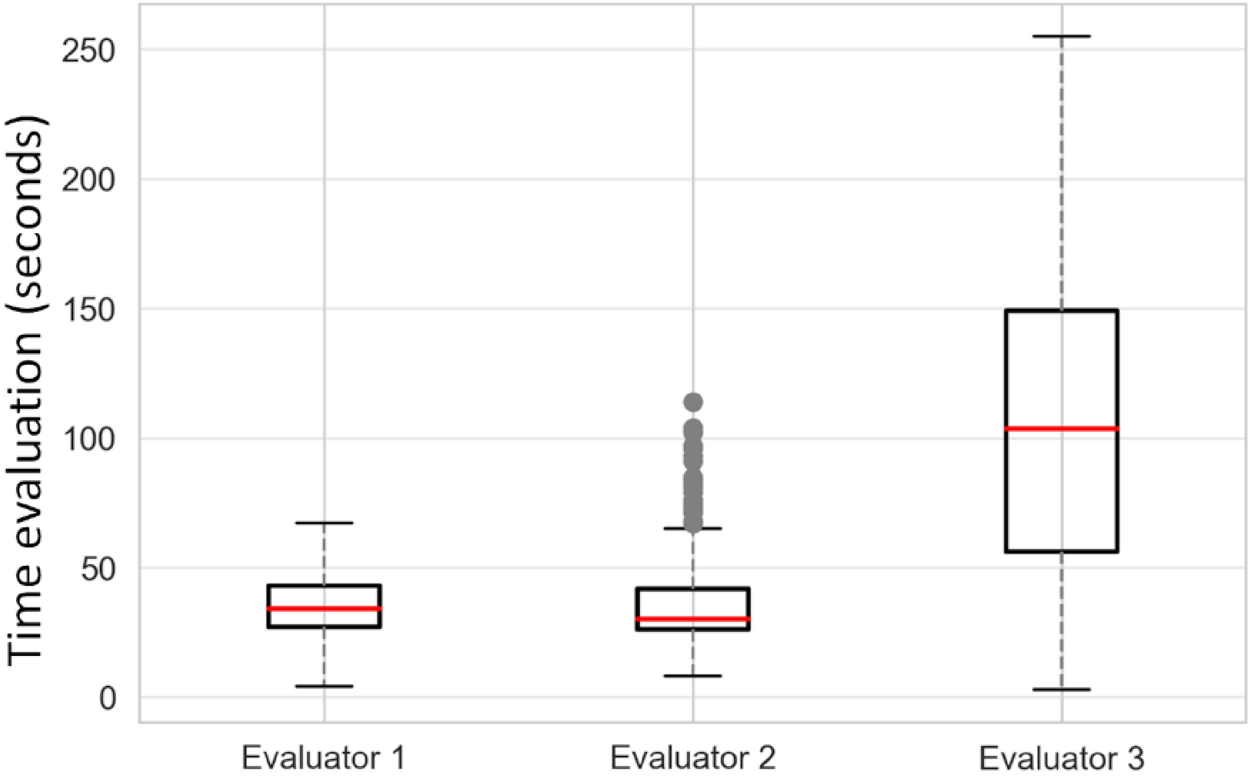
Section	Mean (SD)
Usefulness	4.42 (0.53)
1. It facilitates the assessment of CXRs[a] in pediatric TB[b] studies	4.64 (0.58)
2. It saves me time assessing CXRs in pediatric TB studies	4.31 (0.58)
3. It includes all the items I need to evaluate pediatric TB studies	4.31 (0.58)
Ease of use and learnability	4.47 (0.52)
1. It was simple to use this system	5.00 (0.00)
2. It was easy to learn the system	4.31 (0.58)
3. The templates with the location of the findings facilitate the assessment of the cases	4.31 (0.58)
4. I believe I could become productive quickly using this system	4.31 (0.58)
Interface quality	4.13 (0.58)
1. The way I interact with this system is pleasant	4.00 (0.00)
2. I like using the system	4.31 (0.58)
3. The system is simple and easy to understand	4.31 (0.58)
4. The system is able to do everything I would want it to be able to do	3.91 (1.00)
Reliability	4.26 (0.82)
1. Whenever I made a mistake using the system, I could recover easily and quickly	3.91 (1.00)
2. The system gave error messages that clearly told me how to fix the problems	4.64 (0.58)
Satisfaction and future use	5.0 (0.00)
1. I would use the platform again	5.0 (0.00)
2. Overall, I am satisfied with the platform	5.0 (0.00)

[a] CXR: chest x-ray.

[b] TB: tuberculosis.

Figure 6 presents the completion times of the evaluators. Evaluator 2 demonstrated the shortest completion time, averaging 35.3 (SD 13.2) seconds. Evaluator 1 followed with an average time of 37.8 (SD 19.2) seconds, while evaluator 3 recorded the longest completion time, averaging 110.3 (SD 63.2) seconds. Despite evaluator 3 taking more time, their superior performance and identification of more observations justify the additional time spent. A previous study [22] has indicated that radiologists typically spend an average of 2 minutes and 9 seconds (129 seconds) evaluating and reporting neonatal CXR images, a duration longer than what was observed in our study. However, it is crucial to highlight that our reviewers were tasked solely with marking specific findings' locations, assessing image quality, and delivering a global assessment, without the need to compose a report or dictate findings. In any case, our findings suggest that the platform could serve as a valuable tool for swiftly evaluating cases and annotating findings in CXR images.

Figure 6. Evaluation time in seconds by the 3 evaluators of the 218 examinations.



Next, we present the results from the assessment of 218 examinations in this pilot study. The evaluation of the CXR AP views revealed that 195/219 (89.0%), 167/193 (86.5%), and 150/219 (68.5%) images were rated as "acceptable" by evaluators 1, 2, and 3, respectively. Additionally, 23/219 (10.5%), 26/193 (13.5%), and 65/219 (29.7%) were rated as "poor but readable." However, for the LAT views, the image quality was lower. Specifically, 160/209 (76.6%), 109/161 (67.7%), and 128/208 (61.5%) images were rated as "acceptable" by the 3 evaluators, while 42/209 (20.1%), 46/161 (28.6%), and 59/208 (28.4%) were rated as "poor but readable." Additionally, 7/209 (3.3%), 6/161 (3.7%), and 21/208 (10.1%) LAT views were deemed "not acceptable, not readable." Notably, only evaluator 3 rated all views of the CXRs as "not acceptable, not readable" in 2 examinations, and there was only 1 image that received this rating from all 3 evaluators. The number of images classified in each category by each expert is presented in Figure S1 in Multimedia Appendix 1, while Figure S2 in Multimedia Appendix 1 provides examples of images and their corresponding ratings.

Table 4 displays the performance metrics of the global evaluation. Among the 3 evaluators, evaluator 3 exhibited the highest sensitivity (28.2%), F_1-score (40.8%), and accuracy (60.9%). However, evaluator 3 had the lowest specificity (91.1%), indicating a potential tendency to classify more unlikely TB cases as suggestive of TB compared with the other evaluators. Evaluator 2 demonstrated the highest specificity (98.2%), suggesting proficiency in accurately identifying unlikely TB cases. However, the evaluator displayed the lowest scores for sensitivity (12.4%) and F_1-score (21.7%), indicating challenges in correctly identifying both confirmed and unconfirmed TB cases. Evaluator 1's scores were intermediate across all metrics, except for PPV, which exhibited the lowest score (73.9%). This suggests that while evaluator 1 did not excel in any specific metric, the performance was consistently average across all metrics. To further illustrate the results, Figure 7 showcases the confusion matrices with the corresponding counts of true negatives (top left), true positives (bottom right), false positives (top right), and false negatives (bottom left), while Table S1 in Multimedia Appendix 1 provides the evaluation for each TB diagnostic class.

Table 4. Performance metrics considering sensitivity, specificity, positive predictive value, $F1$-score, and accuracy (N=218)[a].

Metrics	Evaluator 1	Evaluator 2	Evaluator 3
Sensitivity (95% CI)	16.3 (10.5-24.6)	12.4 (7.4-20.0)	28.2 (20.4-37.5)
Specificity (95% CI)	94.6 (88.8-97.5)	98.2 (93.8-99.5)	91.1 (84.3-95.1)
Positive predictive value (95% CI)	73.9 (50.3-63.4)	86.7 (62.1-96.3)	74.4 (58.9-85.4)
F_1-score (95% CI)	26.8 (19.8-35.1)	21.7 (15.2-29.9)	40.8 (33.1-49.1)
Accuracy (95% CI)	56.9 (50.3-63.4)	56.9 (50.2-63.3)	60.9 (54.3-67.2)

[a] All values are in percentages.

Figure 7. Confusion matrices of the 3 evaluators. TB: tuberculosis.

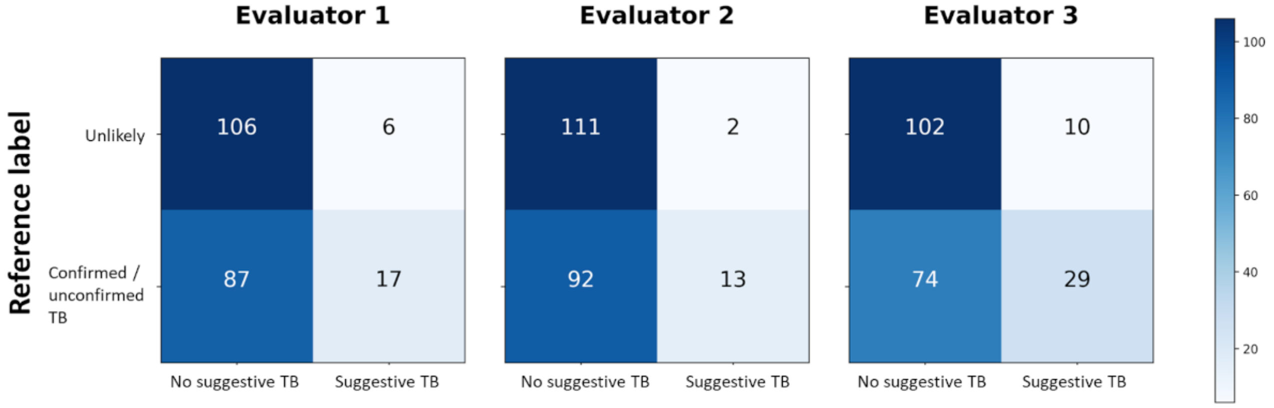


Table 5 displays the number of observations recorded by each of the 3 evaluators in the 3 diagnostic categories, namely, confirmed TB, unconfirmed TB, and unlikely TB, across the 10 examination fields. The total number of observations recorded by the 3 evaluators was 64, 59, and 150, highlighting a substantial difference between evaluator 3 and the other 2 evaluators. This difference was particularly noticeable in the unconfirmed TB and unlikely TB categories. Air space opacification emerged as the category with the highest number of observations by all evaluators, notably in the unconfirmed TB category, where it ranged from 22 to 33, totaling 95 cases. Following closely, lymphadenopathy was the second most frequently observed area, with evaluator 3 recording this finding in 34 examinations across all categories, 22 of which were in the unconfirmed TB category. Additionally, a notable number of observations were recorded in the interstitial opacification field, with evaluator 3 being particularly active in marking this finding in 16 examinations. By contrast, the areas of cavities and calcified parenchyma were only identified by evaluator 3, who marked 4 and 6 examinations, respectively. It is also worth noting that evaluator 3 recorded observations for all examination areas, whereas evaluators 1 and 2 did not record any observations in the cavities and calcified parenchyma areas. Finally, Figure 8 showcases examples of observations for 4 different patients with detailed marking of their findings.

Table 5. Results of the evaluation of the findings by the 3 experts considering the AP[a] and lateral CXRs[b] without additional clinical information. Each data point of the table represents the number of patients where the evaluators reported 1 or more times the presence of the finding. The last row includes all the patients with any of the previous abnormalities. The order of the data comes from the assessment of the findings by evaluators 1/2/3 (N=218).

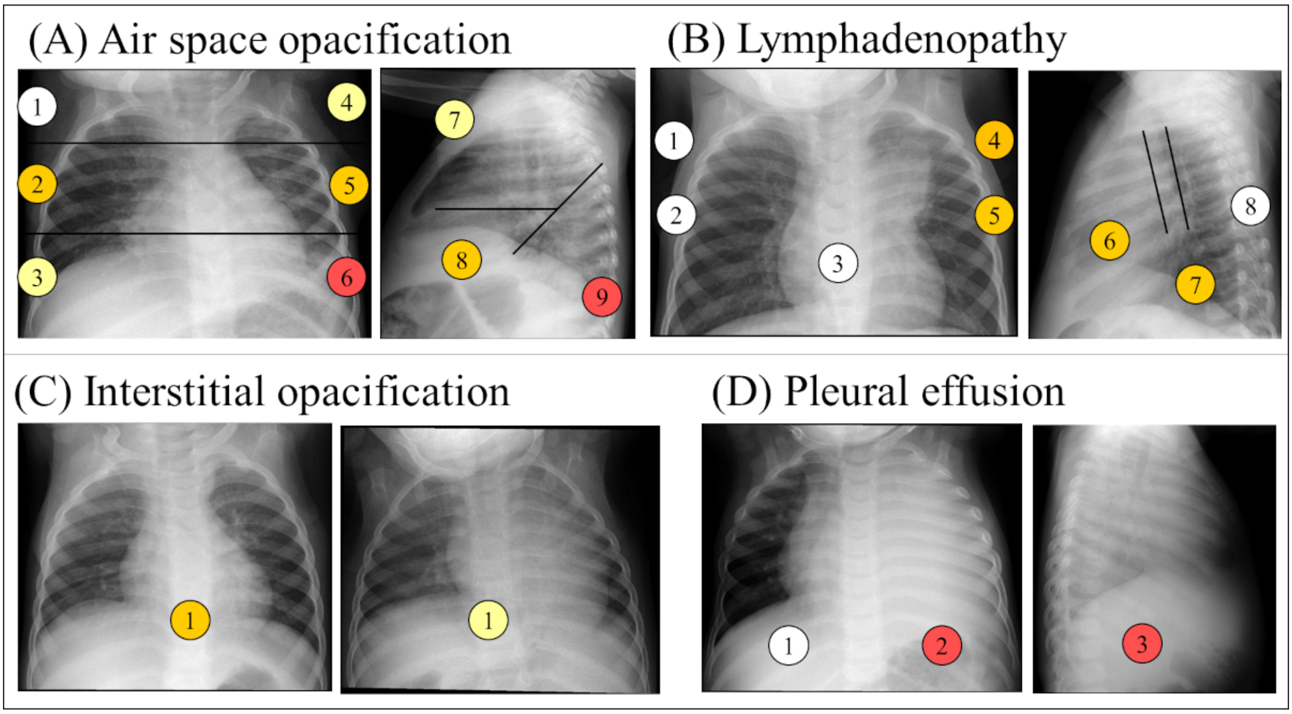
Results	Overall, n	Confirmed, n	Unconfirmed TB[c], n	Unlikely TB, n
Number of patients	218	10	95	113
Airway compression or tracheal displacement or both	4/0/7	2/0/0	2/0/4	0/0/3
Lymphadenopathy	7/7/34	3/1/4	4/4/22	0/2/8
Hyperinflation	4/0/3	2/0/0	2/0/2	0/0/1
Air space opacification	31/42/52	7/7/7	22/30/33	2/5/12
Collapsed lung	5/1/9	0/0/2	4/1/6	1/0/1
Nodular picture	1/2/3	0/0/1	1/2/2	0/0/0
Interstitial opacification	7/1/28	1/0/2	5/1/16	1/0/10
Pleural effusion	5/6/4	0/0/0	5/6/4	0/0/0
Cavities	0/0/4	0/0/0	0/0/3	0/0/1
Calcified parenchyma	0/0/6	0/0/0	0/0/4	0/0/2
Any abnormality	41/46/92	8/7/9	30/33/54	3/6/29

[a] AP: anteroposterior.

[b] CXR: chest x-ray.

[c] TB: tuberculosis.

Figure 8. Example of evaluations of findings in different studies. The locations of the findings are defined in Figure 3. The color of the locations represents the number of evaluators that identified the presence of the finding in that location, being 0 evaluators for white, 1 evaluator for yellow, 2 evaluators for orange, and 3 evaluators for red. (A) Presence of air space opacification in the anteroposterior (AP) and lateral chest x-ray (CXR) views of an examination of a female patient of 11 months classified as unconfirmed tuberculosis (TB) and as suggestive of TB by 1 out of the 3 evaluators. (B) Presence of lymphadenopathy in the AP and lateral CXR views of an examination of a female patient of 11 months classified as confirmed TB and as suggestive of TB by the 3 evaluators. (C) Presence of interstitial opacification on AP CXR views of 2 studies, the one on the left is from a male patient of 1 year and 4 months of age. Both studies were classified as unconfirmed TB and not suggestive of TB. The AP view on the right corresponds to a patient of female of 11 months of age. The examination was classified as unlikely TB and 1 out of 3 evaluators assessed it as confirmed TB. (D) Presence of pleural effusion in the AP and lateral view of an examination of a male of 2 years and 2 months of age classified as confirmed TB and evaluated as suggestive of TB by the 3 evaluators.



To gain a deeper understanding of how various evaluations influence the final diagnosis of TB, we examined the association between the assessments made by each evaluator, including the final evaluation and the initial diagnostic classification. The results of the chi-square test (see Table S2 in Multimedia Appendix 1) indicated that the most significant association for the CXR features was observed with the identification of air space opacification, yielding χ^2_1>20.38 and *P*<.001 for all evaluators. The second most noteworthy finding was the significant association of lymphadenopathies with the initial classification for evaluator 1 (χ^2_1=5.79, *P*=.02) and evaluator 3 (χ^2_1=11.88, *P*<.001). Additionally, the final evaluation showed a significant association with the initial classification, with *P* values of .02, .005, and <.001 for evaluators 1, 2, and 3. These findings are consistent with those presented in Table 5, which highlighted that these fields had the highest number of observations among the rest.

Finally, we investigated the agreement between evaluators using the Cohen kappa score for the interreader agreement for image quality, the global evaluation, and all the different findings (see Table S3 in Multimedia Appendix 1). Concerning image quality, we observed substantial agreement between evaluators 1 and 2 (κ=0.65), but only fair agreement between evaluators 1 and 3 (κ=0.33) and 2 and 3 (κ=0.31), primarily due to evaluator 3 assessing many more images as “poor quality.” The agreement for the global evaluation was very similar, with fair agreement ranging from 0.26 to 0.32. However, for the findings, we found that air space opacification exhibited a moderate to substantial Cohen kappa index, ranging from 0.54 to 0.67. The number of observations identified by the evaluators (as shown in Table 5) and the association with the initial classification (as demonstrated in Table S2 in Multimedia Appendix 1) underscored the significance of air space opacification as a crucial finding. Its large number of observations, strong association, and consistency between different evaluators emphasize its importance in the diagnosis process. Another field demonstrating moderate to substantial agreement was pleural effusion, with Cohen kappa scores ranging from 0.43 to 0.72. However, despite this strong agreement, there were fewer observations and a weaker association with the initial classification. Lymphadenopathies also emerged as an important finding in terms of observation and association, but the agreement was only slight, ranging between 0.13 and 0.21.

Discussion

Principal Findings

Store-and-forward telemedicine has emerged as a valuable solution for improving access to specialist and primary health care advice, leveraging technological advancements to overcome barriers in low-resource settings [13,14]. Our work showcases the potential application of this approach in assessing TB in young children in underserved areas, where the shortage of specialists and the challenges associated with TB assessment in this population may have a greater impact. The positive assessment of the telemedicine system, coupled with the reduced time needed for evaluation, further bolsters the case for utilizing telemedicine in diagnosing pulmonary TB. This not only ensures timely intervention but also promotes efficient health care delivery.

The low sensitivity of x-rays in identifying positive cases in our pilot study corroborates the challenges reported in diagnosing TB in children, as documented in other studies [23-27]. Limited research has offered detailed insights into the global sensitivity and specificity of CXR in young children for TB diagnosis. Kaguthi et al [24] reported sensitivities ranging from 50% to 75% and specificities between 72.9% and 85.2%. However, they acknowledged the imprecision in measuring sensitivity due to the limited number of definitive cases. Berteloot et al [27] reported higher sensitivities (71.4%) and lower specificities (50.0%), although the evaluation process involved a consensus and an older age group of children. Other studies [25,26] have also investigated the performance of TB diagnosis using CXR but focused on the most relevant findings to support the diagnosis [25,26]. Similar to those findings, in our results, lymphadenopathies, opacifications, and pleural effusions were the findings having the strongest association with positive evaluation (as indicated in Table S2 in Multimedia Appendix 1). Integrating a treatment-decision algorithm that incorporates clinical evidence, CXR findings, and the Xpert MTB/RIF assay (or its current version, Xpert MTB/RIF Ultra), as proposed by several studies [2,9], could enhance the performance of the diagnostic process and streamline treatment decisions. This approach could be considered in future developments.

Comparison With Other Studies

In terms of interreader agreement, our findings align, to some extent, with other studies that have also reported slight to moderate agreement [24,25,28]. Kaguthi et al [24] reported poor agreement on abnormalities consistent with TB (κ=0.14) and moderate agreement (κ=0.26) on lymphadenopathy. However, their lower agreement results compared with ours could be attributed to the variability in expertise among the readers. Our results are more closely aligned with other studies in terms of the reader profile [25,27,28]. For instance, Palmer et al [25] reported a moderate agreement (κ>0.4) on specific features such as alveolar opacification, pleural effusion, expansile pneumonia, and enlarged perihilar lymph nodes. Similarly, Berteloot et al [27] reported a κ value of 0.36 between a radiologist and a pediatric pulmonologist. Lastly, Andronikou et al [28] presented a κ value of 0.5 among trained pediatric radiologists, although their data set included older children with a mean age of 9 years.

Limitations

Our pilot study has several limitations. First, the number of confirmed cases is small, and the presence of some important features relevant to diagnosis by CXR, such as airway compression or tracheal displacement, nodular pattern, cavities, or calcified parenchyma, is also limited. This may explain the lack of a stronger association with the TB classification highlighted in other studies [23]. The evaluators’ performance was compared with the case definition, which includes abnormal CXR as one of the criteria for unconfirmed TB. As observed in analogous studies [27,28], our research was constrained by the limited number of studies and readers. Broader validation, including a wider range of studies and readers, may provide more robust insights into the agreement and performance of the evaluations. The expertise of our readers may not fully reflect the typical skill set available in resource-limited settings; however, this challenge can be overcome through the implementation of consensus classifications. Moreover, the approach of conducting double assessments by both nonexperts and experts has been successfully tested in other projects [29,30], suggesting its potential effectiveness in enhancing diagnostic accuracy. By incorporating these methods into our telemedicine platform, we can overcome limitations related to reader expertise and enhance the overall diagnostic process for pediatric TB in resource-limited settings.

Besides the current utilization of the platform as a diagnostic tool for remote evaluation of CXR examinations, we have planned its future use for the systematic assessment of data sets in clinical studies and as a labeling tool for TB findings present in CXR. This will facilitate the training of artificial intelligence segmentation and classification models. The inclusion of new data sets from multiple settings and the expansion of the number of readers will enable a comprehensive validation of the platform. Additionally, it is essential to view CXR as part of a broader diagnostic algorithm for pediatric TB, which includes assessing symptoms; signs of TB; exposure to a TB source patient; results from tests for *M. tuberculosis* infection (eg, tuberculin skin tests or interferon-gamma release assays), microbiological tests (eg, Xpert MTB/RIF, microscopy, or culture for *M. tuberculosis*), and any other relevant supporting tests [15]. Following this approach, we are considering leveraging the platform with a treatment-decision algorithm that incorporates clinical evidence and artificial intelligence models to enable automatic CXR scoring. This integration has the potential to significantly enhance the accuracy and efficiency of TB diagnosis in young children.

Conclusions

TB remains a significant global health challenge, particularly among children, and the COVID-19 pandemic has intensified the situation. CXR imaging is crucial for diagnosis, severity assessment, and treatment response evaluation. In this study, we introduced a novel telemedicine web platform, BITScreen PTB, which utilizes CXR images and clinical information. Its purpose is to streamline remote reading and standardize pediatric TB examinations in resource-limited settings.

Our platform received positive feedback from users, and while there may be room for further improvements to address concerns about reliability and interface quality, it shows promise for future use. Our study underscores the potential of telemedicine platforms such as BITScreen PTB to enhance access to TB diagnosis in children, especially in low-resource settings. Additionally, the platform has the potential to serve as a labeling tool for CXRs to develop and integrate artificial intelligence models, which could enhance the accuracy and speed of TB diagnosis in children, particularly in resource-limited settings.

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Conflicts of Interest

RSJ is an external consultant for MILVUE.

Multimedia Appendix 1
Global evaluation and assessment results with interrater agreement.
[DOCX File , 1729 KB - pediatrics_v7i1e51743_app1.docx]

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Abbreviations

AP: anteroposterior
BCG: Bacillus Calmette-Guérin
BITScreen PTB: Biomedical Image Technologies Screen for Pediatric Tuberculosis
CISM: Manhiça Health Research Center
CXR: chest x-ray
LAT: lateral
MVC: Model-View-Controller
PA: posteroanterior
PPV: positive predictive value
SATVI: South African Tuberculosis Vaccine Initiative
TB: tuberculosis
TUQ: Telehealth Usability Questionnaire
WHO: World Health Organization

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Review

The Report of Access and Engagement With Digital Health Interventions Among Children and Young People: Systematic Review

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Abstract

Background: Digital health interventions are increasingly used to deliver health-related interventions for children and young people to change health behaviors and improve health outcomes. Digital health interventions have the potential to enhance access to and engagement with children and young people; however, they may also increase the divide between those who can access technology and are supported to engage and those who are not. This review included studies that reported on the access to or engagement with digital health interventions among children and young people.

Objective: This review aims to identify and report on access and engagement in studies involving digital health interventions among children and young people.

Methods: A systematic review following the Joanna Briggs Institute methods for conducting systematic reviews was conducted. An electronic literature search was conducted for all studies published between January 1, 2010, and August 2022, across sources, including MEDLINE, CINAHL, and PsycINFO. Studies were included if they examined any aspect of access or engagement in relation to interventions among children and young people. The quality of the included papers was assessed, and data were extracted. Data were considered for meta-analysis, where possible.

Results: A total of 3292 references were identified using search terms. Following the exclusion of duplicates and review by inclusion criteria, 40 studies were independently appraised for their methodological quality. A total of 16 studies were excluded owing to their low assessed quality and flawed critical elements in the study design. The studies focused on a variety of health conditions; type 1 diabetes, weight management and obesity, mental health issues, and sexual health were the predominant conditions. Most studies were conducted in developed countries, with most of them being conducted in the United States. Two studies reported data related to access and considered ethnicity and social determinants. No studies used strategies to enhance or increase access. All studies included in the review reported on at least 1 aspect of engagement. Engagement with interventions was measured in relation to frequency of engagement, with no reference to the concept of effective engagement.

Conclusions: Most digital health interventions do not consider the factors that can affect access and engagement. Of those studies that measured either access or engagement or both, few sought to implement strategies to improve access or engagement to address potential disparities between groups. Although the literature to date provides some insight into access and engagement and how these are addressed in digital health interventions, there are major limitations in understanding how both can be enhanced to promote equity. Consideration of both access and engagement is vital to ensure that children and young people have the ability to participate in studies.

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KEYWORDS

access; engagement; digital health technology; mobile phone; children

Introduction

Background

Worldwide, access to many public services including health information and service provision is available through digital platforms [1]. The COVID-19 pandemic has accelerated the digital shift and highlighted the value it can bring to enabling access to health services and enhancing social connectedness [2]. However, equitable distribution of resources crucial for engaging with digital platforms—such as access to equipment, financial support for connectivity, and digital literacy—is uneven among populations. Consequently, certain groups have greater access to digital services than others [3,4]. It is crucial to focus on equity concerning access to digital health services, ensuring that the gap between those who can and cannot access these services is not widened further [5].

A plethora of literature exists on equity in health and health care; however, the key principles remain the same: that there should be equal access to health care for those in equal need of health care; equal use of health care for those in equal need of health care; and equal (equitable) health outcomes, for example, quality-adjusted life expectancy [6,7]. Equal access for equal need requires horizontal equity, conditions whereby those with equal needs have equal *opportunities* to access health care [8].

Health care providers are increasingly using digital technologies such as smartphones, websites, or SMS text messaging to communicate information to address health needs and in the delivery of health interventions [9]. Digital health interventions are programs that provide information and support for physical and mental health using digital technologies [10,11]. These interventions can be automated, interactive, and personalized, using user input or sensor data to shape feedback, treatment decisions, and treatment delivery [12].

Digital health interventions for children are increasing because of rapid technological advancements and the increasing interest of children and young people in technology [13]. Digital health interventions have been proposed to create opportunity to increase access to health care [14-16]. However, unless access to health care is equitable so that children and young people as consumers of health care within wider communities can use appropriate services in proportion to their need, inequities will create a divide in outcomes [17,18].

Although there is evidence for the effectiveness of digital health interventions developed for children and young people [19,20], understanding how issues related to access and variations by individuals, families, and communities are areas that have not been reviewed and require further discussion.

Objective

This review aimed to identify the reports of access to, and engagement with, digital health interventions among children and young people. The review includes a report of data on access and engagement in studies that report on the effectiveness of digital health interventions as well as evaluations of strategies to increase access and engagement.

Methods

The review followed the Joanna Briggs Institute (JBI) methodology for systematic reviews [21] in design and was conducted according to the PROSPERO protocol (CRD42020170874). The review was conducted in accordance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement.

Search Strategy

A scoping search was conducted to identify key papers and search terms to inform the search strategy. This included the key terms and medical subject headings engagement or equity of access or access to health care and digital health or mobile health or electronic health.

The search strategy was reviewed and refined by a research librarian. The base search strategy was developed on CINAHL. A total of 4 web-based databases, including CINAHL, MEDLINE, PsycINFO, and Embase, were searched for English language publications between January 2010 and August 2021 and updated in August 2022. A manual search in Google Scholar was also conducted. Gray literature sources including OpenGrey, ProQuest Dissertation and Theses (ProQuest), and Google and Google Scholar were also searched to identify unpublished studies. Multimedia Appendix 1 provides the full search strategy. EndNote (Clarivate) was used to remove duplicate citations before screening.

Inclusion and Exclusion Criteria

The review included studies that reported data on access or engagement when reporting the effectiveness of digital health interventions for children and young people. The participants included school-aged children and young people aged 5-18 years. Parents or caregivers of children receiving health services were also included; however, studies that only reported the parent experience were excluded. Studies reporting on health interventions involving 1-way and 2-way communication including web-based platforms, mobile apps, videoconferencing, and SMS text messaging on access or engagement outcomes were included. Qualitative and quantitative studies were included in this review.

Studies that included children aged ≤4 years and ≥19 years were excluded. Studies that reported health professionals, such as nursing staff, medical personnel, health care management and administrators, or researchers, as the primary users of the digital health intervention were excluded. Studies reporting a telephone-based intervention with no additional technological function or where the intervention focused on health records such as patient portals or personal health records were excluded.

Screening

The titles, abstracts, and full papers of the selected records were screened independently by 2 reviewers (SR and MJ) using the abovementioned inclusion and exclusion criteria. Any discrepancies were discussed, and disagreements were resolved by a third reviewer (LW). The reference lists of all included studies were reviewed to identify relevant papers that were not found in the electronic search.

Assessment of Methodological Quality

The quality of the screened papers was critically appraised independently by reviewers (SR and LW) using the appropriate standardized critical appraisal instruments from JBI, including the Checklist for Randomized Controlled Trials, Checklist for Quasi-Experimental Studies, Checklist for Cohort Studies, Checklist for Analytical Cross Sectional Studies, and the Checklist for Qualitative Research [21].

Data Extraction

Data were extracted from the included studies using an adapted version of the standardized data extraction tool from JBI [22]. Two reviewers (SR and MJ) extracted the data from the included papers, and a third reviewer (LW) verified the accuracy of the extracted data, with any disagreement resolved through discussion.

The extracted data included specific details about the study setting and context; the aim and objectives of the study; study design; the sampling of participants, sample size, and the characteristics of the study sample; and details about the interventions and engagement and access outcomes. All data were extracted following a thorough reading of the text to identify qualitative or quantitative findings relevant to the objectives and questions for the review. A second reviewer checked all the data extracted from each paper to enhance certainty.

Data Synthesis

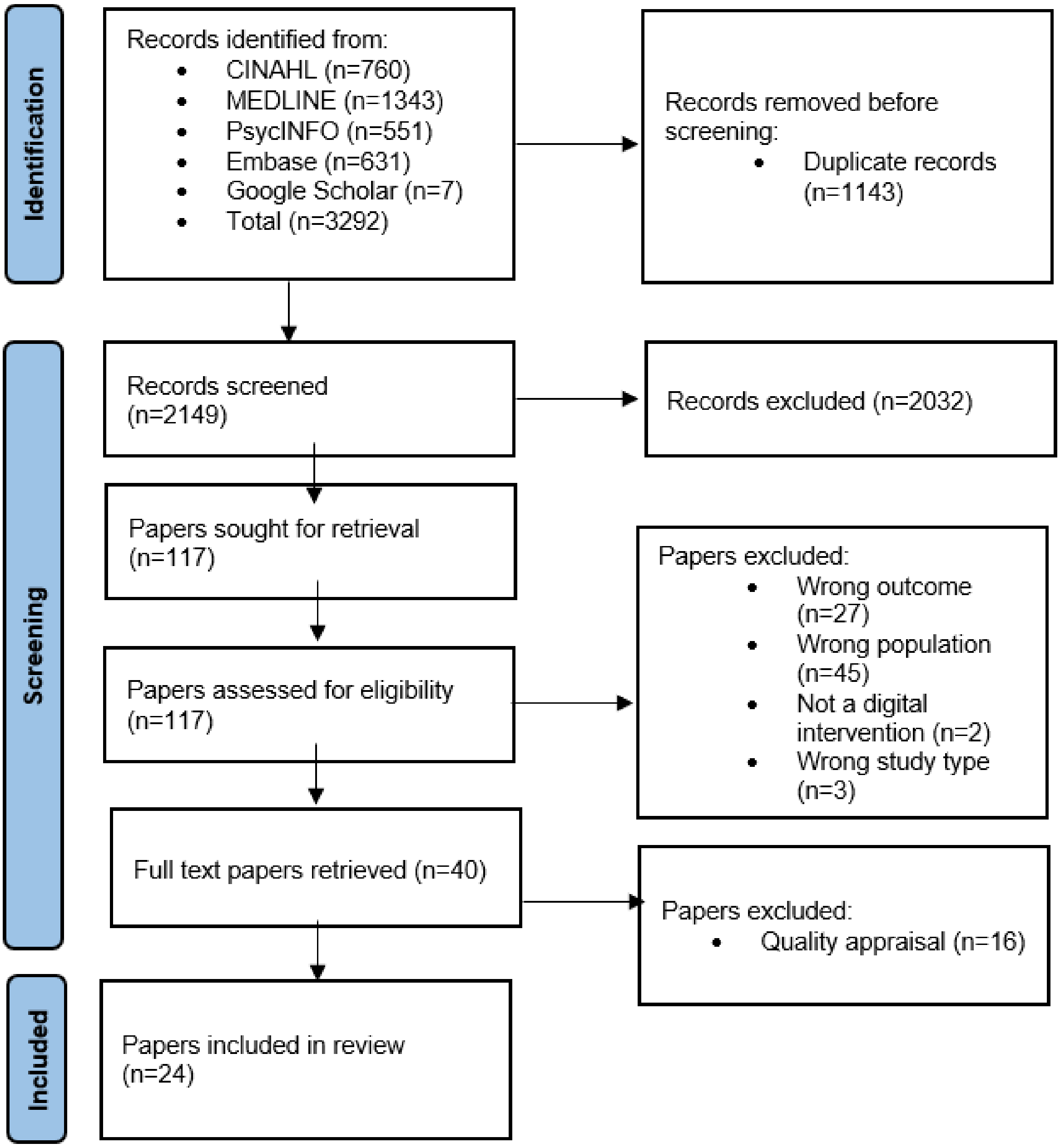
Owing to the heterogeneity between the studies on outcome measures, research design, and the intervention, a meta-analysis was not possible. The findings have been presented in narrative form including tables and figures to aid in data presentation. The process of data synthesis followed the JBI approach of meta-aggregation. The meta-aggregative approach is sensitive to the practicality and usability of the findings extracted and does not seek to reinterpret these findings. A strong feature of the meta-aggregative approach is that it enables the generation of statements in the form of recommendations that can guide researchers, practitioners, and policy makers. In this way, meta-aggregation contrasts with meta-ethnography or the critical interpretive approach to qualitative evidence synthesis, which focuses on reinterpretation and theory generation rather than aggregation.

Results

Study Inclusion

In total, 3292 references were identified using the search terms. The addition of secondary searches of reference lists and gray literature resulted in the identification of no further references. The exclusion of 1143 duplicates resulted in 2149 references. The titles and abstracts of the references were independently reviewed to determine if they met the inclusion criteria, and 2032 references were excluded. The remaining 117 references were retrieved in full text papers and reviewed by 3 reviewers (SR, MJ, and LW) using the inclusion criteria. A total of 77 studies were excluded as they did not meet the inclusion criteria. Of the 77 studies, 45 (58%) were excluded because the age of the child was outside the inclusion range, 27 (35%) did not report on access or engagement, 2 (3%) did not include a digital intervention, and 3 (4%) were opinion pieces or letters to the Editor. A total of 40 studies met the inclusion criteria (Figure 1).

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart of the study selection and inclusion process.



Methodological Quality

A total of 40 studies that met the inclusion criteria were independently appraised for their methodological quality. A total of 16 studies were excluded where the quality of the studies was assessed as low and critical elements of the study design were flawed (Tables 1-5). A cutoff was applied for each research design. A total of 5 randomized controlled trials (RCTs) were excluded because they were unclear or did not report on ≥6 items out of 13 items (Table 1). In addition, 7 quasi-experimental studies were excluded because they were unclear or did not report on ≥4 out of 9 (Table 2). All qualitative studies were retained (Table 3). The 1 cohort study was excluded because it did not meet 5 of the 11 items (Table 4). One cross-sectional study was excluded because it did not meet 4 of the 8 criteria (Table 5). Of note, the mixed methods study was assessed using the criteria for RCTs and qualitative studies for the relevant sections as per JBI guidance.

Table 1. Quality assessment. Randomized controlled trials.

Study	Randomization used for assignment of participants to treatment groups	Allocation to treatment groups concealed	Treatment groups similar at the baseline	Participants blind to treatment assignment	Those delivering treatment blind to treatment assignment	Outcomes assessors blind to treatment assignment	Treatment groups treated identically other than the intervention of interest	Follow-up complete and if not, were differences between groups adequately described and analyzed	Participants analyzed in the groups to which they were randomized	Were outcomes measured in the same way for treatment groups	Were outcomes measured in a reliable way	Was appropriate statistical analysis used	Was the trial design appropriate, and any deviations from the standard randomized controlled trial	Percentage of items assessed as met
Bergner et al [22], 2018	Yes	Yes	Yes	Unclear	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	85
Bunnell et al [23], 2017	Yes	Unclear	Unclear	Unclear	Unclear	No	Yes	Unclear	Yes	Yes	Yes	Yes	Unclear	46
Palermo et al [24], 2020	Yes	Unclear	Yes	No	Unclear	No	Yes	Unclear	Yes	Yes	Yes	Yes	Unclear	54
Hilliard et al [25], 2020	Yes	Unclear	Yes	Unclear	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	69
O'Connor et al [26], 2020	Yes	Unclear	Yes	No	No	No	Yes	No	Yes	Yes	Yes	Yes	Unclear	54
Palermo et al [24], 2020	Yes	Yes	Yes	No	Unclear	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	69
Perrino et al [27], 2018	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	Yes	Yes	Unclear	Yes	Unclear	38
Voss et al [28], 2019	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	85
Whittemore et al [29], 2013	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	85
Widman et al [30], 2017	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	85
Ybarra et al [31], 2019	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	No	Yes	Yes	No	Yes	Yes	77
Zhang et al [32], 2018	Yes	Unclear	Yes	No	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes	69

Table 2. Quality assessment. Quasi-experimental studies.

Study	Clear what is the cause and what is the effect	Participants included in any comparisons similar	Participants included in any comparisons receiving similar treatment and care, other than the intervention of interest	There was a control group	Multiple measurements of the outcome both pre and post the intervention or exposure	Follow-up complete and if not, differences between groups in terms of their follow-up adequately described	Outcomes of participants included in any comparisons measured in the same way	Outcomes measured in a reliable way	Appropriate statistical analysis used	Percentage score
Anderson et al [33], 2018	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	89
Beaudry et al [34], 2019	Yes	Yes	Yes	No	Yes	Yes	Yes	Unclear	Yes	78
Brown et al [35], 2016	Yes	Yes	Yes	No	Yes	Yes	Yes	Unclear	Yes	78
Bunnell et al [23], 2017	Yes	Yes	Unclear	Yes	No	Yes	Yes	Yes	Yes	78
Fortier et al [36], 2016	Yes	N/A[a]	N/A	No	No	Unclear	Yes	Yes	Yes	44
Galy et al [37], 2019	Yes	Yes	Yes	No	Yes	Unclear	Yes	Yes	Yes	78
Kaushal et al [38], 2019	Yes	No	No	No	Unclear	No	N/A	Unclear	Yes	22
Kornman et al [39], 2020	Yes	N/A	No	No	Yes	No	N/A	Yes	Yes	44
Kosse et al [40], 2019	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	78
Larsen et al [41], 2018	Yes	Yes	Yes	No	Yes	Unclear	N/A	No	Yes	56
March et al [42], 2018	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes	78
Myers et al [43], 2015	Yes	No	N/A	No	No	No	N/A	No	Yes	22
McGill et al [44], 2019	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	89
Padman et al [45], 2013	Yes	No	No	No	No	Yes	N/A	Yes	Yes	44
Pramana et al [46], 2014	Yes	No	No	No	No	No	No	Unclear	Yes	22
Sousa et al [47], 2015	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	89
Tu et al [48], 2017	Yes	Yes	Yes	No	Yes	No	Yes	Unclear	Yes	67
Wingo et al [49], 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	78
Yen et al [50], 2019	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	89

[a] N/A: not applicable.

Table 3. Quality assessment. Qualitative studies.

Study	Congruity between the stated philosophical perspective and the research methodology	Congruity between the research methodology and the research question	Congruity between the research methodology and the methods used to collect data	Congruity between the research methodology and the representation and analysis of data	Congruity between the research methodology and the interpretation of results	Statement locating the researcher culturally or theoretically	Influence of the researcher on the research, and vice-versa, addressed	Participants and their voices adequately represented	Research ethical according to current criteria or, for recent studies	Conclusions drawn in the research report flow from the analysis and interpretation, of the data	Percentage score
Bergner et al [22], 2018	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	70
LeRouge et al [51], 2016	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	70
Lopez et al [52], 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	80
Tolou-Shams et al [53], 2019	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	70

Table 4. Quality assessment. Cohort study.

Study	Two groups similar and recruited from the same population	Exposures measured similarly to assign people to both exposed and unexposed groups	Exposure measured in a valid and reliable way	Confounding factors identified	Strategies to deal with confounding factors stated	Participants free of the outcome at the start of the study	Outcomes measured in a valid and reliable way	The follow-up time reported and sufficient to be long enough for outcomes to occur	Follow-up complete, and if not, were the reasons for loss to follow-up described and explored	Strategies to address incomplete follow-up used	Appropriate statistical analysis used	Percentage score
Cueto et al [54], 2019	Yes	No	No	No	Unclear	Yes	No	Yes	Yes	Yes	Yes	55

Table 5. Quality assessment. Analytical cross-sectional studies.

Study	Were the criteria for inclusion in the sample clearly defined?	Were the study subjects and the setting described in detail?	Was the exposure measured in a valid and reliable way?	Were objective, standard criteria used for measurement of the condition?	Were confounding factors identified?	Strategies to deal with confounding factors stated	Outcomes measured in a valid and reliable way	Appropriate statistical analysis used	Percentage score
Dowshen et al [55], 2015	Yes	Yes	Yes	No	No	No	No	Yes	50
Piatkowski et al [56], 2020	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	88

Characteristics of the Studies

Of the 24 studies included in the review (Table 6), 7 (29%) used an RCT design, 12 (50%) were quasi-experimental studies, and 3 (13%) used a qualitative study design. One study used an analytical cross-sectional study design and 1 used a mixed methods design.

Table 6. Study characteristics.

Study	Health condition	Aim and objectives	Country	Study setting	Study design	Type of digital intervention	Age	Gender
Anderson et al [33], 2018	Sickle cell disease	To examine the feasibility of the Intensive Training Program (ITP), a mobile health intervention for youths with sickle cell disease to promote disease knowledge, adherence, and patient-provider communication.	United States	Pediatric sickle cell disease clinic	Quasi-experimental	Mobile app	Children: mean age of children 13 (SD 3.33) years	Children: 16 (50%) children were female
Beaudry et al [34], 2019	Children transitioning from pediatric to adult care with chronic illness	To test the feasibility of a texting platform aimed at increasing engagement among teenagers while teaching essential self-care skills while transitioning to adult focused care	United States	Pediatric inflammatory bowel disease, cardiology, and type 1 diabetes specialty clinics	Quasi-experimental	Text message	Children: mean age of children 15 years; 2 aged 14 years; 1 aged 15 years; 9 aged 16 years; and 1 aged 17 years	Children: sex of children not provided
Bergner et al [22], 2018	Type 1 diabetes	To evaluate the acceptability and feasibility of Check It! a positive psychology intervention to improve adherence in adolescents with T1D[a]	United States	Outpatient pediatric diabetes clinic	Mixed method (RCT[b] and qualitative)	Text message	Children: mean age of adolescents 14.8 (SD 1.5) years	Children: 63 (52.5%) female participants and 57 (47.5%) male participants
Brown et al [35], 2016	Sexual health	To evaluate a behavior change intervention targeting sexual health service uptake among young people delivered using digital media	United Kingdom	Secondary schools	Quasi-experimental pretest posttest design	Website and mobile app	Children: mean age at baseline 15.7 (SD 1.51) years	Children: at baseline 158 (55%) female and 129 (45%) male participants; at follow-up 94 (41%) female 134 (59%) males
Bunnell et al [23], 2017	Mental health	To examine access and completion of a web-based disaster mental health intervention in adolescents and their caregivers affected by the spring 2011 tornadoes in Missouri and Alabama	United States	Community	Quasi-experimental; pretest posttest design	Website	Children: mean age of rural children was 14.5 (SD 1.76) years; mean age of urban children was 14.6 (SD 1.74) years; parents or caregivers: mean age of rural caregivers was 45.0 (SD 9.54) years; mean age of urban caregivers was 45.4 (SD 9.38) years	Children: 329 (49%) rural female participants and 347 (51%) rural male participants; 658 (50%) urban females and 663 (50%) urban males; parents or caregivers: 493 (72.9%) rural caregivers were female and 183 (27.1%) were male; 980 (74.2%) urban care givers were female and 341 (25.8%) were male
Galy et al [37], 2019	Overweight and obesity	To investigate a technology-based program combining education, objective measures of PA[c]), and self-assessment of goal achievement delivered to Pacific adolescents	New Caledonia	School	Quasi-experimental pilot study	Mobile app and wearable tracker device	Children: mean age of children 11.9 (SD 0.57) years; age ranged from 12 to 14 years	Children: sex not provided
Hilliard et al [25], 2020	T1D	To evaluate the feasibility and acceptability of a behavioral intervention delivered to parents of adolescents with T1D via mobile-friendly web app	United States	Diabetes clinic in the hospital	RCT	Mobile app	Children: mean age of children 15.3 (SD 1.5) years; parents: not provided	Children: 47 (59%) female participants and 33 (41%) male participants; parents: 64 (80%) female and 16 (20%) male

Study	Health condition	Aim and objectives	Country	Study setting	Study design	Type of digital intervention	Age	Gender
Kosse et al [40], 2019	Medication self-management asthma	To explore the use and the effective engagement of adolescents aged 12-18 years with the Adolescent Adherence Patient Tool	The Netherlands	Community	Quasi-experimental	Mobile app	Children: mean age of children 15.0 (SD 2.0) years	Children: 48 (55%) female participants and 39 (45%) male participants
LeRouge et al [51], 2016	Weight management (overweight)	To investigate the use of animated avatars and virtual agents to deliver computer-based interventions for chronic weight management ins adolescents	United States	Camp Jump Start	Qualitative	Virtual avatars	Children: mean age of adolescents not provided	Children: sex of children not provided
Lopez et al [52], 2020	Substance use and HIV	To evaluate a technology-based approach to delivering culturally tailored, integrated substance use disorder and HIV risk behavior prevention programs to African American female youths	United States	School and community	Qualitative	Telemedicine	Children: age ranged from 13 to 18 years	Children: all (100%) female participants
March et al [42], 2018	Mental health (anxiety)	To examine program adherence, satisfaction, and changes in anxiety with a publicly available online, self-help iCBT[d] program (BRAVE Self-Help)	Australia	Community	Quasi-experimental	Website	Children: mean age of children 12.9 (SD 2.97) years	Children: 2938 (66.4%) female participants and 1406 (31.8%) male participants; 81 (1.8%) participants identified as another gender category
McGill et al [44], 2019	Diabetes type 1	To evaluate an SMS text messaging intervention in teenagers with T1D assessing factors associated with text responsiveness and glycemic benefit	United States	Outpatient clinic	Quasi-experimental	Text message	Children: mean age of children 14.9 (SD 1.3) years	Children: 76 (52%) female participants and 70 (48%) male participants
Palermo et al [24], 2020	Chronic pain	To evaluate effectiveness and implementation of a digital health delivered psychological intervention for children aged 10-17 years with chronic pain	United States	Pain clinics	Stepped-wedge cluster randomized trial	Mobile app	Children: mean age of children 14.5 (SD 1.9) years	Children: 117 (81.8%) female participants and 26 (19.2%) male participants
Piatkowski et al [56], 2020	Obesity	To examine user characteristics and parenting practices associated with adolescents' initial use of the Aim2Be app; a health behavior modification intervention	Canada	Community	Analytical cross-sectional study	Mobile app	Children: mean age of children 14.9 (SD 1.5) years	Children: 184 (49.6%) female participants and 187 (50.4%) male participants
Sousa et al [47], 2015	Overweight and obesity	To evaluate the effectiveness of an e-therapeutic platform (Next.Step), aiming to promote weight management skills and the adoption of health-promoting lifestyles	Portugal	Pediatric obesity clinic	Quasi-experimental	Website	Children: mean age of children 14.2 (SD 1.51) years	Children: 48 (51.1%) female participants and 46 (48.9%) male participants
Tolou-Shams et al [53], 2019	Mental health and substance abuse	To examine the acceptability of a dyadic (youth and caregiver) SMS text messaging intervention to enhance treatment engagement of the youths attending face-to-face community-based treatment, as referred by probation staff	United States	Community-based Juvenile Probation Department and community-based provider organization	Qualitative	Text message	Children: mean age of children was 17.0 years; caregiver: age ranged from 35 to ≥65 years.	Children: 6 (75%) female participants and 2 (25%) male participants; caregiver: 4 (80%) female and 1 (20%) male

Study	Health condition	Aim and objectives	Country	Study setting	Study design	Type of digital intervention	Age	Gender
Tu et al [48], 2017	Overweight and obesity	To determine whether adolescent and parental adherence to components of an e-health intervention resulted in change in adolescent BMI and waist circumference (WC) z-scores in a sample of overweight/obese adolescents	Canada	Children's Hospital Endocrinology and Diabetes Clinic and Center for Healthy Weights program in British Columbia and by other sources	Quasi-experimental	Website	Children: mean age of children 13.2 (SD 1.8) years; parents: mean age of parents 45.8 (SD 6.2) years	Children: 91 (57.2%) female participants and 68 (42.8%) male participants; parents: 135 (84.9%) female participants and 24 (15.1%) male participants
Voss et al [28], 2019	Autism	To evaluate the efficacy of Superpower Glass, an artificial intelligence–driven wearable behavioral intervention for improving social outcomes of children with ASD[e]	United States	Home environment	RCT	Wearable glasses	Children: mean age of 8.4 (SD 2.46) years	Children: 8 (11%) female participants and 63 (89%) male participants
Whittemore et al [29], 2013	Type 1 diabetes	To compare the demographic and clinical characteristics of young people with T1D on recruitment, participation, and satisfaction with eHealth programs	United States	Clinical sites	RCT	Website	Children: mean age of 8.4 (SD 2.46) years	Children: 177 (55.3%) female participants and 143 (44.7%) male participants
Widman et al [30], 2017	Sexual health	To assess the feasibility and acceptability of Project HEART providing sex education focusing sexual communication skills to reduce the risk of HIV/STDs[f] and unplanned pregnancy among youths	United States	High schools	RCT	Website	Children: mean age of 12.3 (SD 1.1) years	Children: 107 (100%) female participants
Wingo et al [49], 2020	Children with physical disabilities	To test the usability and preliminary efficacy of an eHealth and telecoaching intervention compared with telecoaching alone	United States	Pediatric rehabilitation medicine clinics	Quasi-experimental	Website	Children: mean age of 11.3 (SD 3.3) years; parents: mean age of parents not provided	Children: 29 (58%) female participants and 21 (42%) male participants; parents: 45 (90%) female participants and 5 (10%) male participants
Ybarra et al [31], 2019	HIV prevention	To determine whether technology is an appropriate delivery mechanism for adolescent-focused HIV preventive programing in South Africa	South Africa	Schools	RCT	Text message	Children: mean age of 17.5 (SD 1.2) years	Children: 647 (63.7%) female participants and 368 (36.3%) male participants
Yen et al [50], 2019	Mental Health (suicidal behavior)	To examine feasibility, acceptability, and clinical outcomes of a positive affect skills–based technology-assisted program in an acute setting	United States	Adolescent inpatient psychiatric unit	Quasi-experimental	Text message	Children: mean age of 15.9 (SD 1.5) years	Children: 15 (75%) female participants and 5 (25%) male participants

Study	Health condition	Aim and objectives	Country	Study setting	Study design	Type of digital intervention	Age	Gender
Zhang et al [32], 2018	Diabetes type 1	To investigate adolescents with T1D engagement with an SMS text messaging intervention	United States	Diabetes clinic	Randomized pilot study	Text message	Children: mean age of 15.0 (SD 1.3) years	Children: 25 (52.1%) female participants and 23 (47.9%) male participants

[a] T1D: type 1 diabetes.

[b] RCT: randomized controlled trial.

[c] PA: physical activity.

[d] iCBT: internet-based cognitive behavioral therapy.

[e] ASD: autism spectrum disorder.

[f] STD: sexually transmitted disease.

The studies focused on a variety of health conditions; type 1 diabetes (4/24, 17%), weight management and obesity (5/24, 21%), mental health issues (4/24, 17%), and sexual health (3/24, 13%) were the predominant conditions (Table 6). Most studies (23/24, 96%) were conducted in developed countries. Most studies (15/24, 63%) were conducted in the United States.

Of the 24 studies included in the review, 10 (42%) recruited participants from outpatient clinics, 1 (4%) recruited from the hospital setting, 4 (17%) recruited in schools, and 8 (33%) within community settings. One study recruited participants from both a school and a community setting.

In more than half of the studies (16/24, 67%), more females were recruited than males. In 3 studies, the gender of the child was not provided [23,33,51].

Type of Digital Interventions

Overall, 38% (9/24) of the digital health interventions were web based, 21% (5/24) of the interventions were mobile apps, 29% (7/24) of the interventions used SMS text messaging, 4% (1/24) of the interventions used a website and a mobile app, 4% (1/24) of the interventions were a telemedicine intervention with participants logging in on their home computer or tablet, and 8% (2/24) of the digital interventions combined a website and digital wearable glasses and an app and wearable tracker (Table 6).

Access and Engagement

Access to Digital Health Interventions

The 2 studies that reported access and digital health interventions included 1 that reported on access related to race and ethnicity and access by income and 1 that reported on gender differences in accessing services (Table 7).

Table 7. Report of access and engagement.

Study	Number of participants enrolled	Intervention period	Data reported on access	Engagement; logged in; or interacted at least once	Engagement; frequency; average per day or week	Engagement; intensity of engagement	Engagement; completion of the course	Engagement; acceptance satisfaction
Anderson et al [33], 2018	32 children completed the baseline survey	90 days (6 weeks) participants to enter medication daily	No data reported	28 (87%) participants logged in	Participants logged in average 18 of the 30 days (60% of participants logged in each day)	37% tracking daily entry	27 (84%) participants completed track an entry of medication each day	Ranged from 41.7% to 91.7%
Beaudry et al [34], 2019	13 children enrolled	24 weeks—weekly text messages sent	No data reported	13 (100%) children responded to the chatbot	97% responded to weekly text message	Responses rates ranged from 85% to 100% response to the text message each week	13 children, 100% responded to the last text of the study period. 12 (92%) children completed the final survey	Satisfaction was not measured on the survey. Children reported being motivated to respond to the texts because of its “ease of use” and because they were “friendly.”
Bergner et al [22], 2018	120 parent child dyads enrolled	8 weeks; intervention group to answer weekly text message	No data reported	Information not provided	14% teenagers answered weekly phone reminders (control group) vs 67% in the text (intervention) group (*t*=7.97; *P*<.001)	No other measurement provided	89% of the adolescents and 92% of the parents completed the 3-month follow-up survey	Adolescents and their parents were satisfied with the study, with >87% noting a positive experience.
Brown et al [35], 2016	287 children enrolled at baseline	6 weeks	A digital intervention approach had a significant positive effect on psychological barriers to and antecedents of service access among females. Males reported greater confidence in service access than females.	100%	No measured	At follow-up, all participants reported having accessed the website or web app at least once. 45% had visited ≥2 main intervention pages. 36% indicated that they had not visited any of the core website pages and 21% indicated that they had visited only one of the 19 main intervention pages.	Not measured	Not measured
Bunnell et al [23], 2017	2000 families (parent child dyad)	Intervention period not provided	No data reported	485 (36.7%) urban adolescents and 223 (33.0%) rural adolescents accessed the resource. 503 (38.1%) urban caregivers and 233 (34.5%) rural caregivers accessed the resource.	Not measured	Not measured	384 (79.2%) urban adolescents and 170 (76.2%) rural adolescents completed the course. 313 (62.2%) urban and 128 (54.9%) rural caregivers completed the course.	Not measured

Study	Number of participants enrolled	Intervention period	Data reported on access	Engagement; logged in; or interacted at least once	Engagement; frequency; average per day or week	Engagement; intensity of engagement	Engagement; completion of the course	Engagement; acceptance satisfaction
Galy et al [37], 2019	24 adolescents	4 weeks to 8 one-hour modules	No data reported	24 (100%) adolescents used the electronic tracking device	24 (100%) adolescents wore the electronic tracking device daily	Not measured	21 (84%) adolescents competed the program.	95% of the adolescents rated their satisfaction with the modules as “fun.”
Hilliard et al [25], 2020	80 families enrolled. At baseline randomized to 55 family’s intervention and 25 families usual care control	3 to 4 months	No data reported	All 55 (100%) intervention arm families (parents) downloaded the app and logged in at least one time	53 participants (parents; 96%) logged in at least 1 additional time. 91% of parents used the app ±2 days per week on average. 79.9% of parents logged in each day.	96% of the participants used the strengths tracking section of the app. 90% of the participants viewed the strengths summaries.	78 families (98%) completed follow-up	Intervention participant responses (n=50) on the USE[a]. questionnaire indicated high acceptability of the intervention. Feedback from 48 parents was positive.
Lopez et al [52], 2020	58 African American adolescents	S 11 weekly; 1-hour group sessions with youth participants and 1 20-minute individual session with each parent of participants at some point between weeks 5 and 9 (totaling 12 weeks)	No data reported	53 (91%) adolescents completed the baseline	—[b]	—	39 (67%) completed the intervention	100% would recommend the program to a friend
Kosse et al [40], 2019	103 patients enrolled	6 months	No data reported	87 (84%) patients logged in to the app. 16% of the patients did not download the app.	86 adolescents used the app 1975 times between October 2015 and April 2017. The median app use per person was 17 times.	51% watched at least 1 movie. 65 (75%) adolescents sent or received ≥3 chat messages. 18 adolescents used the peer chat.	26 (weekly) reminders sent to complete the app—individually completed the app 10 times.	Not measured

Study	Number of participants enrolled	Intervention period	Data reported on access	Engagement; logged in; or interacted at least once	Engagement; frequency; average per day or week	Engagement; intensity of engagement	Engagement; completion of the course	Engagement; acceptance satisfaction
LeRouge et al [51], 2016	70 adolescents	Intervention period not provided	A structured protocol of questions including general background questions (ie, age, technology access questions, level of avatar, or virtual agent experience) and then reviewed midfidelity mock-ups of 7 types of graphical embodiments of the character, for the virtual self-avatar or virtual agent.	70 (100%)	Not measured	Not measured	Not measured	Not measured
March et al [42], 2018	4425 young people enrolled	20 weeks with 10 sessions	No data reported	3467 (78.4%) completed the first session	Not measured	48.05% (2126/4425) of the registered participants completed only 1 or 2 sessions. 24.75% (1095/4425) of the participants completed at least 3 sessions.	3.6% (163/4425) completed all 10 sessions	The mean total satisfaction rating was 17.72 (SD 5.16) out of a maximum 25
McGill et al [44], 2019	151 young people enrolled	18 months	No data reported	147 (97%) young people received the SMS text messaging intervention. Received a daily text message to check blood glucose levels.	Over 18 months, 49% of young people responded with ≥1 blood glucose result on ≥50% of days. Declined over time (0 to 6 months 60% response—7 to 12 months 50% daily response); 13 to 18 months 43% daily response	Not measured	Not measured	Not measured
Palermo et al [24], 2020	143 youths enrolled: 73 youths assigned to the treatment group and 70 youths to the control group	8 weeks	No data reported	68 (97%) youths downloaded the app and 54 youths (74%) completed at least 1 module of the intervention.	Not measured	Youths completed an average of 3.1 modules; range 5 (0 to 8)	20 (27%) youths completed the intervention program.	85.7% of youths and rated the WebMAP program as moderately to highly acceptable on the Treatment Evaluation Inventory

Study	Number of participants enrolled	Intervention period	Data reported on access	Engagement; logged in; or interacted at least once	Engagement; frequency; average per day or week	Engagement; intensity of engagement	Engagement; completion of the course	Engagement; acceptance satisfaction
Piatkowski et al [56], 2020	371 adolescents and parent dyads enrolled and completed the baseline assessment	Not provided	No data reported	294 (79.2%) adolescents used the app	Not measured	Not measured	Not measured	Not measured
Sousa et al [47], 2015	94 adolescents enrolled (48 adolescents enrolled in the experimental group and 46 adolescents enrolled in the control group)	24 weeks	No data reported	25 (52.1%) adolescents in the experimental group logged in to the website.	On average, accessed the platform 10.68 times (SD 18.92)	On average analyzed 7.9 (SD 9.25) resources and read 31.8 (SD 47.56) messages from the forums during the 24-week period.	13.7% of the adolescents in the experimental group completed the activities.	Satisfaction was not measured.
Tolou-Shams et al [53], 2019	8 youths	6 months	No data reported	Not measured	Not measured	Not measured	7 (87.5%)	Not measured
Tu et al [48], 2017	159 (90%) adolescent parent dyads participated	8 months	No data reported	15 (9.4%) adolescents and 50 parents (31.5%) did not log in to the intervention website during the entire study period.	Over the 33-weeks intervention adolescents logged into the website an average of 13.4 weeks, and parents logged into the website an average of 7.5 weeks	Adolescents mean percentage of web pages viewed per week, where a total of 83 and 78 pages could be viewed in the first and last 4 months, respectively (typically there were 4-5 pages per week to view).	On average, adolescents and parents completed 28% of the web pages viewed.	Satisfaction was not measured
Voss et al [28], 2019	71 families enrolled; 40 (56.3%) were randomly assigned to the treatment and 31 (43.7%) to the control group	6 weeks; 20-minute sessions at home 4 times a weeks	No data reported	27 (67.5%) of the 40 treatment families engaged with the Superpower glasses.	Families used the glasses 12.1 times over the 6 weeks.	27 (67.5%) families used each of the 3 engagement activities at least once, used the device at home for 20 min 3 times per week. Participants played guess the emotion in 39.8%, capture the smile 23.8%, and unstructured free play 36.4%.	24 (60%) families completed the intervention	Satisfaction was not measured

Study	Number of participants enrolled	Intervention period	Data reported on access	Engagement; logged in; or interacted at least once	Engagement; frequency; average per day or week	Engagement; intensity of engagement	Engagement; completion of the course	Engagement; acceptance satisfaction
Whittemore et al [29], 2013	320 youths enrolled: 167 were allocated to TeenCope intervention and 153 were allocated to managing diabetes intervention.	5 sessions	Black, Hispanic, or mixed-race and -ethnicity youths with type 1 diabetes were less likely to enroll in digital health interventions than White and higher-income youths	148 (90.3%) youths who received the intervention logged in	Not measured	Not measured	250 (78.1%) youths completed at least 4 of 5 sessions. The mean number of sessions completed was 4.08 (SD 1.64) across both groups. 39 (12.2%) completing 1 to 3 sessions, and 31 (9.7%) completing no sessions.	Satisfaction was high with mean satisfaction score was 3.97 (SD 0.71) for TEENCOPE (1 is not at all satisfied and 5 is very satisfied)
Widman et al [30], 2017	107 participants randomly assigned to the intervention group and 115 participants assigned to the control group.	1 session; 45 minutes to complete	No data reported	107 (100%) participants interacted with the website	Not measured	Not measured	107 (100%) participants completed the intervention	Participants found the program to be highly acceptable with 79% of participants reported they would come back to the website again, 88% would recommend the program to a friend, and 94% plan to use the information they learned in the future
Wingo et al [49], 2020	65 parent and child dyads consented and randomized and a total of 32 dyads randomized to the eHealth group and 33 to the telephone only group.	12 weeks	No data reported	24 (75%) eHealth group received the intervention; 26 (78.7%) telephone only group received the intervention.	Not measured	Mean days journal entry: 45.6 food, 46.1 water, and 42.1 physical activity	17 (67%) in the eHealth group compared with 23 (92%) of telephone only group completed the intervention.	Parents indicated they valued phone calls more than the eHealth platform
Ybarra et al [31], 2019	303 youths; 150 intervention and 153 control	8-10 daily text messages sent over 5-week period	No data reported	98% of the intervention participants sent or received a text message	Not measured	Not measured	Not measured	93% of the intervention participant said they somewhat or strongly agreed that they liked the program
Yen et al [50], 2019	20 (83%) adolescents enrolled	4 weeks	No data reported	100% responded	On average, participants responded to text prompts on 72.4% of days	Not measured	19 adolescents completed the intervention.	The intervention was described as good or excellent by >90% of the parents and 100% of the adolescents

Study	Number of participants enrolled	Intervention period	Data reported on access	Engagement; logged in; or interacted at least once	Engagement; frequency; average per day or week	Engagement; intensity of engagement	Engagement; completion of the course	Engagement; acceptance satisfaction
Zhang et al [32], 2018	48 adolescents were enrolled. 24 adolescents and their caregivers in intervention group and 24 in the education group.	8 weeks	No data reported	87% responded	The mean response rate was 76 to the 4 to 5 text messages per week overall. Responses waned over the 8-week period, from 87% in week 1 to 81% in week 5 and 62% in week 8.	Not measured	Not measured	Not measured

[a] USE: Usefulness, Satisfaction, and Ease of use.

[b] Data not reported.

Race and Ethnicity

Equity of service use based on race and ethnicity was explored in 1 study. Whittemore et al [29] reported that Black, Hispanic, or mixed-race youths with type 1 diabetes were less likely to enroll in digital health interventions than White and high-income youths. However, once enrolled, youths of diverse races and ethnicities with type 1 diabetes were as highly satisfied with the eHealth programs as White youths. The results suggest that eHealth programs have the potential to reach diverse youth groups and to be relevant to them; however, considerations relating to access need to be addressed in the study design.

One study reported on access related to gender. Brown et al [35] reported that the digital intervention had a significant positive effect on psychological barriers to and antecedents of service access among females. Males reported greater confidence in service access than females and significantly increased service access by the second follow-up.

Equity of service use based on income was explored in 1 study. Whittemore et al [29] reported that low-income youths were less likely to participate, possibly because of access. However, once enrolled, youths of diverse races and ethnicities and low-income youth with type 1 diabetes were as highly satisfied with the eHealth programs as White youths and those with higher income.

Engagement With Digital Interventions

Overview

Engagement with the digital health intervention was measured by the frequency and intensity of engagement, satisfaction with the digital health intervention, and changes in knowledge or behavior. Of the studies that reported on engagement, most used system use data to capture how the intervention was used by each participant. The studies reported on various aspects of use data including initial log-in, frequency, intensity, and duration of engagement with the program, as described in Table 7.

Initial Log-In

Once enrolled in a digital health intervention, most participants logged in and engaged with the intervention. The percentage of enrolled participants logging in at least once to the digital intervention ranged from 35.6% [23] to 100% [30,34,35,37,50]. One study did not provide this information [22]. In 16 studies, more than three-quarters of the participants logged on at least once to the digital intervention (Table 7).

Frequency of Engagement

Frequency of engagement was measured by the log-in data, number of log-ins recorded per participant, average log-ins per unit of time or total for intervention duration, visits to the site, number of visits per participant, average per unit of time, or total time of visits. Overall, 42% (10/24) of the studies reported the average number of log-ins per unit of time. The measurement of frequency varied across the studies with either daily or weekly measurement with the unit of measurement dependent on the study aims and the frequency of the delivery of the intervention.

Overall, 21% (5/24) of the studies reported on engagement on a daily basis with between 49% [44] to 100% [37] of the participants engaging daily with the intervention. Moreover, 29% (7/24) of the studies reported weekly engagement with the digital health intervention, 13% (3/24) of the studies reported the percentage of participants engaging weekly, and 17% (4/24) of the studies reported the average weekly engagement with the website or app.

The most frequent measurement of the frequency of engagement was daily or weekly response to text messages by participants as reported in 6 studies.

Zhang et al [32] found that adolescent sex was significantly related to engagement (t=2.42; P=.02), with boys demonstrating higher response rates (88%) than girls (67%). However, Whittemore et al [29] found no significant gender difference in enrollment and participation in an eHealth program for adolescents with type 1 diabetes.

Intensity of Engagement and Type of Behavior

The intensity of engagement was measured by pages viewed, modules viewed, number of emails sent, number of posts, and number of experts accessed. Three studies measured the number of log-ins per participant and reported the number of times an app or web page was visited. Zhang et al [32] reported that race and ethnicity were significantly related to engagement (t=3.48; P=.04), with White, non-Hispanic youths responding to more messages (80%) than youths in racial and ethnic minority groups (45%).

One study measured functions used stating the number and percentage of participants who used the 5 functions within the intervention platform [40].

Completion of Modules and Courses

Most studies measured either completion of modules or completion of the course, with completion rates ranging from 3.6% to 100%, with most studies reporting >80% of participants completing modules or the course. Completion of modules, web pages, and courses were measured in 16 studies. In the study with the lowest completion rate [42], completion of all 10 sessions was low (3.6%), but 48% of the participants completed some sessions [40]. Although completion rates were reported in 16 studies, understanding whether these were higher or lower than expected or in direct comparison to face-to-face or other nondigital intervention approach was not clear. Completion of the intervention sessions was high in several studies (Table 7); for example, 84% of the participants completed the intervention in 2 studies [33,37], 95% of the participants completed the intervention in another study [50], to 100% of the participants completing the intervention [37]. The results did not provide insight into whether the digital nature of the intervention increased, decreased, or had a neutral impact on completion rates.

Satisfaction

Satisfaction was measured in 14 studies, with satisfaction measurement methods varying across the studies (Table 7). Of the 14 studies that assessed satisfaction, participants were generally satisfied with the digital intervention, and in 1 study [49] participants were more satisfied with telephone calls than the digital alternative. When reported, satisfaction rates were high, ranging from 42% [33] to 93% [31].

Discussion

Principal Findings

This review found that few studies have reported on how they addressed access and engagement of children and young people in digital health interventions. Most studies (23/24, 96%) included in the review were conducted in developed countries, mainly the United States. Only 2 studies reported data related to access, and no study reported the use of strategies to enhance or increase access. All studies included in the review reported on at least 1 aspect of the engagement of children and young people in interventions. Engagement was assessed in relation to frequency but did not consider whether the level of engagement achieved could be considered effective.

Access to health care includes both the availability of services and the ability of individuals and populations to access services. Inequities in access to health care tend to affect the most susceptible people in our communities and those with the most complex health care needs [17,57]. Until now, the examination of young people's access to digital health interventions has primarily focused on reviewing their engagement after enrollment in the study. However, there has been minimal consideration of equity issues regarding access before enrollment or engagement after enrollment among different groups. There is much work to be done in carefully mapping the factors that may affect access within a population during the conception of a study and planning for how to improve equity in relation to access before recruitment begins. The World Health Organization [58] has developed a framework for planning, developing, and implementing youth-centered digital health interventions. The framework provides guidance on the key considerations at each stage, including whether a digital solution is the best approach and consulting with young people. Examples of considerations for researchers and others to deliberate include ownership of, and access to, digital devices; connectivity in a geographical area; and community consultation to understand the cultural, social, family, and individual beliefs and behaviors related to technology, health, and behavioral change to create a user-centered designed intervention.

Variability in the measurement of engagement with digital health interventions reflects the diversity, complexity, and multiple aims of the digital health interventions. Although there is variability in the measurement of engagement, most young people in the studies included in this review engaged with the digital health interventions once enrolled. The measurement of engagement with interventions was based on use data, frequency and intensity of engagement, and user satisfaction data. There has been no exploration of the relationship between engagement with the digital intervention and the outcome measures. The concept of “effective engagement” [19] was not explored in the papers included in the review. The concept of promoting effective engagement rather than simply more engagement is an area that could yield valuable insights into how to support young people to achieve the goals and intended outcomes of a digital health intervention. Exploring and recognizing the combination of measures to promote and support “effective engagement” is an area for development with the potential to test multidimensional models of engagement [1,59].

The digitalization of health has the potential to improve health outcomes by empowering young people to become active custodians of their own health. There is the potential to improve access and health outcomes for traditionally underserved groups where smartphone ownership and use are higher than the general population [60,61]. However, caution has been advised regarding the digitalization of health, as it tends to favor certain groups while potentially having negative impacts on others. Although there has been exponential growth in the use of the internet, access to health information remains unequal [61].

Equal use for equal need requires conditions whereby those who have an equal need for health care make equal use of health care. Compared with equal access for equal need, this equity principle requires more proactive efforts. Areas related to fiscal and social policy, that influence education, housing conditions, and nutrition, are highly influential and speak to fundamental determinants of health. To promote access and engagement, researchers must first recognize the importance and value of considering these factors and preempt, plan, and document their efforts to make progress.

The limitations of this review include the search for, and inclusion of, papers published in English only. The heterogeneity of the papers meant that a meta-analysis was not possible and a narrative summary was completed. The review included studies that reported on either access or engagement or both; however, improving or addressing these concepts was not the primary aim of the studies. Where the 2 concepts are fundamental to the design and effectiveness of digital interventions, a strength of the review lies in the inclusion of all studies that report on the consideration of access and engagement.

Conclusions

The review identified several gaps and raised important questions for further investigation. Most of the studies reporting on access or engagement, did not seek to improve access to digital technology and focused on the frequency of engagement. Future work should explore how access and engagement can be considered preemptively and assessed throughout the intervention, with the goal of improving the equity of access and effective engagement with digital interventions.

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Data Availability

Data are presented in the manuscript and Multimedia Appendix 1.

Authors' Contributions

LW, EM, and DA were involved in conceptualization, methodology, screening, and bias assessment and wrote the review. MJ and SR were involved in study methodology, literature search, screening, data extraction, data analysis, and bias assessment and wrote the review.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy.
[DOCX File , 13 KB - pediatrics_v7i1e44199_app1.docx]

Multimedia Appendix 2
PRISMA checklist.
[PDF File (Adobe PDF File), 66 KB - pediatrics_v7i1e44199_app2.pdf]

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Abbreviations

JBI: Joanna Briggs Institute
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT: randomized controlled trial

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Review

Young Children and the Creation of a Digital Identity on Social Networking Sites: Scoping Review

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Abstract

Background: There is limited understanding of the concept of the digital identity of young children created through engagement on social networking sites.

Objective: The objective of this scoping review was to identify key characteristics of the concept of digital identity for children from conception to the age of 8 years on social networking sites.

Methods: This scoping review was conducted using the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines. The key databases searched were EBSCO, Web of Science, ProQuest ERIC, and Scopus. Gray literature sources (National Grey Literature Collection, ProQuest Dissertations and Theses, and Google Scholar) were also searched to identify unpublished studies. Articles were selected if they were published in English and reported data on the digital identity of children in relation to social networking sites.

Results: The key terms used in the literature were *sharenting*, followed by *digital footprints* and *children's identities*. Our study revealed 2 approaches to the creation of digital identity: *social digital identity* and *performative digital identity*. The articles in this review most commonly used the term *sharenting* to describe the behavior parents engage in to create digital identities for children on social networking sites. Motivations to post information about children differed among parents; however, the most common reasons were to share with friends and family and create digital archives of childhood photos, termed *social digital identity*. The second motivation was categorized as performative digital identity. The risk of digital kidnapping and identity theft associated with the creation of digital identities also influenced parents' behaviors.

Conclusions: The creation of a digital identity for children is an emerging concept. Our review develops a deeper understanding of sharenting behaviors that can be used to better support parents and their children in creating a digital identity with children and awareness of the potential future impact. We recommend that future studies explore the perspectives of children as key stakeholders in the creation of their digital identity.

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KEYWORDS

digital identity; children; social networking sites; sharenting; scoping review; perspectives

Introduction

Background

Every post made on social networking sites contributes to the development of a digital identity. For some, this occurs naturally through their engagement with social networking sites, and for others, the process is planned or curated. Children and vulnerable populations can be represented on social networking sites without control over the creation of the digital identity developed on their behalf [1-7]. Children's digital identities are often created before the child is born [8,9]. The creation of a child's digital identity can start with parents sharing information about their soon-to-be-born or newly born child on social networking sites [3,10-12]. Digital identity development continues beyond the initial post as images, events, and milestones are shared with or without the permission of the child.

One of the major limitations of the literature on children and social networking sites is the underrepresentation of the voice of the younger child. There is little information available on social networking sites and their use and impact on children and even less from the perspective of children [13-16]. The lack of research with children is mainly attributed to the minimum age requirement for a child to register an account. Each social media site and app has its own criteria for minimum age requirements, which range from 13 to 16 years (13 with parental consent). It is common for parents to either post on behalf of their children or post (knowingly or unknowingly to the child) about their children between conception and the age of 8 years [17].

Although literature on the digital identity of children is emerging [8,12,18,19], evidence on the digital identities of adults has grown rapidly over the past 2 decades [20-25]. Despite the increase in the literature that explores adults' digital identity, the key concepts related to processes and outcomes have not been established [1,20]. Approaches to define digital identity often draw on existing theories, such as the theory of self-presentation by Goffman [26,27]. Goffman [26] describes identity as performative and the world as a stage on which the act is taking place. The performance cannot take place without an audience who is there to validate the social performance [26]. Social networking sites are often seen as a stage in which one is actively trying to manage their impression or performance to be liked by others [28].

Research on adolescents' digital identity (development) also draws on the theory by Goffman [26] and identity development theories such as the stages of psychosocial development were developed by Erikson [29], the identity status theory by Marcia [30], and the concept of networked publics by Boyd [31]. Identity development theories describe the adolescent years as the most important phase of identity development, and little is theorized about young children's identity development [20,29,32]. However, Schachter and Ventura [33] argue that identity formation starts before adolescence and that parents play an active role in their children's identity formation and later identity development. This aligns with the early formation of "digital" identities, which often starts with parents posting about their children on social networking sites.

Objectives

There is limited understanding of the concept of digital identity for young children [21,34]. The purpose of this scoping review was to explore key characteristics in the literature on the concept of digital identity for children from conception to the age of 8 years on social networking sites. The review question was as follows: "What are the key concepts, definitions, and characteristics related to the concept of digital identity as generated through engagement with social networking sites for children from conception to the age of 8 years?"

Methods

Overview

A preliminary search of the Cochrane Database of Systematic Reviews and *JBI Evidence Synthesis* was conducted, and no current systematic or scoping reviews on the topic were identified. The updated methodological guidance for conducting a Joanna Briggs Institute scoping review was used in tandem with the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) to guide this review [35]. The completed PRISMA-ScR checklist can be found in Multimedia Appendix 1. A scoping review was assessed as the most appropriate method, where the purpose of this review was to identify and clarify concepts [36] regarding the digital identity of children. The scoping review protocol was registered with the Open Science Framework and can be retrieved via the web (see the reference for a link to the protocol) [37].

Search Strategy

Relevant databases were searched using a constructed Boolean strategy with subject headings and keywords to reflect the inclusion criteria (the search strategy can be found in Multimedia Appendix 2). The first search was conducted between July 2022 and September 2022, and the second search was conducted between February 2023 and April 2023. The strategy was developed in conjunction with a specialist librarian. The search strategy, including all identified keywords and index terms, was adapted for each included database or information source. The databases EBSCO, Web of Science, ProQuest ERIC, and Scopus were searched. The reference lists of the included studies were cross-checked with search outcomes to identify studies not previously identified. Gray literature sources such as the National Grey Literature Collection, ProQuest Dissertations and Theses, and Google Scholar (the first 200 results) were also searched to identify unpublished studies.

The search terms were as follows: *child* OR *children* OR *infant* OR *toddler* OR *preschooler* (population) AND (*digital* AND *identity*) OR *"digital identity"* OR (*online* AND *profile*) OR *"online profile"* OR (*social* AND *presence*) OR *"social presence"* OR *sharenting* (concept) AND *social media* OR *Facebook* OR *Instagram* OR *Twitter* OR *Snapchat* OR *Tumblr* OR *"social networking"* (context).

Inclusion and Exclusion Criteria

Overview

Studies of any research design that included the presentation of findings on digital identity in relation to children from conception to the age of 8 years on social networking sites were included if a full text could be retrieved. The viewpoint within the studies could be of the young person, family, health professionals, peers, and others. Further inclusion criteria were articles that were peer reviewed, written in English, and published between January 2000 and April 2023 inclusive. Gray literature was included if research findings were reported. No restrictions on the inclusion of studies were applied in relation to the geographic location or setting of the studies except for the generation of the data on social networking sites.

Participants

Social media related to children from conception to the age of 8 years was included. Data related to family members who posted about their children were also included.

Concept

The concept explored was digital identity on social networking sites in relation to children from conception to the age of 8 years. This review focused on web presence on social networking sites, and therefore, literature on digital identity that was purely data generated was excluded. Data-generated identities include, for example, log-ins, personal information saved on websites for identification purposes, and data saved while using apps and playing games. This type of digital identity is discussed elsewhere [38].

Types of Sources

This scoping review included both qualitative and quantitative studies. Quantitative study designs including experimental and quasi-experimental study designs, randomized controlled trials, nonrandomized controlled trials, before-and-after studies, interrupted time-series studies, analytical observational studies (prospective and retrospective cohort studies), case-control studies, and analytical cross-sectional studies were considered for inclusion. This review also considered descriptive observational study designs including case series, individual case reports, netnography, and descriptive cross-sectional studies for inclusion.

Screening

Following the search, all identified references were imported into EndNote (version 20.1; Clarivate Analytics) for the identification and removal of duplicates and then exported to the Joanna Briggs Institute System for the Unified Management, Assessment, and Review of Information (Ovid) for a second identification of duplicates and the independent screening of titles and abstracts against the inclusion criteria by 2 reviewers [39]. Any differences between the reviewers regarding the inclusion or exclusion of articles for full-text review were discussed, and if not resolved, they were referred to a third reviewer. The full texts of the retained articles were independently assessed by 2 reviewers. Any differences between the reviewers were discussed and, if not resolved, they were referred to a third reviewer. The reasons for excluding studies at the full-text review stage were recorded. The study selection, screening, and reasons for exclusion at the full-text review stage are reported in the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram [35] in Multimedia Appendix 1.

Charting the Data

Data extraction tables were developed with the team and used to ensure a uniform data extraction process. Data extraction was undertaken by a minimum of 2 reviewers. The selected studies were analyzed to identify the key characteristics, such as study design, aim, country of study, setting and context, participant characteristics (the age and gender of the children and their families), and sample size. Key terms and concepts related to children's digital identity were identified, and themes and trends were charted. Where required and possible, the authors of the papers were contacted to request missing or additional data for clarification.

Analysis and Presentation of Results

All articles in this scoping review were searched for key terms used in relation to the concept of digital identity. If the term was mentioned ≥2 times, it was included in the count. Key terms were included if they appeared in the main text, titles, abstracts, or keywords but not in references, footnotes, or headers.

Where variations of the term existed, all variations were analyzed as related to the core term. For example, for the core term *children's identities*, variations such as *children's identity*, *child's identity*, *the identity of the child*, or *their (children's) identity* were included. Similarly, variations of *sharenting* such as *oversharing*, *anti-sharenting*, and *grand-sharenting* [40] were analyzed as related to the core term *sharenting*.

The search was carried out using the PDF reader Nitro (Nitro Software, Inc), and words were copied and pasted into the search bar to avoid spelling mistakes. The search strategy included terms such as *identit* to quickly identify all terms related to identity, such as *online identity*, *digital identity*, and *social identity* (*identity* on its own was not counted).

Data were presented in tabular form, which allows for easy comparison between articles. A graphic was chosen as a way to demonstrate the relationships between key terms. Quantitative and qualitative data were extracted into tables to compare the studies, and qualitative data were sorted into key themes. Key trends are discussed in the Results and Discussion sections.

Results

Overview of Results

The search produced a total of 2573 abstracts, 1764 references from database and register searches, and 809 references from searches using other methods (refer to Multimedia Appendix 1 for the PRISMA flowchart [40]). Of the 1764 references, 652 (36.96%) were identified as duplicates, leaving 1112 (63.04%) references. There were no duplicates in the 809 references from other search methods. After title and abstract reviews were completed on all remaining references, 93.53% (1040/1112) of the articles were excluded from the database references and 99% (801/809) were excluded from the references from other search methods. This left 72 articles, of which 1 (1%) was excluded as there was no way to retrieve the full text and there were no contact details for the corresponding author [41]. Of the remaining 71 articles, after the full-text review, 50 (70%) were excluded, with the most common reasons being ineligible phenomena of interest (n=20, 40%), age (n=14, 28%), and the article not being about the child or children (n=8, 16%). This resulted in 21 articles. An additional hand search in March 2023 and April 2023 identified 7 articles for full-text review, of which 6 (86%) were included and 1 (14%) was excluded as it was not about the child or children. This resulted in a total of 27 articles included in this scoping review [7,9,10,17-19,40,42-61].

Characteristics of the Studies

Participants

Overview

The total reported number of participants in this scoping review was 8643, comprising mothers (n=1768), fathers (n=585), grandparents (n=1), and participants reported collectively as parents (n=1841). In total, 4% (1/27) of the articles reported data from child participants (n=68) [59]. The remaining 4263 participants were not identified further. Overall, more female participants (n=4158) than male participants (n=1753) were reported in the articles.

The sample size of the included studies ranged from 1 [18] to 3472 [57] participants. Notably, 30% (8/27) of the articles did not provide sample characteristics [7,43-45,47,48,52,54]. This was due to the study context (eg, content analyses of social networking site posts and photos) [7,43-45,47,48,52,54] and the nature of the articles, such as books or reviews [54] (Table 1).

Table 1. Characteristics of the included studies.

Study, year	Study aim	Study design	Country	Setting and context	Identity type	Participants	Age	Sex
Ammari et al [19], 2015	To investigate how parents decide what to disclose about their children on SNSs[a]	Qualitative	United States	Sharenting and the shared responsibility of parents in managing their children's online identities	SDI[b]	102 parents	Data unavailable	Male and female
Bare [43], 2020	To provide an overview of the images of children being posted to Instagram by parents under the hashtag #letthembelittle	Qualitative	United States	Content analysis of Instagram posts of children with the hashtag #letthembelittle.	SDI and PDI[c]	Unspecified	Data unavailable	Data unavailable
Benevento [44], 2022	To understand how photographs shared on social media connect and express values regarding childhood	Narrative inquiry	Not specified	Analyzing Instagram postings and comments on photos of children on 2 hashtags—#letthekids and #fashionkids	SDI	Not specified	Data unavailable	Data unavailable
Bezakova et al [45], 2021	To identify the extent of the problem of sharing content on minors with family members on social media (*sharenting*), identify legal solutions to the problem, and point out the importance of adequate social mechanisms (media and marketing) to raise awareness of the issue	Analytical-synthetic and comparative research methods	Not specified	Analyzing sharenting of sensitive data on social media, comments, reviews, blogs, web portals, and emails. Identifying legal solutions to protect children.	SDI	Not specified	Data unavailable	Data unavailable
Briazu et al [46], 2021	To investigate how the risks and benefits alongside psychosocial variables affected the Facebook sharenting behavior of mothers of young children	Mixed methods	United Kingdom	Facebook sharenting behaviors of mothers	SDI	190 mothers of young children	62.6% were aged between 25 and 34 y	Female
Brosch [10], 2016	To learn about parents' habits regarding their children on Facebook, especially how much and what kind of information about their children they share	Social media ethnography	Poland	Sharenting on Facebook. Exponential nondiscriminative snowball recruiting.	SDI	168 parents with a child or children aged <8 y	Data unavailable	Data unavailable
Choi and Lewallen [47], 2018	To examine how children are represented on Instagram and how children are depicted in relation to traditional stereotypes	Mixed methods	United States	Content analysis of 510 photos of children on Instagram on children's gender and racial representations on social media	SDI and PDI	Not specified	Data unavailable	Data unavailable

Study, year	Study aim	Study design	Country	Setting and context	Identity type	Participants	Age	Sex
Cino and Dalledonne Vandini [40], 2020	To investigate how boundaries of children's social media presence are understood and experienced within interacting systems regarding the relationship between MILs[d] and DILs[e]	Literature review and qualitative study	United States	Digital dilemmas on their children's digital footprints, privacy, and social media presence created by members external to the family, such as the child's teacher. Analysis of parents' posts on a BabyCenter community, a web-based parenting forum.	SDI	300 parents	Most were female. Specific data are unavailable.	Data unavailable
Dobson and Jay [18], 2020	This paper explored the representation of children and family life, with an emphasis on the "image of the child" that exists on Instagram.	Qualitative	Australia	Perspectives and experiences of an influencer parent sharenting photos on Instagram	SDI and PDI	1 mother	Data unavailable	Female
Er et al [48], 2022	To investigate *sharenting* during the early COVID-19 pandemic and quarantine periods	Qualitative	Turkey	Sharenting during the pandemic and quarantine period. Descriptive content analysis of the Instagram profiles of the parents—401 posts from Instagram	SDI	Unspecified	Data unavailable	Data unavailable
Fox et al [50], 2022	To explore first-time fathers' vulnerabilities and decisions to engage in sharenting, especially given that marketers seek to connect with new parents on social media via engagement tactics that prompt sharenting	Mixed methods	United States	First-time fathers' willingness to sharent on social media and their level of perceived sensitivity to their children's information. Web-based survey on Amazon Mechanical Turk using Prime Panels and grounded theory.	SDI	75 first-time fathers	Aged 20 to 40 y	Male
Fox and Hoy [49], 2019	Study 1: to explore mothers' expressions of vulnerability and how these relations can be linked to their motivations for sharing children's PII[f] on social media. Study 2: to explore mothers of young children in a Twitter chat and the extent to which they post children's PII, as well as the mother's vulnerability.	Mixed methods	United States	Qualitative: interaction of consumer vulnerability of the mother and the reasons and decision to post about their children on social media. Quantitative: interaction of a brand—Carter's, Inc and Children Apparel—with the engagement of mothers on Twitter.	SDI	Study 1: 15 mothers; study 2: 122 participants	Study 1: aged 24-40 y; study 2: data unavailable	Study 1: female; study 2: data unavailable
Hashim et al [51], 2021	To investigate the trends, motives, or purposes behind sharenting by Malaysian parents and their awareness (or lack thereof) of its related privacy issues	Qualitative	Malaysia	Mothers' motives to sharent and the type of content they post frequently and like to update their status with or post on social media	SDI	40 mothers	52.5% were aged between 31 and 40 y	Data unavailable
Holiday et al [52], 2022	To identify how parents self-present in their sharenting posts	Qualitative	United States	Self-representation on Instagram posts about their children	SDI and PDI	Unspecified	Data unavailable	Data unavailable

Study, year	Study aim	Study design	Country	Setting and context	Identity type	Participants	Age	Sex
Jorge et al [17], 2022	To explore how Cristiano Ronaldo, his partner, and his mother shared information about his children on Instagram between 2018 and 2020	Qualitative	Portugal	Sharenting of a celebrity, Cristiano Ronaldo, and his family members. The digital identity of Cristiano Ronaldo's children analyzed through sharenting by Ronaldo, his partner, and his mother on Instagram.	SDI and PDI	3 participants (mother, father, and grandmother)	Data unavailable	Data unavailable
Kopecky et al [53], 2020	To investigate the type of content that parents publish about their children and compare this behavior between Czech and Spanish parents	Quantitative study	Czech Republic and Spain	Comparing sharenting content, extent, and behaviors in 2 countries. The study was conducted on the web (Google Forms distributed through Facebook, Instagram, email, and WhatsApp channels)	SDI	1093 Czech parents and 367 Spanish parents	Czech parents aged 25 to 64 y; Spanish parents aged 21 to 61 y	Men and women
Kumar and Schoenebeck [9], 2015	To gather mothers' narratives and experiences about sharing baby photos on Facebook. To show how identity performance allows mothers to enact—and receive validation of—good mothering.	Qualitative study	United States	Attitudes, opinions, and experiences of sharing baby photos on Facebook and mothers' perceptions of Facebook and other sites	SDI	22 mothers	Aged 25 to 39 y	Female
Kumar [54], 2021	To investigate how power works through 3 fields of discourse that govern parents' social media conduct	Review and qualitative study—"thinking with theory" method	United States	Governmentality and parents' conduct in sharenting	SDI	Unspecified	Data unavailable	Data unavailable
Latipah et al [55], 2020	To describe the sharenting model by millennial parents as a process of exchanging information between parents in parenting, mentoring, education, and child development	Phenomenological approach	Indonesia	Motives, impact, and ways of sharenting. Interview was completed via the web.	SDI and PDI	10 parents	Aged 24 to 35 y	5 female and 5 male
Leaver [7], 2020	To investigate how exactly the digital communication and sharing of and by parents about their children can be balanced with children's rights to privacy both in the present and, more challengingly, in the future	Critical review of parenting practices through examples	Australia	Sharenting children's sensitive information on Instagram, Facebook, wearables, and apps (Owlet Smart Sock and Peakaboo Moments); web safety; and children's rights to opt out	SDI and PDI	Unspecified	Data unavailable	Data unavailable
Marasli et al [56], 2016	To investigate the use frequency and the content of social media sharing and investigate the information a group of parents shared on the web about their children via content analysis	Mixed methods	Turkey	Sharenting on Facebook	SDI	219 parents	41.7% were aged 31 to 40 y	Data unavailable

Study, year	Study aim	Study design	Country	Setting and context	Identity type	Participants	Age	Sex
Mascheroni et al [62], 2023	To investigate the patterns of sharing among a nationally representative sample of parents of children aged 0 to 8 y. To identify the presence of recurrent sharenting styles. To examine the relationship between sharenting styles and parents' sociodemographic information and between sharenting styles and parental practices of privacy management adopted to govern their children's social media presence.	Quantitative	Italy	Sharenting styles, extent of sharenting, and parents' privacy management practices	SDI	1000 Italian parents	Aged 18 to 54 y	Male and female
Minkus et al [57], 2015	To measure adults' sharing of children's PII in web-based social networks, namely, Facebook and Instagram	Mixed methods	United States	Analysis of images shared on Facebook and Instagram	SDI	2383 Facebook users and 1089 Instagram users	≥18 y	Women and men
Morris [58], 2014	To provide insights into the types of child-related content that mothers of infants and toddlers are willing to share on SNSs	Mixed methods	United States	How mothers of young children use Facebook and Twitter and mothers' perceptions on the appropriate site on which to share photos of their children. Survey was completed on the web.	SDI	412 mothers	Aged 19 to 46 y	Female
Sarkadi et al [59], 2020	To investigate children's thoughts about sharenting	Quantitative	Sweden	Children's views on sharenting. Survey was completed on the web.	SDI	68 children	Aged 4 to 15 y	Two-thirds were boys, and one-third were girls
Turgut et al [60], 2021	To investigate what factors affect what parents share on social media about their children	Qualitative study	Turkey	Sharenting and its associated factors and parents' views on legal liability	SDI	88 parents	Aged 22 to 45 y	Data unavailable
Wagner and Gasche [61], 2018	To investigate what factors parents consider when disclosing personal information about their children on SNSs and what strategies they apply	Qualitative	Germany and Austria	Parents' thoughts on drivers and inhibitors of disclosing children's photos on SNSs	SDI	220 mothers	Data unavailable (mean age 31.1 y)	Data unavailable

[a] SNS: social networking site.

[b] SDI: social digital identity.

[c] PDI: performative digital identity.

[d] MIL: mother-in-law.

[e] DIL: daughter-in-law.

[f] PII: personally identifiable information.

Study Origin

Of the 27 studies, 11 (41%) were conducted in the United States [9,19,40,43,47,49,50,52,57,58], 3 (11%) were conducted in Turkey [48,56,60], and 2 (7%) were conducted in Australia [2,18], followed by 1 (4%) study conducted in both the Czech Republic and Spain [52], 1 (4%) conducted in Germany and Austria [61], and 1 (4%) from each of the following countries:

the United Kingdom [46], Malaysia [51], Poland [10], Sweden [59], Italy [62], Indonesia [55], and Portugal [17]. The remaining 7% (2/27) of the studies did not name the country of data origin [44,45].

Context

The main social networking sites used were Instagram and Facebook. A total of 26% (7/27) of the studies focused on Instagram [17,18,43,44,47,48,52], and 15% (4/27) of the studies focused on Facebook [9,10,46,56]. The remaining studies focused on social media more broadly.

Study Design

In total, 48% (13/27) of the studies used a qualitative approach [9,10,17-19,43,44,48,51,52,55,60,61]. A total of 26% (7/27) of the studies used a mixed methods approach [46,47,49,50,56-58]. In total, 11% (3/27) of the studies used a quantitative design [30,53,59]. A total of 7% (2/27) of the studies used both qualitative and literature review methodologies [40,54], and 4% (1/27) of the articles were book chapters [7].

Key Terms and Concepts Used to Describe Digital Identity

In this first part of the *Results* section, we explore key terms and concepts used in relation to the concept of the digital identity of children on social networking sites. We then explore the concept of digital identity in relation to 2 types of behaviors that underpin the development of young children's digital identity.

The Key Term Sharenting

Overview

The term *sharenting* was the most commonly used term in the literature (21/27, 78% of the articles) on the development of children's digital identities [7,10,17,40,44-54,56,59,60]. Of the 27 studies, 5 (19%) studies discussed the term in more detail and provided a definition of *sharenting* [40,45,47,49,50]. Bezakova et al [45] explained the term *sharenting* as "the overuse of social media by parents or legal guardians who share photos or various home videos of minors with the virtual community," whereas Brosch [10] defined *sharenting* as "the practice of a parent to regularly use the social media to communicate a lot of detailed information about their child" and drew on the Collins dictionary definition. All authors appeared to share a similar understanding of the term *sharenting*. Thus, the definition of *sharenting* is widely accepted and used frequently in the context of the digital identities of children on social networking sites.

Digital Footprint

A total of 48% (13/27) of the articles referred to the concept of digital footprint(s) [7,9,10,19,40,45,46,48,50,53,54,60,62]. The term *digital footprints* was sometimes used interchangeably with the term *digital identity*. It often came down to the authors' preference for wording to describe the creation of digital identities for children. For example, Brosch [10] and Bezakova et al [45] explained that children's digital footprints are mostly created by parents early in their child's life, sometimes before or just after the birth of the child or during infancy [10,45]. Brosch [10] further explained that 10.7% of Polish parents in their sample created digital footprints for their unborn children by posting sonogram images, and 8.3% shared photos of the expectant mother on Facebook. As illustrated by this example, the term *digital footprints* was used synonymously with the term *digital identity*.

When the risks of sharing children's content on the web were discussed, the term *digital footprints* was often chosen. Kumar and Schoenebeck [9] discussed the risk of mothers creating digital footprints for their children in relation to the benefits of receiving validation. Mothers in their study were hesitant and uncertain about how their photo-sharing behavior might affect their children's online identity later and restricted their sharing to pictures that were cute and funny and showed milestones. Nevertheless, they found that the benefits of receiving validation via shared content outweighed the mothers' concerns about digital footprints and oversharing. The authors introduced a new term, *privacy stewardship*, to describe "the responsibility mothers take on as they consider what kinds of baby photos are appropriate to share and the implications for their children's digital footprint." In line with this, Cino and Dalledonne Vandini [40] described the pressure and responsibilities of motherhood as mothers are eager to and expected to actively manage their children's digital footprints. The literature suggests that the management of children's digital footprints and identities is mostly considered to be the responsibility of parents, especially mothers [7,9,40,62].

The Use of the Term or Concept of Identity

The different types of identities that were mentioned in relation to children's digital identities on social networking sites are discussed in the following sections.

Children's Identities

The term *children's identities* or variations of this term (eg, *child's identity*) was used in 44% (12/27) of the articles [7,9,17,19,43,44,48,52-54,56]. The term *children's identities* was used to represent a broad concept that often encompassed other subterms or concepts related to identity. A total of 26% (7/27) of the articles that included the term *children's identities* further discussed the concept of *online identity* [9,17,19,43,45,53,60], and 15% (4/27) of the articles discussed the term *digital identity* [17,54,60,62].

Online Identity

All articles that used the term *online identities* discussed how parents were the creators of their children's identities on the web [9,17,19,43,45,53,60]. Similar to the other concepts related to the digital identity of children, *online identity* could often be used interchangeably with the term *digital identity*. However, the context in which *online identity* was used differed from that in which the other terms were used. Of the 27 studies, 5 (19%) studies discussed children's online identities in the context of children's rights and agency over their online identity and the missing consent from children to allow their parents to post about them on the web [17,19,43,45,53].

Digital Identity

The literature did not generate an accepted definition of digital identity; however, some authors briefly discussed the concept and its relationship with *sharenting*. Kumar [54] linked the concepts of digital identity and sharenting: "sharenting is potent thanks to the concept of a 'digital identity,' also called a digital persona, profile, legacy, trail, footprint, or presence" and "Sharenting discourse portrays the creation of a digital identity as a choice, one best left to the child."

Mascheroni et al [62] also linked the 2 terms by discussing the consequences of sharenting on children's digital identity: "Generally speaking, almost half of the parents are reportedly aware of the consequences of sharenting for children's digital identity, but regular sharers show a lower average value, suggesting a lower degree of awareness."

Jorge et al [17] discussed the term *digital identity* in more detail by exploring how celebrity sharenting contributes to the construction of children's digital identities. They found that the parents shared information and photos that aligned with the theme of happy and grateful parenthood and that the family posts represented the children as the extended selves of the father, stepmother, and grandmother.

Thus, there is an understanding that the digital identities are created by parents through sharenting. Here, sharenting is seen as the action (sharing information about the child), and the digital identity is described as the consequence or outcome of the sharenting behavior. Although sharenting was well defined, definitions for children's digital identity were not provided in the articles.

Other terms or concepts that included the word *identity* were used less frequently; for example, *relational identity* was mentioned in 7% (2/27) of the articles, whereas the terms *identity performance*, *mediated identity*, *private identity*, *social identity*, *social media identity*, and *moral identities* only appeared each in 4% (1/27) of the articles. Overall, most articles (19/27, 70%) in this review discussed some form of identity in relation to children's presence on social networking sites.

Sharenting is the behavior that parents engage in when sharing information about their children on social networking sites. This creates long-lasting *digital footprints* on the web that form children's *digital identities*. The literature has identified a number of risks related to the creation of children's digital identities on social networking sites, such as *digital kidnapping* and *identity theft*, especially if the information that was shared contained *personally identifiable information*. These areas will be explored in relation to the concept of the digital identity of young children.

Safety: Digital Kidnapping

A total of 11% (3/27) of the articles in this review discussed the concept of digital kidnapping [43,48,51]. The terms *identity theft*, *personally identifiable information*, and *privacy stewardship* were used in 7% (2/27) of the articles in this review [9,46,49-51,54]. The term *digital kidnapping* is defined as "people who steal a child's identity and photo on social media and pass the child off as their own" [48]. Digital kidnapping is described as one of the risks of creating digital identities for children by sharing images, especially those that include personal information about the child and reveal the child's face [43,48]. Hashim et al [51] found that Malaysian mothers were concerned about digital kidnapping and identity theft and, therefore, were conscious of not sharing locations in their posts and actively hid information regarding places and their children's names and dates of birth.

Children's Digital Identity as an Extension of Parents' Digital Identities

A total of 7% (2/27) of the articles discussed the concept of extended self [17,52]. These 2 articles also discussed the term *relational identity*. In the article by Holiday et al [52], the authors discussed the theory of the "extended self" and applied it to the concept of sharenting. The authors described parents' engagement in sharenting as fundamental to their identity as parents, which the authors argued says more about the parent as an individual than about the depicted child. Following this thought, sharenting is seen as a form of parents' self-presentation that includes children as a component in the definition of the self.

Jorge et al [17] also described parents' representation of children on social networking sites as the extended selves of family members. When children's digital identities on social networking sites are interpreted as extensions of their parents' or family members' identities, parents' and family members' identities form part of the child's digital identity. Accordingly, some articles in this review (4/27, 15%) discussed the digital identity of parents, mothers, and families in relation to the child's digital identity [9,49,54,62].

Overall, the review of the key term and concepts related to digital identity shows that there is limited research defining key terms such as children's *digital identity* and *digital footprints*, whereas *sharenting* is a commonly used and widely accepted term that is clearly defined.

Content and Image Analyses

The Development of Social and Performative Digital Identities

The synthesis of the data generated through content and image analyses generated 2 types of digital identity: "social digital identity" and "performative digital identity." Children's social digital identity creation involves parents who create their children's digital identity by sharing information such as everyday activities and milestones without links to commercial products or promotion of their children. Parents' motivation to create social digital identities for their children is most often to share with family and friends and keep a digital diary [9,10,51,52,54,61], whereas children's performative digital identity is created when parents promote or market their children, often for their own benefit, for example, to promote their clothes and brands [18,44,52]. This means that parents post information and photos of their children to convey a picture of the child that can deviate from the actual identity of the child. These posts often present the child in a neat and fashionable way and can include links to products that parents obtain a financial share of. For example, "mummy" or fashion bloggers (eg, #fashionkids) create performative digital identities for their children that mostly benefit them and often disregard the needs of the child [18,63].

The Use of Social and Performative Digital Identities in the Literature

Overview

Most articles (18/27, 67%) discussed social digital identities exclusively [9,10,19,40,42,45,46,48-51,53,54,56-58,60,61], whereas 30% (8/27) discussed performative digital identities [7,17,18,43,44,47,52,55]. Social digital identities were mostly created on Facebook or discussed in a social media context in general, whereas performative digital identities were mostly created on Instagram. A summary of the types of posted content is presented in Table 2. The percentages indicate the proportion of articles that discussed the different topics.

Table 2. Analysis of posted content related to children on social networking sites (N=27).

Content	Total articles, n (%)	Activity or leisure time, n (%)	Events (birthdays or family), n (%)	Posing or influencer or making income, n (%)	Developmental stages or milestones, n (%)	Family holidays or outings, n (%)	Embarrassing or cute, n (%)	Face visible, n (%)	Name or DOB[a], n (%)	Nudity, n (%)
Social DI[b]	18 (67)	11 (61)	13 (72)	1 (6)	6 (33)	3 (17)	8 (44)	6 (33)	7 (39)	5 (28)
Performative DI	8 (30)	7 (88)	2 (25)	6 (75)	1 (12)	1 (12)	2 (25)	3 (38)	2 (25)	3 (38)

[a] DOB: date of birth.

[b] DI: digital identity.

Social digital identities were often created through images of events such as birthdays and family gatherings, whereas most of the studies that demonstrated a performative digital identity (8/27, 30%) included images and descriptions of children posing for photos, and in some cases, the family made an income from these posts [7,17,18,43,44,47,52,55].

In the following sections, we explain what information (including text and photos) parents typically share when creating social and performative digital identities for children and what motivates them to share this information.

Social Digital Identities

What Parents Share When Creating Social Digital Identities for Their Children

Most studies (10/27, 37%) reported that parents created social digital identities for their children by sharing their happy moments. Brosch [10] found that these happy moments were often recorded during daily life activities, outings, and special events (95.6%). Similarly, most of the mothers in the study by Briazu et al [46] shared information about special days (72.7%) or social activities (52.6%), and some shared information about health (6.7%) or educational issues (5.2%). Brosch [10] found that many parents revealed private information about their children by sharing posts containing images of their children's birthday parties (23.2%), baby videos, birth certificates, kindergarten diplomas, or art (32.7%), as well as sonogram images (10.7%). Information about the child was also shared via posts containing information such as the child's name and date of birth (48.2%). Brosch [10] also found that some of the posts contained embarrassing photos (eg, nude or seminude pictures of the child during bathing or at the beach), photos in which children were in distress (eg, crying or angry), or photos in which children were covered in food after dinner (eg, chocolate on their faces).

Kopecky et al [53] surveyed parents from the Czech Republic and Spain and found that these parents shared photos of celebrations, family moments, holidays, important milestones, and photos that parents considered to be cute or funny. Most parents reported sharing content in which the child could be identified (by face) but did not include sexual content (81.7%). One-fifth of parents shared photos in which the child was partially exposed to the extent that the identity of the child could be determined. A small proportion (3.5%) of parents from the Czech Republic reported sharing nude photos of their young children.

Er et al [48] investigated sharenting behaviors at the beginning of the COVID-19 pandemic. They found that mothers posted more often than fathers and that most posts contained photos and some contained videos of the children. Of the 226 posts they analyzed, 207 included the children's faces, with a limited number of parents blurring their children's faces (n=17). In line with the other studies, the posts were generally happy, for example, expressing the joy of spending time with children and love toward children and showing how children and the family happily played games, cooked, or learned together. The daily lives of the children were also posted, including birthdays, vacations, and anniversaries. A smaller proportion of posts expressed unpleasant situations during the COVID-19 pandemic, such as boredom, complaints, and unhappiness with quarantine.

Cino and Dalledonne Vandini [40] explored the digital identities that are created for children by the mothers' mothers-in-law and the conflict that this raises with the mothers. The content is either shared before the birth of the child (eg, pregnancy status of the mother, gender reveal, or labor) or afterward (eg, daily life activities) and usually against the will or knowledge of the mother.

Fox et al [50] investigated first-time fathers' sharenting behavior and found that fathers tried to avoid posting sensitive information (eg, their naked child). However, they did post about everyday activities such as going to the park, playing, birthdays, and firsts (eg, first tooth). Fathers were aware of security risks and, therefore, hid their children's faces and names.

Hashim et al [51] found that parents mostly shared social events (eg, vacations, events, family activities, and outings; 29.3%), moments (eg, good, funny, happy, important, or special moments; 25.3%), day-to-day activities (13.3%), memories of their children (12%), school activities (10.6%), food (4%), antics (2.6%), and milestones (2.6%) about their children.

Kumar and Schoenebeck [9] interviewed mothers about their sharenting experiences. Mothers described the photos that they shared about their children as cute and funny and explained that the photos often contained family or friends and developmental milestones of the children.

Marasli et al [56] found that the most common theme parents shared about on Facebook was special days (81.4%), such as birthdays, graduations, and year-end shows, followed by social activities (54.98%) and educational issues (30%). Less commonly shared themes included sports and arts activities (18.96%), play activities (17.54%), health issues (12.8%), and recommendations about products for children and informatics (12.32%). Most parents in this study (63.77%) also reported that they liked sharing pleasant things about their children.

Minkus et al [57] used a web-based application programming interface called Face++ to analyze Facebook and Instagram photos. The software identified children via age estimates based on the faces in the photos. Over 25% of the photos on Facebook and 16% of the photos on Instagram with children aged 0 to 7 years had comments that revealed the children's names, and 2.7% (Facebook) and 5% (Instagram) included the word *birthday*. The authors were also able to infer the children's last names from the parents' last names. Overall, 5.6% of Facebook accounts and 19% of Instagram accounts with child photos revealed the name and date of birth of the children, which is enough information to identify them. By further linking the parents' Facebook accounts with public records (eg, voter registration records), the authors were also able to identify the address of the parents and children.

Parents' Motivation to Create Social Digital Identities for Their Children

In this section, we explore mothers', fathers', and mothers-in-law's motivations for creating social digital identities for their children on social networking sites. Briazu et al [46] found that mothers' motivations or perceived benefits of posting about their children were to build connections, gain practical benefits such as asking for parenting advice, gain emotional benefits (eg, pride and joy from their children), and help others, and some mothers did not identify any benefits.

Fox and Hoy [49] found that the desire to be a "good" mother motivated mothers' sharenting behavior. Mothers used sharenting as a coping strategy. They shared their experiences as mothers and information about their children to seek affirmation and social support from others. The authors also explored mothers' motivations *not* to post about their children. Mothers focused on portraying the "right" image of the child and avoided posts that potentially could have made them look like a "bad" parent. It was also important to mothers in this study that their children would not be upset or embarrassed by their posts later in life.

Kumar and Schoenebeck [9] found that most mothers in their study used Facebook as an archive for their children's photos. It was important to these mothers to portray their children and themselves in a favorable light and to receive validation and support as mothers.

Wagner and Gasche [61] investigated German and Austrian mothers' decision-making processes and strategies when sharing about their children. Most mothers indicated that the costs of sharing photos of their children on the web outweighed the benefits, and therefore, more than half of the mothers (60%) never shared photos of their children on social networking sites. The mothers' main motivation to share was social participation (to inform others, to keep others up to date, and to document the children's development), followed by showing how proud they are of their children and the need to be liked, approved of, and accepted by others.

Fox et al [50] found that fathers' motivation to share was not to gain support from others but rather to express humor or spotlight themselves as fathers. Overall, fathers made fewer sharenting decisions, and the main responsibility of sharenting most often lay with the mothers [50].

Hashim et al [51] found that the most common motivation (42.8%) for Malaysian parents to share about their children was to save memories of them. Social networking sites served as an archive or journal for them to refer to at a later stage. The second most common motivator (31.6%) was the desire to share their experiences, information, activities, and feelings about raising children. Other motivations included being influenced by other social media users; staying connected and engaged with others; and motivating, encouraging, and inspiring other parents. In line with this, Turgut et al [60] described parents' motivation to post about their children as related to keeping in touch with others (eg, relatives and friends) and recording and memorizing their children's development. Brosch [10] found that the number of Facebook friends was a significant predictor of sharenting.

Cino and Dalledonne Vandini [40] investigated the motivation of mothers-in-law to post about their grandchildren. They reported that grandmothers' motivation stemmed from a desire to show excitement for the grandchild, which was often at the cost of the parent's desire for agency over their children's digital identities. However, it was noted that grandparents might be less knowledgeable about the internet and web safety and are potentially naiver about sharing information about their grandchildren on the web.

Performative Digital Identities

What Parents Share When Creating Performative Digital Identities for Their Children

Posts that contribute to a child's performative digital identity creation are usually well planned out to present the child in a fashionable or favorable way. Benevento [44] investigated posts with the *#letthekids* and *#fashionkids* hashtags. These are often used by parents who create performative digital identities for their children by sharing well-prepared posts that have been planned out. The hashtag *#letthekids* emerged as a counter to the more established hashtag *#fashionkids*; it stands for "let the kids dress themselves." The author found that *#fashionkids* photos often show the child alone during structured activities outdoors. Children are often displayed smiling or with still expressions posing with their possessions (eg, clothing and accessories). The attention is drawn to the child and their outfit rather than the location or activity. The background locations include well-maintained spaces such as parks, backyards, and playgrounds as well as home settings (eg, bedrooms and kitchens). Although children are often presented as posing with a focus on their clothes, these are most often casual.

In contrast, *#letthekids* photos often show the child during unstructured activities, such as during play, eating in their home environment, or in nature (eg, forest). This hashtag often displays children acting on their own, for example, while playing with their toys in their room, but also sometimes includes family members. The children in the *#letthekids* hashtag often look away or are shown from behind, as if they are not aware of the photo being taken. Interestingly, *#letthekids* posters upload more professional photographs than *#fashionkids* posters and more naked or seminaked pictures of their children than *#fashionkids* posters [44].

Choi and Lewallen [47] investigated children's gender representations on Instagram and found that parents posted more about their female children than about their male children and generally presented both their female and male children with positive emotions in white or gender-typical (ie, pink and blue) clothes. Children on Instagram were often displayed as playing or having fun in indoor settings by themselves. Girls were found to be frequently displayed as engaging in fashion.

Holiday et al [52] explored how parents self-presented in their children's presentation on Instagram. The authors identified 3 presentational categories: *polished*, *promotional*, and *intimate*. Photos in the *polished* category displayed children as visually appealing and suggested that parents invested time and effort in the post to portray an idealized image of the child. The parents were presented as favorably themselves, with possessions including the child. The attention was often directed toward the parents, not the children (via the text or image). Children in this category served as accessories (eg, in the parents' arms or on the side of the photo). Parents typically presented themselves as their "ideal self" in this category. The *promotion* category included posts in which parents used their children to promote their own skills, competencies, services, or products. Finally, the *intimate* category portrayed children more realistically without perfectioning of the image. With a strong focus on the child in the *intimate* category, more information is revealed about the child, which adds to the child's digital identity [52].

Jorge et al [17] explored celebrities' creation of their children's digital identities through sharenting. The authors analyzed Cristiano Ronaldo's family's sharenting practices and the portrayal of the children as the parents' extended selves. The results showed that celebrity sharenting contributes to digital identities through the themes of happy and grateful parenthood and the representation of children as the extended selves of the father, stepmother, and grandmother. Finally, Latipah et al [55] found that millennial parents shared content about their children related to everyday activities that are perceived as fun and that are often displayed as esthetically pleasing, with some posts including the promotion of products.

Parents' Motivation and Motives for Creating Performative Digital Identities for Their Children

Parents who engage in performative digital identity creation for their children have several motives for sharenting. Some parents want to pass on knowledge and educate other parents by providing advice, products, and insights into their daily life activities [18,55], whereas others' motive is to primarily promote their products or clothes [44,52]. In the *promotion* category in the study by Holiday et al [52], the motivation behind posting was often to promote products or services to other parents, whereas parents' motivation in the *intimate* category was often to preserve memories, which is in line with our findings on the motivation to create social digital identities.

Dobson and Jay [18] found that the motive of their case study was to connect with others as the family lived in a rural area. The mother reported that she had made friendships on the web and that followers empathized with her posts and offered support and a sense of community.

In the study by Latipah et al [54], parents' motivation to share about their children was to receive affirmation and social support and to demonstrate the ability to care for their children, social participation, and documentation.

The only study that included children as participants could not be classified as either "performative" or "social" digital identity. In this study, children were asked for their opinion on sharenting [58]. Children aged 4 to 15 years indicated that it is not OK for parents to post photos of their children (them) on social networking sites, whereas sending the photos to relatives was more accepted by the children in the study. The lowest (least acceptable) scores were found among the youngest children (aged 4-6 y) in the study. Irrespective of the participants' age, children wanted to be asked before their parents took or shared photos of them, and they wanted their answers to be listened to.

Discussion

Summary of Principal Findings

Overview

This scoping review identified 27 studies. Participants included mothers and fathers (collectively reported as parents) and grandparents. On the basis of the analysis of the key terms and concepts used in the literature, the following description of how these relate to one another was developed. The creation of a child's digital identity is developed through the behaviors of parents, most referred to as *sharenting*. The behavior of parents through the decisions on the web they make creates a digital identity that can be described as social digital identity or performative digital identity. We found that much of the literature on the concept of the digital identity of children reports on parents, especially mothers, and their sharenting behavior on social networking sites. The most used terms related to digital identity in the literature are *sharenting*, followed by *digital footprint* and *children's identity*. The term *sharenting* is well defined and popular among researchers and the media, whereas the term *digital identity* was less commonly used. We found that the term *digital footprint* was more commonly used than *digital identity*; however, clear definitions were also lacking in the articles in this review. Common across all terms was parents making decisions about what to share about their children, mostly without the children's consent.

The term *digital identity* is more commonly used in the literature on adults [20-25,64,65]. However, we expect a rise in the term digital identity in relation to children in the coming years as there has been a steep increase in research that focuses on the consequences and risks of sharenting [50,66,67]. The use of digital identity terms often depends on authors' preference for words. We found that *digital footprints*, *children's identity*, *online identity*, and *digital identity* were used interchangeably by authors. Together with *sharenting*, these 4 constructs were the most used terms across the articles, suggesting that they are closely related.

Digital Identity Creation: What and Why

We found that most of the content shared by parents was related to *social digital identity* and included sharing special events such as birthdays and family gatherings, as well as everyday activities and leisure time. In the *performative digital identity* category, posts also included content about everyday activities and leisure time but with a focus on children who were posing for a photo, with some posts contributing to the posters' income (eg, influencers). In the *performative digital identity* category, the motives of some parents were to sell products or promote themselves and their children. The content posted appeared carefully prepared and polished. The literature on the digital identity of children frequently made reference to the concepts of safety on the internet and the rights of the child, and these 2 areas will be explored further with reference to the findings of this review.

Safety Risks: Digital Footprints

Although some awareness among parents of the potential risks of creating digital footprints via sharenting and the creation of their children's digital identities was noted, there is still uncertainty about the exact impact and consequences of parental sharing behavior. One of the potential risks, digital kidnapping, was considered by some parents; however, the benefits of sharing were described as outweighing the risks of creating digital footprints and identities [9]. The perceived risks of sharenting may differ depending on the parents' cultural background. For instance, in the study by Wagner and Gasche [61], 60% of German and Austrian mothers reported never having shared a photo of their children on the web. In an Australian study, participants refrained from posting about their children on social media as a strategy for privacy [68]. Other researchers suggest that parents who perceive web-based social networks as a source of support are highly likely to sharent [69,70].

To make an informed decision about whether to share children's content on the web, parents need to receive information and guidance. Researchers and policy makers have started to develop new policies and guidelines for parents. Although there is a need to update existing policies to reflect the addition of online identities [71-73], the focus of many of these guidelines and policies is on children's screen time exposure and not on children's digital identity development or children's right to their digital identity and footprints [71,74,75]. Therefore, we recommend more rigorous research on parents' attitudes toward privacy and the factors influencing their sharing of children's photos and information on the web. Findings from such studies could inform efforts and emerging policies directed at mitigating sharenting behaviors that are associated with web-related risks.

Children's Rights and Privacy

The process of children's digital identity creation most often takes place without the child's permission or input [10,17-19,43,45,52-54,62]. No studies in this review investigated young children's creation of their own digital identities on social networking sites. A study in this review asked children for their opinion on their parents' sharenting behavior [59], and very few of the studies in this review (4/27, 15%) addressed the agency of the child [18,19,54,59]. When digital identities are created early for the child without the input of the child, their right to create their own digital footprint or identity is taken away, leaving them without a voice and choice [45,54,60]. Where possible, children should be involved in the development of their digital identity. Research to identify how this can be achieved and to give voice to the experiences of young children is needed to better understand this important and fast-moving area [19]. Future studies should explore the perspectives of children as key stakeholders in the creation of their digital identity [19,76].

Strengths and Limitations

To our knowledge, this is the first scoping review to map out the literature published on the creation of digital identities among young children through social networking sites. We strove to apply rigorous methods to search and select articles and chart the data. Owing to our strict age range exclusion criteria, we did not review articles that discussed the digital identity of children aged ≥9 years on social networking sites. The use of search terms and the selected databases may not have been exhaustive, and the omission of social networking sites such as YouTube is a limitation. The search was only valid up to April 2023. In the same vein, most of the included studies were conducted in the Western world, with only 7% (2/27) of the studies conducted in Asia and none conducted in Africa or South America. The interpretation of the findings should consider this geographical bias.

Conclusions

Digital identities on social networking sites are created when photos and information about a person are shared. The digital identities of children on social networking sites from conception to the age of 8 years are most often created by their parents (without the children's permission). Children's digital identities can be grouped into 2 categories: social and performative. Parents use the web environment to capture moments that matter to them while also creating positive narratives around the child's life. The content that is shared for each type of identity and the motivation behind the creation of such identities differ. Research into young children and the digital world has focused on areas such as the effects of screen time and child development and digital safety [77-81]. We urge greater attention to the important area of how the digital identity is created, the impact of this, and how young children can be involved in important decisions that affect their lives.

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Data Availability

The data sets generated during and analyzed during this study are available from the corresponding author on reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist and flowchart of the study selection and inclusion process.
[DOCX File , 147 KB - pediatrics_v7i1e54414_app1.docx]

Multimedia Appendix 2
Search strategy.
[DOCX File , 16 KB - pediatrics_v7i1e54414_app2.docx]

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Abbreviations

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

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Original Paper

Digital Interventions for Combating Internet Addiction in Young Children: Qualitative Study of Parent and Therapist Perspectives

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Abstract

Background: Internet addiction is an emerging mental health issue in this digital age. Nowadays, children start using the internet in early childhood, thus making them vulnerable to addictive use. Previous studies have reported that the risk of internet addiction tends to be higher in lower-income regions with lower quality of life, such as Indonesia. Indonesia has high risks and prevalence of internet addiction, including in children. Digital interventions have been developed as an option to combat internet addiction in children. However, little is known about what parents and therapists in Indonesia perceive about these types of interventions.

Objective: This study aims to investigate the experiences, perceptions, and considerations of parents and therapists regarding digital interventions for combating internet addiction in young Indonesian children.

Methods: This study used a qualitative exploratory approach through semistructured interviews. We involved 22 parents of children aged 7 to 11 years and 6 experienced internet addiction therapists for children. The interview data were transcribed and analyzed using thematic analysis.

Results: Participants in this study recognized 3 existing digital interventions to combat internet addiction: Google Family Link, YouTube Kids, and Apple parental control. They perceived that digital interventions could be beneficial in continuously promoting healthy digital behavior in children and supporting parents in supervision. However, the existing interventions were not highly used due to limitations such as the apps' functionality and usability, parental capability, parent-child relationships, cultural incompatibility, and data privacy.

Conclusions: The findings suggest that digital interventions should focus not only on restricting and monitoring screen time but also on suggesting substitutive activities for children, developing children's competencies to combat addictive behavior, improving digital literacy in children and parents, and supporting parental decision-making to promote healthy digital behavior in their children. Suggestions for future digital interventions are provided, such as making the existing features more usable and relatable, investigating gamification features to enhance parental motivation and capability in managing their children's internet use, providing tailored or personalized content to suit users' characteristics, and considering the provision of training and information about the use of interventions and privacy agreements.

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KEYWORDS

addiction therapist; children; digital intervention; internet addiction; digital devices; parents; parental control; mobile phone

Introduction

Background

Digital devices and the internet have useful functions for supporting our daily lives and work. Multiple studies have reported that, nowadays, children start using digital devices in early childhood [1-5]. Digital device ownership has also increased rapidly among young children [6,7]. Providing children with access to the internet can be beneficial for them and their parents, especially for learning and entertainment purposes [8,9]. However, increasing internet use in young children is followed by increasingly urgent risks that they will not be able to self-manage their digital behavior wisely. The addictive use of the internet and digital devices has emerged as one of the most anticipated concerns related to internet use in young children [7,10].

Internet addiction (IA) is defined as a behavioral disorder caused by the excessive and uncontrolled use of the internet and digital devices that can have negative impacts on mental, physical, and social health [11]. Behavioral addiction related to the internet and gaming has been recognized as a diagnosable mental health condition that needs further research in the *International Statistical Classification of Diseases and Related Health Problems, 11th Revision*, and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* [12,13]. IA can have harmful consequences for young children, such as speech delay, physical disorders, personality disorders, aggressive behavior, eating disorders, self-isolation, decreased academic performance, and decreased vision [14-19]. Young children are vulnerable to IA due to their limited self-control, limited digital literacy, incomplete cognitive development, and influence from family and their environment [20-23].

According to the Interactional Theory of Childhood Problematic Media Use (IT-CPU), the development of IA risks in young children (aged <12 years) could be defined from combined psychology, communication, and human-computer interaction perspectives [7]. On the basis of the IT-CPU, the problem in children is jointly influenced by distal factors (eg, the family’s socioeconomic condition, the family’s dysfunction, and the digital environment), proximal factors (eg, children’s behavior and emotion; the family’s behavior, attitude, literacy, and media use; and peers’ technology access), and maintaining factors (eg, parent-child relationships, children’s media use engagement and motivation, and peer influence) [7].

Some approaches to combat IA in young children include education, therapy, digital parenting, strategic physical activity, and digital intervention [24,25]. Although digital interventions are sometimes seen as an effort to “fight fire with fire,” previous studies have reported that they might have the potential to combat IA due to the ability to use technology to promote healthy digital behavior with lower effort [25-27]. Multiple studies have also reported that digital interventions show promising efficacy for combating smartphone addiction in adolescents or adults [28-31].

Some types of digital interventions are common to promote healthy digital behavior, such as parental control and digital well-being software. They offer various functions, such as screen time monitoring and limitations, app management, content restrictions, and location tracking. Parental control software aims to support parents in monitoring and regulating children’s devices remotely (eg, Google Family Link and Apple parental control) [32]. Digital well-being software supports the user in self-monitoring and self-limiting the use of the internet and digital devices [26]. Digital well-being systems are available in stand-alone apps (eg, ActionDash and StayFree) or integrated within operating systems (eg, Android and iOS), devices (eg, Samsung and Oppo), and apps (eg, TikTok, Facebook, and YouTube).

The research and development of digital interventions for young children is still in its infancy [25]. A previous study in South Korea reported that the efficacy of parental control software was not promising in terms of reducing addictive behavior in children [25,33]. In addition, it is not known how digital interventions are currently being used to combat IA in young children. This raises questions about the perceptions and considerations of the people involved in efforts to combat IA in young children and their views on the use of digital interventions. Parents play a vital role in using digital interventions to manage their children’s behavior. IA therapists may also recommend digital interventions to their clients or recommend using them to support IA treatment [34].

Multiple studies have reported that people in lower-income regions (eg, the Eastern Mediterranean, Southeast Asia, and Africa) with a lower quality of life tend to have a higher prevalence of IA [35,36]. In line with those studies, Indonesia is among the countries in Southeast Asia with a high prevalence of IA, including in children [36,37]. Indonesia is a lower-income country with >212 million active internet users, and >30 million of them are children [38,39]. Therefore, this study investigated the use of digital interventions in the Indonesian context as a lower-income country with high risks and prevalence of IA.

Some digital interventions for children are available in Indonesia, such as Google Family Link, Apple parental control, Norton Family, FamiSafe, and Safe Lagoon. However, little is known about the perceptions on digital interventions of children’s stakeholders in Indonesia who are involved in efforts to combat IA. Therefore, this qualitative exploratory study aimed to investigate the experiences, perceptions, and considerations of parents and child IA therapists regarding the use of digital interventions for combating IA in young Indonesian children. We formulated 3 research questions (RQs) to achieve this objective:

1. What are the experiences of parents and therapists in Indonesia with digital interventions to combat IA in young children? (RQ 1)
2. What are the limitations perceived by parents and therapists in Indonesia of digital interventions to combat IA in young children? (RQ 2)
3. What functions are recommended by parents and therapists in Indonesia for digital interventions to combat IA in young children? (RQ 3)

This study contributes to extending the knowledge from parents’ and therapists’ perspectives on the current state, existing perceptions, and future implications of digital interventions to combat IA in young Indonesian children. The findings of this study will be valuable considerations in evaluating the existing interventions and developing better interventions in the future.

Theoretical Framework

The theoretical framework that underlies the RQs in this study is related to the development and evaluation of digital interventions to combat IA in children. This includes digital behavior change interventions (DBCIs), parental mediation, and the Unified Theory of Acceptance and Use of Technology (UTAUT).

According to DBCIs, digital technologies can be used to support health-related behavior change and promote healthy behavior [40]. Using behavior change theories, models, and frameworks in developing digital health interventions can help the design team address the problem effectively [41]. The use of DBCIs can also be beneficial to combat addictive behavior related to the internet and digital devices [27]. Therefore, this approach may be applied to develop digital interventions for combating IA in young children.

Parental mediation theory emphasizes the parents' role in communicating about digital media use with children to mitigate negative impacts [42]. This theory suggests active mediation, restrictive mediation, and coviewing as parental strategies to prevent the harmful effects of digital media on children [42]. The original strategy was refined into 4 mediation activities to adapt to the rapid development of the digital media landscape: gatekeeping (regulation), discursive (discussion), investigative (monitoring), and diversionary (alternative activities) [43]. This theory can be used to support parents in combating IA in their children through digital interventions.

The UTAUT model suggests factors that influence the acceptance of the use of digital health interventions [44]. The UTAUT model is a modification of the technology acceptance model that focuses on digital health interventions [45]. According to this model, performance expectancy, effort expectancy, social influence, facilitating conditions, and internet anxiety can jointly influence the acceptance of an intervention [46]. This model underlies the need to investigate the experiences and perceptions of potential users and health practitioners to increase the acceptance of digital interventions for combating problems.

Methods

Study Design

This study used a qualitative exploratory approach through semistructured interviews to conduct a detailed exploration of the experiences, perceptions, and considerations of digital interventions to combat IA in children [47]. This approach is commonly used to explore stakeholders' perspectives on digital health care interventions [48-50]. Previous studies on IA interventions have also emphasized the need to explore the potential, needs, and considerations regarding digital interventions to improve our efforts to combat problematic internet use in children [51-53]. It is essential to investigate this from the perspectives of children's stakeholders who may have a significant contribution or influence in combating IA in children, such as parents and IA therapists for children. However, little is known about their perceptions and experiences regarding the use of digital interventions to combat IA in children. Therefore, this study contributed to an in-depth investigation of their perspectives through a qualitative exploratory approach to fill the gaps.

This study was systematically reported according to the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist [54]. This checklist consists of 32 items to report important criteria in qualitative research, such as interviews or focus group discussions (Multimedia Appendix 1 [54]). The researchers of this study comprised a PhD candidate and senior researchers (PhDs) from Australia and Indonesia from various cultures and interdisciplinary backgrounds (eg, human-computer interaction, social science, and product design). We have previous experience in digital intervention research for special populations (eg, children, older adults, and people with mental health conditions).

Participants

This study involved 2 stakeholders who have important roles in combating IA in young children, including parents as the primary guardians of their children and IA therapists for children. Parents are typically the main actors who provide digital devices and supervision to their children [55,56]. Therefore, they are responsible for ensuring their children's digital health and well-being. Child addiction therapists in Indonesia are psychologists or psychiatrists who have expertise and experience in working with children with IA risks. They also have a duty to promote the prevention of addictive use. Involving parents and child therapists provided valuable and comprehensive insights into the experiences and considerations of using digital interventions to combat IA in young children.

A total of 28 participants (n=22, 79% parents and n=6, 21% experienced therapists) took part in this study. The inclusion criteria for parents were (1) being the primary guardians of children aged 7 to 11 years, (2) both parents and children being active internet users, and (3) residing with their children. If the parents had more than one child, we asked them to focus on one child who met our inclusion criteria when participating in this study. This was to ensure their consistency in sharing their experience with their children. They were recruited using a convenience sampling strategy through parenting communities in Indonesia. We sent invitations to 20 parenting communities in Indonesia to participate in this study through web-based platforms such as Facebook, Instagram, and WhatsApp. We provided the researcher's contact details (YT) on the invitation so that parents could express their willingness to participate. Of the 33 parents who were initially interested in participating, 11 (33%) refused to participate for personal reasons after knowing the procedure and goals of this study. At the beginning of data collection, we conducted a preliminary test using the Parent-Child Internet Addiction Test (PCIAT) to obtain previous knowledge about whether their children might have a normal, mild, moderate, or severe risk of IA [57]. The PCIAT is a 20-item validated questionnaire to assess children's IA risks through their primary guardian's perspective [58].

Similar to the parents, we recruited therapists through a convenience sampling strategy. The inclusion criteria for the therapists were (1) psychologists or psychiatrists with expertise in IA therapy for children and (2) formally recognized therapists with >4 years of experience. We contacted 10 prominent hospitals and psychology bureaus in Indonesia that offer services related to IA treatment for children. This aimed to obtain information about potential therapists that might meet our inclusion criteria. Initially, we invited 12 therapists, but 6 (50%) refused to participate for personal reasons. The characteristics of the participants in this study are shown in Tables 1 (parents) and 2 (therapists).

Table 1. Parents' sociodemographic characteristics (N=22).

Characteristic	Values
Age (y), mean (SD)	36.1 (5.8)
Gender, n (%)	
Women	20 (91)
Men	2 (9)
Educational level, n (%)	
High school	9 (41)
Bachelor's degree	12 (55)
Master's degree	1 (5)
Occupation, n (%)	
Private employee	6 (27)
Stay-at-home parent	9 (41)
Entrepreneur	5 (23)
Medical practitioner	1 (5)
Teacher	1 (5)
Family location, n (%)	
West Java	12 (55)
Central Java	3 (14)
East Java	2 (9)
Jakarta	2 (9)
South Sumatra	2 (9)
West Sumatra	1 (5)
Family monthly income, n (%)	
<IDR[a] 5 million (<Aus $500 or <US $314.44)	12 (55)
IDR 5-30 million (Aus $500-$3000 or US $314.44-$1886.61)	7 (32)
>IDR 30 million (>Aus $3000 or >US $1886.61)	3 (14)
Number of children, n (%)	
1	8 (36)
2	8 (36)
3	4 (18)
4	2 (9)
Child's age (y), mean (SD)	8.6 (1.4)
Child's gender (women), n (%)	8 (36)
Child's order of birth, n (%)	
First	14 (64)
Second	6 (27)
Third	2 (9)
Devices used by the child, n (%)	
Mobile devices (smartphone or tablet)	22 (100)
Television	18 (82)
Laptop or PC	6 (27)
PlayStation console	2 (9)
Age when the child first used the internet (years), n (%)	

Characteristic	Values
1	8 (36)
2	7 (32)
3	5 (23)
5	2 (9)
Child's PCIAT[b] risk category, n (%)	
Normal	8 (36)
Mild	6 (27)
Moderate	6 (27)
Severe	2 (9)

[a] IDR: Indonesian rupiah.

[b] PCIAT: Parent-Child Internet Addiction Test.

Table 2. Therapists' sociodemographic characteristics (N=6).

Characteristic	Values
Gender, n (%)	
Women	6 (100)
Men	0 (100)
Work experience (y), range	5-14
Location, n (%)	
West Java	2 (33)
Jakarta	2 (33)
Central Java	1 (17)
East Java	1 (17)
Work title, n (%)	
Child or clinical psychologist	3 (50)
Child psychiatrist	3 (50)
Workplace, n (%)	
Public hospital	2 (33)
Private hospital	2 (33)
Psychology bureau	2 (33)

Data Collection

Data collection for this study was conducted from September 2023 to November 2023. As the participants were located in different cities in Indonesia, we conducted the interviews on the web using Microsoft Teams (Microsoft Corporation). Each interview session was conducted by the first author (YT; male) in Bahasa (the national Indonesian language) and lasted 30 to 60 minutes. There was no previous relationship between the interviewer and the participants in this study. Before the interview session, the interviewer explained the objective and scope of this study to each participant. The main topic discussed in the semistructured interviews was the experiences, perceptions, and recommendations regarding using digital interventions to combat IA in children. If the participants were no longer using the digital interventions, they could also share their past experiences and why they stopped using them. The probing questions of the interviews are shown in Multimedia Appendix 2.

We recorded the audio of each interview session. The recordings were transcribed in Bahasa using Google Speech-to-Text and then manually refined by a researcher (YT) who is a native speaker of Bahasa. The interview transcripts were returned to each participant for checking and correction. After that, we translated them into English for data analysis and reporting purposes.

Data Analysis

The data analysis was conducted qualitatively using thematic analysis through five main stages: (1) transcribing, reading, and understanding the data; (2) coding the data; (3) identifying meaningful patterns within the data; (4) defining and grouping the themes; and (5) reporting the findings according to the themes [59]. The NVivo (version 12.0; QSR International) software was used to support coding the data and identifying meaningful patterns within the data. Although the thematic analysis did not rely on quantifiable measures, we presented the frequency of themes, subthemes, or issues discussed as additional information to describe the findings and increase reporting transparency [60,61].

To ensure the quality of the data analysis, we followed the 15 criteria for good thematic analysis proposed by Braun and Clarke [60]. The criteria include the transcription (1 item), coding (5 items), analysis (4 items), overall (1 item), and reporting (4 items) processes [60]. The interview transcripts were checked by the interviewer (YT) and participants to ensure their accuracy. The codes and themes were identified and checked rigorously to ensure the validity and consistency of the analysis. The methods, data, and findings of this study were described and reported with adequate details and transparency. We also provided a good balance between narrative explanations and participants' quotes or stories to report the findings of this study.

We started coding the participants' experiences with digital interventions to combat IA in young children. We analyzed their experiences based on three themes: (1) interventions they recognized to combat IA in young children (eg, "Google Family Link"), (2) interventions used by parents or recommended by therapists to their clients (eg, "Apple Parental Control"), and (3) features used or recommended by the participants and how they used them (eg, "device use monitoring").

The participants' perceptions of digital interventions were coded and grouped into 3 main themes: advantages, limitations, and recommended functions. We coded the advantages they perceived from the interventions they had known (eg, "filtering inappropriate content"). The limitations came from their experiences using or recommending digital interventions (eg, "complicated to use"). In addition, the limitations were expressed as part of the reasons why some participants chose not to use the existing digital interventions (eg, "data privacy issue"). The recommended functions were analyzed based on the functions or features considered useful by the participants (eg, "suggesting substitutive activities").

Ethical Considerations

Ethics approval for this study was obtained from the Swinburne University Human Research Ethics Committee (reference: 20237278-16490; approval date: August 24, 2023). Written informed consent was granted by all participants involved in this study. We did not collect the personal identity of the participants, such as their names or addresses. Each participant was assigned a unique identification number to ensure their anonymity. Each participant in this study was given a voucher for 300,000 Indonesian rupiah (Aus $30 or US $20) in recognition of their participation.

Results

Overview of the Internet Use by the Children of the Participating Parents

The parents who participated in this study had given their children access to the internet since early childhood (age of 1-5 years). However, children started using the internet routinely when entering preschool or primary school (age of 5-7 years). Most children (18/22, 82%) had their own mobile devices (eg, smartphones or tablets), whereas the others had to borrow them from their parents or use them collectively with their siblings. All children of the participants were active users of mobile devices, such as smartphones or tablets, and some of them also actively used televisions (18/22, 82%) and nonmobile devices such as laptops or PCs (6/22, 27%) and PlayStation consoles (2/22, 9%). Their favorite digital activities were watching videos (eg, YouTube, TikTok, and television channels) and gaming (eg, Minecraft, Roblox, Mobile Legends, and Free Fire). All parents agreed that the internet can be beneficial for their children in terms of education and entertainment. Most parents (17/22, 77%) also said that digital devices helped them fill their children's free time and keep the children calm and quiet at home. In addition, parents said that some primary schools had started teaching internet technology and delivering school materials through web-based media.

In general, parents showed awareness of the fact that the excessive and uncontrolled use of the internet could bring harmful consequences to their children. Parents whose children had mild to moderate IA risks based on PCIAT scores conveyed various negative impacts of excessive use on their children. This included decreased school performance or creativity (10/22, 45%), inappropriate use of language (8/22, 36%), aggressive behavior (8/22, 36%), procrastination of other activities (7/22, 32%), self-isolation (6/22, 27%), anxiety when not using the internet (5/22, 23%), poor communication with the family (4/22, 18%), eating problems (eg, food intake avoidance; 4/22, 18%), and eye problems (eg, decreased vision, swollen eyes, and red eyes; 3/22, 14%).

Experiences With Digital Interventions

Parents and therapists generally showed diverse experiences with the use of digital interventions (Table 3). Participants in this study mentioned 3 parental control software they had known to combat IA in young children: Google Family Link, YouTube Kids, and Apple parental control. Google Family Link and Apple parental control offer similar parental control features at the operating system level. A total of 68% (15/22) of the parents and 83% (5/6) of the therapists mentioned Google Family Link, whereas Apple parental control was only mentioned by 17% (1/6) of the therapists. In August 2023, approximately 88% of Indonesian internet users used Android devices, and only 11% used iOS devices [62,63]. This might explain why the participants were more familiar with Google Family Link. In addition, this app is widely available on both the Google Play Store and Apple App Store, whereas Apple parental control is only available for devices with the iOS operating system. One parent said the following:

> *During the pandemic, I gave my child a Samsung tablet because she needed to study online. Since then, I have also tried using that application [Google Family Link]. The app has been available on her tablet since we bought it, so I can use it immediately.*

On the basis of parents' experiences, 18% (4/22) of parents actively used Google Family Link and perceived it as a useful mechanism to manage children's digital behavior. In total, 50% (2/4) of these parents (whose children had a normal IA risk) used most app features, including monitoring, screen time limitations, and app management. They and their partners were working parents, so they used the features to supervise their children remotely because they could not always be home. They felt that the app was helpful for supporting them in monitoring and limiting their children's interaction with technology easily. They communicated the rules about the use of the app clearly to their children so that their children could understand the purpose of using those features. One of the parents said the following:

> *I usually restrict her screen time using Family Link from Google. I've been using this app for a long time because it's been available on my child's tablet since the beginning. Usually, I use it to set the duration of the application she can use and what time the application can be used. I also set the total duration for her to use the tablet in a day so the tablet will be locked after reaching the limit. I think it's quite useful because it can help me organize my daughter, mainly because my husband and I are both working, so we can't monitor her screen time continuously.*

In total, 50% (2/4) of these parents (whose children had mild and moderate IA risks) only used the screen time monitoring and download management features. Through the download management feature, they have to provide parental permission if their children want to download a new app. They used screen time monitoring to understand what apps their children accessed and how much time children spent on each app. However, they only used the feature occasionally (eg, once a week or once a month), and they did not make essential decisions based on screen time monitoring. One of them said the following:

> *I use the one from Google. It's called Family Link, as I remember. I organized it so my child had to ask me for permission whenever she wanted to download a new application...I never knew and never used the other features.*

Another 14% (3/22) of the parents had used Google Family Link in the past but no longer used it because they found it difficult to make appropriate rules for their children and set them up consistently.

YouTube Kids is a child-friendly version of YouTube that features content for children and has some parental control features (Table 3). However, those features can only be used within the YouTube environment. A total of 45% (10/22) of the parents mentioned and used this app, and 33% (2/6) of the therapists mentioned this app as a way to filter inappropriate videos for children. Among the existing digital interventions, YouTube Kids was one of the most popular because all participants' children spent most of their screen time watching videos on YouTube or playing games. They perceived that filtering inappropriate videos on YouTube was one of the most important things to prevent deviant behavior in their children. One parent said the following:

> *She consumes some inappropriate content in YouTube Shorts, even though she doesn't need that information or content. Some explicit pornographic content also appears in videos, even if it's intended for children. I really appreciate features on YouTube to filter such videos. This is really important because I can't always see what my daughter watches.*

Some parents actively used parental control features on YouTube to filter inappropriate videos for children (10/22, 45%) and limit access to YouTube (3/22, 14%). However, 18% (4/22) of the parents said that sometimes their children did not like the available child-friendly videos on YouTube Kids, so they tended to find content on other apps such as Google or social media (eg, TikTok and Instagram). One of them said the following:

> *My child now doesn't want to use YouTube Kids because he can't find interesting videos there. Maybe he doesn't like videos for children anymore. Now, he is more interested in short videos from YouTube shorts or TikTok. He often watches short videos on TikTok using my account because I don't allow him to create his own account.*

In total, 50% (3/6) of the therapists actively recommended the use of parental control software to help parents control their children's internet use. One of them said the following:

> *I think it can help parents. In my opinion, parents need help to make their job easier in supervising their children. Such software can be utilized if parents are willing and capable of learning how to use it.*

However, they did not recommend it to all clients because they thought that some parents may not have the adequate willingness, capability, or life circumstances to use it. While they knew about Google Family Link and YouTube Kids, they did not recommend which app to use specifically. The other 50% (3/6) of the therapists reported that they sometimes mentioned parental control software as an option for parents to control their children's behavior but they never recommended it. One of them said the following:

> *I tell them there are such apps [parental control software]. However, I don't really understand what applications can be used because I don't understand technology well. I just advise parents to try such applications, but personally, I never try it myself.*

Parents perceived that the digital interventions mentioned in Table 3 could be beneficial in supporting the supervision of their children remotely (11/22, 50%) and filtering inappropriate content for their children (15/22, 68%). Similarly, 67% (4/6) of the therapists also expressed those benefits. One of them said the following:

> *This [digital interventions] can make it easier for families to monitor how long their children play [digital devices] or what kind of applications are safe*

> *to be used. It’s very useful, but many people don’t know about this. We need to let them know so they can monitor their children remotely.*

In total, 50% (3/6) of the therapists also perceived the benefit of digital interventions in providing continuous supervision. One of them said the following:

> *Sometimes parents are limited and busy with their own business, so they cannot control their children for 24 hours a day. Applications like this [parental control apps] will definitely help parents control their child continuously.*

In addition, the therapists believed that digital interventions could provide creative ways to educate parents and children on healthy internet use and support the work of IA practitioners such as themselves. With a limited number of mental health workers and low awareness of healthy internet use in Indonesia, this type of intervention may help their work in raising awareness and promoting healthy digital behavior in Indonesian children. One therapist said the following:

> *In the app, we may provide education about parental digital literacy that can help our work. Interesting education via digital devices will be more popular and exciting than conventional education like seminars or classes that we usually do.*

Table 3. Summary of the digital interventions known and used by parents and therapists.

Attribute	Parents	Therapists
Interventions known	• Google Family Link[a] • Key features: • Screen time monitoring • Screen time limitations • App management • App restrictions • Content restrictions • Location tracking • YouTube Kids[b] • Key features: • YouTube content filtering • YouTube access limitation	• Google Family Link[c] • Key features: • Screen time monitoring • Screen time limitations • App management • App restrictions • Content restrictions • Location tracking • YouTube Kids[d] • Key features: • YouTube content blocking • YouTube access limitation • Apple parental control[e] • Key features: • Screen time monitoring • Screen time limitations • Download management • App restrictions • Content restrictions
Interventions used by the parents or recommended by the therapists	• Google Family Link[f] • Features used: • Screen time monitoring[g] • Screen time limitations[h] • App management[f] • App restrictions[h] • Content restrictions[h] • YouTube Kids[b] • Features used: • YouTube content filtering[b] • YouTube access limitation[g]	• Parental control apps in general[i] • Features recommended to their clients: • Screen time monitoring[i] • Screen time limitations[d] • App restrictions[d] • Content restrictions[i]
Perceived advantages of digital interventions	• Supporting parents in monitoring and supervising their children remotely[j] • Filtering inappropriate content[a]	• Supporting parents in monitoring and supervising their children remotely[k] • Filtering inappropriate content[k] • Providing continuous supervision[i] • Providing creative ways to educate parents and children[d] • Overcoming the lack of internet addiction practitioners in Indonesia[d]

[a] 68% (15/22) of parents.

[b] 45% (10/22) of parents.

[c] 83% (5/6) of therapists.

[d] 33% (2/6) of therapists.

[e] 17% (1/6) of therapists.

[f] 18% (4/22) of parents.

[g] 14% (3/22) of parents.

[h] 9% (2/22) of parents.

[i] 50% (3/6) of therapists.

[j] 50% (11/22) of parents.

[k] 67% (4/6) of therapists.

Limitations of the Existing Digital Interventions

Although most participants recognized the existence of digital interventions to encourage healthy digital behavior in their children, the existing interventions were not highly used. Both parents and therapists perceived that digital interventions might be beneficial to encourage healthy internet use and combat IA in young children. However, they also highlighted some limitations with the existing interventions, which may discourage some of them from using the interventions (Textbox 1).

Textbox 1. Limitations of the existing interventions.

Parents

- Parents finding it difficult to use and set up the app (12/22, 55%)
- Parents being unable to set appropriate rules (9/22, 41%)
- Incompatibility with family culture (4/22, 18%)
- Jeopardized parent-child relationships (4/22, 18%)
- Data privacy issues (2/22, 9%)

Therapists

- Parents finding it difficult to use and set up the app (4/6, 67%)
- Parents being unable to set appropriate rules (3/6, 50%)
- Incompatibility with family culture (2/6, 33%)
- Functions not comprehensive (3/6, 50%)
- Children’s privacy issues (2/6, 33%)

The most frequent limitations expressed by the parents and therapists were associated with the parents’ capability and knowledge of how to use the software and create appropriate rules through the interventions. A total of 55% (12/22) of the parents expressed their limitations in using the software. One said the following:

> *The problem is that applications like that [parental control software] seem complicated. Honestly, I’m a mother who doesn’t really understand technology.*

Similarly, 67% (4/6) of the therapists perceived that some Indonesian parents might not be capable of using and willing to use parental control software. In total, 33% (2/6) of the therapists also had difficulties in learning how to use the digital interventions. One said the following:

> *I tell them [clients] that there is parental control software as an option. However, because I don’t really understand the technology well, I advise parents to try such applications, but I can’t teach them how to use it.*

A total of 41% (9/22) of the parents expressed their limitations in creating appropriate rules through the interventions. One said the following:

> *Even if I can control my child through the app, I have to learn what kind of restrictions should be applied to him* [her child]

Similarly, 50% (3/6) of the therapists were concerned that parents with low digital literacy and capability would find it difficult to use the features. Although the features are helpful, parents might still be confused about setting appropriate rules for their children. One of them said the following:

> *We might be able to limit screen time, but the application can only function well if parents set it properly. The question is whether the parents can use it correctly or not.*

Most of their clients were also confused about finding proper substitutive activities after limiting their children’s screen time.

A total of 18% (4/22) of the parents and 33% (2/6) of the therapists were also concerned about the apps’ incompatibility with family culture in Indonesia. They reported that some content and tips suggested by the existing interventions did not suit their social values and beliefs. For example, one parent said the following:

> *Once, I used the feature to filter child-friendly videos because my child really likes watching videos on his tablet. However, I found videos that, sorry to say this, promoting LGBT, which is completely unacceptable because it is not appropriate with our religion and culture.*

Parents shared other concerns about using digital interventions. A total of 18% (4/22) of the parents thought that the features of the existing interventions might make children uncomfortable, thus jeopardizing the relationship between parents and children. One parent said the following:

> *In the past, I wanted to use an application called [Google] Family Link, but my husband and I decided not to use it for some reasons. We want to give more trust to my daughter because she might feel pressured if she feels like she is always being watched.*

In total, 9% (2/22) of the parents said that they were worried about using parental control software because they had to synchronize multiple devices and input personal data. As some interventions have app management features, they also worried that the system could access and remove confidential data on their devices. One parent said the following:

> *I have to connect my device to my child's device, and that application can delete or move applications on my child's device. If they can do that, I'm afraid that they may also access or even delete my personal data.*

Therapists reported other limitations of the existing interventions in terms of limited functions and trust issues in children. They highlighted that some essential functions are needed in digital interventions. One said the following:

> *Many things must be improved to be truly helpful, and they [digital interventions] must be made functionally more holistic. For example, they can provide education for parents and children, personalized supervision for parents, and child-friendly content recommendations that are interesting.*

Related to the trust issues, one therapist said the following:

> *Parents might be over-worried and end up using the app excessively. For example, they spy and track a child's phone without proper communication. No matter what, children aged seven or above need to be given some privacy.*

Therapists also had concerns that some children might trick the system if their parents could not provide proper understanding and communication about the rationale behind their supervision through digital interventions such as parental control software. This would make the parents falsely feel that everything is under control.

Recommended Functions of Digital Interventions

The participants recommended some functions that may be useful in combating IA in young children (Textbox 2). Parents and therapists suggested some functions for a digital intervention, such as supporting parental supervision, suggesting substitutive activities, monitoring and limiting internet use, and suggesting child-friendly content. One parent said the following:

> *Many parents don't direct their children to do other activities, so the children will get bored if they don't spend time with their gadgets [digital devices]. Parents must be able to direct their children to other activities that are positive and interesting for children. It would be helpful if the app could help the parents with that.*

Textbox 2. Recommended functions.

Parents

- Supporting parental supervision (14/22, 64%)
- Suggesting substitutive activities (9/22, 41%)
- Monitoring and limiting use (9/22, 41%)
- Suggesting child-friendly content (8/22, 36%)
- Supporting parental decision-making in regulating children's digital behavior (4/22, 18%)

Therapists

- Supporting parental supervision (3/6, 50%)
- Suggesting substitutive activities (3/6, 50%)
- Monitoring and limiting use (3/6, 50%)
- Suggesting child-friendly content (3/6, 50%)
- Developing children's competencies to combat addictive behavior (5/6, 83%)
- Improving parental digital literacy (4/6, 67%)
- Supporting parents in communicating internet use rules (2/6, 33%)

One therapist also discussed the need for some functions:

> *In my opinion, parents need help to make their job easier in supervising their children. An application might help. For example, it can recommend good content for children, monitor the device use in real-time, and make children stop playing smoothly.*

Parents expected that the interventions would simplify their efforts in making essential decisions regarding education and rules for their children. This is because many parents were confused about regulating their children's internet use although they knew their children used the internet excessively. They were also afraid that their rules would make their children uncomfortable or offended. One said the following:

> *I'm often confused with the daily decision I should make about regulating my child. It's really difficult to handle. I want to give him the internet to make him happy, but I need a clue on how best to control him all the time.*

Therapists perceived that parental control software might help supervise children's digital activities to support behavior change in children. However, they said that parents and children cannot solely rely on screen time limitations or device restrictions to address the problem. One therapist said the following:

> *What is more important is how parents understand the rules, communicate the rules, and make children understand the rules. Therefore, I advise parents that we cannot completely depend on limitations and blocking through the apps.*

In total, 67% (4/6) of the therapists also suggested the need for digital interventions to have comprehensive coverage in managing their children's internet use, such as across devices or apps. One said the following:

> *I think it would be more useful if we could limit them at the device [operating system] level. Restrictions on single application become less effective because children can use more than one application.*

Therapists highlighted the need for other essential elements to combat IA in children: proactive parental supervision, developing children's competencies to combat addictive behavior, effective parent-child communication, proper education on healthy internet use, and enjoyable real-world activities. One therapist said the following:

> *I think a comprehensive intervention is needed. For example, there may be education, real-time measurement, and the ability to carry out addiction prevention over time.*

Another therapist had an interesting argument on developing children's competencies:

> *The family factors can prevent young children from addiction, like developing children's foundations [to combat addictive behavior], good communication, and happy life. We should realize that one similar software may cause a different response. Some children may be addicted to it, but not the others. Therefore, preventing addiction will be more powerful if the parents build their children's foundations from the beginning. With good foundations, children will not easily become addicted when given negative stimulus from the internet.*

Discussion

Experiences With Digital Interventions to Combat IA in Young Children

In this study, we explored the experiences, perceptions, and considerations of parents and therapists regarding digital interventions to combat IA in young Indonesian children. This study investigated multiperspective views from parents, who are the primary guardians of young Indonesian children, and child therapists, who have expertise and experience in working with children with IA risks. The participating parents and therapists generally perceived that digital interventions such as parental control software could increase parents' capability to promote healthy digital behavior in their children in the long term. This perception aligned with the DBCI concept that using behavior change principles in digital interventions could be useful to promote healthy behavior in their users [40]. In this case, promoting healthy digital behavior was considered beneficial to combat IA in young children. Other studies have also highlighted the similar potential of DBCI use for addressing the problem, and the current interventions primarily focus on screen time regulation [24,25].

The participants similarly perceived the advantages of using digital interventions for combating the problem, such as supporting parents in monitoring and supervising their children remotely (15/28, 54%) and filtering inappropriate content for children (19/28, 68%). In addition, the therapists perceived more benefits, such as facilitating continuous parental supervision (3/6, 50%) and supporting health practitioners' work to promote and educate parents and children on healthy internet use (2/6, 33%).

Almost all participants (26/28, 93%) highlighted the role of parents as the key to developing healthy or risky digital behavior in their children, especially in children aged <12 years. This is because parental influence and mediation significantly impact children's digital behavior [22,42,56]. In the context of young children, no one is more influential than parents, although other parties can also influence them (eg, siblings and peers). Parents provide their children with the internet, so they are responsible for managing their children's internet use [55]. In addition, children aged <12 years are generally still in the cognitive development phase [64], so they may not have good self-regulation and self-efficacy [65]. However, parents often, intentionally or not, expose their children to risky digital behavior [55,66]. The findings showed that many parents (13/22, 59%) were confused about educating their children and regulating their healthy digital behavior. As digital parenting is something new, they may not necessarily be able to regulate their children's internet use well even though various monitoring and restricting features are available [56]. Therefore, the interventions may not only intervene with children's use of technologies but also with parents' management of their children's technology use. The interventions should be able to support and educate parents on how to encourage their children's healthy digital behavior effectively.

Participants in this study recognized 3 digital interventions to combat IA in the form of parental control software: Google Family Link, Apple parental control, and YouTube Kids. Despite the positive sentiment on the potential of digital interventions, the use of the existing features of those systems among the participants was not convincing. This is because, of the 28 participants, only 4 (14%) parents actively used Google Family Link, 10 (36%) parents used YouTube Kids, and 3 (11%) therapists actively recommended using parental control software to their clients. In addition, the parental control features on YouTube Kids can only monitor and limit children's internet activities while watching YouTube content. Therapists argued that the regulations at the app level would be less effective because children typically interact with more than one app, device, or streaming service. This statement was supported by the findings that all children of the participating parents used more than one app daily (eg, YouTube, Minecraft, and TikTok) and many parents (18/22, 82%) gave their children access to more than one device (eg, smartphone, tablet, and television).

A total of 50% (2/4) of Google Family Link users used all features except location tracking. Their children had normal addiction risks based on the PCIAT score, and they reported the usefulness of the app in helping them supervise their children when the parents were busy with their activities. This may be initial evidence that the proper use of digital intervention features could be helpful for parents in combating IA in their children. However, we need further evidence on the mechanism of the app in preventing or reducing IA in children. Another 50% (2/4) of Google Family Link users only used 2 features of the app: screen time monitoring and parental permission to download new apps. However, they reported that they only monitored children's screen time occasionally (eg, once a week or once a month) and did not make essential decisions based on monitoring. Therefore, we could not explore their overall experiences with using the app.

Limitations of Digital Interventions to Combat IA in Young Children

The participants expressed some limitations that may underlie the lack of use of the existing digital interventions. The limitations might also decrease participants' motivation to use digital interventions. Both parents and therapists mentioned 3 similar limitations with these interventions: the parents' difficulties in using the apps, the parents' difficulties in setting appropriate rules through the apps, and the incompatibility of the features or content with family culture in Indonesia.

Parents and therapists highlighted that one of the most significant obstacles in combating IA in children are the parental limitations in terms of capability and time to educate their children and manage their digital behavior. This parental issue could be the main barrier to using digital interventions for supporting internet use parenting [67,68]. Therefore, the interventions should support and simplify parental efforts to manage their children's digital behavior, as suggested in the UTAUT model [46]. The capability of computer systems in digital interventions should be used to support, assist, and simplify parental efforts in sustainably educating their children and regulating their digital behavior. If the intervention requires many complex settings and actions, parents may feel that it will add load and complexity to their lives. No matter how good the features are, the intervention will be less practical if the potential users have no intention of using it and capacity to use it. We cannot assume that all parents have adequate digital literacy and capability [69]. Thus, it is essential to match the interventions to parents' digital capabilities, capacity to engage, and other limitations. In addition, the therapists were also worried that children would outsmart or work around the regulations or restrictions, leading parents to mistakenly feel that everything is under control. Therefore, the interventions should be designed to include a range of scenarios and conditions so that children cannot work around or override them [70].

A total of 21% (6/28) of the participants in this study perceived that the existing digital interventions might not suit some families' cultures in Indonesia. For example, they reported that some child-friendly content suggested on YouTube Kids was inappropriate based on their own cultures and beliefs. In other cases, parents felt that the screen time restriction feature might elicit the impression of distrust toward their children, so they felt uncomfortable using it. Considering the culture of the users is very important when developing digital health interventions for children [71-73]. Reflecting on such cases, it is crucial to consider the potential users' cultures in developing digital interventions to combat IA.

Parents expressed concern that using limitation or restriction features may lead to negative experiences for children and jeopardize parent-child relationships. Other studies have also highlighted that healthy parent-child relationships are essential in combating IA [74-76]. Therefore, it is important to consider that the interventions should not harm the relationship between parents and children. For example, the system may assist parents in communicating the rules appropriately so that their children can understand and accept them well. Providing a positive experience to the parents is also essential to avoid any frustration so that they can provide better supervision and communication to their children. For example, we could facilitate parents' experience of the benefits of their efforts through the interventions or create engaging gamification features that simplify evidence-based information and support parents in establishing rules for their children in novel and attractive ways (eg, short videos, animations, and role-playing).

Concerns about data privacy and security were also reported by 9% (2/22) of the parents due to the nature of parental control software systems. The software typically has privacy warnings and agreements presented to its users [77,78], but parents may still not understand or be confident in using it. In addition, related studies have reported privacy problems with the current parental control software, such as accessing personal data and sharing user data with third parties without appropriate consent and transparency [79,80]. Therefore, further studies are needed to investigate how the developers overcome this privacy concern and how those privacy issue warnings and agreements are delivered to ensure that the users feel confident and secure in using the software.

Therapists perceived other limitations in terms of functional and children's privacy issues. In total, 50% (3/6) of the therapists highlighted some essential functions not covered in the existing interventions, such as proactive parental supervision, children's competencies to combat addictive behavior, parent-child communication enhancement, proper education on healthy internet use, and enjoyable real-world activity suggestions. Other studies have also reported the absence of similar functions in the existing parental control software, such as maintaining family relationships, parental mediation, and social support [70,81].

A total of 33% (2/6) of the therapists also emphasized that the need for the use of digital interventions should not raise any privacy issues in children, which can jeopardize the parent-child relationship. Parents should be responsible for protecting children's privacy in web-based environments [82]. However, the therapists had experiences with parents becoming overprotective since using parental control software. They reported rare cases in which their clients (parents) seemed to be overmonitoring their children almost all the time, which could create other family relationship problems. This issue has not been discussed much in the context of digital health interventions for children. Therefore, we need further research studies to investigate how this issue affects children and how to address the issue appropriately.

Recommended Functions for Digital Interventions to Combat IA in Young Children

The participants in this study recommended several functions for digital interventions to combat IA in young children. They suggested some functions that were covered in the interventions discussed in this study, such as parental supervision (17/28, 61%), use monitoring and restrictions (12/28, 43%), and child-friendly content filtering (11/28, 39%). This means that those functions should be maintained and improved in the interventions. However, the participating parents expressed some suggestions to improve the implementation of those functions.

One of the main parental limitations identified in this study was the parents' confusion or inability to determine and enforce appropriate supervision for their children. In line with this problem, 18% (4/22) of the parents recommended decision-making support features to guide them in monitoring and creating appropriate rules for their children. This feature may complement and improve the monitoring and restriction functions that already exist in the interventions. We may adopt the concept of decision support system software in the context of promoting healthy digital behavior in young children [83]. The digital interventions may also capture and use some valuable data from the children (eg, screen time, web-based activities, and favorite content) as input to provide tailored or personalized decision-making suggestions for the parents [84].

Regarding use restrictions, both parents and therapists similarly expected the system not to jeopardize the relationship between parents and children. Providing digital interventions with proper education and suggestions may help parents communicate the rules better so that their children can understand and accept them properly. For the content filtering function, the participants expected that the suggested content would be appropriate for their culture, social values, and beliefs. Providing culture-specific or personalized features for the users may help address their expectations [85,86].

The participants also recommended functions that might not exist in the interventions discussed. In total, 41% (9/22) of the parents and 50% (3/6) of the therapists recommended the need to suggest substitutive activities for children. Parents often feel confused about providing proper and positive activities for their children apart from internet activities. Some parents also relied on the use of digital devices as an option to fill their children's free time. Therefore, to prevent internet overuse, it would be helpful if the system could suggest alternative activities that suit the needs and preferences of their children. The activities suggested should be attractive enough for children to shift from the virtual to the physical world [87].

Therapists highlighted that digital interventions should be used to develop children's competencies in understanding internet use properly to combat addictive behavior. According to the IT-CPU theory, children's behavior and attitude toward internet use can significantly influence their IA risks [7]. Therefore, developing children's competencies to combat addictive behavior may help prevent or reduce IA risks in young children. In total, 67% (4/6) of the therapists also emphasized the need to improve digital literacy levels in children and parents. This is supported by previous studies that reported the significant contribution of improving digital literacy through education to the success in combating IA in children and adolescents [69,88,89]. Digital interventions were seen as potential tools to provide education in more interesting ways (eg, gamified learning) and increased accessibility [90,91].

In this study, parents were concerned that regulating internet use through the system would jeopardize their relationship with their children. This is also supported by the IT-CPU theory that the parent-child relationship is one of the maintaining factors that influence the IA risk in children [7]. In line with this concern, 50% (3/6) of the therapists expressed the need for digital intervention features to support parents in communicating internet use rules to their children. It is important to consider how the interventions may help parents not only set the rules but also deliver and communicate them to the children properly. The use of gamification features (eg, turning the rules into missions with accomplishment rewards and using animated videos or avatars to explain the importance of the rules) may help make it easier for children to understand and accept the rules [42,92,93].

Implications for Future Digital Interventions

Reflecting on the findings of this study, some implications can be derived related to the design of digital interventions and other aspects that influence the use and acceptability of digital interventions to combat IA in young children. The participants in this study expressed some limitations of the key features of the existing interventions (eg, screen time limitation, screen time monitoring, and content filtering) that discouraged them from using the interventions. Nevertheless, they still perceived those features as helpful for combating IA in children. For example, parents may limit children's screen time through the system but still have difficulty providing substitutive activities. In other cases, parents can monitor children's screen time, but they may still be confused about creating and communicating the appropriate rules based on monitoring. Therefore, this study suggests the need to improve the existing features to be more usable and relatable for the parents to increase their motivation and capability to use the interventions.

According to the UTAUT model, the acceptability of the interventions will be better if we can provide functions that are perceived as beneficial by the potential users [46]. The findings of this and other related studies highlight that the existing features in digital interventions (eg, screen time monitoring and limitations) might not be sufficient to combat IA in young children [33,70]. Our findings suggest that digital interventions should focus not only on restricting and monitoring screen time but also on suggesting substitutive activities for children, developing children's competencies to combat addictive behavior (eg, attitude toward internet use and self-regulation), improving digital literacy in children and parents, and supporting parental decision-making to promote healthy digital behavior in their children. To provide continuous and comprehensive intervention, it is also essential to develop interventions that can cover all the devices or apps that children use. For example, we may develop the interventions to have control over the entire device (operating system) or across devices as children may use more than one app or device.

The appropriateness of the features or content provided by digital interventions could also determine the users' perception, engagement, and acceptability [46,94]. The findings of this and other digital health intervention studies report similar concerns that some features or content provided by the interventions might be inappropriate for the users' culture or beliefs [72,73]. Participants in this study recognized and used the existing interventions developed by big technology multinational companies (eg, Google, YouTube, and Apple). Therefore, the features or content provided by the digital interventions may need to be adjusted to suit their unique characteristics and culture.

To our knowledge, no digital intervention has been developed for the Indonesian context to date. Given the higher prevalence of IA in lower-income regions such as Indonesia [35,36], further studies may be needed to develop culture-appropriate digital interventions for vulnerable populations in these regions. In addition, we suggest adopting tailoring or personalization mechanisms to deliver suitable features or content based on the users' characteristics and culture. These mechanisms can also be beneficial to increase behavior change intention in combating addictive behavior [27,95].

Parents play an important role in supervising and educating children to combat IA [70]. This explains why existing digital interventions for young children typically involve parents in combating IA [52]. In this study, we found that parents perceived barriers to using the existing digital interventions due to their limitations in terms of capability, knowledge, and skills to use the interventions and create appropriate rules. These limitations emphasize the need to provide adequate training for parents to increase their motivation and capability to use digital interventions [96,97]. Collaborating with parents in designing digital interventions may also be beneficial to understand their limitations and suit their needs [98]. In addition, we may support parents through gamification features, such as goal setting, progress tracking, rewards and punishments, and visualization of the results of their supervision, to enhance their ability and engagement in supervising their children [99,100].

Privacy issues related to the use of digital interventions cannot be overlooked. The acceptability of digital interventions may decrease due to parents' distrust of data security and the findings of other studies that have reported privacy violation cases by parental control software [79,80]. Although the interventions typically have privacy warnings and agreements [77,78], we should ensure that the parents can understand and accept the provisions properly; otherwise, they will be reluctant to use the interventions. In addition, providing education on this issue may help parents feel more confident in using the interventions. Another privacy issue raised was related to children's privacy problems due to excessive parental supervision (eg, overmonitoring or being overprotective). Although there is a lack of discussion of this issue in the context of internet use, therapists emphasized the need to consider this in future interventions to avoid other family problems. We argue that improving parents' knowledge of digital parenting and assisting their decision-making through digital interventions may help address this issue.

Limitations of This Study

This study has several limitations. This study may have limited generalizability as we used a small number of participants and a nonrandom sampling strategy (convenience sampling). Therefore, reader discretion is needed in considering the context of this study when using or applying the findings.

In this study, we involved parents and therapists as the children's stakeholders in combating IA, but we did not collect data from children. Therefore, further studies may be needed to complement the results of this study by exploring children's experiences with and perceptions of related topics.

To achieve the objective of this study, we focused on exploring participants' experiences and perceptions regarding the digital interventions already available in Indonesia. Other digital interventions might have been developed in other contexts or regions, but we did not include them in this study. Further studies may be needed to investigate other interventions not included in this study.

Most participating parents (20/22, 91%) in this study were mothers or female individuals. This is because, in the culture of most Indonesian families, the mother typically has a role as the primary guardian of the children. As we required the participation of the primary guardians of children, we did not prioritize an equal proportion of mother and father participation. Nevertheless, the children of the participating parents had quite a balanced gender proportion (64% boys and 36% girls). In addition to this, we found no significant differences between mothers' and fathers' perspectives in this study.

Conclusions

This study shed light on the experiences, perceptions, and considerations of parents and therapists regarding the use of digital interventions for combating IA in young Indonesian children. Participants in this study perceived the benefits of digital interventions in continuously promoting healthy digital behavior in young children and supporting parents in regulating their children's internet use. However, the participants did not highly use the existing interventions due to some limitations. This includes essential issues such as the interventions' functionality and usability, parental capability, cultural incompatibility, parent-child relationships, and privacy.

Our findings suggest that digital interventions should focus not only on restricting and monitoring screen time but also on suggesting substitutive activities for children, developing children's competencies to combat addictive behavior (eg, attitude toward internet use and self-regulation), improving digital literacy in children and parents, and supporting parental decision-making to promote healthy digital behavior in their children. Suggestions for future digital interventions are provided, such as making the existing features more usable and relatable, investigating gamification features to enhance parental motivation and capability in managing their children, providing tailored or personalized content to suit users’ characteristics, and considering the provision of training and information on the use of interventions and privacy agreements.

This study contributes to extending the knowledge from parents’ and therapists’ perspectives on the current state, existing perceptions, and future implications of digital interventions to combat IA in young Indonesian children. The findings of this study will be valuable considerations in evaluating the existing interventions and developing better interventions in the future. For future work, we aim to collaborate with multiple stakeholders (eg, parents, children, teachers, peers, and therapists) to develop digital interventions to combat IA in young children by continuously encouraging healthy digital behavior and improving parental mediation of children’s internet use. The findings of this study will be the primary considerations for future work in developing digital interventions to prevent or reduce IA risk in children.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
COREQ (COnsolidated criteria for REporting Qualitative research) Checklist.
[DOCX File , 23 KB - pediatrics_v7i1e55364_app1.docx]

Multimedia Appendix 2
Semistructured Interview Questions.
[DOCX File , 29 KB - pediatrics_v7i1e55364_app2.docx]

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Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research
DBCI: digital behavior change interventions
IA: internet addiction
IT-CPU: Interactional Theory of Childhood Problematic Media Use
PCIAT: Parent-Child Internet Addiction Test
RQ: research question
UTAUT: Unified Theory of Acceptance and Use of Technology

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Original Paper

Exploring the Feasibility and Acceptability of Technological Interventions to Prevent Adolescents' Exposure to Online Pornography: Qualitative Research

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Abstract

Background: Amid growing concern over children's access to online pornography, policy makers are looking toward new and emerging technological concepts for unexplored solutions including artificial intelligence and facial recognition.

Objective: This study sought to explore and ideate emerging technological interventions that are feasible, acceptable, and effective in preventing and controlling the exposure of young people to online pornographic material.

Methods: We conducted a series of qualitative co-design workshops with both adult (n=8; aged 32-53 years) and adolescent participants (n=4; aged 15-17 years) to ideate potential technological interventions that are feasible, acceptable, and effective at preventing and controlling the exposure of young people to online pornographic material. A story stem methodology was used to explore participants' attitudes toward two unique technological prototypes.

Results: Participants expressed a generally favorable view of the proposed technological concepts but remained unconvinced of their overall utility and effectiveness in preventing the intentional viewing of pornography by young people. Age-appropriate parent-child conversations remained participants' preferred approach to mitigating potential harms from pornographic material, with parents also expressing a desire for more educational resources to help them better navigate these discussions. User privacy and data security were a primary concern for participants, particularly surrounding the use and collection of biometric data.

Conclusions: Internationally, policy makers are taking action to use age assurance technologies to prevent children's access to online pornography. It is important to consider the needs and opinions of parents and young people in the use and implementation of these technologies. Participants in this study were generally supportive of new and emerging technologies as useful tools in preventing the accidental exposure of young people to online pornographic material. However, participants remained less convinced of their ability to avert intentional viewing, with substantial concerns regarding technological efficacy, adaptability, and user privacy. Further, co-design and prototype refinement are needed to better understand user acceptability and comfortability of these new technological interventions, alongside additional research exploring sociocultural differences in information needs and user experiences.

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KEYWORDS

pornography; sexual health; young people; co-design; online safety; age verification; adolescents; attitudes; acceptability; usability; feasibility

Introduction

Background

Internationally, the median age of first intentional viewing of pornography is around 13 years; however, the majority of young people are exposed unintentionally at an even younger age [1-5]. Accidental viewing may be more harmful than intentional access due to the shock and distress experienced upon unexpected or unwanted exposure to pornographic material [6]. Consultations by the Australian eSafety Commissioner found that it was widely considered that pornography is harmful for younger children, but that the balance between harm and benefit is more nuanced for older teens and adults [3].

In recent years, the use of restrictive technology, such as internet filters, has become a common approach to preventing children's early exposure to pornography [7]. However, these technologies are very unpopular with young people and their parents. A 2021 study, for example, found that only 22% of young Australians supported internet filters blocking pornographic content at a national level, while a 2014 study from the United States found that two-thirds of adults opposed censorship of pornography [8,9]. In research with parents in Australia, the United Kingdom, and the United States, very few had used internet filters [10-12]. A key barrier to use was the belief that the technology was ineffective and could be easily bypassed by young people, with other concerns including the impact on the parent-child relationship, data security and privacy, and a lack of perceived need [2,3,10-12].

But technology continues to evolve, with advances, including natural language processing and visual processing, and products, like age verification and kid-safe internet searches, gaining increased attention [13-17]. Technologies can also incorporate behavioral interventions, such as pornography literacy education or self-monitoring and metrification [18,19]. These technologies offer unexplored opportunities and barriers to families in keeping children safe. Furthermore, there have been renewed efforts from governments to implement policy solutions. For example, age verification for access to online pornography is legislated in Germany and France [20,21]. In 2023, the Australian eSafety Commissioner published the Age Verification Roadmap, which considered the feasibility of and evidence for mandatory age verification mechanisms for access to online pornographic content throughout Australia [3]. In 2024, the Australian Government announced an age assurance trial to explore technologies to prevent children's access to online pornography [22]. With these policies being implemented, it is vital to consult the community about how they could be applied. It is within this context, that our paper contributes to an emerging evidence base, and provides important insights into the acceptability and feasibility of new-age verification technologies.

Research Aims

This study seeks to gain a better understanding of user attitudes to emerging technology and policies relating to pornographic access and identify barriers and opportunities for implementing interventions. We used co-design methods to work with parents and young people to explore how these technologies could be used. This research project aimed to ideate technological interventions that are feasible, acceptable, and effective in preventing and controlling the exposure of young people to pornography.

Methods

Phase 1: Discovery and Concept Design

In the first phase of this study, the research team sought to establish what current and emerging technological solutions have been proven or have shown promising efficacy toward the prevention of young people from online sexual harm and exposure to online explicit material. Researchers from the Monash Sustainable Development Institute Evidence Review Service were engaged in July 2022 to conduct a rapid systematic review of contemporary literature and practice, with additional information collected via expert interviews and bibliographic analysis [23]. A final report was delivered to the research team in November 2022.

Following the discovery process, the research team evaluated the existing technological solutions, as well as emerging developments, contexts, and attitudes identified through the evidence review to create a series of speculative prototypes to be tested with research participants. Two of these technological concepts were developed and refined (Textbox 1). The purpose of these concepts is not to present the best possible prototypes but to generate critical discussion about different features of technology.

Textbox 1. Technological concepts.

"SafeAgeID"

This concept seeks to harness facial imagery processing techniques to analyze a user's facial profile and determine an approximate age. This may include measuring ratios between facial features, detecting the degree of wrinkling on a user's face, or measuring a range of points around the nose and eyes. It is proposed that, when installed on users' devices, the "SafeAgeID" app would require a facial scan validation prior to accessing explicit content. If a young person attempts to view restricted materials and fails a facial validation assessment, a notification will be sent to the young person's parent or guardian with information about the attempted access, and the material will be blocked from view on the young person's device.

"PornScreenPro"

This concept seeks to combine both parental monitoring software and internet filters into a single app. The "PornScreenPro" technology would allow parents or guardians to set certain restrictions and limits on the type of material available to view on each device and would also allow the active or passive monitoring of explicit content access, generating regular reports and notifications about trends and viewing activity. This technology could also be used by adults as a form of self-monitoring and reflection, similar to other forms of self-metrication, for example, step counting [18].

Phase 2: Co-Design Workshops

The second phase of the study involved generative co-design workshops. Data from these workshops was used to generate two outputs: (1) a thematic exploration of participant attitudes toward new technological interventions (described in this paper), and (2) a set of design principles and specifications for further development of potential low-fidelity technological prototypes (not described in this paper).

Recruitment

Participant recruitment was facilitated by an external research recruitment agency based in the Melbourne area. The agency sent a brief advertisement to an existing network of suitable participants, and those interested in participating were then directed to complete an online expression of interest survey through the REDCap (Research Electronic Data Capture; Vanderbilt University) platform. Respondents were eligible to participate if they were either adolescents aged between 13 and 18 years or a parent or legal guardian of an adolescent aged between 8 and 16 years. Participants were required to be proficient in English and experiencing economic hardship or social disadvantage, determined through self-reported access to a government-issued health care card or receipt of income support at the time of research. Socioeconomic disadvantage was included because of evidence that digital health interventions can exacerbate inequity when the “digital divide” is not addressed [24,25]. Therefore, we included those experiencing disadvantage to purposefully co-design interventions that met this group’s needs.

Research recruiters contacted suitable candidates following their expression of interest to confirm their eligibility and availability and to provide additional information about the workshop content and structure. Confirmed participants were then sent an email invitation with selected workshop times, along with participant information and consent forms. All participants provided informed written consent including informed parental consent for all participants younger than 18 years of age.

Participants

In total, 12 individuals took part in the research workshops: 8 parents and 4 adolescents. Parents were aged between 32 and 53 years, 75% (n=6) of parents identified as female, 50% (n=4) of parents had a tertiary education, and 38% (n=3) of parents spoke a language other than English at home. Adolescent participants were all aged between 15 and 17 years, and 75% (n=3) of adolescents identified as female. All were current high school students, with 25% (n=1) of adolescents speaking a language other than English at home.

Workshop Procedure

In mid-2023; two 90-minute workshops were held online via Zoom (Zoom Video Communications, Inc) with participating parents across consecutive weeks. A third in-person workshop was held over a 2-hour period with adolescent participants at an inner-city university campus.

Each workshop was facilitated by a multidisciplinary team including a public health researcher, a digital information researcher, and a design practitioner. Across all workshops, researchers used a story-stem completion methodology to explore participants’ perspectives toward the proposed technological concepts [26]. This relatively novel qualitative method presents participants with an incomplete hypothetical scenario and invites participants to complete the narrative by drawing on their own unique experiences, expectations, and mean-making processes [27]. This methodology was specifically selected by the research team as it not only allowed insight into the perceived acceptability and feasibility of the two technological concepts but also generated a greater understanding of each participant’s broader attitudes toward young people’s online interactions and themes of adolescent sexual development. As a speculative method, story-stem completion is particularly useful for exploring concepts or technologies that may not exist or that participants may not have experienced before [28]. As an approach that uses a third-person narrative, it is also excellent for eliciting participants’ knowledge, thoughts, and feelings about sensitive themes [29].

All participants were first given a brief overview of the technological concepts being evaluated including their proposed use and expected functions. A series of story stems were then presented one-by-one to participants, featuring two hypothetical, yet realistic scenarios (Textbox 2). The names in the story stems were deliberately chosen for their gender-neutral associations in Australian English, allowing participants to form their views and apply their gendered lenses to the story stems. Facilitators read aloud the first scenario (part A), and participants were then encouraged to continue the hypothetical story arc individually in a separate worksheet, drawing upon their own experiences and perspectives to complete the narrative. Each anonymous response was collected from participants, before being read aloud by the facilitators with group discussions and reflections to follow. In poststory discussions, facilitators prompted participants to consider and discuss the likelihood of the stories happening in real life, preferred outcomes of stories, how their responses would differ in different circumstances (eg, older or younger child), how the stories made them feel, modifications they would make to the concepts, and other unintended consequences of these technologies. Participants were then given a second related story stem (part B) that continued the first story arc to elicit further insights following slight changes in the hypothetical narrative. Once again, participant responses were collected and discussed as a group, with researchers prompting deeper discussions as needed. This process was repeated for the second technological concept, with new hypothetical scenarios used. Both parents and adolescent participants responded to the same story stem scenarios, with parents completing one concept per workshop, while adolescents completed all story stems in a single workshop.

Following the conclusion of each workshop, the research facilitators also participated in a collective debrief lasting between 20 and 40 minutes, in which key discussion themes and participant responses were further explored. This provided the opportunity for the research team to not only share their professional perspectives on the key insights gained from each workshop but also reflect on the workshop process and refine any minor issues for future sessions.

Textbox 2. Workshop story stems.

Technological concept 1: "SafeAgeID" facial scan recognition

- Part A
    - Harper is 8 years old. At lunchtime, Harper heard the term "threesome" being used by friends but did not understand what it meant. At home, Harper uses the family iPad and types "threesome" into Google.
    - Harper finds a video in the search results and clicks on the link. The iPad suddenly blurs everything on the screen and asks for a facial scan before being allowed to continue to view the explicit video.
- Part B
    - The age verification technology scans Harper's face and decides Harper is probably younger than 18 years and blocks the porn site. The SafeAgeID app instructs Harper to ask for an adult's help to proceed.
    - SafeAgeID app sends a notification to Harper's parents about an attempted porn site viewing, with the date, time, porn video's URL, and the image of Harper's face from the scan.

Technological concept 2: "PornScreenPro" monitoring platform

- Part A
    - Jo is 13 years old and uses the family computer to watch videos and games, and do schoolwork. Jo clicks on a link friends have shared for a porn video. A parenting app called "PornScreenPro" is installed on the computer, and it sends Jo's parents a notification that porn content has been detected as part of their child's internet activity.
    - Along with the notification message, PornScreenPro sends guidance to Jo's parents on how to talk to a 13-year-old about pornography and internet safety in an age-appropriate way.
- Part B
    - Jo is now 19 and watches porn fairly regularly. Lately, Jo has been watching more porn and finding that the content needs to be more graphic or extreme in order to "get off."
    - Jo's phone has a default activity monitor for activities like running and walking, time spent on social media, TV shows, movies, and porn. Jo gets a notification message, "You have watched porn for 36 hours this month, that is 22 hours more than last month."
    - Jo can look at the advice the app offers on reducing pornography use. It also has information about porn's impact on relationships and expectations around sex. It can also suggest pornography that is less extreme or violent.

Data Collection and Analysis

All data, including debrief discussions, workshop audio recordings, and story stem responses, were transcribed and checked for accuracy by researchers. A collaborative iterative thematic analysis approach was adopted to capitalize on the highly multidisciplinary perspectives of the research team [30]. This analysis process was undertaken by two researchers (JT and STK) from the public health and design and technology fields, respectively, with the aim of better integrating specific technological design implications alongside broader themes of young people's sexual health and development.

Following transcription, researchers first familiarized themselves with the data before creating an independent set of initial codes using NVivo 14 software (Lumivero) and the Miro online platform. The research team then met to discuss this preliminary analysis and to compare initial codes and emerging themes. A second, more extensive round of independent thematic analysis was then undertaken, with initial codes refined and developed into more distinct themes. The research team once again met to discuss the corresponding analyses, and following minor revisions, merged the datasets into a single thematic framework that is reflective of the collective perspectives and understandings of the research team [31].

Ethical Considerations

Ethics approval was granted by the Alfred Health Human Research Ethics Committee (ID 663/22). All participants gave informed consent. All adult participants were provided with an AU $100 (US $68) gift voucher as an appreciation for their time, while adolescent participants were provided with an AU $120 (US $81) gift card for their contributions and to compensate for the additional travel expenses. All data were deidentified.

Results

Overview

Three key themes were identified by researchers from the data, with several subthemes further explored. The key themes and subthemes are outlined in Textbox 3 below.

Textbox 3. Key themes and subthemes.

Theme 1: limitations of technology

- Workarounds and circumvention
- Perceived utility of self-monitoring technology

Theme 2: technology as a secondary tool

- First line of defense against accidental exposure
- Age-appropriate conversations remain paramount
- Additional support for parents and guardians

Theme 3: customizable and secure design

- Privacy and data security
- Configurable options for a diversity of users

Theme 1: Limitations of Technology

Workarounds and Circumvention

Throughout each workshop, participants readily identified limitations that the proposed technologies may encounter when applied to real-world conditions. Participants saw the clear potential for these technologies to prevent accidental exposure. However, most mentioned the inability of these technologies to prevent the intentional access of pornography and other online explicit content. Both adult and adolescent participants strongly believed that young people were likely to easily circumvent the restrictive barriers of the proposed technologies, especially when deliberately seeking to view explicit content.

> *It'd be pretty easy to get around the face IDs if you really wanted to see something.* [Adolescent]
>
> *The workarounds kind of rang true to me, that [young people] would try to get around the technology in some way.* [Parent]

Participants described the various ways in which young people were likely to bypass both technological concepts including gaining access through older or alternative devices, seeking access through older siblings or friends, or convincing parents to temporarily disable the technology. Further strategies to navigate the restrictive technologies included using alternative search terminologies such as slang words, emojis, or languages other than English.

> *...the other thing I did note that was interesting was how the child could then try another way of searching for the [explicit] word … for young teenage boys, an eggplant [emoji] signifies something different so, you know, it's the different connotations that people may use, and these technologies will not, or cannot really prevent.* [Parent]

Similarly, several participants also questioned the ability of both technological concepts to prevent harmful exposure through different mediums such as adult cartoons or anime, text-based content, and audio recordings. There was also concern that other forms of harmful online activities, such as sexting or acts of child grooming, would go uncensored, as they were not as easily identifiable as traditional image-based pornographic content.

> *I feel like we're a bit reliant on this technology and only the imagery, but not the text sort of content.* [Parent]
>
> *...you think you're providing this safe platform, whereas they could still go and look up a whole written story about what a threesome was, and that wouldn't be blocked.* [Parent]

Perceived Utility of Self-Monitoring Technology

When discussing the merits of the "PornScreenPro" concept, both adult and adolescent participants questioned the utility of such monitoring technologies, particularly when applied to older adolescents with a developing sexual identity and curiosity for pornographic content.

> *I think the whole concept of the [PornScreenPro] app to a teenager or young adult is not something that is suitable at that age, especially if it's a male. They've just finished high school, the world is their oyster, they're exploring, you know, their sexuality, meeting up with friends, learning different things, and I think the last thing they need or would pay heed to would be an app that sort of prevents them from doing that.* [Parent]

Participants also felt that older adolescents were unlikely to pause and reflect on their own behaviors and pornographic consumption at such an age, even when notified or provided with supportive resources. Consequently, many felt that the "PornScreenPro" app would quickly become a nuisance to users, leading to the technology either being ignored or disabled with enough time.

> *One thing that jumped out at me as being really consistent is that the majority of the [story stem] narratives talked about disregarding the [PornScreenPro] app. Young people didn't care about info on the app, turned off notifications, found them annoying.* [Parent]
>
> *I think if you're at that stage [of life] you're not going to see a notification about [harmful pornographic consumption] and be like "ah maybe I'll look at that," you'll just be like "I don't really care."* [Adolescent]

Theme 2: Technology as a Secondary Tool

First Line of Defense Against Accidental Exposure

Despite the limitations identified above, there was still an overarching agreement among both parent and adolescent participants that these novel technological interventions had a place in protecting young people from online harms, with general support for their further refinement and development. Participants discussed how these new technologies could still be beneficial tools, acting as a "first line of defense" against the accidental exposure of younger children to pornography and other explicit content.

> *Whether the child goes looking for answers when they're not ready, well hopefully this technology, once its released, it would screen out and block those because they're not of age yet, or they're not, you know, ready for it.* [Parent]

Age-Appropriate Conversations Remain Paramount

However, participants reiterated that these apps should not be seen as a "fail-safe" solution and that there was still an important need for close parental oversight and engagement. More specifically, both adult and adolescent participants overwhelmingly agreed that age-appropriate conversations remained the most suitable and preferred course of action for addressing concerns of online harm to young people.

> *I feel like there's a danger that people would think that it was a fail-safe technology … and that the most important aspect is that it shouldn't replace those ongoing conversations about being safe online.* [Parent]
>
> *[Jo's] parents get the link and are not sure what to do so they approach the situation carefully. They realise that it was an accidental mistake and so are cautious on talking to her but do make it a point in the future to educate her about porn in a safe way. Over the next few days its forgotten and Jo is careful not to click on random links again.* [Parent story stem response]

Indeed, many of the participant's hypothetical story-stem responses described an "ideal" outcome whereby parents avoided emotional responses and instead opted for a more empathetic and educational conversation.

> *[The parents] are glad that this technology has blocked their underage child's access. Next few days, the parents sit the child down to ask why she went searching and what would she like to know. Parents propose the next time the child is curious, she should approach the parents first.* [Parent story stem response]
>
> *Ideally, after some confusion and perhaps further failed attempts at accessing the content, Harper would feel comfortable enough to ask one of her parents about the definition of the term [threesome].* [Adolescent story stem response]

Some parents further suggested that adopting these technological apps in their homes would also act as a catalyst for them to have the necessary conversations about online safety with their children before any exposures occur.

> *...if this technology actually existed you would of kind of have to have some of those conversations already about these filters, like "these things exist, there's this app on the iPad that will help stop you from seeing inappropriate content."* [Parent]

Additional Support for Parents and Guardians

Yet, while participants placed significant importance on having these open and informed conversations with young people, several parents also expressed a lack of confidence in their own ability to do so. Many parents felt unprepared for what they described as "difficult" and "awkward" conversations and reflected that they felt less technologically literate in today's online world.

> *We [parents] have sort of I guess been brought up with a limited sort of technology and our children are obviously, it's a second language for them, you know, they understand sometimes more than we do so I feel at times they may be able to actually get around it more than we actually can.* [Parent]

Parents expressed a desire for more educational resources on how to discuss pornography and internet safety in age-appropriate ways and felt that this information must accompany any internet monitoring technology.

> *We understand our children but don't get a good sense of how to educate them in the proper way. They may not really listen.* [Parent]

Several parents also stated that these conversations remain a shared responsibility, with the school system and educators also needing to play a strong role in delivering appropriate cybersecurity and sexual health education.

> *Teachers still play critical role within the school to educate the children, the students, rather than the parent. Parents can play a supporting role.* [Parent]

Theme 3: Customizable and Secure Design

Privacy and Data Security

User safety and data security were a paramount concern for many participants. Several parents expressed a lack of confidence in the ability of third-party apps to protect user information, with numerous participants referencing recent large-scale cyberattacks on Australian organizations, and how these data breaches had further heightened their anxiety regarding online privacy.

> *So many sites have been hacked lately that we would normally think are really secure, like telecommunications and banking.* [Parent]

There was a particularly strong apprehension from parents toward the safe storage of biometric data, with facial scans and images of young people seen as especially sensitive. Some felt that the collection and storage of such sensitive biometric data would in fact attract greater attention from cyber-criminals, with the technology acting as a “beacon” for malicious actors to gain access to young users and their valuable personal data.

> *Having those photos of the children, are they going to be safe? That was my concern as well, just like how everyone mentioned, and too much information being out there so those were my two concerns that I’ve just been pondering about… in some way this technology would be a bit of a beacon for groomers and people wanting to access children.* [Parent]

While these privacy concerns did not undermine participants’ overall assessment of the utility of the technological interventions per se, participants did articulate a strong desire for further information on the safety mechanisms of the proposed technologies. Many felt that these concerns would need to be thoroughly addressed before they felt comfortable using the different apps.

> *I think mostly parents would be accepting of it, I think maybe, I think you’d hit the majority of parents, at least yeah, but I still think the biggest concern would be the face ID technology and the collection of data and identity and I think that yeah that would be the biggest concern.* [Parent]

Configurable Options for a Diversity of Users

Additionally, while participants were quite forthcoming with their own thoughts and reflections on the proposed technologies, many were also acutely aware of and frequently vocalized the need to consider alternative perspectives and value systems in the development process. Both parents and adolescents sought to highlight that each person, family, and sociocultural group may hold different attitudes toward sex, pornographic content, and young people’s sexual development more generally. Consequently, participants expressed a desire to see flexible and highly configurable options available within the proposed technologies to suit the individual needs of users and the unique sociocultural requirements of different family groups.

> *Yeah, because for different households, maybe we say ok I’ve got a 10-year-old, I think my 10-year-old is not ready for that but if another 10-year-old in another household goes “mum and dad, I want to learn about this” then they do the age verification and then its ok for them.* [Parent]

> *I hope that if this kind of technology comes out it would kind of help with acknowledging the fact people choose to [use the technology] for different reasons … it depends on why they’re using it, and how they’ve been brought up. I feel that a technology that addresses that kind of diverse range of people using it would be the most impactful like positively.* [Parent]

Discussion

Principal Results

Both adult and adolescent participants in this study expressed a general level of support for the use of age verification technologies in the regulation of pornography and other online materials for young people. This finding is consistent with other recently published studies, which have indicated similar levels of acceptance for such restrictive strategies aimed at safeguarding online environments. In 2021, the eSafety Commissioner surveyed 1200 Australian adults, with 78% of respondents supporting the use of age verification mechanisms as a means to verify minimum user age on pornographic websites [32]. In a similar survey conducted the following year, just 4% of young Australians believed that online pornography should remain unrestricted by age, with 59% also supporting the implementation of age verification technologies [33]. Comparable research conducted in both the United Kingdom and New Zealand has found similar levels of acceptance. Close to 83% of surveyed UK parents supported the introduction of age verification processes for access to pornographic websites [34], while 71% of young adults in New Zealand were in favor of restricting access to online pornography for teenagers and young children [35]. Our findings, therefore, add to a growing body of evidence suggesting sustained acceptance among the broader population for the use of such technologies within this context.

As a stand-alone strategy, however, these restrictive technologies have clear limitations, particularly in their ability to prevent young people from intentionally viewing explicit online content. In a survey of American high schoolers for instance, 98% of young participants stated that they had no difficulties in circumventing traditional internet filters in order to gain access to pornography [36]. Similarly, research from Australia, the United States, and the United Kingdom has consistently found a strong perception of inefficacy toward these restrictive filtering technologies among the general public [7]. It is unsurprising, therefore, that participants in this study echoed this perspective when discussing the merits of the two proposed technologies. While participants were generally supportive of the new technological approaches, few were convinced of their overall ability to prevent intentional exposure to explicit content. Both cohorts remained firm in their belief that young people were still likely to circumvent both the “SafeAgeID” and “PornScreenPro” apps. This skepticism may be attributed, in part, to the heavy reliance of both proposed technological concepts on traditional restrictive internet filtering practices to prevent exposure to online material. While novel features, such as facial imaging, may allow for a more streamlined and acceptable age verification process, both concepts remain similarly limited in their capacity to prevent intentional access due to the numerous perceived workarounds young people may exploit.

In isolation, restrictive strategies, such as age verification technologies, are therefore unlikely to provide sufficient online protection and support to young people, particularly as their sexual interests and preferences evolve. Instead, participants expressed a strong preference for informed and age-appropriate conversations as an additional and primary method for minimizing potential harm from online material. Yet crucially, participants also had a perceived deficit in their own knowledge and confidence when it came to initiating these conversations with their child, expressing a desire for additional resources to support them with this process. While comparable studies [9,35] have observed similar views from parents and caregivers toward the necessity of these conversations, there remains a dearth of literature exploring what “age-appropriate” exactly entails including the age and contexts in which these conversations should be undertaken. Acknowledging and supporting the essential role of parents and caregivers in guiding young people’s exposure to pornography is crucial, given that active parental mediation in online activities has been shown to diminish risky online behaviors and promote healthier sexual development [37-39]. Additional research is therefore required to enhance our understanding of the specific information parents require to facilitate these crucial conversations, along with determining the optimal timing and contexts for conducting these discussions with young people.

Finally, the findings of our co-design study have implications for future prototype design and development. Participants expressed a desire for more configurable options within the proposed apps to better suit their family’s needs and sociocultural understandings of pornographic content, including what types of media are screened, and to allow for families to select what they are comfortable with their children accessing. Future prototypes should also have the capability to adapt to different age groups, providing parents the ability to enforce stricter controls for younger users and gradually allow more autonomy as children mature, or as parents decide they are ready to access different content. The controls of future apps should ensure adults can watch pornographic content without being restricted or tracked unless voluntarily selected. The apps should be inclusive and accessible for all users, including those who do not speak, read, or write English, or people with disabilities. This could involve text-to-speech features, multilingual capabilities, easy-to-read fonts, and other accessibility features. Finally, supportive educational resources should be developed and provided in tandem with future technological applications to ensure better user acceptability, with a particular need for further information on user privacy and security, and broader information about the app’s design in easy-to-understand language.

Study Limitations

The findings of this study need to be considered in light of several limitations. Participant recruitment was undertaken via an external research recruitment agency, drawing from a network of individuals who had previously indicated a willingness to participate in research. This may have introduced a level of self-selection bias, with the views expressed by our participants potentially differing from those of disadvantaged parents and young people more broadly. Workshops were also carried out within a group setting, leaving the potential for social biases to influence participant responses (eg, social desirability). This bias may have been reduced somewhat by having participants individually complete written story stems, before discussing their thoughts with the group. We were able to analyze these written data in addition to what participants were willing to say in the group discussions. The use of story-stem methodology also brings additional methodological limitations, as story completion frequently replicates the conventional structure of Western storytelling [40]. This is particularly important to note when evaluating the narratives expressed within a culturally and linguistically diverse participant cohort, whereby cultural intricacies, alternative viewpoints, and diverse narrative structures may have been overlooked or misunderstood. Finally, while the novel technological concepts proposed to participants were developed through an extensive evidence review process, they remained speculative and hypothetical prototypes, and thus, participant opinions and feedback were formed based on incomplete information and may change with supplementary details (ie, participant concerns over app security and privacy).

Implications for Future Research

This study provides insights into the wants, needs, and concerns of parents and young people toward emerging restrictive age verification technologies. Further co-design and prototype development are needed to incorporate the findings from this study, with further iterative testing and consultation with key stakeholders to ensure user acceptability and user comfortability. Given the rapidly changing nature of the technological landscape, advances in age verification technology should be monitored closely for future relevance and application, particularly advancements in generative artificial intelligence-driven biometric systems such as facial image processing. Additionally, there is a need for the development of supportive resources for parents and other users of these proposed technologies to address concerns of privacy and user configurability. Further research is needed to better understand the information needs of parents when conducting age-appropriate conversations, including what “age-appropriate” means for different family units, and guidance on when and how to facilitate these discussions. Consideration must also be given to the sociocultural context of users, with further research needed to understand how differences in language, culture, and religion may influence parental information needs and the overall acceptability of the proposed technologies.

Conclusions

As policy makers continue to pursue age verification and other restrictive strategies to limit children’s and adolescents’ exposure to pornography, it is vital to understand how these tools are perceived by potential users. Parents and adolescents in this study agreed that such technology is useful as a “first line of defense” against the accidental exposure of young people to online explicit materials, but that these tools are less likely to be useful or acceptable for preventing intentional pornography access. Concerns over privacy, efficacy, and adaptability need to be considered when implementing future tools or policies. Most importantly, both parents and adolescents insisted that technology alone was not the answer; parent-child conversations and comprehensive sexual health and pornography education were the ultimate solutions to addressing the potentially harmful impact of pornography on young people.

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Data Availability

The datasets generated or analyzed during this study are not publicly available because it may be identifiable, but selected data can be made available from the corresponding author upon reasonable request.

Authors' Contributions

Study conception and design by MSCL, DM, and SC. Material preparation and data collection were performed by NC, STK, and DM. Data analysis was led by STK and JT. The first draft of the manuscript was written by JT and MSCL, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

REDCap: Research Electronic Data Capture

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Original Paper

Building a Sustainable Learning Health Care System for Pregnant and Lactating People: Interview Study Among Data Access Providers

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Abstract

Background: In many areas of health care, learning health care systems (LHSs) are seen as promising ways to accelerate research and outcomes for patients by reusing health and research data. For example, considering pregnant and lactating people, for whom there is still a poor evidence base for medication safety and efficacy, an LHS presents an interesting way forward. Combining unique data sources across Europe in an LHS could help clarify how medications affect pregnancy outcomes and lactation exposures. In general, a remaining challenge of data-intensive health research, which is at the core of an LHS, has been obtaining meaningful access to data. These unique data sources, also called data access providers (DAPs), are both public and private organizations and are important stakeholders in the development of a sustainable and ethically responsible LHS. Sustainability is often discussed as a challenge in LHS development. Moreover, DAPs are increasingly expected to move beyond regulatory compliance and are seen as moral agents tasked with upholding ethical principles, such as transparency, trustworthiness, responsibility, and community engagement.

Objective: This study aims to explore the views of people working for DAPs who participate in a public-private partnership to build a sustainable and ethically responsible LHS.

Methods: Using a qualitative interview design, we interviewed 14 people involved in the Innovative Medicines Initiative (IMI) ConcePTION (Continuum of Evidence from Pregnancy Exposures, Reproductive Toxicology and Breastfeeding to Improve Outcomes Now) project, a public-private collaboration with the goal of building an LHS for pregnant and lactating people. The pseudonymized transcripts were analyzed thematically.

Results: A total of 3 themes were identified: opportunities and responsibilities, conditions for participation and commitment, and challenges for a knowledge-generating ecosystem. The respondents generally regarded the collaboration as an opportunity for various reasons beyond the primary goal of generating knowledge about medication safety during pregnancy and lactation. Respondents had different interpretations of responsibility in the context of data-intensive research in a public-private network. Respondents explained that resources (financial and other), scientific output, motivation, agreements collaboration with the pharmaceutical industry, trust, and transparency are important conditions for participating in and committing to the ConcePTION LHS. Respondents also discussed the challenges of an LHS, including the limitations to (real-world) data analyses and governance procedures.

Conclusions: Our respondents were motivated by diverse opportunities to contribute to an LHS for pregnant and lactating people, primarily centered on advancing knowledge on medication safety. Although a shared responsibility for enabling real-world data analyses is acknowledged, their focus remains on their work and contribution to the project rather than on safeguarding ethical data handling. The results of our interviews underline the importance of a transparent governance structure, emphasizing the trust between DAPs and the public for the success and sustainability of an LHS.

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KEYWORDS

ethics; learning health care systems; pregnancy; lactation; real-world data; governance; qualitative research

Introduction

Background

In many areas of health care, learning health care systems (LHSs) are seen as a promising method for learning from real-world experiences [1,2]. In an LHS, health care and research are aligned to accelerate research and outcomes for patients and have the potential to develop scientific knowledge based on health information and research data by directly implementing new insights from analyses to the clinical practice [3].

For some patient populations, an LHS approach may be considered one of the most promising ways forward, for example, the group of pregnant and lactating people, who are often excluded from controlled clinical research studies and for whom there is still a poor evidence base for medication safety and efficacy. In real life, numerous medications, which are key to the health of the pregnant person, have been used safely and effectively in pregnancy with minimal risk to the fetus and pregnant person, but we do not systematically learn from these experiences [4-8]. Current information on medications used during pregnancy and lactation is fragmented and spread across different countries and data sources, including pregnancy or medicine cohorts, registries, research groups, and the pharmaceutical industry [9]. Examples of such data sources are the European system for the evaluation of safety of medication use in pregnancy in relation to risk of congenital anomalies (EUROmediCAT), the European Network of Teratology Information Services (ENTIS), and national population registries or regional cohorts. Accessing and analyzing these unique data sources in a system of continuous learning could help more effectively clarify how medications impact pregnancy outcomes.

In general, a remaining challenge of data-intensive health research, which is at the core of an LHS, has been obtaining meaningful access to data. A way to impact the field of pregnancy and lactation is through collaborations between various organizations (including public-public and public-private). These organizations, known as data access providers (DAPs), often possess or have access to vast amounts of routine (health care) data, which reflect routine health care encounters and processes, and they have valuable expertise in managing large data sets. Collaborating with private organizations can also be beneficial, as they also possess relevant data and resources. In addition, private organizations, such as medicines marketing authorization holders, require evidence on the effects of medications during pregnancy to comply with regulatory requirements and to update product information. Public-private partnerships present their own set of challenges, such as ownership, benefits and effectiveness, impact on public interest, and achieving a social license, all of which have been discussed in the literature on public-private partnerships [10,11]. In addition, frequently discussed in the context of LHS development is the challenge of establishing a sustainable collaboration capable of consistently facilitating the processes of data collection, analyses, and dissemination of research results [2,12-14].

At the same time, there is a growing expectation for these DAPs as data controllers and processors to extend their focus beyond regulatory compliance and actively safeguard the privacy and appropriate use of data. The General Data Protection Regulation (GDPR) includes various rules and principles for data controllers to ensure transparency and adherence to principles, such as fairness, purpose limitation, data minimization, accuracy, storage limitation, integrity and confidentiality, and accountability, while granting certain rights to persons whose personal data are being processed (GDPR, Articles 5 and 6) [15]. Ultimately, DAPs are viewed as moral agents who must respect ethical principles such as transparency, trustworthiness, responsibility, and community engagement [16].

To realize a sustainable and ethically responsible LHS, it is important to know whether people working for these organizations acknowledge their role and responsibility in safeguarding the responsible use of data and the dissemination of research outcomes to the public. Rising expectations with respect to DAPs' responsibility for the ethical use of data and data ownership do not necessarily mean that each of these organizations has a dedicated governance structure to safeguard these principles or that people working for DAPs feel as if they are a moral actor in an LHS. Moreover, apart from the obvious differences in management and reward systems among DAPs [17], these organizations may also have different motivations for collaborating in an LHS. Furthermore, their perspectives on the sustainability of an LHS and their roles once the project phase concludes may also diverge.

Objectives

In this study, we aimed to explore the views of people working for DAPs who participate in public-private partnerships to build a sustainable LHS. We were especially interested in the views of DAPs contributing to the Innovative Medicines Initiative (IMI) ConcePTION (Continuum of Evidence from Pregnancy Exposures, Reproductive Toxicology and Breastfeeding to Improve Outcomes Now) project, which aims to build an LHS for pregnant and lactating people [18]. Using a qualitative interview design, we hoped to identify, better understand, and juxtapose people's views and interests in collaborating in an ecosystem that uses routine health data to generate new knowledge for pregnant and lactating people and their doctors. By providing insight into the views and interests of people representing DAPs in this particular LHS, this study intends to inform a governance framework for LHSs and, in turn, to help facilitate the development of a sustainable LHS in which public and private organizations collaborate. Moreover, this study aims to contribute to the ongoing discourse on moral responsibilities associated with responsible data handling and dissemination of research findings, particularly by exploring whether DAPs themselves perceive and articulate this moral responsibility.

Methods

Design

We conducted a qualitative study to collect the views and interests of people who work for organizations and who act as a DAP in the ConcePTION project. This qualitative interview study is a substudy of the IMI ConcePTION project (Textbox 1). IMI ConcePTION was used as the primary case study during the interviews and as the source for participation selection. The study was reported following the COREQ (Consolidated Criteria for Reporting Qualitative Research) [19]. We conducted semistructured interviews with a topic list (refer to the general topic list in Textbox 2). The topic list was based on the topic list used for another qualitative interview study, in which we asked women during preconception, pregnancy, and nursing what they thought about an LHS for pregnant and lactating women [20]. The topic list was also based on an analysis of the challenges of public-private partnerships, LHSs, and responsible data sharing [1,10,21], as well as discussions among the research team. To mitigate the potential for socially desirable responses from our respondents, it was determined that the topic of moral responsibility regarding the use of data and the dissemination of research findings would not be included in the general topic list. Instead, an opportunity for spontaneous or organic discussion of the topic was provided during the course of the interview. Moreover, it was expected to be, for example, discussed under topic 2: “expertise and dual roles.” This topic provided an opportunity for DAPs to elucidate their roles and responsibilities concerning their primary organization; their involvement in the ConcePTION consortium; and in certain instances, their clinical obligations.

Textbox 1. Description of the initiation, aim, and composition of the Innovative Medicines Initiative (IMI) ConcePTION (Continuum of Evidence from Pregnancy Exposures, Reproductive Toxicology and Breastfeeding to Improve Outcomes Now) project.

In April 2019, the IMI ConcePTION project was launched, which aims to establish a trusted ecosystem that can efficiently, systematically, and in an ethically responsible manner generate and disseminate reliable evidence-based information regarding the effects of medications used during pregnancy and breastfeeding to women and their health care providers. The ConcePTION consortium consists of European public and private stakeholders, including national public health institutes, the European systems for the evaluation of safety of medication use in pregnancy in relation to risk of congenital anomalies (EUROmediCAT), the European Network of Teratology Information Services (ENTIS), research institutes, universities, and pharmaceutical companies. The ConcePTION consortium is currently a public-private partnership; however, the approach of ConcePTION to collect and learn from real-world data on the safety of medicines during pregnancy and breastfeeding is similar to what may also be called a learning health care system [6].

Textbox 2. General topic list used during the qualitative study to guide the interviews.

Topic list

- Willingness to participate
- Expertise and dual role
- Future (after consortium agreement ends)
- Conditions for working for the ConcePTION (Continuum of Evidence from Pregnancy Exposures, Reproductive Toxicology and Breastfeeding to Improve Outcomes Now) learning health care system
- Added value

Sample and Setting

To capture a wide range of interests and perspectives (contrast maximization), a variety of people from different types of organizations and different countries were identified. We aimed to include people working as DAPs in partnering organizations and third parties in the ConcePTION project. To be able to invite people working for different DAPs, we distinguished between private (pharmaceutical companies and private centers) and public organizations (universities, teratology information centers, public health services, and hospitals), countries, regions, collaborative partnerships, and occupations. Respondents were recruited using purposeful sampling with the help of colleagues from the ConcePTION consortium. The respondents were approached via email. Most of the interviews started with an introductory question related to the work of the respondent and the process of data collection, storage, and analysis within their organization. We then used the topic list to continue with the interview. Although the approach of ConcePTION is similar to that of an LHS, we used the terms ecosystem and network interchangeably. This is because the term ecosystem is commonly used within the consortium and is more familiar to the respondents. The interviewer (MJH) created a safe space for respondents and invited them to share their views and experiences by emphasizing (1) the privacy and confidentiality arrangements, (2) their autonomy during the interview (eg, regarding answering questions, stopping the interview, and asking for clarification), and (3) the option to review the transcript before analysis. These points were emphasized by the interviewer before seeking verbal consent. The interview allowed respondents to introduce or emphasize new issues that they considered relevant. Therefore, it is important to emphasize that the results reflect personal views and do not represent the views of the entire organization for which the respondents work.

Data Collection

The interviews were conducted by MJH (trained qualitative researcher, female) using the topic list. The topic list was refined after 2 pilot interviews. Furthermore, according to the technique of constant comparative analysis, the interview topics evolved as the interviews progressed alongside data analysis [22]. Data were collected from November 2021 to February 2022. The interviews were conducted in English and Dutch and took place via a secure communication platform. The interviews took 33 to 60 minutes, with an average duration of 43.8 (SD 75) minutes. In 12 out of 14 interviews, there had been no previous contact between the interviewer and the respondent. In 2 out of 14 interviews, the interviewer and the respondent had contacted each other before for project-related work. During and after the interview, MJH made notes to enhance the data and to provide a clear context for data analysis. The interviews were audiotaped, transcribed verbatim, coded, and stored anonymously. Verbal consent was obtained from all the respondents. One respondent requested to read the transcript before analysis.

Data Analysis

After transcription, we analyzed the interviews according to the thematic analysis method and by using a backward and forward approach between data collection and analysis to develop codes [22]. An initial coding list was developed based on the topic list. Subsequently, the transcripts were coded. The coding list was evaluated and adapted, and all interviews were coded using NVivo 12 software (Lumivero). To enhance the validity of our results, an intern (medical student, Bachelor of Science) also read and coded 8 randomly chosen interviews out of 14 pseudonymized interviews to check for consistency of the thematic framework and critically read the coding list. In the course of the analysis, codes were adapted, and additional codes were added to the coding list where necessary. A meaning pattern was identified across the data set, leading to the formulation of interpretative higher-order themes. The themes capture the views and interests of the DAPs regarding the ConcePTION ecosystem. The themes represent both topics that were often discussed by respondents and a variety of views that are helpful in the development of a sustainable ecosystem of continuous learning. The findings, including the coding list and formulated higher-order themes, were discussed by the complete research team (MJH, RvdG, MCJMS, and JJMvD). Thematic saturation was reached when additional data did not lead to any new emergent themes after 14 interviews [23]. Furthermore, a member check was executed during the last phase of data analysis. A draft version of the manuscript was sent to all respondents, inviting them to provide feedback and discuss the accuracy and interpretation of our results [24].

Ethical Considerations

The research protocol, including the procedure for obtaining informed consent, was reviewed by the institutional research support office at UMC Utrecht. As no intervention was imposed on the participants, this study was exempt from ethics review under the Dutch law. All participants were provided with a letter of information and gave their verbal consent for participation and recording as required under the Dutch law that implements the GDPR (*uitvoeringswet algemene verordening gegevensbescherming*). Each participant was assigned a study ID number to protect their privacy and confidentiality. Furthermore, their names, the names of their workplace, and other names of the consortium members mentioned in the interviews were redacted by the interviewer MJH. The participants were not compensated for participating in the study.

Results

Overview

Of the 23 DAPs that were approached, 14 agreed to participate in the study, 4 declined, and 5 did not respond. A total of 14 semistructured interviews were conducted with 18 people involved in IMI ConcePTION. A total of 2 DAPs were represented by 2 employees of the same organization or research collaboration. The interview respondents worked in different organizations, including universities, public health centers, hospitals, teratology information centers, pharmaceutical companies, and private centers. Table 1 shows the respondents' characteristics. We could not share all details to ensure the privacy of the respondents.

Because of the constant comparative analysis during the qualitative study, we enhanced our interview guide. During the first couple of interviews, the subject of (moral) responsibility was not (always) organically discussed. Therefore, we added to the second topic "expertise and dual roles," the possibility of asking DAPs directly about their sense of responsibility and to whom that responsibility was directed, if relevant. We still decided to leave the answers open and not steer too much in the direction of the sense of *moral* responsibility regarding the use of health data and dissemination of research findings to avoid socially desirable answers.

On the basis of the interviews, we formulated 3 main themes characterizing the views and reflections of DAPs on the development of a knowledge-generating ecosystem for pregnant and lactating people. These themes emerged consistently across all interviews. We provide representative quotations to illustrate these themes (Table 2).

Table 1. List of characteristics of the respondents, categorized based on the respondent number, type of organization, whether it is a public or private organization, and the general location of the organization.

Respondent number	Type of organization	Public or private organization	General location of the organization
R01	University	Public	Southern Europe
R02	Research institute	Public	Southern Europe
R03	Pharmacoepidemiologic research institute	Public	Central Europe
R04	Research institute	Public	Northwestern Europe
R05	Hospital	Public	Central Europe
R06	University	Public	Northern Europe
R07	University	Public	Western Europe
R08	Pharmaceutical company	Private	Central Europe
R09	Public health service	Public	Middle East
R10	Pharmaceutical company	Private	Western Europe
R11	University	Public	Northwestern Europe
R12	Hospital	Public	Northwestern Europe
R13	Health center	Private	Middle East
R14	University	Public	Northwestern Europe

Table 2. Representative quotations (Q) from the respondents (R) used to illustrate the identified themes.

Themes and quotation number	Quotation and respondent number
Theme 1: opportunity and responsibility	
Q1	"It was another opportunity for us to exchange data on a wider basis. ...share with one another might be an interesting experience." [R09]
Q2	"The first thing to remember, is that we want to be important. We want to continue being bold. Because at the end, it's big; ConcePTION. It has a lot of power. We want to be there. Not for, only for some type, scientific purposes. But the main one is, to include our data." [R02]
Q3	"Think it's two things. One is we feel the obligation, because we have a large database, so it's a moral obligation I think—or we think. And the other one is also because we like working in this team." [R03]
Q4	"I'm excited to be in this field, because you can help people improve their health whether it's women or children, doing this study, or in other types of study we do. I'm not sure I'd use the word responsible in that context, but definitely it's a motivating factor." [R14]
Q5	"Then we would have some safeguards that we are the ones who say 'Yes, this data can be used,' or the results. We have obligations to the data providers; we need that these are full in. So the problem is if we have like one day to review the results and then something is published, we will kind of have problems with our obligations." [R03]
Theme 2: conditions for participation and commitment	
Q6	"To be sure that at least we have one [person] working on this. And that it is a very stable income. Because otherwise we are looking for the calls [tenders] and running for them. And yeah, it takes a lot of time, and when we spend time on this, we don't spend time on thinking about the research we're performing." [R07]
Q7	"We are a research institute, and we get evaluated every seven years, and we are measured on publications mostly. So, research is a value for us and publications is important for us, and especially also first and last authorships. So we need to focus our resources on getting some publications." [R03]
Q8	"There needs to be some rules, an agreement about our participation and how much pharma can affect the processes and how much pharma can receive from this and every package actually, so it should be in some agreement written down." [R13]
Q9	"What I would want is to have more time to discuss things like double programming and also to decide like decisions implicitly made." [R03]
Theme 3: challenges for a knowledge-generating ecosystem	
Q10	"[In] the end, you're going to need a person who understands the data and to analyze [the data] how is the meaning of the data? Because if you are, at the end, just a numbers situation. You are not thinking about this biological play. Classical or not. Or if it makes sense with your kind of population." [R02]
Q11	"In many countries that are strict data privacy rules and when for a given observation, there are like less than four observations, the results are masked. ...that means that I cannot use the data when combining data from several studies. So one thing that I think would be beneficial is to see if there would be data privacy rules that would be lifted for pregnancy studies." [R08]
Q12	"So, but it's a big assumption. Because academia is involved, you know,..., taking care of [the governance; the data privacy]. And ...they will handle the trust part. I trust them or [when academia] are taking the lead in this project, I'm like: 'okay I think they will take care of everything.' ...They [academic partners] are extra careful, and that extra carefulness is making collaborating complex and difficult." [R10]
Q13	"But here one of the biggest questions is the sustainability. So how this platform will be, I'm saying platform and it's not the exact quote, but how this platform will be sustained after ConcePTION." [R08]

Theme 1: Opportunity and Responsibility

Most respondents wanted to contribute to the ConcePTION project because they viewed the project as an *opportunity* to (1) contribute to the goal of creating knowledge on the safety of medication used during pregnancy and lactation; (2) look at medication safety and birth defects in a larger context (European wide); (3) collaborate and share experiences with other registries, databases, and the like (quotation 1); (4) stimulate scientific research; (5) learn from others and their registries; and (6) showcase their databases and share expertise (quotation 2).

Respondents also emphasized the need to use real-world data. Some respondents mentioned that they feel it is their *responsibility*, or as 1 respondent expressed, *moral obligation* to contribute because of the database or resources they have access to. They felt that they, with their organization, were in a position to contribute to something important, and therefore, they must (quotation 3). Some have been working for a very long time on this specific topic and have already contributed greatly to solutions to close the knowledge gap regarding medication safety in pregnancy and lactation. Only a few mentioned that they felt responsible for helping these groups of people; others saw the lack of knowledge more as a motivation to contribute to the ConcePTION ecosystem (quotation 4).

Besides articulating a responsibility toward pregnant and lactating people, their offspring, and their doctors, the respondents of the private industry also explained that they need to generate knowledge because it is a requirement from the European Medicines Agency and Food and Drug Administration. As they are required to research medication safety among pregnant people, this was considered to be another type of obligation and, with that, a different type of willingness to participate.

A few respondents also expressed feeling a responsibility for enabling research and the quality of the data analyses, and because of that, they wanted to be involved in the decision-making regarding the development and testing of analytical scripts within the research ecosystem.

Finally, 1 respondent also mentioned their responsibility and obligations toward other *data providers*. Some organizations receive data from other organizations, such as health insurance providers. Because of these obligations, they wanted to remain in control of some of the review processes in terms of data programming and analyses (quotation 5). However, challenges in this regard were also discussed stemming from time and financial constraints as well as short research deadlines. None of the respondents discussed their role as data controllers, which involves the responsibility to determine the purpose and manner in which personal data are processed.

Theme 2: Conditions for Participation and Commitment

Respondents explained that their willingness to collaborate within the ConcePTION LHS depends on certain conditions that need to be in place.

Resources and Support

In all interviews, financial resources were discussed as an important condition. Interestingly, financial resources were mentioned as important for reasons beyond the immediate need to cover resource costs associated with participation in a project. Financial resources were discussed in the following ways: (1) as a stable flow of income, preferably contracted for an extended period and covering all the planned activities, and (2) as a source of funding. A stable flow of income is beneficial for attracting and training more employees in this area of work and will help with distributing tasks and becoming more specialized and efficient in the field of pharmacoepidemiology. Agreements on financial support are also necessary for planning and being less dependent on other sources to keep “the system running” (ie, tendering; quotation 6). Regarding sources of funding, some respondents specifically stated that they cannot receive funding from the private industry. They believe that because they are independent (public) institutions, there would be a conflict of interest.

Other respondents mentioned that besides financial resources, they also need IT and computational resources to perform the actual analyses and to ensure that they can keep up with the heavy computational work, which is necessary for sustaining the data analyses.

Some respondents mentioned that they are not used to writing certain types of protocols or experience challenges when receiving ethics approval for studies. Some respondents suggested that ConcePTION could benefit from having a permanent staff to provide support and address questions about timelines, deadlines, funding, ethics, and events.

Scientific Output and Motivation

The importance of scientific output was emphasized during the interviews. Some respondents worked in academic institutions whose aim was to produce scientific publications (quotation 7). Therefore, their willingness to participate in an ecosystem is also affected by whether they get to perform and design studies within the ConcePTION LHS and publish the results in scientific journals. Some respondents also emphasized the need to ask more scientific questions and implement more scientific methods within the network. They mentioned that working within the ConcePTION ecosystem should be different from tendering for projects from pharmaceutical companies. Finally, respondents also wanted to feel motivated to commit to the ConcePTION ecosystem. According to them, motivation is stimulated in different ways, but most importantly, by scientific interest in the project, autonomy regarding work, respect for expertise, and good working relationships. A few respondents also emphasized the importance of offering valuable and easily accessible knowledge to pregnant and lactating people as well as health care providers as a prerequisite for contributing to the ecosystem. They felt that generating valuable information for these stakeholders is the most important goal of an ecosystem such as ConcePTION.

Safeguards

Safeguards were also mentioned as a condition for working for the ConcePTION ecosystem. A few respondents were hesitant regarding the role of the pharmaceutical industry in the processes of formulating research questions, cowriting protocols, and analyzing results (quotation 8). According to them, industry involvement could conflict with the primary goal of the research, or they considered it challenging to align the goals of private and public industries. Other respondents, who worked for pharmaceutical companies, regretted this view and argued that collaboration is very much needed and possible because of independently determined regulations that govern both public and private organization research into the effects of medicines. They stressed that trust and open-mindedness toward each other are important for a good collaboration.

Another safeguard mentioned by some respondents was related to transparency. They argued that in a large network and with a developing ecosystem, it is important to be able to track every step and decision made regarding techniques and methods. One respondent explained how several decisions are made in the process of data analyses, which can influence the quality and value of the results (quotation 9). A few respondents also mentioned that to safeguard the quality of data analyses, especially in the developmental phase of the ecosystem, decisions about technical aspects such as programming and writing scripts for analyses need to be transparent for all DAPs. In this way, DAPs can perform their own quality checks, if desired, and provide valuable feedback.

Theme 3: Challenges for a Knowledge-Generating Ecosystem

When asked about their perspective on the development of a knowledge-generating ecosystem, respondents talked about the challenges they have experienced thus far and which, according to them, are relevant when building the ecosystem.

Data (Is Not Information)

Some respondents explained that there were challenges in harmonizing the databases and executing studies because of the heterogeneity of the data across all databases. Some respondents also mentioned that it may be challenging to generate reliable information based on such heterogenic data, databases, and IT systems. Most importantly, data are not (yet) information or knowledge. To overcome this challenge, respondents discussed 3 types of solutions. First, to be able to interpret data and develop valuable information, many respondents emphasized the need to involve experts who know the data and the real-life health care context of the persons whose personal data are being processed and data points represented in the different data sets (quotation 10). Second, respondents mentioned the need for security and quality assessments to ensure that analytic scripts fit the data and are run correctly at every organization. Third, a few respondents preferred to work in small teams so that they could exchange experiences with scripts, data analyses, and research questions. According to them, working in small teams creates a better overview of the possibilities and limitations of data.

Governance

Some respondents experienced challenges owing to governance procedures. On the one hand, it was mentioned that these procedures are challenging because countries have different data privacy rules, which sometimes complicate the ability to perform observational studies (quotation 11). On the other hand, it was mentioned that these procedures are challenging because their own company or organization restricts certain (research) activities. Some respondents argued that in academia, people exert extreme caution regarding governance, which creates an additional barrier to collecting, sharing, and analyzing data. One respondent assumed that the involvement of academic institutions in the consortium implied that matters such as data handling, privacy and confidentiality, and trust were adequately addressed. However, according to the respondent, this also led to an increase in bureaucratic steps, making collaboration more intricate and challenging (quotation 12). Furthermore, respondents agreed that having fragmented governance procedures led to slow processes and unfulfilled opportunities. According to these respondents, a clear overview of what can be done with the data could be of great help.

Concerning governance, some respondents discussed the need for trust between all collaborators, especially regarding the aim of the ecosystem and methods used within the ecosystem. It was also mentioned that people need to trust the decisions made by people taking a more leading role in the ecosystem and that trust between the public and private participants is necessary to ensure that robust knowledge is going to be generated transparently within the ecosystem. Finally, many respondents emphasized the need for a good sustainability model for the ConcePTION LHS (quotation 13).

Discussion

Principal Findings

The results of our analysis indicate that respondents felt responsible to participate in an LHS for pregnant and lactating people. Although respondents emphasized the professional opportunities that come with participating in a large public-private partnership, many respondents collaborated because they wanted to help develop an ecosystem that can transform real-world data into new knowledge on medication safety and efficacy.

Moral Responsibility

From our interviews, it seems that people mainly reflect upon their views and responsibilities from the perspective of their professional role as a data analyst or pharmacoepidemiologist. As a result, most answers were linked to the more technical side of realizing a system in which real-world data can be used, together with a sense of moral responsibility toward the quality of their data, databases, and data analyses (under theme 1 and as mentioned in quotation 5). On the one hand, technological responses are not surprising because of the expertise of our respondents. On the other hand, our respondents work at the core of data processing and analysis, which means that their role is also to handle the data ethically. Some respondents mentioned that they assume that compliance with rules and regulations is being taken care of by other departments of their organization or other people within the LHS, and therefore, they did not worry so much about the ethical handling of data. However, compliance with rules and regulations is a narrow understanding of handling data ethically because it often solely refers to protecting the privacy and confidentiality of persons whose personal data are being processed—an aspect extensively discussed in the interviews and sometimes perceived as a complicating factor for research. Although many respondents viewed contributing to ConcePTION as an opportunity to generate new information for pregnant and lactating people, there appears to be a lack of widespread moral responsibility toward handling data from the perspective of pregnant and lactating people. Some respondents also considered pregnant and lactating people themselves to be disconnected from the work they are responsible for. However, during the member check, some respondents expressed that they did not feel accurately represented in the portrayal of their views on this topic. For them, it was important to recognize that they feel responsible for contributing to the ConcePTION project [25].

Trust and Transparency

Interestingly, trust and transparency were discussed as important aspects of the relationship between the participating organizations. Respondents explained that trust and open-mindedness are important conditions for working toward a common data model and getting everyone to share the same vision for the LHS. In the literature on public-private partnerships, big data research, and data-intensive research in health care, trust is also often mentioned as a crucial principle for effective collaboration [10,26,27]. During the interviews, there was hesitancy among respondents about the prospects of public-private collaboration. Some respondents mentioned that they believe they are officially constrained by their institution to closely collaborate with the pharmaceutical industry or cannot share any data (pseudonymized or not) with the pharmaceutical industry. This constraint challenges the effectiveness of the collaboration and, as a result, might complicate the development of a sustainable LHS as a public-private partnership. Interestingly, the ConcePTION project currently operates as a consortium under a consortium agreement, making reference to the European Network of Centers for Pharmacoepidemiology and Pharmacovigilance code of conduct (2010) [28]. The European Network of Centers for Pharmacoepidemiology and Pharmacovigilance code of conduct aims to maximize transparency and promote scientific independence. Furthermore, a consortium agreement typically addresses the issues of a conflict of interest by making agreements on ownership and intellectual property, obligations and rights of the participating parties, and third-party agreements. It seems that although many of the concerns of our respondents are addressed in the consortium agreement, they are not aware of these arrangements or they still experience dilemmas regarding the collaboration and their own interests, which can lead to a continued lack of trust between the public and private industries. It might be worthwhile to close this gap between the consortium agreements and the experiences of collaborators by ensuring that everyone understands the consortium structure. In the literature on large research consortia, it has been argued that transparency is important for realizing an appropriate governance framework for these types of complex collaborations. Here, transparency refers to the accessibility and visibility of the governance structures. For example, within a consortium, good governance requires that those internal or external to the project know what governance structures and procedures are in place, what mechanisms for legitimate decision-making have been adopted, and where the authority and responsibility for different types of actions are located in the consortium [17]. Our interviews underline the importance of transparency in the context of governance of an LHS with public and private organizations. One solution is the installation of a separate independent body, especially when the contractual agreement of the consortium has ended. Some scholars have suggested a Data Access Committee that can help protect persons whose personal data are being processed from foreseeable harm, stimulate social value, and mandate clear lines of accountability, terms of reference, and membership [29].

Public Trust

The above-described perceptions of trust are of course important; however, both the literature and our previous interview study with women during preconception, pregnancy, and nursing show that public trust is also of crucial importance for the development of an LHS [20]. In the literature, it is emphasized that it is important to meet the public expectations for transparency when developing an LHS, which in turn will strengthen or maintain trust in not only the LHS but also the institutions working within the LHS [26]. People anticipate that their voluntary contribution of data will be used to enhance the care for others and they expect that their good faith will not be taken advantage of. Therefore, much depends on the extent to which uses of personal data are seen as serving the public interest and conducted by those with a public interest orientation. It is of great importance that in an LHS, public interest is considered to realize transparency, increase responsibility, and earn the trust of the public. Interestingly, some of our respondents seem to expect that others in their organization are taking care of these principles that are important for public trust or are, again, not fully aware of the governance and arrangements within the organization or the collaboration.

Future of an LHS for Pregnant and Lactating People

Many respondents viewed the ability to conduct scientific research within a broader context as a crucial opportunity. Engaging with a diverse range of organizations can not only enhance the quality of data analyses but also improve the integrity of individual databases. Although research is essential in a knowledge-generating ecosystem, the implementation of research within the health care system is equally important. Respondents affiliated with academic institutions emphasized the significance of publishing new findings in scientific journals, as this is a key aspect of their professional responsibilities. In an LHS, it is imperative to move beyond the conventional practice of publishing primarily in scientific journals and instead prioritize the ethical integration of learning within the delivery of care [30]. This approach would allow for the continuous improvement of care through the application of new insights, while also ensuring the proper management of data. Pharmaceutical companies have already applied this method to a certain extent by generating evidence and translating findings onto product labels and educational materials for health care providers. Perhaps, the dissemination of new insights is an area in which these parties should work together and learn from each other. As LHSs mature, it is crucial that all stakeholders recognize and embrace the system’s necessity and value, extending beyond the project phase to include patients, physicians, scientists, institutional boards, pharmaceutical companies, governments, and other relevant parties.

Limitations

Our study had several limitations. First, we have tried to purposefully include both public and private industry partners; however, we have received more responses from people working in public organizations. Thus, we were not able to include people working in the eastern part of Europe, which challenges the generalizability of our findings, as Eastern European organizations might reflect a different culture and attitude toward an LHS. Second, although we wanted to avoid socially desirable responses, the topic of moral responsibility regarding data handling was not always organically discussed during the interviews. To address this topic, the interviewer directly asked some respondents about their sense of responsibility for specific aspects of their work. Openly discussing the topic could have influenced the initial position of the respondent. We would also like to emphasize that we spoke to individuals who represent their organization in the context of the consortium; however, they do not represent the views of their organizations. Therefore, their views were subjective and might differ from those of other people working in the same organization. It would be interesting to understand the views of DAPs outside the context of pregnancy. As mentioned in the *Introduction* section, in many areas of health care, LHSs are seen as a promising way to learn from real-world data. To establish a successful LHS, more research is needed on the perspectives of the stakeholders involved.

Conclusions

To conclude, people working for DAPs have different reasons for contributing to a project such as IMI ConcePTION, which aims to build an LHS for pregnant and lactating people. The most common motivation was opportunity. The opportunities included creating knowledge on medication safety during pregnancy, examining medication safety in the European context, collaborating with and learning from other experts, stimulating scientific research, presenting their database, and securing financial support. Although many respondents expressed a responsibility to enable real-world data analyses, their focus was primarily on their work and contribution to the project rather than safeguarding ethical data handling from the perspective of pregnant and lactating people. The results of our interviews underline the importance of a transparent governance structure that addresses decision-making processes, authority, responsibility, and accountability. Trust is crucial for the success and sustainability of a public-private LHS, relying on the relationship between DAPs and public trust. For an LHS, it is essential that all relevant stakeholders recognize and embrace the need for and added value of the system itself.

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Data Availability

The data sets generated and analyzed during this study are not publicly available because individual privacy could be compromised. In addition, no permission was obtained from the participants for public availability. The data set is available from the corresponding author (MJH) upon reasonable request.

Authors' Contributions

MJH, RvdG, MC, and MCJMS were responsible for the concept and design of the study. MJH was responsible for recruiting participants. MJH was responsible for data collection, initial drafting of the manuscript, and conducting the thematic analysis, to which RvdG, MCJMS, and JJMvD provided substantial input along the way. RvdG, MCJMS, MC, and JJMvD revised the manuscript critically. All authors approved the final version of the manuscript.

Conflicts of Interest

MCJMS is leading a department that conducts regulatory-required research for COVID-19 vaccine manufacturers based on the European Network of Centers for Pharmacoepidemiology and Pharmacovigilance code of conduct and is the project coordinator of Innovative Medicines Initiative ConcePTION (Continuum of Evidence from Pregnancy Exposures, Reproductive Toxicology and Breastfeeding to Improve Outcomes Now).

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Abbreviations

ConcePTION: Continuum of Evidence from Pregnancy Exposures, Reproductive Toxicology and Breastfeeding to Improve Outcomes Now
COREQ: Consolidated Criteria for Reporting Qualitative Research
DAP: data access provider
ENTIS: European Network of Teratology Information Services
GDPR: General Data Protection Regulation
IMI: Innovative Medicines Initiative
LHS: learning health care system

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Evaluation of Parents' Use of a Child Health Care Information App and Their Health Literacy: Cross-Sectional Study

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Abstract

Background: Recently, digital media, including internet websites and smartphone apps, have become popular resources for parents in searching for child health care information. Higher health literacy among parents in obtaining adequate health care information and making proper decisions may lead to improved child health outcomes and a reduction in the burden on health care professionals. However, few studies have examined the association between the provision of child health care information apps and parents' health literacy.

Objective: This study aims to evaluate whether parents' use of an app that provides child health care information is associated with their health care knowledge, their health literacy, and emergency room visits for their children.

Methods: Participants were recruited during checkups for their 1.5-year-old children at health centers within Saku City in 2022. Parents who agreed to participate were included in this study; individuals were excluded if they were not the mother or father of the child or did not have a smartphone. Participants were asked if they had used the Oshiete-Doctor app, which was distributed by Saku City free of charge to improve the home nursing skills of parents and guardians. Sociodemographic data of parents and children, data on health care knowledge about children, data on the frequency of emergency room visits in the past 6 months, and health literacy scores (HLSs) of parents (measured with the HLS-EU-Q47 [European Health Literacy Survey Questionnaire]) were collected from participants in this cross-sectional survey. Univariable and multivariable analyses were conducted to examine the associations of app use with health care knowledge, health literacy, and emergency room visits.

Results: In total, 251 respondents completed the survey (response rate: 251/267, 94%). Although the proportion of health care workers was significantly higher among app users than among non–app users (*P*=.005), no other participant attributes were significantly associated with the use of the app. The proportions of participants with higher health care knowledge and participants with higher total HLSs were significantly higher among app users than among non–app users (*P*=.001 and *P*=.003, respectively). After adjusting for potentially confounding covariates, these proportions were still significantly higher among app users than among non–app users (*P*=.02 and *P*=.007, respectively). Emergency room visits were significantly more frequent among app users than among non–app users (*P*=.007) in the univariable analysis, but the association was not significant (*P*=.07) after adjusting for sociodemographic variables.

Conclusions: This study showed a significant association between parents' use of a child health care information app and higher child health care knowledge and health literacy. The use of the app may lead to more appropriate health decisions and behaviors in children's health care. Future studies are needed to evaluate the association between app use and emergency room visits.

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KEYWORDS

health literacy; European Health Literacy Survey Questionnaire; HLS-EU-Q47; child; preschool; parent education; health care knowledge; apps; digital media; emergency room visit; mobile phone

Introduction

Despite the increased health concerns during the COVID-19 pandemic, parents were discouraged from visiting medical facilities to avoid infection [1], and opportunities for classes and social gatherings to provide health care information to their children were limited. Ishikawa et al [2] reported a decline in health literacy among people during the COVID-19 pandemic.

Health literacy is the ability to access, understand, evaluate, and apply health care information, and it is related to health behaviors and outcomes [3]. Greater parental health literacy in obtaining adequate health care information and making proper decisions may lead to appropriate health care service use, which, in turn, may result in improved child health outcomes while alleviating health care professional burdens.

In recent years, mobile health (mHealth) has emerged as an effective approach to improving health literacy. Digital media, including internet websites and smartphone apps, have become popular resources for parents in searching for health care information [4]. A cross-sectional study conducted in Switzerland reported that >90% of parents with children younger than 2 years use digital media to obtain health care information regarding their children, and their main reason for doing so is having 24-hour access to such information [5]. mHealth apps are wellness programs that are available on smartphones and other mobile devices. In 2017, more than 325,000 mHealth apps became available worldwide [6]. Parents have high expectations for mHealth apps. According to a focus group study in Australia, child-rearing mothers place a high value on using web-based sources and apps to receive information and support [7].

There is great potential for using mHealth apps to obtain information, and an increasing number of initiatives use apps to provide health education [8]. A systematic review showed that IT-based interventions can result in positive health literacy outcomes [9]. For example, providing information via an app, in addition to the traditional method of providing printed booklets during pregnancy, reduces the risk of postpartum depression [10]. Further, a study in China reported that an app-based intervention that included injury prevention significantly improved the safety behaviors of parents of preschool children [11].

The inappropriate use of pediatric emergency departments is a growing concern worldwide [12,13]. In Japan, many municipalities provide free medical care for children. Consequently, many visits to pediatric emergency rooms are nonurgent. Previous studies suggested that lower parental health literacy, in addition to sociodemographic factors, is associated with increased nonurgent emergency room visits [14,15]. One of the possible benefits of improving health literacy through apps is the potential to reduce the inappropriate use of pediatric emergency departments. However, few studies have examined the association between the provision of child health care information apps and parents' health literacy.

Since 2016, we have been conducting a project in which a health care information app for parents—Oshiete-Doctor (which translates to *Doctor, tell me*)—is being used to improve parents' nursing skills at home. This app is free and uses numerous friendly illustrations to make information accessible to parents with low health literacy. The app is supervised by pediatricians and provides information on emergency room visits and knowledge on home care for childhood diseases. The app is expected to help parents make appropriate decisions regarding their children's health care.

This study aimed to evaluate the associations between parents' use of the health care information app and their health literacy, their health care knowledge, and pediatric emergency room visits for their children. We hypothesized that parents using the app would be more likely to have correct knowledge about their children's health care, have higher health literacy, and use the pediatric emergency room less frequently when compared to parents who do not use the app.

Methods

Ethical Considerations

This study was approved by the Institutional Review Board of Teikyo University (approval number: 22-011-2). Participants' selection of the item "Agree to participate" in the introductory statement of the questionnaire was considered as consent to participate in this study. The statement introduced this study and described that participation was voluntary, consent could be withdrawn at any time, data would be anonymized, and participants would be offered a ¥500 (US $3.30) Amazon gift voucher as compensation.

Study Participants and Data Collection

Parents of 1.5-year-old children who participated in the medical checkups provided at 3 health centers in Saku City, Nagano Prefecture, between May 11 and October 5, 2022, were recruited. The principal investigator (MS, a pediatrician) explained the study to each participant, and those who agreed to participate were included in this study.

Individuals were excluded if they were not the mother or father of the child or if they did not have a smartphone. The city staff collected the questionnaires.

Description of the App

The Oshiete-Doctor app, which was developed in 2016, is funded by Saku City and is provided free of charge to improve the home nursing skills of parents and guardians. It provides information on the following five topics: guidelines regarding hospital visits for children who are sick, explanations for child illnesses, information on vaccinations, information on childcare support groups, and disaster countermeasures for children. In Saku City, information regarding the app is distributed to all citizens when they register for birth certificates at the city office. The app is used throughout Japan and has been downloaded nearly 400,000 times.

Measures

Health Literacy Score

The Japanese version of the HLS-EU-Q47 (European Health Literacy Survey Questionnaire) [16] was modified to measure parental health literacy (ie, parents' health literacy scores [HLSs]). The original HLS-EU-Q47 was developed to measure health literacy in the general population based on a conceptual framework reflecting 4 information-processing dimensions (accessing, understanding, appraising, and applying) within 3 health domains (health care, disease prevention, and health promotion) [17], and it has been validated in a Japanese population [15]. The difficulty level of each item was rated on a 4-point Likert scale (1=very difficult; 2=difficult; 3=easy; 4=very easy), with a higher score indicating higher health literacy. In this study, we used 16 questions in the health care domain (items 1-16) by replacing "you" with "your child" to measure parental health literacy related to child health (eg "On a scale from very easy to very difficult, how easy would you say it is to find information about symptoms of illnesses that concern *your child*?"). In the health care domain, health literacy refers to the ability to access information on medical or clinical issues; understand, interpret, and evaluate medical information; make informed decisions on medical issues; and comply with medical advice [17]. We considered the questions in the health care domain to be appropriate for evaluating the competencies that users can improve by referring to the app. First, the app provides information on symptoms of children's illnesses (question 1), treatments (question 2), and emergency procedures (question 3) to help parents access accurate information. Second, this app includes detailed instructions on emergency procedures for children, hospital visits (question 7), and medications (question 6 and question 8) to promote accurate understanding of the information. Third, by providing accurate information that is verified by a physician, the app helps parents improve their competency for evaluating medical information (question 9 and question 12). Fourth, the app introduces recommendations for visiting a doctor and managing children who are sick (question 13), as well as for emergency medical calls (question 15). As a result, the capacity to make decisions and apply medical behaviors can be improved. We included the set of questions used in this survey in Multimedia Appendix 1. The total scores for the health care domain and the subscale scores for each dimension (ie, accessing, understanding, appraising, and applying) within the health care domain were calculated. Following a previous study [18], scores of participants who answered fewer than 80% of the questions were excluded from the analysis. The index score was standardized to unified metrics, ranging from 0 to 50, by using the following formula: (mean − 1) × (50/3). The Cronbach α for the total scale was 0.886. In the analysis, participants were divided into 2 groups based on their median scores. Although binarization may result in information loss, we believed that the benefits of binarization are significant, in that it facilitates data interpretation and reduces model complexity.

Health Care Knowledge

Health care knowledge was assessed by using the following three statements on important and common pediatric emergencies, for which the app provides information: (1) "if your child develops a fever at night, you should take him/her to the hospital immediately, even if he/she is healthy and hydrated"; (2) "when a child is drowning, you should notice because he/she will be making noises"; and (3) "when a child vomits due to gastroenteritis, disinfection with alcohol is effective." Responses to these statements were rated on a 4-point Likert scale (1=agree; 2=somewhat agree; 3=somewhat disagree; 4=disagree), with higher scores indicating better health care knowledge. The total scores for the three statements were calculated as the health care knowledge scores. In the analysis, health care knowledge scores were divided into high or low scores based on the median.

Emergency Room Visits

Respondents were asked about the number of emergency room visits that their children had within the past 6 months.

Use of the Oshiete-Doctor App

The use of the Oshiete-Doctor app was assessed based on their answers to the following question: "Do you use apps for childhood illnesses or well-being?" The respondents were asked to select 1 or more of the following four options: (1) "Oshiete-Doctor app"; (2) "Q-SUKE, the app developed by the Fire and Disaster Management Agency"; (3) "other apps"; and (4) "did not use an app." Based on their responses, respondents were classified as either Oshiete-Doctor app users or Oshiete-Doctor app nonusers.

Sociodemographic Data

We included sex, age, education status, self-rated economic status, current health care worker status, gestational weeks, birth weight, birth order, and past medical history of the children in our analysis. Education status was divided into 3 categories (high school graduate or lower, vocational school and 2-year college, and university graduate or higher) and then classified as "university graduate" or "non–university graduate." With regard to self-rated economic status, participants reported their subjective economic status as "very good," "good," "fair," "poor," or "very poor." Self-rated economic status was then classified as "very good - good," "fair," or "poor - very poor." With regard to current health care worker status, participants who answered that they were health care workers were categorized as "yes," whereas participants who answered that they were not health care workers were categorized as "no." Gestation weeks were classified as either "<37 weeks" or "≥37 weeks." Birth weights were classified as either "<2500 g" or "≥2500 g." Birth order was divided into 4 categories (first, second, third, and fourth or more) and then classified as either "first child" or "second child or more." With regard to the past medical history of the children, participants who answered that their children had any past medical history were categorized as "yes," whereas participants who answered that their children did not have any past medical history were categorized as "no."

Data Analysis and Statistics

Continuous variables were described as summary statistics (mean and SD or median and quartiles), while categorical variables were expressed as frequencies and percentages. The participants were divided into 2 groups based on their use of the Oshiete-Doctor app, and sociodemographic characteristics were compared by using the chi-square test or 2-tailed *t* test.

We also conducted univariable analyses (chi-square test or *t* test) and multivariable analyses (multiple logistic regression analyses) to examine the association between participant demographics and HLSs, as well as the association between emergency room visits and health care knowledge scores.

In the multivariable analysis, we included attributes of parents (sex, age, education, self-rated economic status, and health care professional status) and children (sex, birth order, and past medical history) as variables.

We included these variables because previous studies have shown that they may influence the association between pediatric emergency visits and parental health literacy [19-21]. A *P* value of <.05 was considered statistically significant. Stata 17 (StataCorp LLC) was used to analyze the data.

Results

Respondents' Characteristics

A flowchart of the survey is shown in Figure 1. A total of 251 respondents completed the survey (collection rate: 267/300, 89%; response rate: 251/267, 94%). Of them, 109 (43.4%) used the app. As shown in Table 1, 90.8% (228/251) of the respondents were female, 37.1% (93/251) had a university degree or higher, and 46.2% (116/251) of their children were firstborn. Overall, 20.3% (51/251) of the respondents were health care workers, and this proportion was significantly higher among app users than among non–app users (*P*=.005). No other participant or child attributes were significantly associated with app use.

Figure 1. Study participant flow diagram.

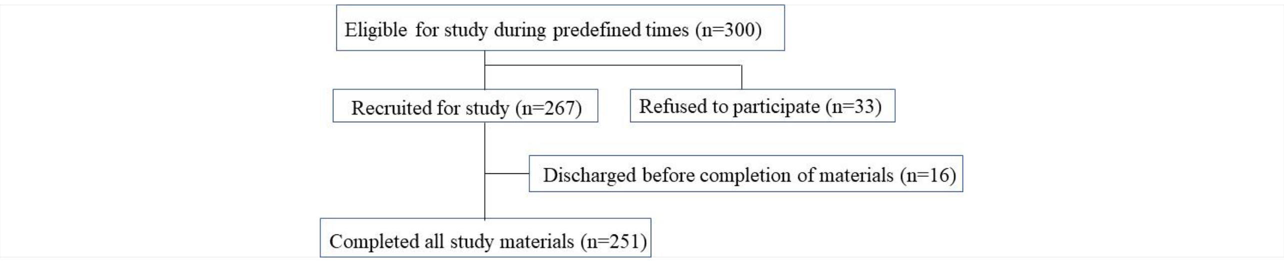

Table . Characteristics of app users and app nonusers.

Characteristics		App users (n=109)	App nonusers (n=142)	All participants (N=251)	*P* value[a]
Sex, n (%)					.08
	Female	104 (95.4)	124 (87.3)	228 (90.8)	
	Male	5 (4.6)	15 (10.6)	20 (8)	
	Missing data	0 (0)	3 (2.1)	3 (1.2)	
Age (y), mean (SD)		33 (5)	33 (6)	33 (5)	.95
Education, n (%)					.13
	High school graduate or lower	18 (16.5)	37 (26.1)	55 (21.9)	
	Junior or technical college	44 (40.3)	48 (33.8)	92 (36.7)	
	College degree or above	45 (41.3)	48 (33.8)	93 (37.1)	
	Missing data	2 (1.8)	9 (6.3)	11 (4.4)	
Self-rated economic status [b] **, n (%)**					.14
	Poor	17 (15.6)	33 (23.2)	50 (19.9)	
	Normal	67 (61.5)	87 (61.3)	154 (61.4)	
	Good	23 (21.1)	19 (13.4)	42 (16.7)	
	Missing data	2 (1.8)	3 (2.1)	5 (2)	
Health care worker, n (%)					.005[c]
	No	75 (68.8)	119 (83.8)	194 (77.3)	
	Yes	31 (28.4)	20 (14.1)	51 (20.3)	
	Missing data	3 (2.8)	3 (2.1)	6 (2.4)	
Gestation wk, n (%)					.55
	<37	6 (5.5)	9 (6.3)	15 (6)	
	≥37	76 (69.7)	82 (57.7)	158 (62.9)	
	Missing data	27 (24.8)	51 (35.9)	78 (31.1)	
Child's birth weight (g), n (%)					.84
	<2500	9 (8.3)	9 (6.3)	18 (7.2)	
	≥2500	74 (67.9)	82 (57.7)	156 (62.2)	
	Missing data	26 (23.9)	51 (35.9)	77 (30.6)	
Child's birth order, n (%)					.93
	First	51 (46.8)	65 (45.8)	116 (46.2)	
	Second	38 (34.9)	48 (33.8)	86 (34.3)	
	Third	12 (11)	19 (13.4)	31 (12.4)	
	Fourth or more	4 (3.7)	4 (2.8)	8 (3.2)	
	Missing data	4 (3.7)	6 (4.2)	10 (4)	
Child's past medical history, n (%)					>.99
	No	99 (90.8)	127 (89.4)	226 (90)	
	Yes	7 (6.4)	9 (6.3)	16 (6.4)	
	Missing data	3 (2.8)	6 (4.2)	9 (3.6)	

[a] *P* values were generated using a *t* test or chi-square test.

[b] The "Self-rated economic status" indicates the current financial status of the participants on a 3-point scale ("good"=3; "normal"=2; "poor"=1).The

data were treated as a categorical variable.

[c] Significant at the *P*<.05 level.

Association Between App Use and the Health Care Knowledge Score

Health care knowledge scores were examined in terms of app use (Table 2).

Table . Differences in the proportions of parents with higher health care knowledge scores by app use.

	Univariable analysis			Multivariable analysis	
	App users, n/N (%)	App nonusers, n/N (%)	OR[a] (95% CI; *P* value)	Parents included in analysis, n	aOR[b] (95% CI; *P* value)[c]
High health care knowledge score	80/109 (73.4)	74/142 (52.1)	2.5 (1.5-4.3; .001[d])	218	2.1 (1.1-4.0; .02[d])
High score for knowledge about night fever	99/108 (91.7)	127/141 (90.1)	1.2 (0.5-2.9; .67)	217	0.7 (0.3-2.1; .56)
High score for knowledge about drowning	100/108 (92.6)	133/141 (94.3)	0.8 (0.3-2.1; .58)	197	0.5 (0.1-1.6; .25)
High score for knowledge about alcohol disinfection	80/109 (73.4)	77/141 (54.6)	2.3 (1.3-3.9; .003[d])	217	2.4 (1.3-4.4; .007[d])

[a] OR: odds ratio.

[b] aOR: adjusted odds ratio.

[c] Attributes of caregivers (sex, age, education, economic status, and health care worker status) and children (sex, birth order, and past medical history) are adjusted in the logistic regression analysis.

[d] Significant at the *P*<.05 level.

In the univariable analysis, the proportion of parents with higher health care knowledge scores was significantly higher among app users than among non–app users (*P*=.001), and the proportion of parents with higher scores regarding alcohol disinfection during gastroenteritis was significantly higher among app users than among non–app users (*P*=.02).

After adjusting for parent and child characteristics in the multivariable analysis, these differences remained statistically significant (*P*=.003 and *P*=.007, respectively).

Association Between App Use and Health Literacy

The mean HLS of the participants was 24.2 (SD 7.3). The differences in the proportions of parents with higher health literacy, as measured with health care-related subscales of the HLS-EU-Q47, by app use, are shown in Table 3.

In the univariable analysis, the proportion of parents with higher total HLSs was significantly higher among app users than among app nonusers (*P*=.03), and the proportion of parents with higher HLSs for the evaluation subscale was significantly higher among app users than among app nonusers (*P*=.03).

After adjusting for parent and child characteristics in the multivariable analysis, the difference in the proportion of parents with higher total HLSs between app users and app nonusers remained statistically significant (*P*=.008).

Table . Differences in the proportions of parents with higher health literacy, as measured with health care–related subscales of the HLS-EU-Q47[a], by app use.

	Univariable analysis			Multivariable analysis	
	App users, n/N (%)	App nonusers, n/N (%)	OR[b] (95% CI; *P* value)	Parents included in analysis, n	aOR[c] (95% CI; *P* value)[d]
High total score	53/102 (52)	50/132 (37.9)	1.8 (1.1-3.0; .03[e])	206	2.2 (1.2-4.0; .008[e])
High access score	55/105 (52.4)	66/133 (49.6)	1.1 (0.7-1.9; .67)	209	1.1 (0.6-2.0; .76)
High understanding score	68/108 (63)	78/141 (55.3)	1.4 (0.8-2.3; .23)	216	1.3 (0.7-2.4; .34)
High evaluation score	53/108 (49.1)	49/140 (35)	1.8 (1.1-3.0; .03[e])	215	1.8 (0.99-3.2; .056)
High application score	48/107 (44.8)	50/135 (37)	1.4 (0.8-2.3; .22)	211	1.8 (0.96-3.2; .07)

[a] HLS-EU-Q47: European Health Literacy Survey.

[b] OR: odds ratio.

[c] aOR: adjusted odds ratio.

[d] Attributes of caregivers (sex, age, education, economic status, and health care worker status) and children (sex, birth order, and past medical history) are adjusted in the logistic regression analysis.

[e] Significant at the *P*<.05 level.

Association Between App Use and Emergency Room Visits

In the univariable analysis of the association between a history of emergency room visits in the past 6 months and app use, emergency room visits were significantly more frequent among app users (26/102, 25.5%) than among non–app users (15/130, 11.5%; odds ratio [OR] 2.6, 95% CI 1.3-5.3; *P*=.007). This association was not significant in the multivariable analysis (parents included in analysis: n=216; adjusted OR 1.9, 95% CI 0.94-4.0; *P*=.07), in which the total HLS (a binary variable) was added to the adjusted variables (model 1).

Discussion

Principal Results

This is the first study to examine the associations between the use of an app for parents that was developed in Japan and child-rearing parents' health care knowledge, their health literacy, and emergency room visits for their children. The mean HLS of the participants was 24.2 (SD 7.3), which is similar to that in previous studies [16,22]. Recently, the internet has become an indispensable tool for gathering information, and mobile apps have played a significant role. Similarly, a greater number of maternal and child health interventions using mHealth technology have been observed in the field of maternal and child health [23], and mobile apps are used to support maternal and child health care interventions [24].

Our app provides knowledge about health care for children. A significant association was found between app use and accurate health care knowledge. Fadda et al [25] reported that their smartphone app intervention for parents increased parents' knowledge of measles-mumps-rubella vaccination and parents' psychological empowerment toward vaccinating their children. They demonstrated the effectiveness of interventions that use mobile devices to provide information. These findings are consistent with those of our study. However, in our study, there were no statistically significant differences between app users and app nonusers with high scores for the statement about visiting the emergency room at night if their child had a fever (*P*=.56) and the statement regarding their response to their child drowning (*P*=.25). This may be because these two statements were easy for most participants to answer correctly (correct answers for the statement about night fever: 226/249, 90.8%; correct answers for the statement about drowning: 233/249, 93.6%).

This study found a significant association between app use and parental health literacy. The measure of health literacy used in this study was designed to assess the subjective manageability of health-related tasks, focusing on both individuals and the underlying circumstances in which health-related tasks are performed [26]. The use of the Oshiete-Doctor app may lower the barriers to accessing, understanding, appraising, and applying health care information and thus result in the greater manageability of child health care.

Contrary to our expectations, we found a positive association between the use of the app and emergency room visits in the past 6 months. However, a systematic review reported an association between low parental health literacy and increased emergency room visit rates [27]. One possible reason for the contradictory result from the systematic review is that our study did not evaluate the appropriateness of emergency room visits. Although we hypothesized that the use of the app would reduce unnecessary emergency room visits, a higher emergency room visit rate may reflect more careful attention to the child and appropriate decisions based on the app. Another possibility is that the parents may have downloaded the app after experiencing an emergency room visit. In the region where this study was conducted, the app is widely known among health care professionals, who may have recommended the app to parents who visited the emergency room. Future studies are needed to evaluate the association between app use and emergency room visits.

Limitations

There are several limitations to this study. First, the HLS-EU-Q47 has a limitation in its self-reporting formula. Therefore, the survey results may reflect the subjective manipulation of the participants and may not always correspond to the objective findings. However, it has been used for comparative studies in other countries, and there is also a Japanese version [16]; therefore, its reliability and validity have already been established, which is why it was chosen in our study. Second, this study was observational and could not rule out the influence of confounding environmental factors (except for the use of other apps) that could have contributed to the increase in parents' health literacy. In addition, as this was a cross-sectional study, there is a possibility of causal reversal. Third, a high proportion of medical personnel was observed in this study (51/251, 20.3%). Nagano Prefecture, which includes Saku City, has more medical personnel per 100,000 people when compared to the national average. For example, the number of public health nurses per 100,000 people is 82.6, which is nearly double the national average (44.1 per 100,000 people) and makes Nagano Prefecture the region with the most public health nurses in the country [28]. Therefore, it may be difficult to apply our results to parents of 1.5-year-old children from other regions. However, this study exhibits small participant bias because it was conducted with participants of a municipal infant health examination. In Japan, health checkups are available for all infants, and the follow-up rate is very high. In addition, the collection rate was very high because of the full cooperation of the city. Therefore, the results are expected to accurately reflect the reality of parents raising infants and children in this region.

Conclusions

This study showed a significant association between parents' use of a child health care information app and higher health literacy and health care knowledge. The use of the app may help parents increase their knowledge and ability to manage their children's health by lowering barriers to accessing, understanding, evaluating, and applying health information. Future studies are needed to evaluate the impact of app use on health behaviors, including emergency room visits.

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Data Availability

Data are available from the co-corresponding authors (MS and HI) on reasonable request.

Authors' Contributions

MS and HI equally contributed to the manuscript as the co-corresponding authors. MS and HI conceptualized and designed the study. MS collected, analyzed, and interpreted the data and drafted the initial manuscript. AS and HI supervised data collection and contributed to the analysis and interpretation of the data. All authors critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agreed to be accountable for all aspects of this study.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Health literacy score questions in this survey (modified from the HLS-EU-Q47 [European Health Literacy Survey Questionnaire] health care domain).
[DOCX File, 16 KB - pediatrics_v7i1e48478_app1.docx]

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Abbreviations

HLS: health literacy score
HLS-EU-Q47: European Health Literacy Survey Questionnaire
mHealth: mobile health
OR: odds ratio

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Response Rate Patterns in Adolescents With Concussion Using Mobile Health and Remote Patient Monitoring: Observational Study

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Abstract

Background: A concussion is a common adolescent injury that can result in a constellation of symptoms, negatively affecting academic performance, neurobiological development, and quality of life. Mobile health (mHealth) technologies, such as apps for patients to report symptoms or wearables to measure physiological metrics like heart rate, have been shown to be promising in health maintenance. However, there is limited evidence about mHealth engagement in adolescents with a concussion during their recovery course.

Objective: This study aims to determine the response rate and response rate patterns in concussed adolescents reporting their daily symptoms through mHealth technology. It will also examine the effect of time-, demographic-, and injury-related characteristics on response rate patterns.

Methods: Participants aged between 11-18 years (median days since injury at enrollment: 11 days) were recruited from the concussion program of a tertiary care academic medical center and a suburban school’s athletic teams. They were asked to report their daily symptoms using a mobile app. Participants were prompted to complete the Post-Concussion Symptom Inventory (PCSI) 3 times (ie, morning, afternoon, and evening) per day for 4 weeks following enrollment. The primary outcome was the response rate pattern over time (by day since initial app use and the day since injury). Time-, demographic-, and injury-related differences in reporting behaviors were compared using Mann Whitney *U* tests.

Results: A total of 56 participants were enrolled (mean age 15.3, SD 1.9 years; n=32, 57% female). The median response rate across all days of app use in the evening was 37.0% (IQR 27.2%-46.4%), which was significantly higher than the morning (21.2%, IQR 15.6%-30.5%) or afternoon (26.4%, IQR 21.1%-31.5%; *P*<.001). The median daily response was significantly different by sex (female: 53.8%, IQR 46.2%-64.2% vs male: 42.0%, IQR 28.6%-51.1%; *P*=.003), days since injury to app use (participants starting to use the app >7 days since injury: 54.1%, IQR 47.4%-62.2% vs starting to use the app ≤7 days since injury: 38.0%, IQR 26.0%-53.3%; *P*=.002), and concussion history (participants with a history of at least one prior concussion: 57.4%, IQR 44.5%-70.5% vs participants without concussion history: 42.3%, IQR 36.8%-53.5%; *P*=.03). There were no significant differences by age. Differences by injury mechanism (sports- and recreation-related injury: 39.6%, IQR 36.1%-50.4% vs non–sports- or recreation-related injury: 30.6%, IQR 20.0%-42.9%; *P*=.04) and initial symptom burden (PCSI scores greater than the median score of 47: 40.9%, IQR 35.2%-53.8% vs PCSI scores less than or equal to the median score: 31.9%, IQR 24.6%-40.6%; *P*=.04) were evident in the evening response rates; however, daily rates were not statistically different.

Conclusions: Evening may be the optimal time to prompt for daily concussion symptom assessment among concussed adolescents compared with morning or afternoon. Multiple demographic- and injury-related characteristics were associated with higher daily response rates, including for female participants, those with more than 1 week from injury to beginning mHealth monitoring, and those with a history of at least one previous concussion. Future studies may consider incentive strategies or adaptive digital concussion assessments to increase response rates in populations with low engagement.

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KEYWORDS

concussion; mHealth; response rate; adolescents; reporting behavior; remote monitoring; engagement; monitoring; adolescent; teen; youth; remote patient monitoring; mobile health; injury; neurobiological; neurobiological development; quality of life; academic; academic performance; mHealth engagement; tertiary care

Introduction

Concussion is a significant public health problem that affects approximately 20% of adolescents in the United States each year [1,2]. The prevalence of lifetime concussions has been estimated to be between 6.5% and 18.3% among adolescents aged 13-17 years [3], with approximately 13.7% experiencing persistent symptoms for at least 3 months [4]. Given the critical developmental changes that occur during this period, persistent symptom burden and delayed recovery from concussion may negatively affect adolescents' neurobiological and cognitive development [5].

Adolescents with a concussion can present with a variable symptom burden and recovery trajectories. Prior studies have shown that sex, age, nonadherence to medical care, injury mechanism, and previous history of concussion have been associated with prolonged recovery times [6-9]. For example, patients less likely to adhere to follow-up recommendations had a higher risk of prolonged recovery than those who demonstrated consistent medical adherence [9]. Given the variability in symptom burden and recovery, concussion evaluation, treatment, and follow-up recommendations must be individualized for each adolescent [10]. For instance, based on an individual's symptom constellation, treatments could be tailored into multiple lines such as cognition, vision, and behavioral therapies [10-12]. Individualized treatment relies on the real-time monitoring of symptoms in natural environments [13].

The adoption of ecological momentary assessments using mobile health (mHealth) has increased for monitoring disease prognosis and rehabilitation [14,15], and can be used in concussion symptom monitoring. mHealth apps have been developed for patients with a concussion to report their real-time symptoms and activities multiple times per day to collect more granular information on symptom trajectory than is provided during periodic clinic visits [16,17].

Previous studies have used mHealth technology to facilitate follow-up for patients with traumatic brain injury, providing an opportunity for patients to report important details on the variability of symptoms and other sequelae [14,18]. Patients can provide real-time symptoms instead of relying on memory at the next in-person visit, which can be influenced by recall bias [19]. Documenting symptom presence and intensity in the moment can improve the reliability of self-report data and augment care individualization. While these studies show promise for these mHealth technologies, understanding the parameters that influence a patient's engagement with the technology is critical to optimizing future implementation. Adolescents represent a unique patient population in this regard, as they are both high users of mobile technology while at the same time generally less engaged health care consumers [20]. In a systematic review, Wen et al [15] summarized nearly 20 studies that used mHealth technology to engage youth from a variety of clinical settings, reporting that patients on average responded to 77% of the prompts. These studies examined a wide range of patient behaviors across several diseases. Specific to concussion, several studies examined mHealth technologies to track symptoms or activity after injury. Reporting behaviors (eg, response rate) ranged from 50% to 90% due to differing assessments, tracking frequencies, and duration of follow-up [15-17,21,22]. Furthermore, these studies tend to reduce response rates to a single number (eg, the percentage of days in which participants completed responses divided by the number of prompts received [15,23]), with limited exploration of variability in response patterns within a day, across recovery duration, or by certain patient or injury characteristics. Understanding trends and factors influencing adolescent reporting behaviors is important to assist both clinicians and researchers in designing mHealth strategies to investigate concussion recovery trajectories and provide individualized management strategies.

The objectives of this study were to determine the response rate pattern over time to prompts for reporting daily symptoms in concussed adolescents through mHealth technology; identify the time of day when response rates were the highest; and examine the effect of time-, demographic-, and injury-related characteristics on response rate patterns.

Methods

Ethical Considerations

This study was approved by the Children's Hospital of Philadelphia institutional review board (17-013875 and 18-014862). Participants or their parents or legal guardians provided verbal assent or written informed consent. Of note, while participants received a financial incentive to participate in the overall study, they did not receive additional compensation to respond to the mHealth prompts. Data were deidentified.

Study Design and Participants

This study was a prospective observational cohort study approved by our institution's review board. Participants with a concussion aged 11-18 years were recruited between September 28, 2018, and June 8, 2021, from the concussion clinic of our tertiary care academic medical center and a suburban school's athletic teams as part of a larger prospective observational study [24]. The diagnosis of concussion was made by a trained sports medicine pediatrician following the most recent international consensus statement on concussion [25]. All participants had an initial in-person clinical assessment, either as part of a clinic visit or in the school's athletic training room, within 28 days of injury. Enrollment in the mHealth study could occur at this initial visit or a subsequent visit. Participants were excluded from enrollment in the larger study if they were still recovering from a previous concussion (or within 30 days of clearance from a previous concussion). Participants were excluded from this analysis if there were missing demographic or injury variables. Injury mechanism and concussion history were not recorded for 1 participant, who was thus excluded from specific subgroup analyses.

Upon enrollment, participants were instructed to download the mHealth tool onto their smartphones via an SMS text message invitation. This tool allowed the participants to report their symptoms 3 times daily for 28 days following enrollment. The details of the mHealth tool are described below.

For analyses, participant age, sex, date of injury, injury mechanism, and concussion history were abstracted from the electronic medical record.

mHealth Tool

Recovering Concussion Update on the Progression of Symptoms (ReCoUPS) is a mobile app protocol developed by the study team for patients to report real-time symptoms and activities following concussion. The ReCoUPS app “pings” (prompting with a chime or vibration) participants 3 times per day: morning (9 AM to 1 PM), afternoon (4-7 PM), and evening (8 PM). Participants reported symptoms using the Post-Concussion Symptom Inventory (PCSI) [26]. The adolescent PCSI (used for participants aged ≥13 years) includes 21 concussion symptoms rated using a 7-point Likert scale from 0 (none) to 6 (severe), with total symptom scores ranging from 0 to 21 and total symptom severity scores ranging from 0 to 126. The child PCSI (used for younger children aged <13 years) is a 17-item symptom checklist with symptoms rated on a 3-point scale from 0 (none) to 2 (a lot), with total symptom scores ranging from 0 to 17 and total symptom severity scores ranging from 0 to 34. The PCSI has been demonstrated to be a valid and reliable symptom assessment in the pediatric setting [26].

Data Analysis

The response rate was computed through 2 time-based approaches: (1) response rate by days since first app use and (2) response rate by days since injury. The two response rates examine response trends over time, examining the median response across days following injury. These 2 time-based response rates differ from one another as patients enrolled in the app during regular clinical visits that occurred at varying times since injury.

Specifically, response rate by days since first app use and response rate by days since injury were calculated as the number of completed prompts on a given day divided by the number of prompts received on that day across all participants for each day since first app use and each day since injury, respectively. Response rate was examined both by session time (morning, afternoon, and evening prompts; equation 1 in Multimedia Appendix 1) and daily (responding at least once per day, equation 2 in Multimedia Appendix 1). Thus, response rate by day represents the percentage of participants who completed prompts each session time (or at least once daily) on each day (ie, single value per day and time series for response rate trend).

Additionally, subgroup response rates were computed. Subgroups included demographics (sex and age), injury features (injury mechanism, concussion history, initial symptom burden on enrollment), and time between the date of injury and date of first app use (ie, days from injury to app use). The age range was categorized as younger teens (ie, ages 11-14 y) and older teens (ages 15-18 y). Days from injury to app use was categorized into two groups: ≤7 days and >7 days. Initial symptom burden was categorized into two groups based on the median initial PCSI score of the overall sample: ≤47.0 points and >47.0 points. Since there were only complete initial PCSI scores for children aged 13-18 years, this scale was relevant for all participants with valid data.

Descriptive statistics were used to summarize demographic and injury characteristics. For continuous variables, means with SDs were computed for normally distributed data, and medians with IQRs were computed for skewed data. For categorical variables, frequencies were computed. For each type of response rate, the Friedman test was used to examine the differences in response rate based on session time (ie, morning, afternoon, and evening). Post hoc analyses were performed via pairwise Mann Whitney *U* test with Bonferroni *P* value adjustment. Differences in response rate by days since first app use were tested across demographic-related (ie, sex and age), injury-related (ie, injury mechanism, concussion history, and initial symptom burden on enrollment), and days from injury to app use subgroups through Mann Whitney *U* tests. Comparisons of response rate by days since injury based on sex, age, injury mechanism, concussion history, and initial symptom burden were performed using Mann Whitney *U* test. Differences in the initial symptom burden at the clinical visit by all subgroups were also tested via Mann Whitney *U* test. All statistical analyses were performed using R version 4.2.2 (R Foundation for Statistical Computing). The significance level was set at .05.

Results

Sample Composition

The final sample included 24 (43%) male participants and 32 (57%) female participants with an average age of 15.3 (SD 1.9) years. The flowchart of participant inclusion is shown in Figure 1. Table 1 summarizes the demographic and injury characteristics of the study cohort. The final injury-related subgroups included 34 (61%) participants with sports- and recreation-related injuries and 21 (38%) with non–sports- and recreation-related injuries. There were 30 (54%) participants with a history of at least one prior concussion and 25 (45%) without concussion history. No significant differences in the initial symptom burden at clinic visits by demographic- and injury-related groups were observed.

Figure 1. Flowchart of participant selection in this study.

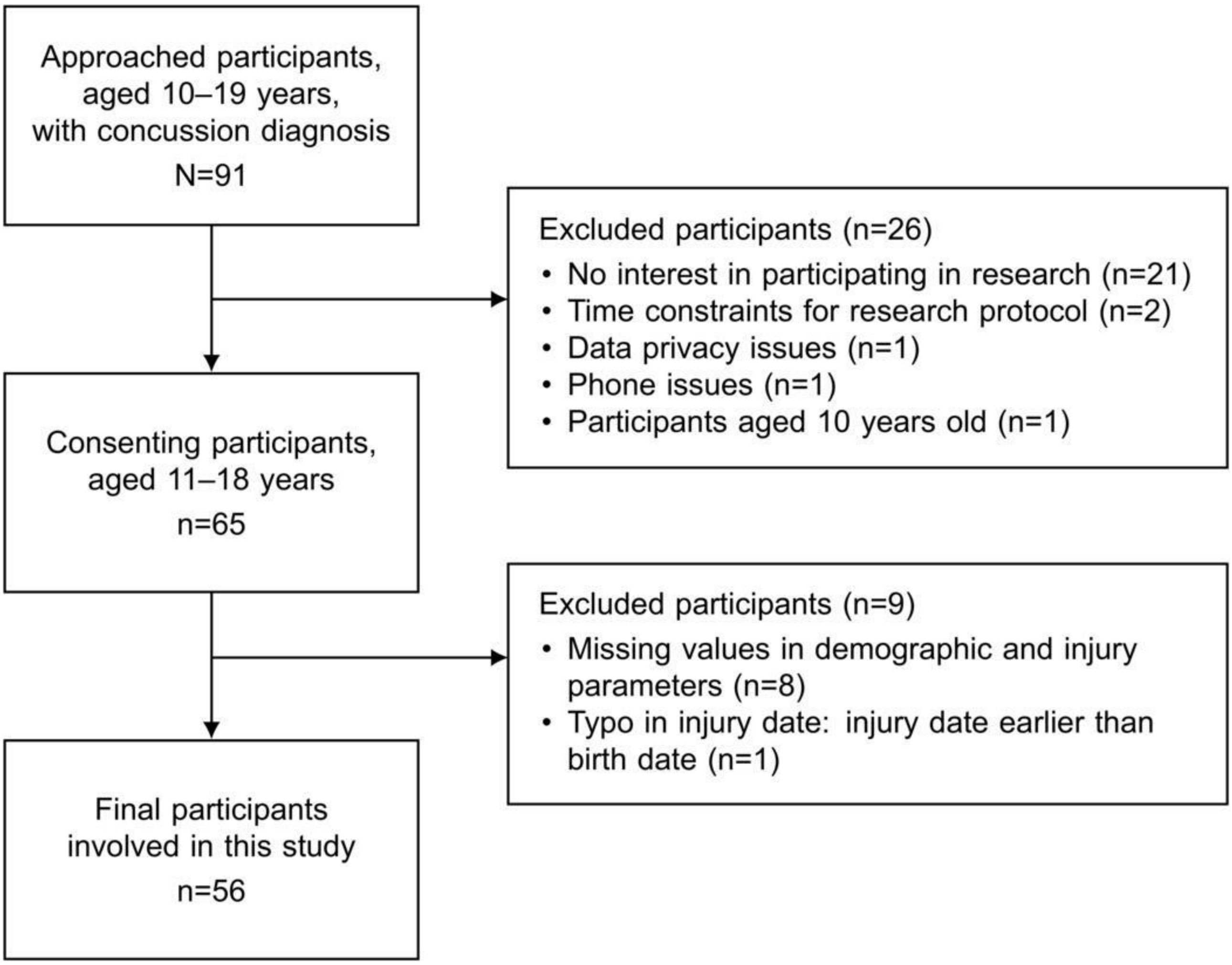


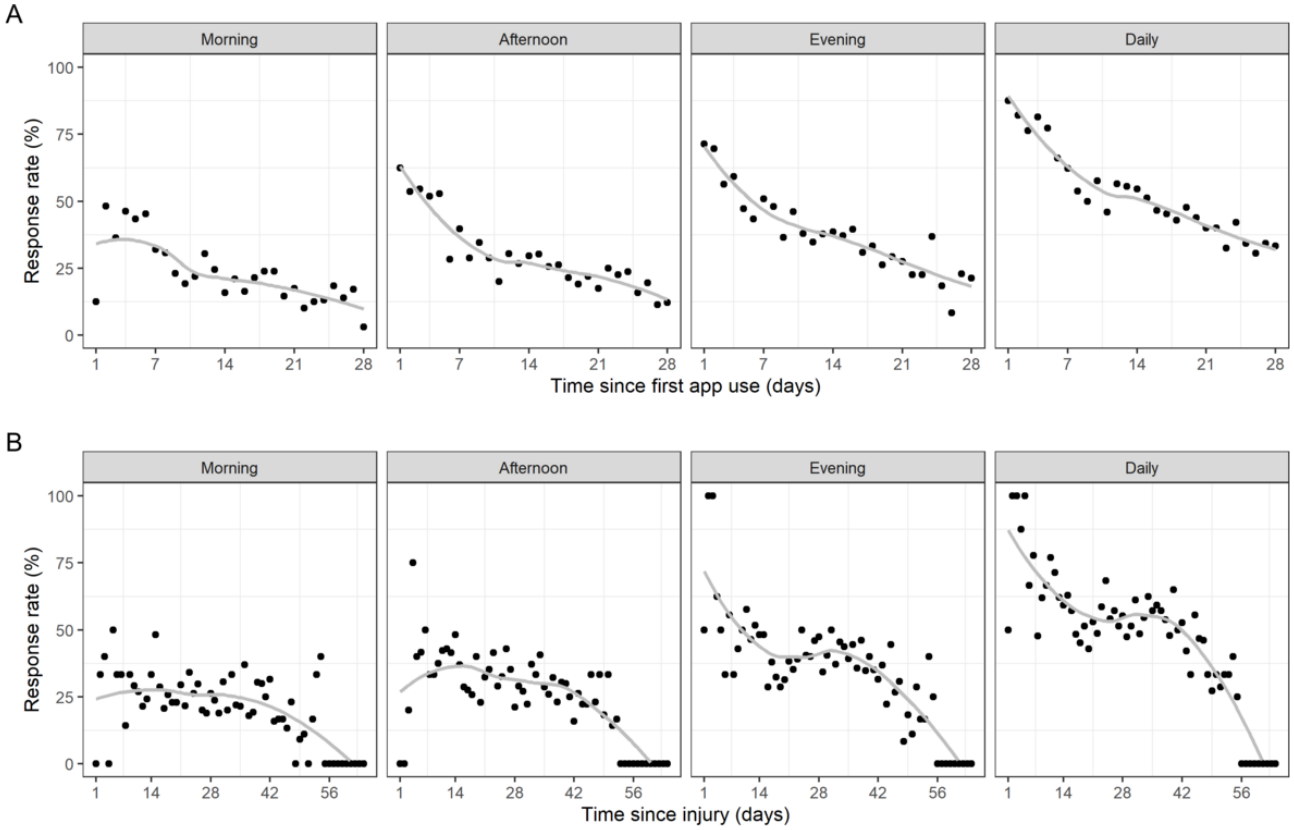
Table . Demographic and injury characteristics of participants (N=56).

		Value
Sex, n (%)		
	Female	32 (57)
	Male	24 (43)
Race/ethnicity, n (%)		
	Non-Hispanic White	40 (71)
	Non-Hispanic Black	2 (4)
	Hispanic	4 (7)
	Other	10 (18)
Mechanism of injury, n (%)		
	Sports- and recreation-related injury	34 (61)
	Non–sports- and recreation-related injury	21 (37)
	Not reported	1 (2)
Previous history of concussion, n (%)		
	Yes	30 (53)
	No	25 (45)
	Not reported	1 (2)
Age at injury (years), median (IQR)		15.0 (14.0-17.0)
Post-Concussion Symptom Inventory total score at initial clinic visit, median (IQR)		47.0 (27-68)
Days since injury at enrollment, median (IQR)		11.0 (6-21)

Overall Response Rate Pattern

The response pattern varied substantially over time. On average, response rates by days since first app use started high (49/56, 88% of participants responded at least once on the first day of using the app) and decreased by approximately 50% over the duration of the study, with the steepest declines within the first 10 days (Figure 2, top). When considering variations by session time, the evening response rate was generally higher than the morning and afternoon response rates. The daily response rate by days since injury also started high, declined to approximately 50% (18/34) at day 21, plateaued until day 35, and then decreased sharply until the completion of the study period (Figure 2, bottom). The plateau reflects the varying times post injury that participants enrolled in the study (Figure S1 in Multimedia Appendix 1). For example, 23% (15/56) of the participants started using the app between days 21 and 28 post injury.

Figure 2. Response rate pattern by morning, afternoon, and evening, and daily by (A) days since first app use and (B) days since injury. Each black dot indicates the response rate that day, defined as the number of participants who completed prompts divided by the number of participants who received notifications for that day. The solid gray lines represent smoothed trend lines through local regression. A daily response was defined as a participant completing a response at least once per day (morning, afternoon, or evening).



Response Rates by Days Since First App Use

Figure 3 and Table 2 show comparisons of response rate patterns by days since first app use for time-, demographic-, and injury-related groups. Overall, the evening response (median 37.0%, IQR 27.2%-46.4%) was significantly higher than the morning response (median 21.2%, IQR 15.6%-30.5%; *P*<.001). For demographic-related comparisons, many of the differences were driven by differences in the evening response rates. For female patients with concussion, evening (median 44.4%, IQR 33.0%-52.6% vs median 25.0%, IQR 14.3%-34.1%; *P*<.001) and daily response rates (median 53.8%, IQR 46.2%-64.2% vs median 42.0%, IQR 28.6%-51.1%; *P*=.003) were significantly higher than those in male patients with concussion. There were no significant differences by age. For injury-related comparisons, afternoon (median 30.4%, IQR 24.7%-39.0% vs median 24.3%, IQR 14.0%-30.9%; *P*=.04) and evening response rates (median 39.6%, IQR 36.1%-50.4% vs 30.6%, IQR 20.0%-42.9%; *P*=.04) in the sports- and recreation-related injury group were significantly higher than those in the non–sports- and recreation-related injury group; however, daily rates were not statistically different. Participants with a history of at least one prior concussion had significantly higher responses rates at every session time than those without injury history (eg, median daily response rate: 57.4%, IQR 44.5%-70.5% vs 42.3%, IQR 36.8%-53.5%; *P*=.03). Participants who started to use the app after 7 days post injury demonstrated significantly higher morning (median 23.8%, IQR 17.2%-34.6% vs median 14.3%, IQR 8.9%-23.9%; *P*=.006), evening (median 42.1%, IQR 31.0%-53.0% vs median 22.6%, IQR 16.4%-38.2%; *P*=.002), and daily responses rates (median 54.1%, IQR 47.4%-62.2% vs median 38.0%, IQR 26.0%-53.3%; *P*=.002) than those who started to use the app sooner. Participants whose initial symptom burden was larger than the median PCSI score showed higher evening response rates than those whose burden was smaller than or equal to the median PCSI score (median 40.9%, IQR 35.2%-53.8% vs median 31.9%, IQR 24.6%-40.6%; *P*=.04); however, daily rates were not statistically different.

Figure 3. Comparisons of daily response rate by days since first app use by (A) sex, (B) age group, (C) days from injury to app use, (D) concussion history, (E) initial symptom burden, and (F) injury mechanism. The solid lines represent smoothed trend lines through local regression. Daily response was defined as a participant completing a response at least once per day (morning, afternoon, or evening). Response rate was defined as the number of participants who completed prompts divided by the number of participants who received notifications for that day. PCSI: Post-Concussion Symptom Inventory.

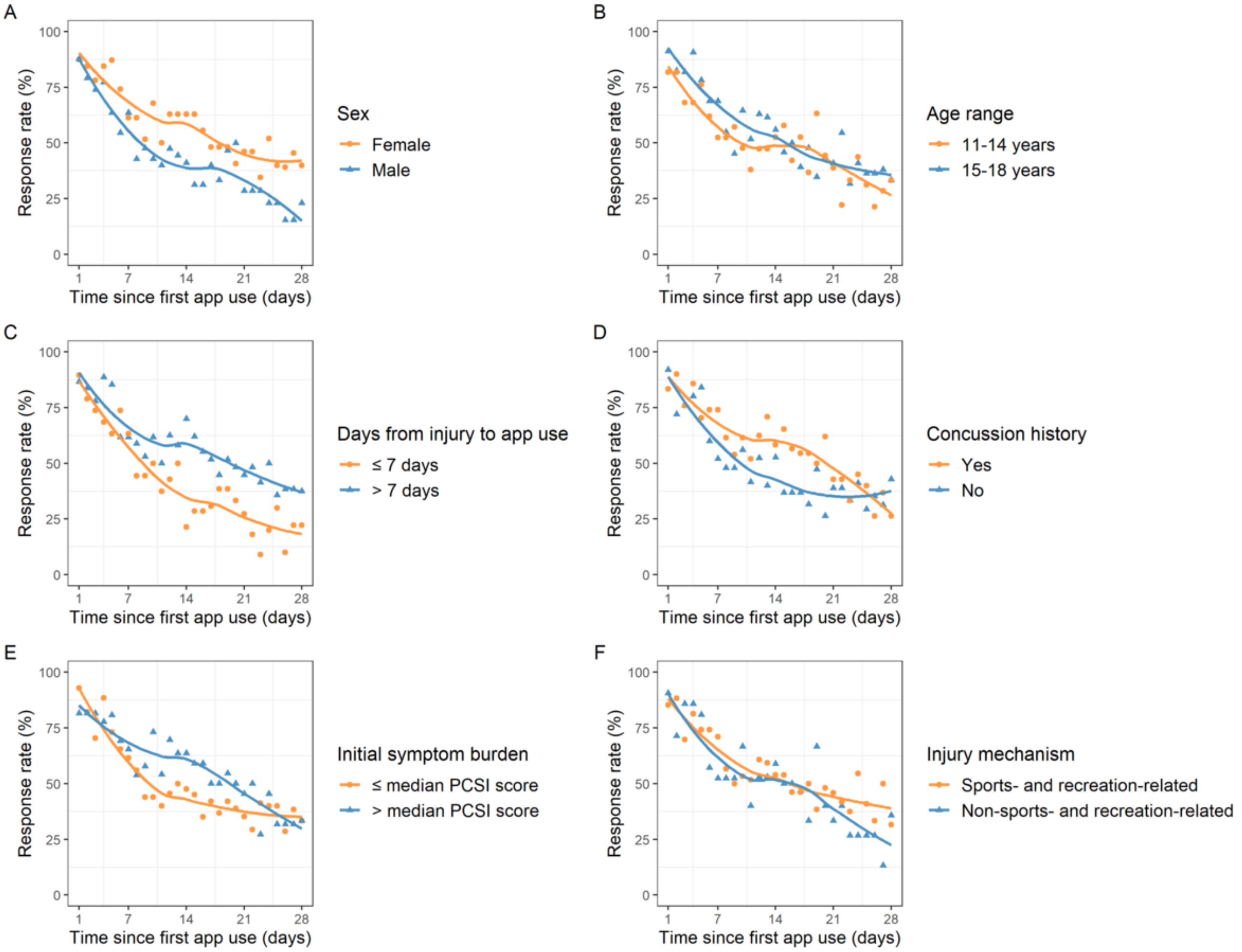


Table . Response rate by days since first app use overall and by time-, demographic-, and injury-related features. The value in the table represents the median response rate across the reporting days and is complementary to the time trends in Figure 3.

Variables	Morning (%)		Afternoon (%)		Evening (%)		Daily (%)	
	Median IQR	*P* value	Median IQR	*P* value	Median IQR	*P* value	Median IQR	*P* value
Overall	21.2 (15.6-30.5)	—[a]	26.4 (21.1-31.5)	—	37.0 (27.2-46.4)	—	48.8 (41.6-58.8)	—
Days from injury to app use		.006		.05		.002		.002
≤7 days (n=19)	14.3 (8.9-23.9)		22.6 (13.5-30.4)		22.6 (16.4-38.2)		38.0 (26.0-53.3)	
>7 days (n=36)	23.8 (17.2-34.6)		29.8 (20.7-39.0)		42.1 (31.0-53.0)		54.1 (47.4-62.2)	
Sex		.07		.05		<.001		.003
Male (n=24)	16.7 (7.7-29.4)		21.2 (15.1-33.9)		25.0 (14.3-34.1)		42.0 (28.6-51.1)	
Female (n=32)	22.6 (18.2-32.3)		31.4 (22.9-38.0)		44.4 (33.0-52.6)		53.8 (46.2-64.2)	
Age group (years)		.58		.81		.40		.34
11-14 (n=22)	21.1 (13.4-24.4)		27.0 (18.5-39.3)		36.8 (26.0-42.9)		47.5 (37.8-58.9)	
15-18 (n=34)	21.7 (13.6-36.8)		26.7 (22.1-30.9)		39.4 (28.2-47.3)		50.9 (40.5-65.6)	
Injury mechanism		.05		.04		.04		.31
SRR[b] injury (n=34)	23.1 (20.8-35.5)		30.4 (24.7-39.0)		39.6 (36.1-50.4)		52.5 (46.1-63.0)	
Non-SRR injury (n=21)	19.0 (6.7-27.1)		24.3 (14.0-30.9)		30.6 (20.0-42.9)		51.2 (35.1-60.8)	
Concussion history		.01		.01		.02		.03
Yes (n=30)	22.9 (19.0-36.5)		33.3 (23.3-42.6)		43.2 (33.0-50.5)		57.4 (44.5-70.5)	
No (n=25)	12.2 (10.5-26.7)		21.6 (16.4-28.0)		31.6 (21.9-44.0)		42.3 (36.8-53.5)	
Initial symptom burden		.35		.69		.04		.06
Score >47 (median score; n=27)	19.5 (13.6-30.8)		28.2 (21.9-36.5)		40.9 (35.2-53.8)		56.1 (48.9-69.3)	
Score ≤47 (median score; n=25)	23.3 (16.4-32.0)		24.5 (17.6-37.2)		31.9 (24.6-40.6)		43.1 (38.8-57.4)	

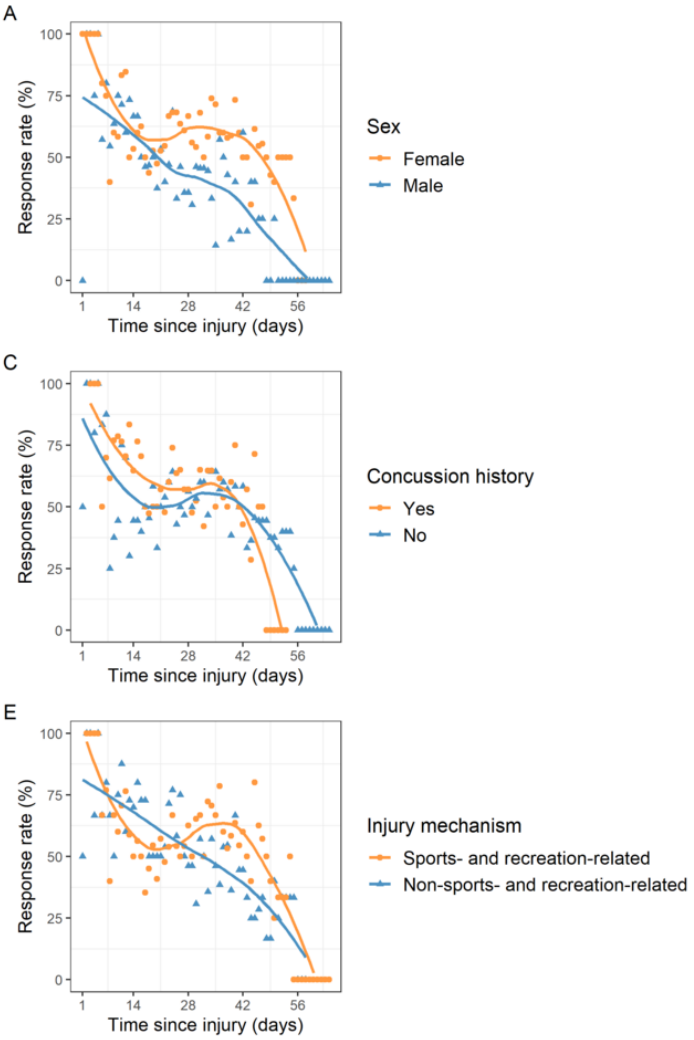
[a] Not applicable.

[b] SRR: sports- and recreation-related.

Response Rates by Days Since Injury

Figure 4 and Table S1 in Multimedia Appendix 1 show comparisons of response rate patterns by days since injury for demographic- and injury-related groups. Plateau periods were observed approximately 3-6 weeks post injury. Some of the subgroup patterns for days since injury followed those reported for days since app use. Evening response rates (median 37.0%, IQR 26.3%-46.0%) were significantly higher than morning (median 21.7%, IQR 12.8%-30.1%; *P*<.001) or afternoon response rates (median 28.1%, IQR 16.4%-35.1%; *P*=.003). Session and daily response rates in female patients with concussion were significantly higher than those in male patients with concussion (eg, median daily response rate 58.1%, IQR 50.0%-67.7% vs median 40.0%, IQR 0.0%-55.2%; *P*<.001). Participants with a history of at least one prior concussion had significantly higher session and daily response rates than those without a history of concussion (eg, median daily response rate 57.1%, IQR 50.0%-70.3% vs 45.5%, IQR 37.2%-58.3%; *P*=.003). Effects of injury mechanism and initial symptom burden were no longer significant when considering days since injury (*P*=.07-.88), and age group began to show an effect, with older teens demonstrating a slightly higher daily response rate than younger teens (median 54.4%, IQR 43.0%-66.7% vs median 50.0%, IQR 35.6%-57.1%; *P*=.03).

Figure 4. Comparisons of daily response rate by days since injury by (A) sex, (B) age group, (C) concussion history, (D) initial symptom burden, and (E) injury mechanism. The solid lines represent smoothed trend lines through local regression. Daily response was defined as a participant completing a response at least once per day (morning, afternoon, or evening). Response rate was defined as the number of participants who completed prompts divided by the number of participants who received notifications for that day. PCSI: Post-Concussion Symptom Inventory.



Discussion

The purpose of this study was to investigate the self-reporting of symptom behaviors via an mHealth app (ReCoUPS) among adolescents with a concussion. Generally, response rate patterns varied between and within participants and days. Approximately half of the study sample responded at least once per day, with the evening representing the session time with the highest engagement across the enrollment period. Multiple demographic- and injury-related characteristics were associated with higher daily response rates, including female participants, longer time from injury to initiating mHealth monitoring, and history of a previous concussion. While not significant when considering daily response rates, there were session time differences in response rate by initial symptom burden and injury caused by sports and recreation activities. Responses by age did not show significant differences.

As expected, response rates started high, with nearly 90% of patients responding at least once on the first day of app use, then declined over time. Participants were not given reminders aside from the scheduled “pings” to complete a symptom evaluation. A prior study using a similar version of this app explored different incentive strategies and demonstrated how features like incentives that are more engaging and motivating for youth can increase response rates [27]. The decreasing engagement may reflect concussion recovery, as symptom presence and severity decreased over time in the studies using mHealth technology to monitor patients with a concussion [17,21,28,29]. Regarding response patterns across the three daily time points used in this study, evening (ie, prompts were sent at 8 PM and remained open until midnight) had the highest response rate and may be the optimal time to prompt adolescents in assessing their concussion symptoms. As evening hours may be less busy from school and extracurricular commitments, adolescents may prefer spending time in other activities using electronic devices (eg, smartphones and tablets), increasing the chance to respond to mHealth prompts.

Our findings reiterate the importance of sex differences in concussion. Female adolescents showed significantly higher response rates than male adolescents over recovery duration—for both time since injury and time since first app use. Factors attributing to response differences may be related to the manifestation of sex-based differences in symptoms that stem from differences in anatomy, biological underpinnings, and pubertal stage [6,30,31]. Behavioral expression and socially constructed roles associated with gender may also explain the higher rates in female adolescents [32]. For example, female adolescents have been shown to be more willing to report symptoms after concussion [33] and with greater frequency [6]. Particularly in digital use, female adolescents were found to have stronger motives for interpersonal communication and self-expression than male adolescents [34,35], which may explain why higher response rates were observed in female adolescents while using the mHealth app in this study.

Clear reporting differences existed between adolescents with and without concussion history. Adolescents with a concussion history had nearly twice the morning and afternoon response rates than those with no concussion history. For trends over time, similar patterns were observed. Studies have shown that adolescents with a history of a previous concussion continue to endorse more physical, cognitive, and fatigue symptom domains [36,37], and have longer recovery [8,38] than those without a concussion history. Persistent symptom presence and severity in adolescents with previous concussions may drive them to monitor their symptom patterns more carefully and frequently than those without a concussion history. Additionally, adolescents with a concussion history may have established trustworthy relationships with clinical providers during previous health care visits and, thus, may be more likely to follow assigned mHealth instructions such as reporting daily symptoms.

Adolescents with sports- and recreation-related injury demonstrated slightly higher response rates than those with non–sports- and recreation-related injury, particularly for the afternoon and evening session times. The desire to return to play may primarily motivate adolescents with a concussion to adhere to the instructions from health care providers with the hope of shortening recovery time [39,40]. Especially for adolescent athletes, there is a concern that absence from games or practice can let teammates down or even lead to their replacement on the team [41,42]. Individual desire to maintain team and peer acceptance in sports, and social support may drive adolescents who are injured via sports-related mechanisms to actively engage in mHealth solutions.

The differences in response rate between higher-than-median symptom burden versus lower-than-median symptom burden were inconsistent. For example, evening and daily response rates in participants with higher symptom burden were greater; however, morning response rates showed the opposite trend. High symptom burden may affect self-reporting behaviors both positively and negatively [28]. Adolescents with a concussion and higher symptom burden may demonstrate a stronger motive to engage with medical care compared to those with a lower symptom burden, facilitating mHealth app use to report daily symptoms. Alternatively, electronic devices (eg, computers, mobile phones, and tablets) may induce concussion-related symptoms such as headache and increased sensitivity to light [43,44], which could prevent adolescents with a concussion from adhering to digital health services or interventions. Our finding warrants further study to investigate symptom burden–related barriers that prevent self-reporting to mHealth services.

Reporting behavior was also affected by the time between injury and initial engagement with the app. Our finding showed that adolescents whose first use of the mHealth app was more than 7 days post injury demonstrated greater response rates than those whose first use was within 7 days of injury. Our finding may imply that the adolescents whose symptoms are sustained or even increased after 7 days post injury may have stronger motives in engaging in processes to support their recovery. Early presentation for medical care has been found to lower the risk of prolonged recovery [7,38,45]; therefore, those who present later and thus engage with the app later may be motivated to find ways to relieve symptom burden and may view regular engagement with the app as one means to do so. Encouraging reporting in the early period may be needed to help adolescents and families understand their symptom trajectory as well as how their health care provider can use that information to determine the next steps.

Older adolescents (ages 15-18 y) demonstrated slightly greater daily response rates than younger adolescents (ages 11-14 y), although most differences were not significant. Although it has been suggested that younger adolescents may be more likely to self-report concussions due to less negative perceptions of reporting injuries [46,47], ecological momentary assessment research has suggested that young children may find self-report methods more challenging to engage in [48]. Additionally, a larger foundation of concussion knowledge may guide older adolescents to report symptoms more regularly; previous research has suggested an association between age and concussion knowledge [46,49,50]. The younger participants may be less informed about concussion knowledge and therefore less likely to report.

There were several limitations in this study. First, the sample size in this study was small, though similar to or greater than other mHealth studies on patients with concussion. These data provide guidance for considerations for the implementation of mHealth in future studies of youths with a concussion with larger sample sizes. Second, our study enrolled adolescents aged 11-18 years, but participants were predominantly older adolescents (ages 15-18 years). Thus, the results should not be extrapolated to the younger pediatric population. Third, participants were predominantly White. This limitation warrants further study to investigate the application of mHealth technology in diverse communities, which may help clinicians and researchers understand the barriers to digital health equity, especially for non-Hispanic Black communities [9]. Fourth, because concussion cases were from a specialty care referral program, reporting behaviors may be biased toward adolescents who seek specialist care, which may include a population with more prolonged recovery. Lastly, our response rates were lower than some existing literature [23,29,48]; however, this was likely due to the lack of incentive strategies, lack of reminder prompts, and longer tracking duration compared to those studies. Dynamic incentivization showed higher response rates (IQR 47.6%-82.5%) in youths with concussion from the emergency department setting when tracking their daily symptoms compared with flat incentivization (IQR 20.6%-68.3%) [27].

In summary, adolescents with concussion demonstrated the ability to regularly report concussion symptoms via an mHealth tool in their natural living environment without financial compensation. To optimize future mHealth tool use from both the research and clinical perspectives, and for adolescents with concussion, evening may be the best prompt time. Response rates among adolescents varied by certain demographic- and injury-related characteristics. Multiple groups were more likely to engage in reporting daily symptoms: female patients, those who had a longer time from injury to app use, and those with a history of prior concussions. Using mHealth apps to document symptom presence and intensity daily can improve the reliability of self-reported data on symptom history at regular clinic visit intervals by eliminating the reliance on memory. Accurate and reliable measurement of postconcussion symptoms on a more granular basis than is captured during clinical visits could further improve clinical decision-making for personalized treatment. This is particularly important for a concussion, which is a dynamic traumatic brain injury in which symptom burden can increase or decrease rapidly. To promote adolescents' adherence to mHealth use, especially for those groups who had low engagement in the monitoring app studied herein, future studies may improve mHealth app features like adding reminder prompts and using incentive strategies or adaptive digital concussion assessments to increase response rates.

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Conflicts of Interest

DJW has been retained by the National Collegiate Athletics Association in litigation to provide expert epidemiological testimony on the long-term effects of concussion in sports. The other authors have no conflicts of interest to declare.

Multimedia Appendix 1
Supplementary equations, figure, and table.
[DOCX File, 73 KB - pediatrics_v7i1e53186_app1.docx]

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Abbreviations

mHealth: mobile health
PCSI: Post-Concussion Symptom Inventory
ReCoUPS: Recovering Concussion Update on the Progression of Symptoms

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Original Paper

Mobile App/Web Platform for Monitoring Food Oral Immunotherapy in Children: Longitudinal Clinical Validation Study

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Abstract

Background: Milk and egg allergies significantly impact the quality of life, particularly in children. In this regard, food oral immunotherapy (OIT) has emerged as an effective treatment option; however, the occurrence of frequent adverse reactions poses a challenge, necessitating close monitoring during treatment.

Objective: This study aims to evaluate the ability of a new mobile/web app called OITcontrol to monitor milk and egg OIT.

Methods: Patients undergoing milk or egg OIT were recruited and divided into 2 groups: the active group used the OITcontrol app in conjunction with standard written monitoring methods, whereas the control group relied solely on written diaries. Investigators documented hospital doses, hospital reactions, and administered treatments on the website. Patients recorded their daily allergen home-dose intake, home reactions, and administered treatments using the app. The following variables were compared between both groups: number and severity of hospital and reported home reactions, patient's adhesion to the OITcontrol app or written diary or both in terms of daily home-dose intake and home reactions recording, and treatment and dose adjustment compliance at home in case of reaction.

Results: Sixteen patients were assigned to be monitored using the OITcontrol app along with additional written methods (active group), while 14 patients relied solely on a written paper diary (control group). A similar distribution was observed in terms of sex, age, basal characteristics, allergen treated in OIT, premedication, and sensitization profile. Active patients reported a comparable number of hospital and home reactions compared with the control group. In terms of recording system usage, 13/16 (81%) active patients used the OITcontrol app, while 10/14 (71%) control patients relied on the written diary. Among active patients, 6/16 (38%) used both methods, and 1 active patient used only written methods. However, control patients recorded home reactions more frequently than active patients (*P*=.009). Among active patients, the app was the preferred method for recording reactions (59/86, 69%), compared with the written diary (15/86, 17%) or both methods (12/86, 14%; *P*<.001). Treatment compliance in home-recorded reactions was similar between both groups (*P*=.15). However, treatment indications after an adverse reaction were more frequently followed (*P*=.04) in reactions recorded solely in the app (36/59, 61%) than in the written diary (29/71, 41%) or both systems (4/12, 33%). Moreover, compliance with dose adjustments after a moderate-severe reaction in home-recorded reactions was higher in the active group than in the control group (*P*<.001). Home reactions recorded only in the app (16/19, 84%) were more likely to follow dose adjustments (*P*<.001) than those recorded in the written diary (3/20, 15%) or using both methods (2/3, 67%).

Conclusions: The OITcontrol app appears to be a valuable tool for monitoring OIT treatment in children with food allergies. It proves to be a suitable method for recording daily home dose intakes and reactions, and it seems to enhance adherence to treatment indications following an adverse reaction as well as compliance with dose adjustments in home reactions. However, additional studies are necessary to comprehensively grasp the benefits and limitations of using the OITcontrol app in the management of OIT.

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KEYWORDS

adverse reactions; egg allergy; food oral immunotherapy; mHealth; milk allergy; monitoring

Introduction

Food allergies are increasingly prevalent worldwide, particularly within the European population [1]. Children, in particular, often experience allergies to common foods such as eggs and milk, which can lead to severe reactions [2]. Notably, these allergies constitute a significant factor in causing anaphylaxis during early childhood [3]. Research indicates that approximately 50% of children with allergies naturally outgrow their milk and egg allergies. However, a substantial number of patients do not experience spontaneous resolution of these allergies [4,5]. The prevailing method for treating food allergies involves the complete avoidance of the allergen. However, with milk and egg allergies, which are found in numerous everyday foods, steering clear of the allergen is challenging. Consequently, over 20% of children and adolescents who experience anaphylaxis are already aware of the allergen, necessitating avoidance [3]. Indeed, food allergies in children significantly impact the quality of life for parents and caregivers, particularly in terms of the self-management of the condition [6].

Oral immunotherapy (OIT) for food, involving the oral administration of allergens to induce tolerance, has proven to be an effective treatment for persistent food allergies in children, despite the occurrence of frequent adverse reactions [7-9]. In typical OIT protocols, incremental doses of the allergenic food are administered in a hospital setting, and once tolerated, these doses are continued daily at home. This daily allergen consumption continues until the target food dose is reached, marking the completion of the buildup phase [10]. Subsequently, the established target dose is maintained at home to sustain the acquired tolerance, marking the beginning of the maintenance phase. Although most reactions typically occur during the hospital-based buildup phase, it is noteworthy that reactions can also manifest during the maintenance phase, after home dose intake [11,12]. Patients undergo education on avoiding potential cofactors and managing potential reactions at home [13]. Furthermore, it is crucial to adjust the prescribed allergen dose in the event of a reaction [14] or if patients are experiencing an intercurrent disease [10]. This information, along with specific treatment guidelines for addressing reactions at home, is typically conveyed verbally and in writing to caregivers and patients undergoing OIT treatment. Indeed, the management of OIT necessitates vigilant oversight both from the medical staff during hospital-based doses and from patients and their families during home-based doses.

Certain studies have reported an enhancement in the quality of life for patients treated with OIT at the culmination of the buildup phase [15-19]. However, contrasting findings exist, with some studies demonstrating no discernible differences [20] and others even describing a decline in the quality of life for certain patients following OIT treatment [21]. It has been suggested that the absence of improvement in quality of life after OIT could be linked to the numerous hospital visits required during the up-dosing phase [22] and the frequent occurrence of adverse reactions [23].

To assist patients in managing home doses and provide targeted information in conjunction with OIT treatment, a web platform designed for health staff and a hybrid mobile app for patients, named OITcontrol (University of Navarra, Pamplona, Spain), have been developed. OITcontrol enables medical staff to record doses and reactions in the hospital, and caregivers/patients can use it to log information regarding doses and reactions while at home. OITcontrol serves as a reminder for the timing and administration instructions for daily home doses. Additionally, it provides guidance on specific treatments following a reaction and offers evidence-based dose adjustment instructions through dedicated algorithms [24-26].

The objective of this study was to assess the effectiveness of the OITcontrol app in monitoring patients undergoing food OIT treatment, with a focus on (1) evaluating its capability to document adverse reactions occurring at home, and (2) examining patient adherence to specific recommendations regarding home adverse reactions, including prescribed treatment and adjustments for the next day's dose.

Methods

Study Population

This study was conducted in Spain, specifically at the Hospital Universitario Donostia in Donostia-San Sebastián and Hospital Ramón y Cajal in Madrid. The participants were patients aged either 2 years and older for those diagnosed with milk allergy or between 5 and 18 years old for those diagnosed with egg allergy. The diagnosis was established through immunoglobulin E (IgE)–derived clinical history and positive skin prick tests, IgE sensitization to the allergenic food, or both. These patients were invited to undergo OIT treatment in accordance with the

Spanish OIT guidelines [10], with the study period spanning from April 2019 to April 2021. Parents of patients or their legally authorized representatives, and in the case of a mature minor, the children themselves, were provided with comprehensive information regarding the risks and benefits associated with the OIT treatment. Those patients who opted for OIT and reported the use of smartphones were extended an invitation to participate in the study. The participants were monitored until they completed the OIT buildup phase or until the predetermined conclusion of the study in April 2021.

Ethics Approval

Before participation, written informed consent was acquired from all involved patients, adhering to the prevailing ethical-legal regulations, as outlined in the Helsinki Declaration. The study protocol received approval from the ethics committees of all participating hospitals (2018.199 University of Navarra; PI2017053, Euskadi; Hospital Universitario Ramón y Cajal).

Allergy Diagnosis

For patients undergoing milk or egg OIT, a skin prick test was conducted using commercial extracts of milk, alpha-lactalbumin, beta-lactoglobulin, and casein for milk allergy, whereas white and yolk egg, ovomucoid, and ovalbumin were used for evaluating egg allergy. Measurements of wheal and flare sizes were taken 15 minutes after the test, and wheals with a diameter equal to or greater than 3 mm were deemed positive [27]. The determination of specific IgE levels for the entire extract (milk or white and yolk egg) and its components (alpha-lactalbumin, beta-lactoglobulin, and casein for milk or ovomucoid and ovalbumin for egg) was conducted using fluorescence enzyme immunoassay with ImmunoCAP (Thermo Fisher). Specific IgE values equal to or exceeding 0.35 kUA/L were classified as positive.

Food OIT Treatment Protocols

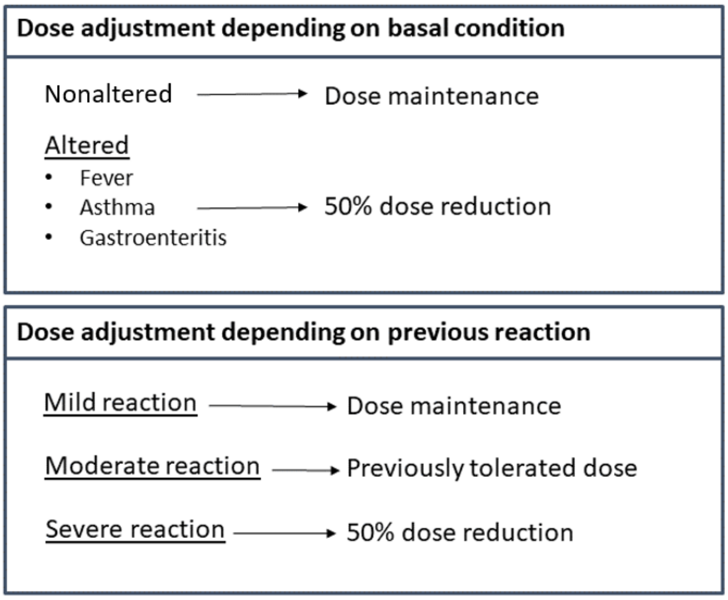
Patients underwent treatment with initially grouped dosing schedules at the hospital, in accordance with the Spanish OIT guidelines [14]. Subsequently, weekly increments in hospital doses were administered. The allergen dose that was tolerated at the hospital was then maintained daily at home between hospital visits. For milk OIT, ultra-high temperature milk was used until, whenever feasible, the final dose of 200 ml milk was reached. For egg OIT, the process involved the use of lyophilized egg white powder (ovo-des; Cantabria Labs Nutrición Médica), pasteurized egg white, or boiled whole egg until the target of 4000 mg of egg white powder, 30 ml of pasteurized liquid egg white, or 1 boiled whole egg was achieved, respectively, where possible [14].

Intervention

Before commencing OIT, patients were consecutively recruited, ensuring a balanced distribution between the control group (PaperPRO group) and the active group (OITcontrol group). The medical staff provided oral and written general recommendations to all patients and caregivers (referred to as patients hereafter). All patients were given detailed explanations and written instructions regarding various aspects, including how to administer the allergen dose, a list of cofactors to avoid, guidelines for treating different types of home reactions, and instructions for dose adjustment following a moderate/severe reaction or in the presence of altered basal conditions (axillary fever of ≥38°C, asthma, or gastroenteritis; Figure 1) [8-10]. Patients underwent training to manage home reactions, which included the use of specific medication tailored to each type of reaction (Table S1 Multimedia Appendix 1) [24]. Furthermore, within the category of severe reactions, written recommendations for patients outlined 2 additional severe reactions: anaphylaxis, which was considered when 2 or more symptoms distinct from oral allergy syndrome (OAS) were reported, and anaphylaxis with bronchospasm, when bronchospasm was one of the symptoms accompanying anaphylaxis. For these scenarios, prescriptions of epinephrine and a combination of epinephrine and bronchodilator (salbutamol) were provided, respectively. The term "anaphylaxis" is used in the "Results" section to describe an anaphylactic reaction, irrespective of the presence of bronchospasm. The severity of reactions was categorized based on Sampson's severity classification into mild, moderate, and severe reactions [28].

Patients were instructed to maintain a daily record of the allergen dose taken and any reactions experienced, noting the type of reaction and the administered treatment, in a paper-based diary as part of patient-reported outcomes (PaperPRO). Furthermore, individuals in the active group were provided training on the utilization of the OITcontrol app on their smartphones to document home doses and reactions. These patients were also encouraged to concurrently use the written diary (OITcontrol group).

Figure 1. Patient's specific information described in the written diary or implemented in the OITcontrol app.



OITcontrol App

OITcontrol is a mobile app designed for patients, available on Google Play (Google LLC) or Apple Store (Apple Inc.) [29], and a website for health staff [30], accessible through 3 distinct user interfaces: (1) The doctor's interface for prescribing allergen and rescue treatment, accessible as a website platform recommended for use on a computer; (2) the interface for nurses or health personnel responsible for administering food/medication doses, accessible as a website platform intended for use on a tablet; and (3) the patient interface, available as a mobile app, accessible exclusively through the log-in credentials provided by the doctor (Figure 2).

Within OITcontrol, when a doctor prescribes an OIT treatment for a patient, the app allows for the prescription of allergen dose increases, scheduled step rises following the OIT protocol, and outlines home/hospital treatment procedures in the event of a reaction (doctor's credentials are necessary for access). Once the treatment commences, the app provides daily reminders for the patient's dose, indicates the observation time, and incorporates an algorithm outlining actions and treatments to be used in the case of a home reaction, contingent on the type of reaction [24] (Table S1 Multimedia Appendix 1). Each symptom is associated with a specific indication in the app. In addition, the app computes 2 additional severe reactions: anaphylaxis, identified when 2 or more symptoms distinct from OAS are reported, and anaphylaxis with bronchospasm, recognized when anaphylaxis occurs alongside symptoms of bronchospasm, mirroring the written recommendations. The app provides general recommendations on how to take the daily dose, including guidance on avoiding cofactors, taking the dose at a consistent time, and the need for observation and rest after dose intake. These recommendations align with those provided in writing to every patient.

The platform/app is designed to retain the last tolerated allergen dose on a daily basis. It does not automatically prescribe increases in allergen dose. However, it is programmed to automatically decrease the dose in 2 specific situations:

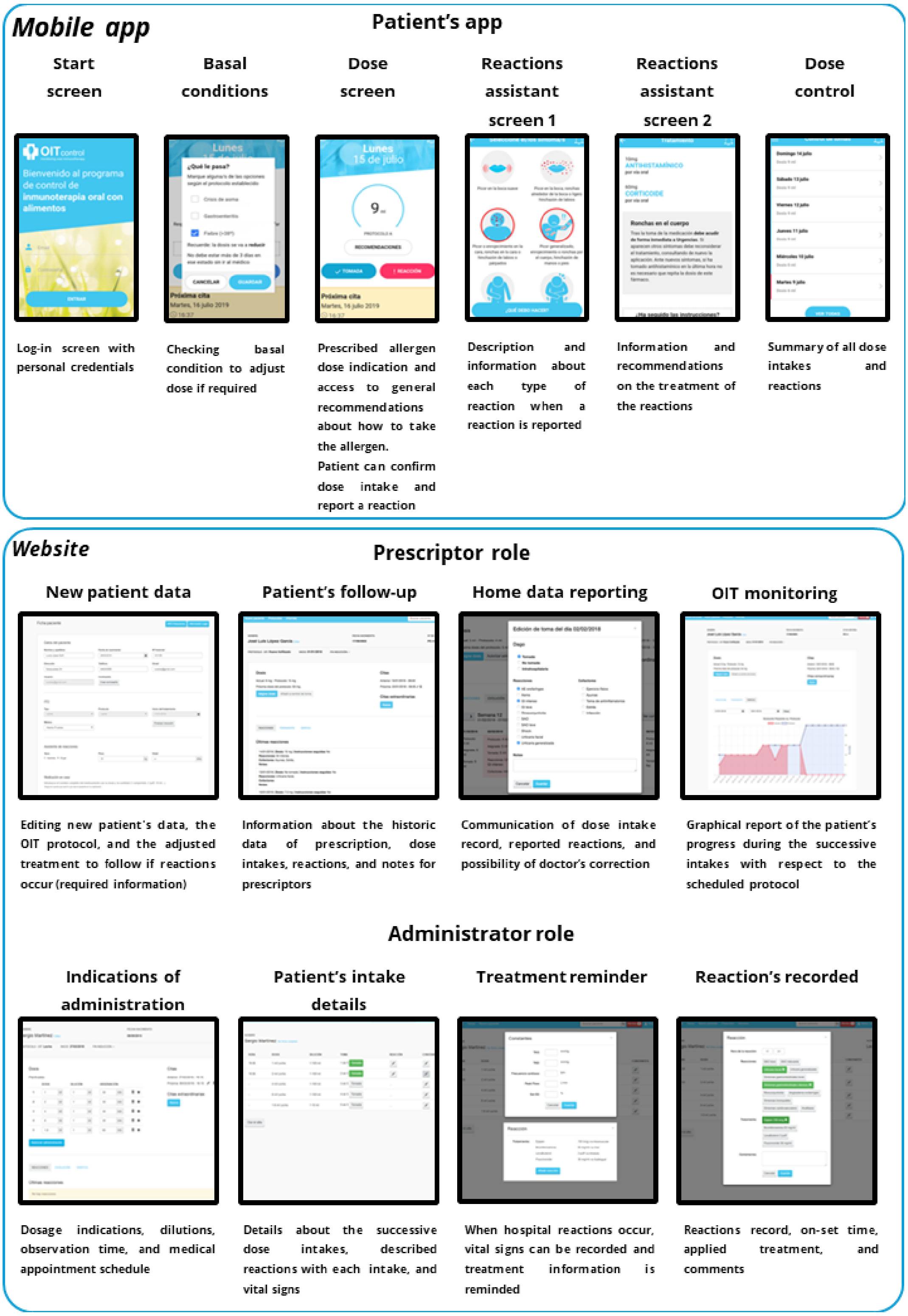
- When the basal condition is linked to a reaction, such as in the presence of gastroenteritis, fever, or an asthma attack, the app automatically decreases the dose to half of the scheduled amount [8,10].
- In the event of a moderate/severe reaction, the app adjusts the dose for the next day [8,26] (Figure 1).

OITcontrol facilitates guiding the patient through home treatment and enables medical staff to closely monitor the patient, even when they are at home.

For the health staff, OITcontrol serves several functions:

- It accumulates the complete OIT history of the patient, including protocol modifications, allergen doses linked to reactions, and cofactors involved in reactions. This information is provided by the patient at home and by the health staff during hospital visits. These data are accessible in real-time, constituting an electronic data capture system.
- It serves as an electronic prescription tool for drugs and allergen doses, allowing doctors to prescribe electronically.
- It sends real-time notifications about the patient's reactions. In the case of a severe reaction, a second notification is dispatched via email.
- It facilitates the management of hospital dose administrations, covering both the multiple-dose initial phase and the unique-dose weekly increase. It generates a summary of the hospital visit, which can be integrated into any digital history system. The app allows for the export of structured text containing patient-specific data for seamless integration.
- It conducts an anonymous analysis of clinical data from hospital patients, considering factors such as the type of reactions, age, sex, and assigned protocol.

Figure 2. Visual description of the functions and usability of the OITcontrol app for patients and website for medical staff.



Log-in screen with personal credentials

Checking basal condition to adjust dose if required

Prescribed allergen dose indication and access to general recommendations about how to take the allergen. Patient can confirm dose intake and report a reaction

Description and information about each type of reaction when a reaction is reported

Information and recommendations on the treatment of the reactions

Summary of all dose intakes and reactions

Editing new patient's data, the OIT protocol, and the adjusted treatment to follow if reactions occur (required information)

Information about the historic data of prescription, dose intakes, reactions, and notes for prescriptors

Communication of dose intake record, reported reactions, and possibility of doctor's correction

Graphical report of the patient's progress during the successive intakes with respect to the scheduled protocol

Dosage indications, dilutions, observation time, and medical appointment schedule

Details about the successive dose intakes, described reactions with each intake, and vital signs

When hospital reactions occur, vital signs can be recorded and treatment information is reminded

Reactions record, on-set time, applied treatment, and comments

Data Collection

The OIT buildup phase was organized into weekly hospital visits with interhospital home doses. Investigators documented hospital doses, the type of reactions that occurred during hospital visits, and the administered treatment. At home, all patients were encouraged to record daily outcomes in a written diary, including the amount of the daily allergen dose taken, instances of reactions, the type of symptoms experienced, and the treatment administered. Moreover, active patients were encouraged to use the OITcontrol app to document comparable information. The use of the OITcontrol app or a written diary was deemed effective when at least five consecutive home doses had been registered or when 1 reaction had been recorded during the follow-up. The medical staff documented the information in the digital clinical history regarding home dose intakes and home reactions reported verbally by the patients during weekly hospital visits.

Users' Satisfaction Questionnaire

An anonymous electronic satisfaction questionnaire regarding the use of the OITcontrol app was distributed to the initial 10 patients in the OITcontrol group. Additionally, 11 previous patients were included in the survey to verify the correct performance and use of the app before initiating the validation study. These participants were recruited from both the Hospital Universitario Donostia in Donostia-San Sebastián and Hospital Ramón y Cajal in Madrid. The same questionnaire was administered after the first and fourth week of app use. The questionnaire included a few demographic questions and inquired about the general impression of the app, the assessment of texts and screens, and the evaluation of terminology. The respondents provided ratings on a scale ranging from 1 (poor) to 5 (good) or from 1 (poor) to 9 (good) for the 22 items included in the questionnaire.

Statistical Analysis

The distribution of variables was assessed for normality using the Shapiro-Wilk test. Normally distributed quantitative values were presented as mean and SD, while nonnormally distributed quantitative values were described as medians and IQRs (Q1-Q3). Qualitative values were reported as frequencies (percentages). Proportions were compared using the chi-square test or Fisher exact test when the expected frequencies were below 5. Quantitative variables were analyzed using the Student *t* test or Mann-Whitney *U* test based on normality. The clinical statistical analysis was conducted using Stata IC 12.0 (StataCorp LLC). Differences with a *P* value <.05 were considered statistically significant.

Results

Baseline Characteristics of the Sample

Thirty participants were enrolled in the study, with 16 patients monitored using both written methods and the OITcontrol app (ie, the OITcontrol group) and 14 patients monitored solely through a written paper diary (ie, the PaperPRO group). A comparable distribution was observed concerning sex, age, basal characteristics (bronchial asthma/previous anaphylaxis with OIT food), the allergen used in OIT, premedication, and sensitization profile (Table 1).

No significant differences (*P*=.07) were observed in terms of follow-up time between PaperPRO patients (median 146.5 days, Q1-Q3 98-213 days) and OITcontrol patients (median 196.5 days, Q1-Q3 147.5-336.5 days). However, it is worth noting that 5/14 (36%) PaperPRO patients and 13/16 (81%) OITcontrol patients (*P*=.01) underwent OIT treatment during the COVID-19 pandemic. In fact, a similar number of hospital dose increases were observed between PaperPRO patients (mean 9.9, SD 6.4) and OITcontrol patients (mean 14, SD 9.5; *P*=.18). Likewise, the number of home OIT days was comparable between the PaperPRO group (median 128, Q1-Q3 89-192) and the OITcontrol group (median 167.5, Q1-Q3 135-287.5; *P*=.11).

Table 1. Baseline characteristics of the sample.

Characteristics	PaperPRO group (n=14)	OITcontrol group (n=16)	*P* value
Female, n (%)	5 (36)	10 (63)	.14
Age (years), mean (SD)	6.9 (1.9)	7.6 (3.7)	.75
Asthma, n (%)	5 (36)	7 (44)	.65
Previous anaphylaxis with OIT[a] allergen, n (%)	7 (50)	13 (81)	.08
OIT with egg, n (%)	8 (57)	8 (50)	.70
OIT with milk, n (%)	6 (43)	8 (50)	.70
Antihistaminic premedication, n (%)	0 (0)	4 (25)	.07
Omalizumab premedication, n (%)	1 (7)	1 (6)	.92
Total immunoglobulin E value (kU/L), median (Q1-Q3[b])	494.5 (120-858)	258 (87-931)	.57
In egg OIT patients			
OIT with egg, n (%)	8 (57)	8 (50)	.70
Specific immunoglobulin E (kUA/L), median (Q1-Q3)			
Egg white	7.7 (2.2-13.8)	9 (5.7-16.2)	.56
Egg yolk	1.9 (0.5-4.4)	3 (1.1-7.6)	.40
Ovalbumin	4 (0.6-8.8)	4.9 (1.4-9)	.67
Ovomucoid	4.1 (0.5-14.1)	8.1 (4.5-17.3)	.21
Prick test diameter (mm), median (Q1-Q3)			
Egg white	7 (3-9.7)	8 (6.5-11)	.46
Egg yolk	5 (2.2-7.5)	6.5 (3-8)	.67
Ovalbumin	6.2 (2.7-10)	9 (6-10)	.53
Ovomucoid	5.5 (4.2-9.7)	9.5 (7-15)	.19
In milk OIT patients			
OIT with milk, n (%)	6 (43)	8 (50)	.70
Specific immunoglobulin E (kUA/L), median (Q1-Q3)			
Milk	5.9 (3.9-7.8)	8.6 (3.8-19.8)	.70
Alpha-lactalbumin	1.1 (0.4-3.2)	0.4 (0.1-9.8)	.30
Beta-lactoglobulin	0.7 (0.4-1.4)	0.5 (0.2-0.9)	.52
Casein	3.7 (1.6-9.4)	2.8 (0.8-13.6)	.56
Prick test diameter (mm), median (Q1-Q3)			
Milk	4.7 (3-5)	4.7 (3.5-10.2)	.56
Alpha-lactalbumin	5.5 (4.5-6)	3 (0-7)	.49
Beta-lactoglobulin	6.7 (5.5-9.5)	7 (3.5-9.2)	.43
Casein	7.5 (3-9)	3.7 (1-12)	.56

[a] OIT: oral immunotherapy.

[b] Q1-Q3: first quartile-third quartile.

OIT Adverse Reactions

PaperPRO patients experienced 5 hospital reactions, while OITcontrol patients experienced 19 hospital reactions. Table 2 summarizes hospital reactions. In the PaperPRO group, the 5 hospital reactions were experienced by 5 different patients (1 reaction per patient), whereas in the active group, the 19 reactions were experienced by only 3 patients (the first patient had 1 reaction, the second had 3 reactions, and the third had 15 reactions). No differences were observed regarding the number of hospital reactions per patient, the number of hospital reactions per hospital dose given, the type of reactions, or the severity of the reactions between both groups of patients.

Concerning home reactions, PaperPRO patients reported 56 home reactions, while OITcontrol patients reported 97 home reactions (*P*=.70). Table 3 summarizes home reactions. More than one-half of all patients included in the study (19/30, 63%)

experienced a home reaction. Globally, only moderate home reactions were more frequently reported by PaperPRO patients than OITcontrol patients (*P*=.047). However, no differences were observed regarding the specific type of reaction between both groups of patients.

Table 2. Hospital reactions.

Reactions	PaperPRO group (n=14)	OITcontrol group (n=16)	*P* value
Hospital reactions, n	5	19	.45
Hospital reaction/hospital visit, median (Q1-Q3[a])	0 (0-0.1)	0 (0-0)	.18
Patients with hospital reactions, n (%)	5 (36)	3 (19)	.29
Hospital reaction/patient, median (Q1-Q3)	0 (0-1)	0 (0-0)	.45
Type of hospital reaction			
Mild reactions, reactions (affected patients), n	2 (2)	5 (2)	>.99
Mild OAS[b]	0 (0)	1 (1)	.35
Relevant OAS (lip edema/perioral urticaria)	1 (1)	2 (1)	.96
Facial urticaria/angioedema	1 (1)	0 (0)	.29
Mild gastrointestinal symptoms	0 (0)	2 (1)	.35
Moderate reactions, reactions (affected patients), n	3 (3)	7 (1)	.31
Acute generalized urticaria	1 (1)	1 (1)	.92
Rhinoconjunctivitis	2 (2)	6 (1)	.52
Severe reactions, reactions (affected patients), n	0 (0)	7 (2)	.18
Severe gastrointestinal symptoms	0 (0)	1 (1)	.35
Oropharyngeal discomfort	0 (0)	3 (1)	.35
Bronchospasm	0 (0)	3 (1)	.35
Anaphylaxis	0 (0)	0 (0)	>.99
Anaphylactic shock	0 (0)	0 (0)	>.99

[a] Q1-Q3, first quartile-third quartile.

[b] OAS: oral allergy syndrome.

Table 3. Reported home reactions.

Reactions reported	PaperPRO group (n=14)	OITcontrol group (n=16)	*P* value
Home reactions, n	56	97	.70
Home reactions/home doses, median (Q1-Q3[a])	0 (0-0.06)	0 (0-0.07)	.76
Patients with home reactions, n (%)	9 (64)	10 (63)	.12
Home reactions/patient, median (Q1-Q3)	3 (0-5)	2.5 (0-11.5)	.70
Mild reactions, reactions (affected patients), n	38 (6)	73 (8)	.53
Mild OAS[b]	12 (3)	37 (7)	.17
Relevant OAS (lip edema/perioral urticaria)	11 (3)	6 (4)	.95
Facial urticaria/angioedema	7 (3)	3 (3)	.72
Mild gastrointestinal symptoms	8 (3)	27 (5)	.47
Moderate reactions, reactions (affected patients), n	13 (6)	2 (2)	.047
Acute generalized urticaria	3 (3)	1 (1)	.23
Rhinoconjunctivitis	10 (4)	1 (1)	.09
Severe reactions, reactions (affected patients), n	5 (3)	22 (6)	.21
Severe gastrointestinal symptoms	1 (1)	8 (3)	.32
Oropharyngeal discomfort	3 (2)	9 (4)	.42
Bronchospasm	1 (1)	0 (0)	.28
Anaphylaxis	0 (0)	5 (3)	.09
Anaphylactic shock	0 (0)	0 (0)	>.99

[a] Q1-Q3: first quartile-third quartile.

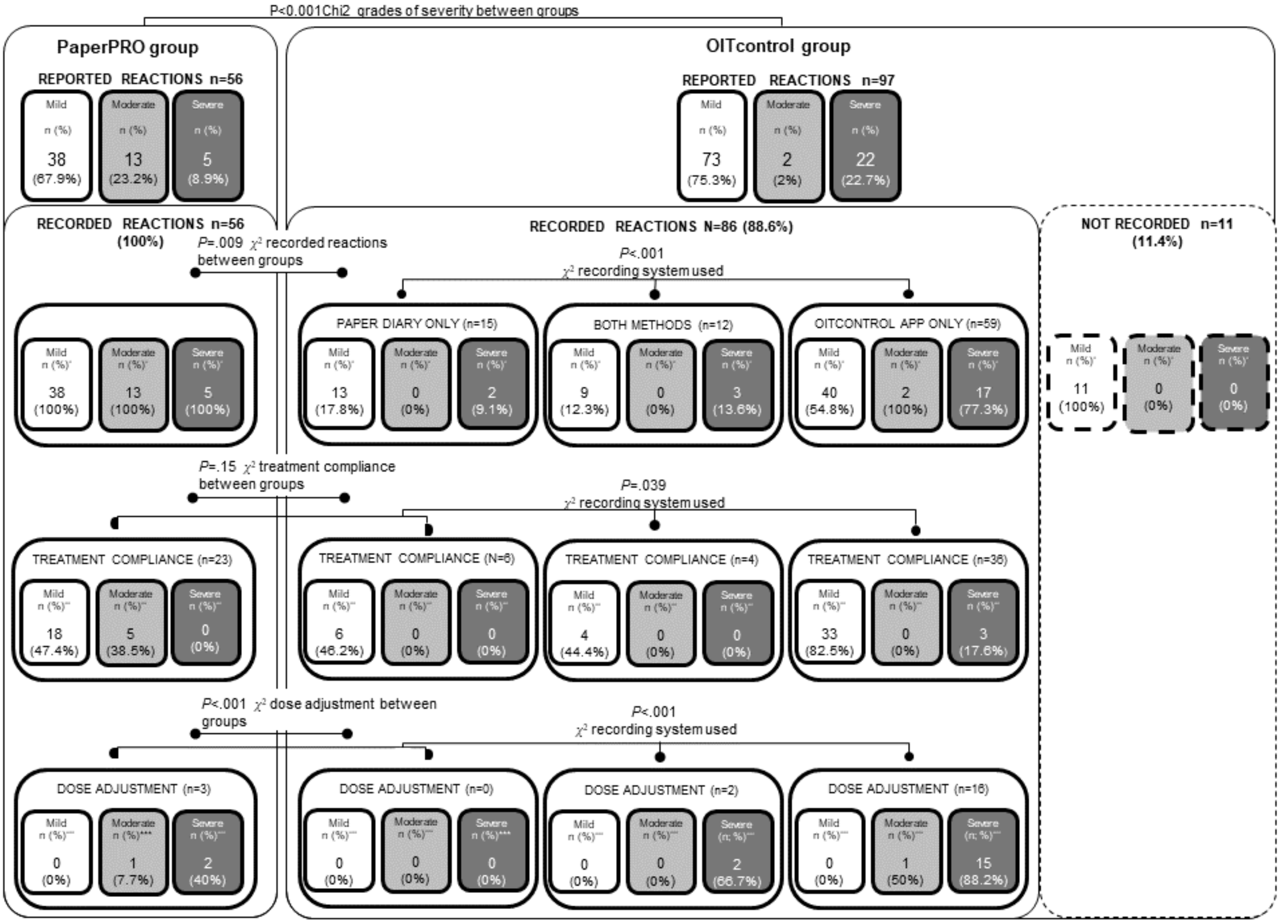
[b] OAS: oral allergy syndrome.

Home Data Recording

In the OITcontrol group, 81% (13/16) of patients used the OITcontrol app, while in the PaperPRO group, 71% (10/14) used the written diary (*P*=.53). As mentioned previously, patients in the OITcontrol group were advised to record daily taken allergen doses and home reactions using both methods: the written paper and the app. Following these recommendations, 38% (6/16) of OITcontrol patients used both methods. One active patient used only the written diary without using the OITcontrol app. Interestingly, none of the patients collected all daily dose intakes, regardless of the monitoring method used.

When analyzing reported reactions, every home reaction experienced in the PaperPRO group was recorded in the written diary (56/56, 100%), while 89% (86/97 reactions) of the home reactions experienced in the OITcontrol group were recorded (*P*=.009). Active patients preferred using only the app (59/86, 69%) rather than the written diary (15/86, 17%) or both methods (12/86, 14%) to record home reactions (*P*<.001). These data are summarized in Figure 3. Every reaction recorded by the OITcontrol group in both recording methods, written diary and OITcontrol app, was documented using the same description regarding allergen dose, type of symptoms, and administered treatment.

Figure 3. Summary of reported and recorded home reactions in both study groups, including the number of reactions documented, the treatment compliance and the dose adjustment performed after a moderate or severe reaction in recorded reactions through written diary, OITcontrol® app, or a combination of both monitoring systems. * Percentage of recorded reactions among reported reactions for each severity grade in each group. ** Percentage of reactions that followed indicated treatment among recorded reactions for each severity grade in each group. *** Percentage of reactions that follow dose adjustment after a moderate-severe reaction among recorded reactions for each severity grade in each group.



App Assistance Evaluation

Treatment compliance in home-recorded reactions was analyzed between both groups and the monitoring method used. The indicated treatment was followed in 23 of the 56 (41%) recorded reactions in the PaperPRO group and in 46 of the 86 (53%) home-recorded reactions in the OITcontrol group (*P*=.15). Analyzing the monitoring system used, treatment was observed to be followed more frequently (*P*=.04) in reactions recorded only in the app (36/59, 61%) than in the written diary (29/71, 41%) or both systems (4/12, 33%; Figure 3). In general, treatment compliance was observed more frequently (*P*<.001) in mild reactions (61/100, 61%) than in moderate (5/15, 33%) and severe reactions (3/27, 11%). However, it is worth noting that in recorded mild reactions, treatment compliance was quite high, possibly because no treatment was indicated for the frequently reported mild OAS (every recorded mild OAS was correctly managed in both groups: 12 in the PaperPRO group and 31 in the OITcontrol group). In fact, mild reactions excluding mild OAS (18/57, 32%), moderate (5/15, 33%), and severe reactions (3/27, 11%) followed treatment prescription correctly in similar rates (*P*=.11). Interestingly, in most of the reactions where prescribed treatment was not followed, the common attitude among patients was not to apply any treatment, which was consistent across both groups. Detailed data are provided in Tables 4-6.

Dose adjustments after a moderate-severe reaction in home-recorded reactions were analyzed between both groups and the monitoring method used. Among the 18 doses that should have been adjusted after a moderate-severe reaction in the PaperPRO group, only 3 (17%) were adjusted. By contrast, among the 24 recorded doses requiring adjustment after a moderate-severe reaction in the OITcontrol group, 18 (75%) were correctly adjusted (*P*<.001). In general, dose adjustment was more frequently performed (*P*<.001) in those reactions recorded only in the app (16/19, 84%) than in those recorded in the written diary (3/20, 15%) or in both methods (2/3, 67%). The severity of reactions was associated with better compliance, as adjustments were made after severe reactions (19/27, 70%) more frequently (*P*<.001) than after moderate reactions (2/15, 13%). Data are summarized in Figure 3.

Table 4. Comparison of the adequacy of the treatment applied in recorded reactions of written diary users from both groups of patients.[a]

Written diary (indicated treatment)	Treatment applied					
	None	AH[b]	AH and CST[c]	EPI[d]	EPI and BD[e]	BD
None	*14* [f]	0	0	0	0	0
AH	33	*14*	0	0	0	0
AH and CST	0	2	*1*	0	0	0
EPI	6	0	0	*0*	0	0
EPI and BD	0	0	0	0	*0*	1

[a] The number of reactions among both groups of patients is represented by comparing the treatment applied and indicated treatment in written diary-recorded reactions.

[b] AH: antihistamine.

[c] CST: corticosteroid.

[d] EPI: epinephrine.

[e] BD: bronchodilator.

[f] Italicized values indicate the number of patients that followed the prescribed treatment correctly.

Table 5. Comparison of the adequacy of the treatment applied in recorded reactions of OITcontrol app users from both groups of patients.[a]

Written diary (indicated treatment)	Treatment applied					
	None	AH[b]	AH and CST[c]	EPI[d]	EPI and BD[e]	BD
None	*27* [f]	0	0	0	0	0
AH	8	*6*	0	0	0	0
AH and CST	0	1	*0*	0	0	0
EPI	10	3	1	*3*	0	0
EPI and BD	0	0	0	0	*0*	0

[a] The number of reactions among both groups of patients is represented by comparing the treatment applied and indicated treatment in the OITcontrol app–recorded reactions.

[b] AH: antihistamine.

[c] CST: corticosteroid.

[d] EPI: epinephrine.

[e] BD: bronchodilator.

[f] Italicized values indicate the number of patients that followed the prescribed treatment correctly.

Table 6. Comparison of the adequacy of the treatment applied in recorded reactions of OITcontrol app and written diary users from both groups of patients.[a]

Written diary and OITcontrol (indicated treatment)	Treatment applied					
	None	AH[b]	AH and CST[c]	EPI[d]	EPI and BD[e]	BD
None	*2* [f]	0	0	0	0	0
AH	5	*2*	0	0	0	0
AH and CST	0	0	*0*	0	0	0
EPI	0	2	1	*0*	0	0
EPI and BD	0	0	0	0	*0*	0

[a] The number of reactions among both groups of patients is represented by comparing the treatment applied and indicated in both OITcontrol app– and written paper–recorded reactions.

[b] AH: antihistamine.

[c] CST: corticosteroid.

[d] EPI: epinephrine.

[e] BD: bronchodilator.

[f] Italicized values indicate the number of patients that followed the prescribed treatment correctly.

Users’ Satisfaction Questionnaire

A total of 15 users answered the questionnaire in the first week, and 11 responded in the fourth week. Among the 15 users answering in the first week of app use, 7/15 (47%) were females, with most aged between 35 and 44 years (8/15, 53%); 5/15 (33%) were between 45 and 54 years and 2/15 (13%) were between 25 and 34 years; 9/15 (60%) of them reported very frequent use of a smartphone (1=no use to 5=very frequent use: 3/15, 20%, rated the use 4/5; 2/15, 13%, rated the use 3/5; and 1/15, 7%, rated the use 2/5). In general, the app received positive ratings, being considered easy to use in most functions and screens, with suitable text. However, there were suggestions that error messages could be clearer. The questionnaire results are summarized in Tables 7-9.

Table 7. Results of the usability questionnaire after 1 week and 4 weeks of use of the OITcontrol app: general opinions.

Questions and rating	Results at 1 week of use	Results at 4 weeks of use
OITcontrol app is		
1=terrible to 5=wonderful, mean (SD)	3.9 (0.7)	4.3 (0.6)
1=frustrating to 5=easy, mean (SD)	4.1 (0.7)	4.3 (0.6)
1=boring to 5=exciting, mean (SD)	3.6 (0.8)	3.8 (0.9)
1=difficult to 5=easy, median (Q1-Q3[a])	5 (4-5)	5 (4-5)
1=too slow to 5=too fast, mean (SD)	3.3 (1)	3.2 (0.9)
1=unreliable to 5=highly reliable, median (Q1-Q3)	3.9 (3.9-4.4)	3.9 (2.8-4.4)
1=noisy to 5=noiseless, mean (SD)	4.4 (0.6)	4.7 (0.5)

[a] Q1-Q3: first quartile-third quartile.

Table 8. Results of the usability questionnaire after 1 week and 4 weeks of use of the OITcontrol app: opinion about how easy/difficult is to use different functions.

Questions	Rating	Results at 1 week of use	Results at 4 weeks of use
Know I should take the dose	1=difficult to 5=easy, median (Q1-Q3[a])	5 (5-5)	5 (5-5)
Know how to take the dose	1=difficult to 5=easy, median (Q1-Q3)	5 (4-5)	5 (4-5)
Know indications after reaction	1=difficult to 5=easy, mean (SD)	4.6 (0.5)	4.6 (0.5)
Record the dose intake and its additional information	1=difficult to 5=easy, mean (SD)	4.6 (0.5)	4.8 (0.4)
Receive the alarm at the dose intake time	1=difficult to 5=easy, mean (SD)	3.9 (1)	4 (1.2)
Consult past dose intake record	1=difficult to 5=easy, median (Q1-Q3)	5 (4-5)	5 (4-5)
Consult the next hospital visit	1=difficult to 5=easy, median (Q1-Q3)	5 (4-5)	5 (4-5)
To correct mistakes	1=difficult to 5=easy, mean (SD)	3.5 (0.9)	3.5 (1.2)

[a]Q1-Q3: first quartile-third quartile.

Table 9. Results of the usability questionnaire after 1 week and 4 weeks of use of the OITcontrol app: opinions about text and screens.

Questions	Rating	Results at 1 week of use	Results at 4 weeks of use
The texts on the screen are...difficult or easy to read?	1=difficult to 9=easy, median (Q1-Q3[a])	8 (7-9)	8 (7-9)
Is the information highlighted helpful?	1=absolutely not to 9=of course yes, median (Q1-Q3)	8 (7-9)	8 (7-9)
Is the transition from one screen/information to another confusing or clear?	1=confuse to 9=clear, median (Q1-Q3)	8 (7-8)	7 (6-8)
Does the use of terms...encourage or discourage its use?	1=discourage to 9=encourage, mean (SD)	5.9 (2.3)	5.8 (2.5)
Does the use of terms encourage or discourage learning?	1=discourage to 9=encourage, mean (SD)	6.2 (2.5)	6.3 (2.1)
Error messages...are they confusing or clear?	1=confuse to 9=clear, mean (SD)	6.6 (1.7)	5.5 (2.5)
The messages that appear on the screen...Are they difficult or simple?	1=difficult to 9=simple, mean (SD)	7.9 (1.1)	8.2 (0.9)

[a]Q1-Q3: first quartile-third quartile.

Discussion

Principal Findings

This study demonstrates that OITcontrol, a patient advisor app incorporating medical algorithms, goes beyond serving as an electronic report and is an effective method for monitoring home OIT. Moreover, our findings suggest that OITcontrol emerges as an appealing method for overseeing OIT treatments, as it has been predominantly used by the active group. Additionally, instructions provided by the app have been adhered to more consistently than the written indications regarding treatment and dose adjustments following a reaction.

eHealth technology has seen widespread adoption in recent years, particularly in the context of respiratory allergy [31-33]. Conversely, the application of eHealth technology in food allergy has primarily focused on the development of mobile apps designed to complement patient care. These apps often provide features such as allergen-free product searches, meal planners, or tools for locating allergy-adapted restaurants [34,35]. OITcontrol aligns with the objectives of eHealth apps, serving not only the beneficial purposes for patients with allergies but also catering to the needs of clinicians and researchers [36]. It exemplifies the use of health informatics by automating physician orders [37].

Previous reports have indicated that as few as 20% of patients are genuinely compliant with paper-based diaries [38]. In our sample, reporting compliance was remarkably high. PaperPRO patients exhibited perfect adherence in recording home reactions, surpassing the OITcontrol group. In the OITcontrol group, patients displayed a preference for recording home reactions within the app. This observation may be due to the control group's potentially better performance when using only 1 monitoring system, as opposed to the active group using 2 systems. Alternatively, it could be indicative of underreporting of home reactions by the control group, possibly trivializing or forgetting to report reactions when using standard methods compared with having an additional monitoring intervention.

Indeed, a previous electronic web-based reporting system implemented for OIT, which focused on dose and home reactions reporting, demonstrated higher adherence than that observed in our sample. However, the rate of reported home reactions was quite similar to our data [39]. Nevertheless, Nachshon et al [39] highlighted some limitations of this monitoring web-based system, including challenges related to the patient's description of reactions. In this regard, OITcontrol provides a tabulated selection of reactions rather than an open-ended description box. It appears that these predefined reactions are effectively described, as treatment compliance and dose adjustment after a reaction were more successful, particularly for those reactions recorded in the app.

Home reactions documented in the OITcontrol app were more consistently treated correctly compared with those recorded in the written diary, despite the fact that treatment compliance was notably low, particularly among patients experiencing moderate and severe reactions. It is worth noting that epinephrine is underused in cases of anaphylaxis, even among well-informed and trained parents familiar with the use and indications of autoinjectors. This could be attributed to reasons such as the unavailability of the autoinjector, difficulty in recognizing anaphylaxis, and concerns about potential adverse effects [40-45]. In our limited sample, patients who required self-injectable epinephrine rarely used it, irrespective of whether they followed written or electronic recommendations. However, the correct treatment in mild reactions was more frequently adhered to. Further, a larger sample of patients is needed to assess whether the OITcontrol app could enhance treatment compliance for home reactions and contribute to adjusting home doses after moderate-severe reactions. Our data, albeit based on a limited number of reactions, suggest that OITcontrol app recommendations regarding dose adjustment were followed more consistently than written recommendations.

Conclusions

In conclusion, the OITcontrol app appears to enhance treatment and dose adjustment compliance in home reactions, although further studies are needed to confirm the efficacy of the app in this regard. As a monitoring system, the OITcontrol app is deemed a suitable method in OIT treatment for recording daily dose intakes and home reactions during the buildup phase.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary Table S1: Clinical description, classification, and treatment of reactions.
[DOCX File , 131 KB - pediatrics_v7i1e54163_app1.docx]

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Abbreviations

AH: antihistamine
BD: bronchodilator
CST: corticosteroid
EPI: epinephrine
IgE: immunoglobulin E
OAS: oral allergy syndrome
OIT: oral immunotherapy

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Original Paper

Industry 4.0 Technologies in Maternal Health Care: Bibliometric Analysis and Research Agenda

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Abstract

Background: Industry 4.0 (I4.0) technologies have improved operations in health care facilities by optimizing processes, leading to efficient systems and tools to assist health care personnel and patients.

Objective: This study investigates the current implementation and impact of I4.0 technologies within maternal health care, explicitly focusing on transforming care processes, treatment methods, and automated pregnancy monitoring. Additionally, it conducts a thematic landscape mapping, offering a nuanced understanding of this emerging field. Building on this analysis, a future research agenda is proposed, highlighting critical areas for future investigations.

Methods: A bibliometric analysis of publications retrieved from the Scopus database was conducted to examine how the research into I4.0 technologies in maternal health care evolved from 1985 to 2022. A search strategy was used to screen the eligible publications using the abstract and full-text reading. The most productive and influential journals; authors', institutions', and countries' influence on maternal health care; and current trends and thematic evolution were computed using the *Bibliometrix* R package (R Core Team).

Results: A total of 1003 unique papers in English were retrieved using the search string, and 136 papers were retained after the inclusion and exclusion criteria were implemented, covering 37 years from 1985 to 2022. The annual growth rate of publications was 9.53%, with 88.9% (n=121) of the publications observed in 2016-2022. In the thematic analysis, 4 clusters were identified—artificial neural networks, data mining, machine learning, and the Internet of Things. Artificial intelligence, deep learning, risk prediction, digital health, telemedicine, wearable devices, mobile health care, and cloud computing remained the dominant research themes in 2016-2022.

Conclusions: This bibliometric analysis reviews the state of the art in the evolution and structure of I4.0 technologies in maternal health care and how they may be used to optimize the operational processes. A conceptual framework with 4 performance factors—risk prediction, hospital care, health record management, and self-care—is suggested for process improvement. a research agenda is also proposed for governance, adoption, infrastructure, privacy, and security.

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KEYWORDS

Industry 4.0; Fourth Industrial Revolution; bibliometrics; maternal health care; antenatal care; postnatal care; lean operations; maternal; pregnancy monitoring; pregnancy; maternal care; monitoring; thematic analysis; data mining; machine learning; IoT; Internet of Things; artificial intelligence; deep learning; digital health; wearable; mobile phone

Introduction

The Fourth Industrial Revolution, often referred to as Industry 4.0 (I4.0), has revolutionized all sectors with smart technology [1]. For example, Dolgui and Ivanov [2] posit that I4.0 technologies improve efficiency in manufacturing with minimal use of resources. The increased adoption of I4.0 technologies drives the cyber-physical transformation of manufacturing, logistics, and supply chain in business. There has been a heightened interest in adopting and adapting I4.0 technologies in health care delivery [3]. Li and Carayon [4] point out that using I4.0 tools has transformed the provision of digital health services, such as electronic health records, wearable devices, and storage, among other tools, and has led to improved health outcomes and quality of care. Implementing I4.0 in health care has led to a new term being coined, "Health 4.0," which is a deployment of health care driven by the success of I4.0 [5]. Maternal health care is one aspect that can benefit from increased efficiencies and quality of care. According to Ahsan et al [6], several health professionals are using new technologies to monitor and improve the quality of patient care they provide remotely. For example, the condition of the mother and the fetus can be monitored using nonintrusive remote monitoring tools [7,8]. The literature on I4.0 is expanding exponentially, with each successive evolution characterized by an increase in the development and innovation of new tools to facilitate how patients and service providers interact. Sustainable Development Goal (SDG) 3.1 [9] aims to ensure access to health care facilities and reduce the global maternal mortality ratio to less than 70 per 100,000 live births. The challenge faced by society and organizations is determining how best they can take advantage of I4.0 technology to ensure the success of SDG 3.1.

While previous research has explored the general potential of I4.0 technologies for health care, specific applications in maternal health care remain underexplored. Luo et al [10] offer valuable insights through a bibliometric analysis but lack a deeper exploration of real-world impacts on practices, policies, and patient outcomes. Similarly, Guo et al [11] highlight the growth of artificial intelligence (AI) research in health care but fail to delve into specific applications with the most significant potential for improvement. Existing reviews on I4.0 technologies [5,6,12] offer broad overviews of applications and management but lack specific use cases and their long-term societal and health care system impacts. This study addresses this gap by investigating the challenges and successes of implementing I4.0 technologies in various maternal health care settings. A conceptual framework for implementing I4.0 technologies in maternal health care is proposed. Further, we highlight insights and directions by mapping the thematic landscape of I4.0 in maternal health care. A research agenda is also developed for future research direction. A total of 136 papers were analyzed bibliometrically. The objectives were to (1) determine the most productive and influential journals in I4.0 research in maternal health; (2) determine authors', institutions', and countries' influence on I4.0 research in maternal health; (3) investigate the current trends and thematic evolution of I4.0 research in maternal health; and (4) develop a conceptual framework for guiding the implementation of I4.0 technologies in maternal health.

In addition, to gain further insight into the use of I4.0 technologies in health care, three research questions were explored: (1) What are the most critical applications of I4.0 in maternal health care? (2) To what extent is I4.0 technology used in maternal health care? and (3) What are the open research issues and areas for future research?

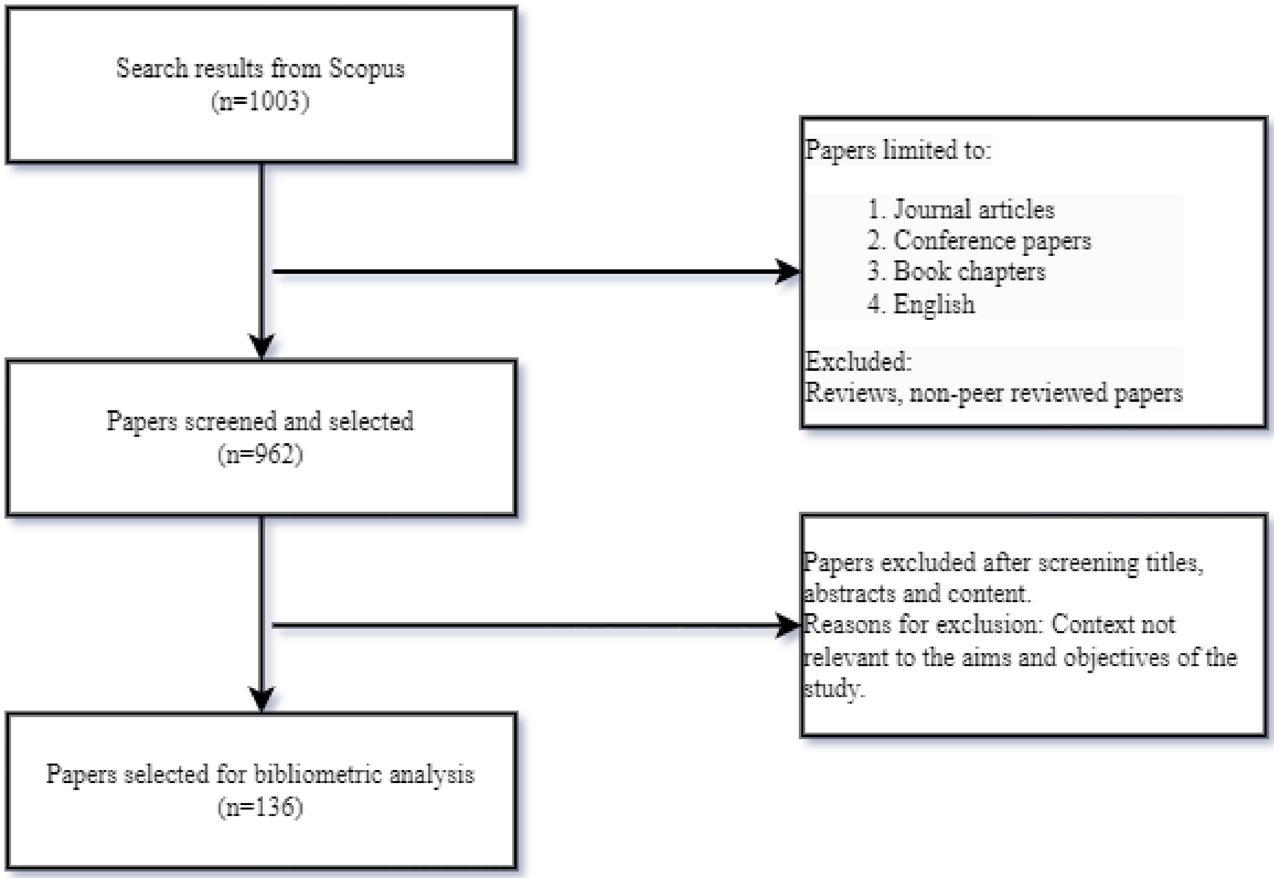
Methods

Search and Screening Strategy

The first step was to search for relevant research. The search was conducted on the Scopus electronic database because it indexes peer-reviewed research used by multidisciplinary researchers. Only articles in English (journals, conference papers, and book chapters) were reviewed to focus the study. According to Paul et al [12], I4.0 applications, the Internet of Things (IoT), big data analytics (BDA), cloud computing, blockchain, and AI have had a significant impact on Health 4.0. A search string was thus formulated to focus only on these I4.0 technologies (applications). The primary focus was also limited to maternal health care. The following search string was thus formulated: *(("IoT" OR "Internet of Things") OR (Big Data Analytics) OR ("Cloud Computing" OR "Cloud") OR ("Blockchain" OR "Block chain") OR ("Artificial Intelligence" OR "AI")) AND (maternal)).*

A total of 1003 unique papers in English were retrieved using the search string, and 136 papers were retained after implementation of the inclusion and exclusion criteria, covering 37 years from 1985 to 2022. Our search strategy encompassed all published scholarly literature on the application of IoT, AI, BDA, cloud computing, and blockchain technologies in the domain of maternal health care. We included journal articles, conference proceedings, and relevant book chapters. To ensure the quality and focus of the analysis, we restricted our selection to (1) papers published in the English language and (2) those directly addressing I4.0 technologies and maternal health care. We excluded from the analysis editorials, news articles, discussion comments, and review papers; articles that discuss maternal health care but does not mention I4.0 technologies; and articles that highlight I4.0 technologies but merely mention maternal health care. Figure 1 illustrates the retrieval strategy.

Figure 1. Flowchart summarizing the retrieval strategies.



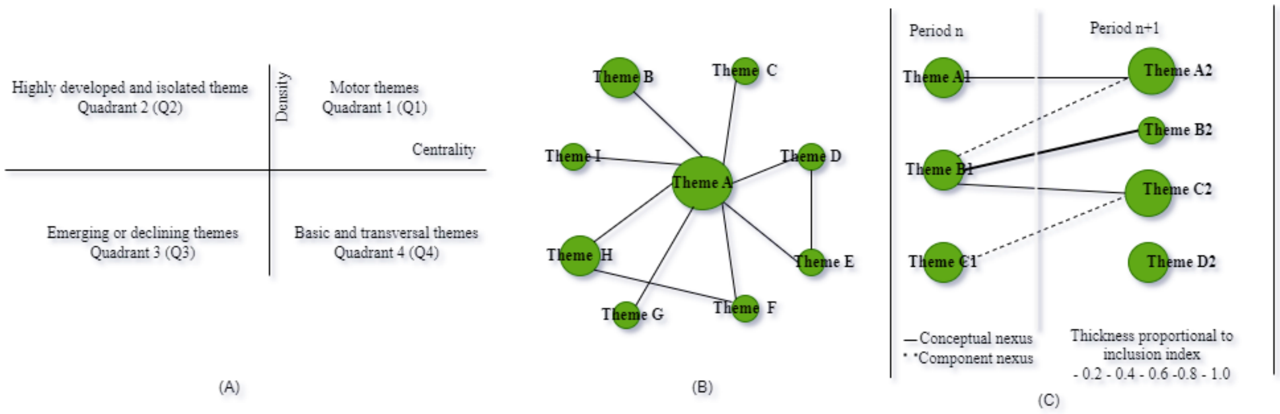
A total of 623 authors contributed to the literature between 1985 and 2022. The papers were mainly cowritten, with an average of 5.22 authors per paper. All the papers were multiauthored, save for 1 paper. The earliest publication was by Hernandez et al [13] , entitled “Expert system for prediction of foetal condition during labour,” presented at the *IEEE-Engineering in Medicine and Biology Society Annual Conference* in 1985. The latest published paper by Jaba Deva Krupa et al [14], entitled “An IoMT enabled deep learning framework for automatic detection of foetal QRS: A solution to remote prenatal care,” was published in the *Journal of King Saud University - Computer and Information Sciences*.

Method of Analysis

Bibliometric techniques were used to analyze the development of I4.0 technologies in maternal health care. Bibliometrics research has been used extensively to map the development of research, including lean supply chain management [15], traceability and lifecycle relationship [16], health technology research [10], supply chain management [17], AI in health care [11], and the theory of constraints [18]. According to Cobo et al [19] and Noyons et al [20], bibliometric analysis has 2 main objectives: research mapping analysis and academic performance analysis. Science mapping as a bibliometric technique helps monitor the structure and evolution of research by reviewing relationships among authors, disciplines, and areas of study [21]. Performance analysis quantitatively and qualitatively measures an entire field of research to determine the most effective and productive research. Further, Cobo et al [19] state that while most research focuses on measuring the scientific performance of a group of actors (countries, universities, departments, and researchers), there is a need to measure the performance of given research conceptually by interrogating specific themes or whole thematic areas.

The *Bibliometrix* R package [22] was used to compute the descriptive statistics and bibliometric analysis, including the articles’ analysis, based on the year of publication, citations, authors, affiliation, keywords, coauthorship, and thematic evolution. The conceptual science mapping was conducted following the 4-step methodology proposed by Cobo et al [19]. The first step is to detect research themes. For each period, keywords are extracted from the identified papers to build a network based on a keyword co-occurrence. The nodes represent the keywords, while an edge connects 2 nodes if they coappear in a set of papers [15]. Similar items constitute a cluster and are calculated based on the frequency of keyword co-occurrences. The second step is to visualize identified themes and thematic networks. A graphic representation of the detected themes is presented in a strategic diagram (Figure 2) and a thematic network [23]. Two dimensions are used to characterize each theme—centrality and density. Centrality measures the degree of interaction of the network with other networks, while density is the internal strength of the network [24]. According to Cobo et al [19], the themes can be classified into four quadrants: (1) motor themes (quadrant 1): they exhibit strong centrality and high density; themes in this quadrant are considered well-developed and suitable for structuring a research field; (2) niche themes (quadrant 2): these are highly developed and isolated themes considered of marginal importance to the research field; (3) emerging or declining themes (quadrant 3): these themes exhibit low density and centrality; thus, they may be considered emerging or disappearing; and (4) basic themes (quadrant 4): these represent relevant but not well-developed themes. The third step is to analyze the evolution of detected themes. The research themes are analyzed using an evolution map. The last step is to carry out the performance analysis. The production and scientific impact is measured quantitatively and qualitatively.

Figure 2. (A) Strategic diagram, (B) thematic network, and (C) thematic evolution [23].



Results

Overview

This section describes the evolution of I4.0 in maternal health care in terms of publications, citations, and impact by analyzing the following bibliometric indicators—published articles, most productive and influential journals, most productive and influential authors, and most productive and influential institutions and countries. The bibliometric performance analysis is structured into 2 parts—the production and impact of papers and the impact of authors, journals, countries, and research areas.

Publications and Citations

Figure 3 shows the distribution of publications per year and the number of publications (NP) has increased in recent years. Three periods can be observed in the development of publications—1985-2005, 2006-2015, and 2016-2022. The initial period spans 20 years, with only 1 publication in 1985 indicating that I4.0 technologies still needed to be fully adopted in maternal health care. The second period saw 14 publications. However, it can be noted that there was a fluctuation in terms of publications. There was an exponential growth in publications in the last period, with 121 articles published (121/136, 88.9% of all publications in 1985-2022). The annual growth rate of publications for this period is 15.84% compared to the overall growth rate, which stands at 9.53%, implying an increasing NP.

Figure 3. Distribution of publications (1985-2022).

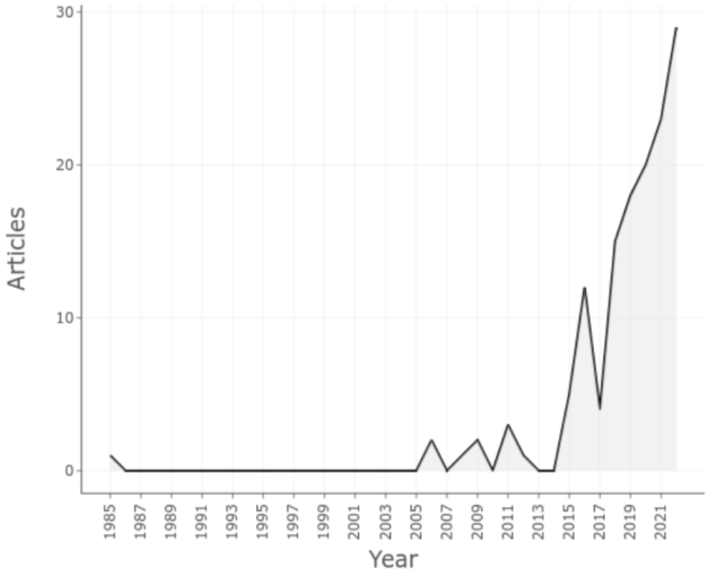
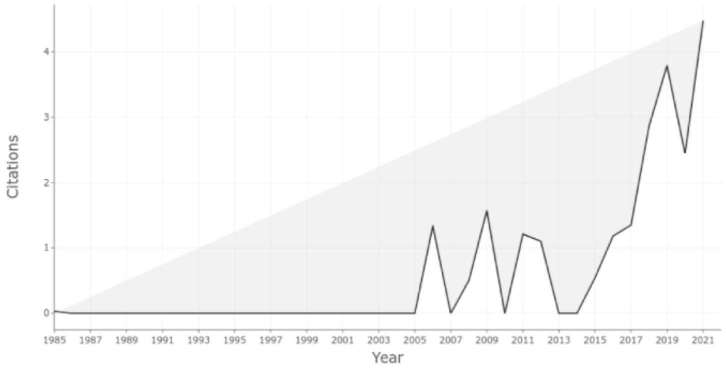


Figure 4 shows the average citations per year. The trends mirror the publications per year with no citations before 2005. However, from 2006 to 2015, there were fluctuations in citations, with the highest average (1.59, SD 0.40) for the period recorded in 2009. In the last period, there was a gradual increase in the number of citations from a low of 0.5 to a high of 4.5 per year. The increase in research may be traced back to 2011 when the term “Industry 4.0” was first coined [10]. Given their identified advantages, there was a deliberate effort to increase and adopt I4.0 technologies [25]. The slow and sporadic adoption within health care can be attributed to several factors; extensive capital investments were required to implement these technologies and train the workforce, thus averting job disruption risks [26]. Studies also underscore limitations like a lack of adequate infrastructure, a shortage of digital skills among the workforce, the risk of security breaches, the potential disruption of existing jobs, and challenges in ensuring consistent data quality as significant barriers to I4.0 integration [27,28].

Figure 4. Citations by year (1985-2022).



Most Productive Authors and Authors Impact

Table 1 shows the most productive authors during the 1985-2022 period. It gives the NP of the first 10 productive researchers. Moreira and Rodrigues have produced the highest NP with 8 each. They are followed by 4 other researchers with 5 publications each. These results indicate that the research on implementing I4.0 technology is widespread, with no one dominant researcher in the field. Table 1 also shows the most relevant authors and their local impact. It quantifies the contribution of an individual author to a published set of articles. The publication start year indicates the first year the author was published.

Table 1. Top 10 most relevant authors and author’s local impact.

Authors	NP[a]	h_index	g_index	m_index	TC[b]	PY_start[c]
Moreira	8	6	8	0.857	122	2016
Rodrigues	8	6	8	0.857	122	2016
Axelin	5	4	5	1.000	85	2019
Azimi	5	4	5	1.000	85	2019
Liljeberg	5	4	5	1.000	85	2019
Rahmani	5	4	5	1.000	85	2019
Saleem	4	4	4	0.571	86	2016
Abelha	3	2	2	0.250	7	2015
Kumar	3	3	3	0.600	67	2018
Machado	3	2	2	0.250	7	2015

[a] NP: number of publications.

[b] TC: total number of citations.

[c] PY_start: the year of first publication of articles.

Top 10 Most Local Cited Authors

Local cited authors measure how many times the authors have cited an author included in this corpus. Accordingly, this can be interpreted as a measure of the impact of authors conducting research on I4.0 in maternal health care. Moreira and Rodrigues, authors with more scientific production and the highest impact, are cited more (4 times) by other authors in the corpus. It should be noted that the low number of citations may be attributed to the fact that the core technologies behind I4.0 in maternal health care are still in development and are yet to gain wider traction and acceptance [3,12].

Most Local Cited Sources, Most Relevant Sources, Source Local Impact, and Source Dynamics

The local citations are taken from the reference lists and measure the number of times other papers in the corpus cite a paper. The paper has to appear in at least 1 of the reference lists of the other papers in the collection. In our collection, we have 2244 cited sources. *Fertility and Sterility* stands out with 63 articles, followed by *American Journal of Obstetrics & Gynecology* with

50 articles, *Reproductive Medicine and Biology* with 33 articles, *PLOS ONE* with 32, *Human Reproduction* with 31 articles, and with *BMC Pregnancy and Childbirth* at number 5 with 25 articles.

The most relevant source is the *Lecture Notes in Computer Science* (including subseries *Lecture Notes in Artificial Intelligence* and *Lecture Notes in Bioinformatics*), with 4 publications and a total citation count of 10. The *Journal of Maternal-Fetal & Neonatal Medicine* has the most citations with a total of 44 citations. However, with 3 publications, it is the third most relevant source.

Most Relevant Affiliations

The most relevant affiliation is the University of Turku in Finland with 11 articles, followed by Brazilian universities, namely, the University of Fortaleza (second with 7 articles), the National Institute of Telecommunications (fifth with 5 articles), and the Instituto Federal De Educação (eighth with 4 articles). The University of California and the University of California, Irvine in the United States are tied for third, with 6 articles each. The rest of the institutions are from Asia, accounting for 4 of the top 10 relevant affiliations—Shenzhen Technology University (sixth with 5 articles) and Anna University, Jinan University, and King Saud University, with 4 articles each.

Country Scientific Production and Most Cited Countries

The United States is positioned in the first place with a frequency of 80; followed by India with a frequency of 50; and China, Brazil, and Portugal making up the top 5 with a frequency of 34, 30, and 17, respectively. The top 10 most prolific countries are thus located in the United States, Asia, and Europe. However, it can be noted that some research focusing on I4.0 technologies in health care emanates from Africa. Most of this research is concentrated in East Africa—Kenya (n=5), Tanzania (n=2), and Uganda (n=2)—with a frequency of 9 combined. Nigeria is the most prolific country in Africa, with a frequency of 8. South Africa has a frequency of 2.

The most cited countries represent the origin of scientific production referenced by the authors from the collection. Most of the articles reference articles with their origin—Finland (77 citations); Canada (67 citations); the United States (61 citations); and China and Portugal, with 60 citations each.

Most Global and Local Cited Papers

Table 2 shows the 10 most relevant studies sorted by total citations. A globally cited paper is an article in the collection that has been cited by other papers indexed by a particular database, which in this study was Scopus. The total number of citations represents the total citations received by a selected article "all over the world." The most frequently cited work was "Missing data resilient decision-making for health care IoT through personalisation: A case study on maternal health" [29]. The objective was to develop a personalized missing data resilient system in an IoT monitoring system, as data acquisition is generally interrupted in long-term monitoring systems. The paper has 55 citations and averages 13.75 per year.

Table 2. Top 10 most globally cited papers.

Paper	TC[a]	TC/y[b]
Azimi et al [30]	55	13.75
Catley et al [31]	41	2.41
Moreira et al [29]	36	9.00
Akbulut et al [32]	36	7.20
Rigla et al [33]	35	7.00
Sayers et al [34]	31	2.21
Kumar et al [35]	22	11.0
Moreira et al [36]	22	4.40
Miyagi et al [37]	21	5.25
Tejera et al [38]	21	1.75

[a] TC: total number of citations.

[b] TC/y: total number of citations per year.

The leading papers on I4.0 in maternal health care are presented in Table 3. Only the first 10 top publications are presented based on the local citations. All the papers were published within the last 5 years (2017-2021). The most cited paper is by Azimi et al [30], which is also the most globally cited publication.

Table 3. Top 10 most influential papers on I4.0 in maternal health care.

Authors	Title	Summary of research	Source	LC[a]	GC[b]
Azimi et al [30]	Missing data resilient decision-making for health care IoT through personalisation: a case study on maternal health	This research proposed an approach that considers variability and context information to minimize bias when inputting missing data values.	FGCS[c]	3	55
Miyagi et al [39]	Feasibility of deep learning for predicting live birth from a blastocyst image in patients classified by age	An AI[d] classifier using deep learning with convolutional neural networks (CNN) was developed. The model used images of blastocysts categorized by maternal age to predict the likelihood of achieving a live birth. The authors argue that the model provides an efficient, quick, and economical diagnosis means and permits remote examination.	RMB[e]	2	21
Lopez et al [40]	Wearable technology model to control and monitor hypertension during pregnancy	A technological model was proposed to monitor the care of pregnant women through alerts provided by a group of health parameters. The model combines a group of the patients' parameters, such as blood pressure, heart rate, and physical technology with a wearable device.	CISTI[f]	2	15
Yarlapati et al [41]	Early prediction of LBW cases via minimum error rate classifier: a statistical machine learning approach	The authors reformulated a forecasting problem as a classification problem between low birth weight (LBW) and not low birth weight (NOT-LBW). They implemented a model using health indicators of pregnant women for early detection of potential LBW.	ICSC[g]	2	8
Moreira et al [42]	Smart mobile system for pregnancy care using body sensors	Presents a mobile monitoring solution to indicate high-risk pregnant women enduring hypertension. The mobile system alerts health care staff if there is a change in hypertension condition during pregnancy.	ICST[h]	2	20
Ueno et al [43]	Pregnancy prediction performance of an annotation-free embryo scoring system on the basis of deep learning after single vitrified-warmed blastocyst transfer: a single-center large cohort retrospective study	The authors discussed an embryo assessment model, iDAScore, developed using deep learning. The model performed better than an annotation-dependent ranking tool or traditional embryo assessment tools.	FAS[i]	1	7
Li et al [44]	The impact of healthcare monitoring technologies for better pregnancy	The authors performed an experimental analysis based on a sample of 315 pregnant women. The study highlighted a high recognition and acceptance of wearing wearable Internet of Things (IoT) devices during pregnancy by pregnant women.	ICET[j]	1	2
Huang et al [45]	Using deep learning in a monocentric study to characterise maternal immune environment for predicting pregnancy outcomes in the recurrent reproductive failure patients	The researchers applied artificial intelligence to analyze patients' medical information with recurrent reproduction failure (RRF). A machine learning model to predict the pregnancy outcomes for patients with RRF at any gestational period, namely, biochemical pregnancy, clinical pregnancy, ongoing pregnancy, and live birth was developed	FII[k]	1	5
Sarhaddi et al [46]	Long-term IoT-based maternal monitoring: System design and evaluation	An IoT-based system to monitor maternal health during pregnancy and postpartum was developed. Further, an artificial intelligence method for analyzing the data was integrated. The researchers implemented a proof-of-concept monitoring system for an actual human participant study.	SSS[l]	1	5
Mhajna et al [47]	Wireless, remote solution for home fetal and maternal heart rate monitoring	The researchers developed a solution to fuse information gathered from a wireless abdominal belt that is self-applied to obtain fetal heart rate (FHR) and maternal heart rate (MHR).	AJOG[m]	1	17

[a] LC: local citations.

[b] GC: global citations.

cFGCS: Future Generation Computer Systems.

[d] AI: artificial intelligence.

[e] RBM: Reproductive Medicine and Biology.

[f] CISTI: Conference on Information Systems and Technologies.

[g] ICSC: 2017 IEEE International Conference on Smart Computing (SMARTCOMP).

[h] ICST: 2016 International Conference on Selected Topics in Mobile & Wireless Networking (MoWNeT).

[i] FAS: Fertility and Sterility.

[j] ICET: 2021 IEEE 4th International Conference on Electronics Technology.

[k] FII: Frontiers in Immunology.

[l] SSS: *Sensors*.

[m] AJOG: American Journal of Obstetrics & Gynecology.

Thematic Evolution of the Field

The first period from 1985 to 2005 and the second period from 2006 to 2015 were combined since the first period had only 1 paper published. The evolution of I4.0 development in maternal health care was thus analyzed across 2 periods, from 1985 to 2015 and from 2016 to 2022. Figures 5 and 6 represent the strategic maps of the main themes and trends for each period based on the authors' 250 most frequently used words. Table 4 lists the keywords per cluster (I4.0 technologies) by their frequency.

Figure 5. Thematic map for the period 1985-2015.

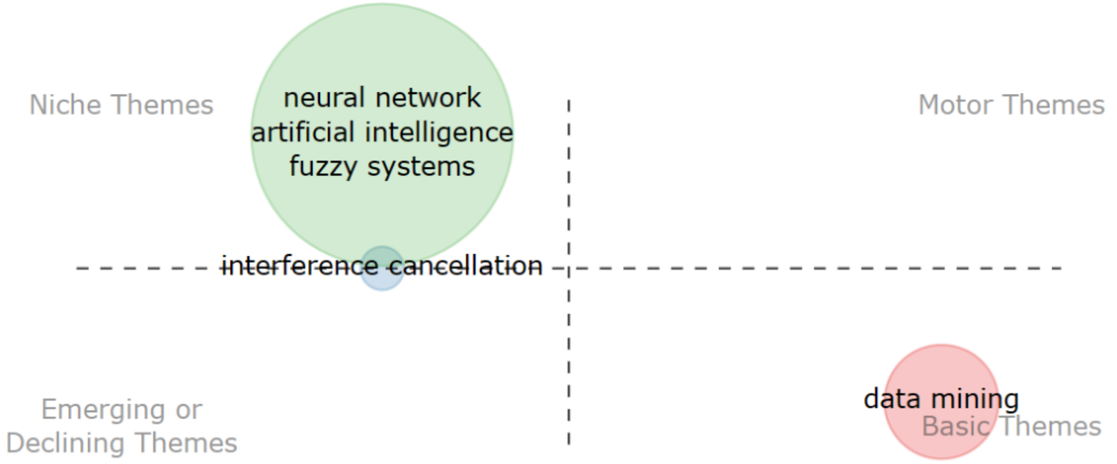


Figure 6. Thematic map for the period 2016-2022. ECG: electrocardiogram.

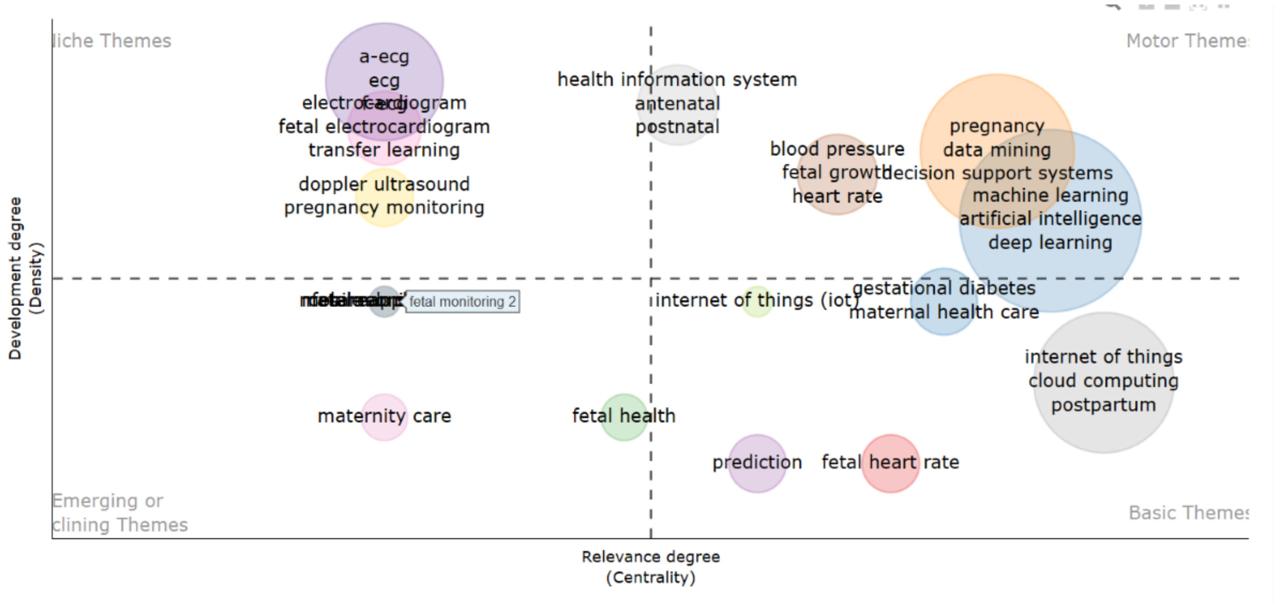


Table 4. Cluster keywords and period.

Period and cluster	Keywords
1985-2015	
Neural network	"Neural networks," "artificial intelligence," and "fuzzy systems"
Data mining	"Data mining"
2016-2022	
Machine learning	"Artificial intelligence," "deep learning," "neural networks," "risk prediction," "telemedicine," and "digital health"
Internet of Things	"IoT," "wearable devices," "m-healthcare," and "cloud computing"

The most highly developed theme was neural networks, including AI and fuzzy systems. Artificial neural networks were mostly used as classifiers. Normal, hypertensive, and preeclamptic pregnancies using maternal heart rate variability indexes were explored [38]. Another predominant use case was the prediction of high-risk preterm births using neural networks [31]. AI and fuzzy systems were used to analyze extracted fetal electrocardiogram data [48,49].

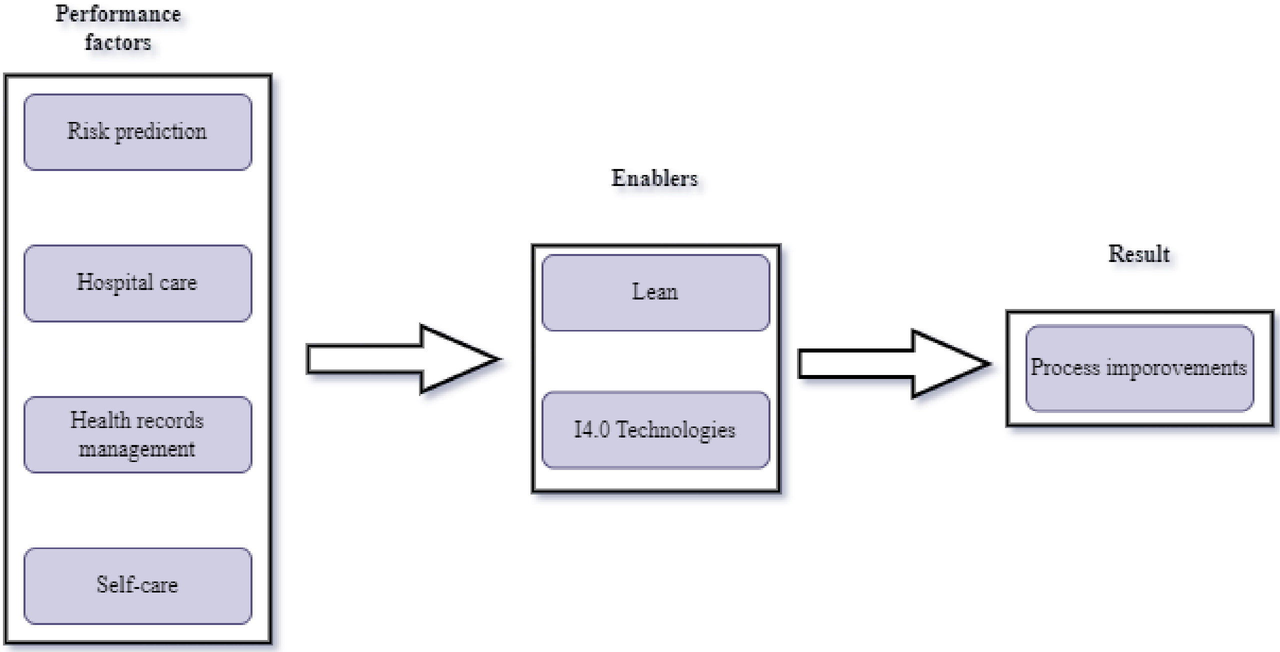
Figures 5 and 6 show that there has been a shift in themes focusing on I4.0 from niche themes that are considered of marginal importance in the research field to themes with high density and centrality. From 2016 to 2022, new themes such as deep learning, IoT, and cloud computing were developed. Prior to the 2016-2022 period, several factors hindered the widespread adoption of cloud computing in health care. These included concerns among users regarding data security and privacy, a perceived loss of control over data governance, and a lack of trust in the compliance practices of cloud service providers [50,51]. In 2016-2022, cloud computing was widely accepted despite security concerns and regulations were adopted to address these concerns [52]. Moreira et al [42] and Lopez et al [40] developed an IoT-based system to monitor hypertension in pregnant women, with alerts sent in the event of a change in hypertension. Sarhaddi et al [46] combined the IoT and AI to monitor maternal health during pregnancy and postpartum. Vitals of pregnant women were collected using sensors and further analyzed for anomalies using AI. Mhajna et al [47] developed a self-applied wireless abdominal belt to obtain fetal heart rate and maternal heart rate. Conoscenti et al [53] postulated that connected devices spread sensitive personal patient data and thus privacy can only be guaranteed by the system's technical design. They proposed a peer-to-peer system, particularly blockchain, to architect privacy-preserving in IoT systems. Fernandez-Carames and Fraga-Lamas [54] used blockchain to ensure, among others, seamless authentication, data privacy security, and robustness against attacks. However, it must be noted that from the identified I4.0 technologies that have impacted health care, as suggested by Paul et al [12], blockchain in maternal health care has not gained widespread adoption in health care; this may be due to technical challenges, regulatory uncertainties, and the lack of interoperability between different blockchain platforms [3].

Discussion

Conceptual Framework

The World Health Organization recommends that all pregnant women have at least 4 antenatal care (ANC) assessments carried out in the following cycles: 8-12 weeks, 24-36 weeks, 32 weeks, and 36-38 weeks [55]. According to Busumani et al [56], timely ANC booking helps to identify and monitor expecting mothers who might be at risk. Recordkeeping is essential when it comes to monitoring patients' health. For example, good ANC is crucial as it aims to prevent or detect complications during pregnancy. Pregnant women are encouraged to share information with their health care providers during pregnancy. Sibanda et al [3] posit that 1 area that stands to benefit from adopting manufacturing practices is maternal health care. With many processes in maternal health care, it stands to benefit by adopting Lean practices. According to Ilangakoon et al [57] , Lean practices are tools and techniques used in manufacturing to improve processes. The authors further suggest that Lean tools and techniques, when used in health care (Lean health care), simplify health care processes by adding value and eliminating processes that lead to waste. This section suggests a conceptual framework adapted from Ilangakoon et al [58] and a research agenda. Figure 7 shows the conceptual framework that combines I4.0 technologies and Lean practices in health care as developed from the reviewed literature.

Figure 7. Conceptual framework. I4.0: Industry 4.0.



Four factors contributing to the operational performance in maternal health care were identified from the reviewed literature and they are risk prediction, hospital care, health records management, and self-care. These factors must be optimized to streamline services and focus on value-adding services. Therefore, from the literature and the work by Ilangakoon et al [58] , I4.0 technologies and Lean practices were identified as enablers. When performance is optimized, it results in improved patient care, timely disease diagnosis, ease of access to patient records by all stakeholders, patient involvement in their care, and innovative product development.

As noted in Table 5, to enhance operational performance in maternal health care, 4 critical factors from the literature were identified: risk prediction, hospital care, health records management, and self-care. Directly optimizing these factors influences the delivery of value-adding services such as timely treatment, risk analysis, self-monitoring, and reduced hospital wait times. We propose that I4.0 technologies and Lean practices can enable this optimization. For example, AI-powered risk prediction tools facilitate timely disease diagnosis, while secure and accessible electronic health records promote patient involvement in their care. We anticipate enhanced patient outcomes, seamless information sharing among collaborators, and improved treatment plans by effectively using these enablers. Our results highlight the prominence of I4.0 technologies, AI, cloud computing, BDA, and IoT in improving maternal care. As expected, blockchain technology, being relatively new, is less widely adopted within the health care sector at present.

Table 5. Performance improvement of maternal processes with I4.0 technologies.

Performance factor	Process improvement	Sources
Risk prediction	Timely treatment and risk analysis may prevent more extended hospitalizations, detailed examinations, and waiting for diagnostics. With AI[a] and BDA[b], longer diagnostic processes and corrective treatment plans can be managed more effectively. Doctors can predict risk and find mitigatory measures.	[35,39,41,59]
Hospital care	The waiting time of the patient to receive medical service or preparation when being admitted to the hospital in an emergency is an issue that needs consideration. In the event of a complicated pregnancy, vital parameters of the patient can be sent ahead before admission into a hospital so that precautionary arrangements may be made and waiting time saved. Using the IoT[c] and the cloud to store sensor data allows vital parameters to be collected and sent before admission.	[14,60,61]
Health records management	During ANC[d] and postnatal care, different stakeholders play a role in managing a pregnant woman, depending on the state of the pregnancy. In a hierarchical health care system, if a lower-level facility cannot assist, they may refer the pregnant woman to a higher-level facility. However, in some cases, the woman can visit any secondary health care facility by self-referral. Thus, records must be kept for ease of sharing between health facilities and to remove the burden of carrying out tests that would have been done at another facility. This also reduces the time to treatment.	[5,6]
Self-care	Unlike other care processes, ANC is preventive and may be carried out at home or a health care facility accessible to the mother. Frequent consultations are encouraged. However, it can be noted that these consultations might clog the hospital systems and, in some developing countries, care facilities may be further from where the expectant mother is. Systems using the IoT, cloud computing, BDA, and AI have been developed to allow for home-based care. Sensors monitor the woman at home and provide data to caregivers remotely. In the event of an anomaly, alerts are sent. The expectant mother can also self-monitor through smart wearable devices or smartphones.	[7-9]

[a] AI: artificial intelligence.

[b] BDA: big data analytics.

[c] IoT: Internet of Things.

[d] ANC: antenatal care.

Conclusions

Discussion

This paper reviewed the state of the art in the evolution and structure of I4.0 technologies in maternal health care and how they may be used to optimize the operational processes. The study examined the state of research over the period of 1985-2022. We critically evaluated 37 years of I4.0 technologies in maternal health care to identify the main research themes in the field, identify opportunities, and set a research agenda. The study period was divided into 3 periods—1985-2005, 2006-2015, and 2016-2022. For analysis purposes, the first 2 periods were combined. A total of 136 publications during the entire period were identified and reviewed. There was a notable increase in the last period accounting for 121 publications. The research in this period reflects the innovative use of I4.0 technologies. The tools developed help doctors lessen the burden of constantly monitoring patients by providing automated recommendations to patients sent through wearable devices or smartphones. Technologies such as the IoT and cloud computing allow for easy data collection, data sharing among medical practitioners, and remote care of expectant mothers, while AI and BDA allow medical practitioners to gain more insights into patient data.

A noteworthy increase in the amount of research literature can be observed in bibliometric performance. Moreira and Rodrigues are the most prolific authors who have been key in developing I4.0 in maternal health care. Regarding scientific mapping, a conceptual framework was developed from the identified clusters with 4 performance factors suggested—risk prevention, hospital care, health records management, and self-care. Furthermore, how I4.0 technologies can be used to improve operational processes was discussed.

Contributions to Theory, Implications for Practice, and Research Agenda

The main contributions of this study were identifying research themes and their evolution, a conceptual framework informed by the literature, and performance factors to optimize operations in maternal health care processes.

Regarding implications for practice, our research has suggested a conceptual framework with 4 performance factors—risk prediction, hospital care, health records management, and self-care, which serve as pillars to optimize operations in maternal health care. This could be useful for health care facilities that want to optimize their operations, those overwhelmed by patients, or those in resource-limited countries with a huge turnover of health care professionals. Moreover, innovative ideas may be adapted to suit their environments from the identified use cases of I4.0 technologies in maternal health care. Further stakeholders such as policy makers, technologists, and health care professionals need to consider the areas that have a potential impact on technological advancement and they are explained in the next section.

Telemedicine and Remote Medicine

The IoT significantly expands the potential for remote monitoring and self-care in maternal health, reducing the frequency of hospital visits. Stakeholders must explore how wearables and remote monitoring devices enhance prenatal and postnatal care access, particularly within underserved communities. Key considerations include improving affordability, addressing the digital divide, and providing appropriate patient training to ensure equitable access to these technological advancements.

AI, Data Sharing, and Analytics

AI promises to improve predictive modeling to identify high-risk pregnancies at an earlier stage, enabling earlier interventions. Additionally, AI can contribute to developing personalized treatment plans for individual patients. However, addressing the potential for bias within data sets used for these applications is crucial to ensure equitable outcomes for all patients. Secure data-sharing platforms driven by technologies such as blockchain have the potential to facilitate the exchange of maternal health data across institutions while maintaining patient privacy. Big data analysis derived from these data can then inform public health interventions aimed at reducing disparities in maternal health care access and outcomes.

I4.0 Technologies and Collaboration

In pursuing effective maternal care practices, effective collaboration models are crucial for developing and implementing technology-driven maternal care solutions. Key considerations should be the best practices in building effective partnerships among all stakeholders, namely policy makers, technologists, and health care professionals.

Regulatory Frameworks and Ethics

Interdisciplinary teams should prioritize addressing ethical concerns related to privacy, consent, and equity when deploying new technologies, especially AI use in health care [62]. Considerations should be made on how teams can work together to address the ethical issues regarding privacy, patient consent, and equitable deployment of I4.0 technologies. Furthermore, with a lack of regulatory frameworks for deploying these technologies, stakeholders should proactively address the regulatory complexities.

Regarding theoretical contributions, our bibliometric review helped identify the leading journals for literature and publication, the universities and institutions leading in research, and the most prolific and leading researchers in the field for possible collaboration. The review outlined the research field’s evolution and development and suggested a research agenda. In terms of the latter, a researcher may be able to discover new research avenues in the following sections.

Governance Considerations for Implementing I4.0 Technologies in Health Care

Much research focused on the use of AI in maternal health care. However, most of the reviewed literature was conceptual in the form of frameworks, models, and prototypes with no implementations on production systems. This can be attributed to ethical issues in adopting AI in mainstream systems. There is thus scope for further research to identify the challenges and obstacles limiting the implementation of prototypes in an actual medical setting and the development of ethical frameworks. IoT-based systems collect data from various devices (“things”) remotely from expectant mothers to be used in health care facilities to monitor them and, in some cases, made available to research institutions. The issue now is who the owners of the data are. How should that data be used? The ownership of health data is a sensitive issue that warrants further scrutiny.

Developing Adoption Frameworks or Models

It can be noted that most of the research to solve challenges in maternal health care is coming from outside Africa, yet the continent has a high maternal mortality rate. However, the developed solutions can be adapted to the African context. Health care processes are many and varied and most are not standardized, which brings challenges in adapting the developed solution to another context. Another issue is the interoperability challenges between disparate systems. There is scope for further research on developing frameworks and models to guide the interoperability of disparate systems. Furthermore, research is needed on how the I4.0 technologies can be applied in maternal health care to optimize processes and integrate them into existing systems.

Infrastructure, Privacy, and Security Mechanisms

IoT applications collect data through the use of many sensors, and in most cases, they are used in conjunction with technologies such as cloud computing to store data. Data are analyzed for insights using BDA tools. Adequate infrastructure is required for flexible performance and management of large volumes of data, which is an issue that is critical in the proper performance of IoT applications. Unauthorized access to sensor data in transit or stored on the cloud threatens patient data integrity and this problem needs to be resolved. Blockchain and more specifically, nonfungible tokens have been used to secure and guarantee data ownership. This open research area needs to be explored within the context of maternal health care.

Limitations

Our study has limitations that deserve acknowledgment. While we are confident that Scopus, a multidisciplinary database publishing peer-reviewed research, provided a valuable foundation for our analysis, future studies could benefit from including additional databases like Web of Science to potentially capture a broader range of relevant publications. Additionally, the scope of explored I4.0 technologies could be broadened. This study focused on 5 key technologies, but future research could investigate the potential applications of 3D printing, augmented reality, virtual reality, digital twins, and cyber-physical systems in improving maternal health care. Finally, while “maternal health” was a broad keyword for this initial investigation, a more refined set of keywords might be necessary in future studies to ensure a comprehensive capture of specific research within the broader field.

Conflicts of Interest

None declared.

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Abbreviations

AI: artificial intelligence
ANC: antenatal care
BDA: big data analytics
I4.0: Industry 4.0
IoT: Internet of Things
NP: number of publications
SDG: Sustainable Development Goal

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Original Paper

Perceived Acceptability of Technology Modalities for the Provision of Universal Child and Family Health Nursing Support in the First 6-8 Months After Birth: Cross-Sectional Study

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Abstract

Background: Child and Family Health Nursing (CFHN) services provide universal care to families during the first 2000 days (conception: 5 years) to support optimal health and developmental outcomes of children in New South Wales, Australia. The use of technology represents a promising means to encourage family engagement with CFHN services and enable universal access to evidenced-based age and stage information. Currently, there is little evidence exploring the acceptability of various models of technology-based support provided during the first 2000 days, as well as the maternal characteristics that may influence this.

Objective: This study aims to describe (1) the acceptability of technology-based models of CFHN support to families in the first 6 months, and (2) the association between the acceptability of technology-based support and maternal characteristics.

Methods: A cross-sectional survey was undertaken between September and November 2021 with women who were 6-8 months post partum within the Hunter New England Local Health District of New South Wales, Australia. Survey questions collected information on maternal demographics and pregnancy characteristics, perceived stress, access to CFHN services, as well as preferences and acceptability of technology-based support. Descriptive statistics were used to describe the characteristics of the sample, the proportion of women accessing CFHN services, maternal acceptability of technology-based support from CFHN services, and the appropriateness of timing of support. Multivariable logistic regression models were conducted to assess the association between maternal characteristics and the acceptability of technology-based CFHN support.

Results: A total of 365 women participated in the study, most were 25 to 34 years old (n=242, 68%), had completed tertiary level education or higher (n=250, 71%), and were employed or on maternity leave (n=280, 78%). Almost all (n=305, 89%) women reported accessing CFHN services in the first 6 months following their child's birth. The majority of women (n=282-315, 82%-92%) "strongly agreed or agreed" that receiving information from CFHN via technology would be acceptable, and most (n=308) women "strongly agreed or agreed" with being provided information on a variety of relevant health topics. Acceptability of receiving information via websites was significantly associated with maternal employment status (*P*=.01). The acceptability of receiving support via telephone and email was significantly associated with maternal education level (adjusted odds ratio 2.64, 95% CI 1.07-6.51; *P*=.03 and adjusted odds ratio 2.90, 95% CI 1.20-7.00; *P*=.02, respectively). Maternal age was also associated with the acceptability of email support (*P*=.04).

Conclusions: Technology-based CFHN support is generally acceptable to mothers. Maternal characteristics, including employment status, education level, and age, were found to modify the acceptability of specific technology modalities. The findings of this research should be considered when designing technology-based solutions to providing universal age and stage child health and developmental support for families during the first 2000 days.

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KEYWORDS

maternal; postnatal; postpartum; acceptability; technology; digital health; first 2000 days; child health; experience; experiences; attitude; attitudes; opinion; opinion; perception; perceptions; perspective; perspectives; acceptance; cross sectional; survey; surveys; questionnaire; questionnaires; pediatric; pediatrics; infant; infants; infancy; baby; babies; neonate; neonates; neonatal; newborn; newborns; nurse; nurses; nursing

Introduction

The first 2000 days of a child's life (conception: 5 years) is a critical time for physical, cognitive, social, and emotional development [1]. Routine health care services or interventions provided in early life have been shown to be protective of poor health outcomes and improve early life experiences, such as learning outcomes, mental well-being, and relationships, as well as healthy growth and development [2,3]. Future health outcomes for children are influenced by these early life experiences and exposures, and subsequently the cumulative effects of positive or negative later life experiences [3].

Given the first 2000 days are a critical period of child health and development, the World Health Organization and governments internationally have released policy frameworks and guidelines that outline strategies and objectives to support the health and development of children during the first 2000 days [4,5]. One example is the First 2000 Days implementation strategy, a government framework that has been released in New South Wales (NSW), Australia [1,6]. A key objective within this framework is that NSW Health provides universal access to child and family health care via Child and Family Health Nursing (CFHN) services. CFHN services support the health and development of children from birth to 5 years across the state through a family centered approach. Services routinely offered by CFHN services include universal health home visits in the first month of a child's life, postnatal care, immunizations, child health, and developmental checks (through the Personal Health Record or "Blue Book"), feeding support and maternal psychosocial assessments and screening [1]. Despite the availability of this comprehensive service, only half of the 100,000 families of children born each year within NSW continue to access CFHN services within the first year [7], limiting the capacity of CFHN services to provide ongoing and universal health care to families consistent with best practice guidelines.

The delivery of health care services via technology represents a promising way to increase family engagement with CFHN services and provide universal access to evidence-based information consistent with recommendations. In Australia, the COVID-19 pandemic resulted in the widespread adoption of digital technologies to deliver health care services [8-10] including care routinely offered by CFHN services. For example, CFHN services at a local and state level currently use technology, such as telehealth, email, and social media, to support the delivery of care to women and families across NSW [11,12]. While emerging evidence supports the effectiveness and acceptability of nurse-delivered telehealth consultations [11,12], to our knowledge, there is little evidence of the acceptability of other models of technology-based support provided to families during the first 2000 days.

While characteristics, such as age, education, computer literacy, ethnicity, employment, socioeconomic position, and gender, have been associated with the uptake and acceptability of digital health interventions more broadly [13,14], there is limited evidence that comprehensively examines associations between maternal characteristics and the acceptability of technology-based CFHN services, which may be important for designing services that are tailored to individual needs [15]. Given the current evidence gaps, this study aimed to describe (1) the acceptability of technology-based models of CFHN support to families in the first 6 months, by differing health topics, as well as preferences for timing of information receipt; and (2) the association between the acceptability of technology-based support by maternal characteristics hypothesized to influence adoption of technology-based interventions.

Methods

Ethical Considerations

This study is reported in accordance with the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines [16]. Ethical approval to undertake the study was obtained from the Hunter New England (HNE) Human Research Ethics Committee (16/11/16/4.07), Aboriginal Health and Medical Research Council (1236/16), and the University of Newcastle Human Research Ethics Committee (H-2017-0032). This research was conducted in compliance with informed consent guidelines and adhered to national law and regulations regarding the protection of personal information, privacy, and human rights.

Study Design and Setting

A cross-sectional survey conducted via computer-assisted telephone interview (CATI) was undertaken between September and November 2021 with women who were 6-8 months post partum within the HNE Local Health District of NSW, Australia. The HNE area is a socioeconomically and geographically diverse region covering approximately 130,000 square kilometers, encompassing major metropolitan, regional, and remote locations [17]. In 2020, there were 10,377 births in the HNE region, accounting for 11.2% of births in NSW [18].

Context

In NSW, CFHN services provide public health care to women and their families in the child's first 5 years of life. Health professionals that attend to these services include child and family health nurses, registered midwives, doctors, allied health workers, Aboriginal health workers, and practitioners [19]. Across NSW, there are approximately 417 CFHN services, and approximately 16.3% of CFHN services are located in the HNE Local Health District [19]. The provision of CFHN services may include but not be limited to health home visits, breastfeeding or infant feeding education and support, maternal and child routine screening (ie, maternal psychosocial screening and child vision and hearing screening), child health checks, immunizations, contraception, mental health, and parenting education [20].

Sample and Recruitment

Women who were 26-37 weeks (6-8 months) post partum, had received antenatal care from public maternity services in the HNE region (responsible for the provision of antenatal care to approximately 70% of women across the district) [17,18] and had previously participated in an antenatal survey while pregnant and agreed to be contacted for future surveys were eligible to participate in the study [21,22]. As per eligibility criteria for the initial antenatal survey, women were ineligible if they were younger than 18 years of age, had an unfortunate pregnancy-related outcome, including stillbirth or death of child, or were not proficient in English preventing them from undertaking the survey unaided.

Recruitment Procedure

All women in the sampling frame (N=713) were invited to participate in the CATI via a mailed written information statement. The written information statement included an outline of the purpose of the survey and a toll-free number to opt-out or decline survey participation. Electronic medical record data (ie, child's date of birth and live birth) and previous antenatal survey data (ie, consent to be contacted again) were used to generate a weekly sample of eligible women over an 8-week period. A weekly sample of 100 women were approached to participate in the study for the first 6 weeks, with 68 and 47 women approached in the final 2 weeks of recruitment, respectively. Participants were approached in descending order of their child's date of birth (ie, parents of older babies were approached first).

Recruitment Procedure for Non-Aboriginal Women

One week after information statements were mailed, non-Aboriginal women were contacted via telephone and invited by a female interviewer to participate in the survey through a CATI. Women received up to 10 phone attempts over a two-week period to invite study participation. As per formal ethics approval, verbal consent to participate in the study was sought from women during the CATI. Women who declined to participate during the CATI were offered the opportunity to complete the web-based survey. Women who opted to complete the web-based survey were sent an individual survey link to their mobile number or email address. Prior to accessing the web-based survey, women were reminded, on the survey's display screen, that participation was voluntary and that it was possible to decline the survey at any point. Women's consent into the study and survey completion status (both via the CATI and web-based) were saved into a central survey database held by the research team.

Recruitment Procedure for Aboriginal and Torres Strait Islander Women

As per advice received through local cultural consultation processes, women of Aboriginal or Torres Strait Islander origin and/or women who attended or were enrolled to attend an Aboriginal Maternal and Infant Health Service as identified via medical record data were sent an SMS text message after the mail out of the information statement. The SMS text message offered women one of three options as follows: (1) to complete the survey via CATI; (2) to complete the web-based survey; or (3) to decline participation. As per the procedures described above, women who opted to complete the web-based survey were sent an individual survey link to their mobile number which was active for 2 weeks. Women who opted to complete the survey via telephone or did not reply to the SMS text message within 5 days were contacted via telephone and invited to participate in the study by a female interviewer. Women who declined participation via SMS text message were recorded in the central survey database. All women who opted to complete either the telephone or web-based survey were given the opportunity to identify as Aboriginal or Torres Strait Islander or both (regardless of their previous medical record or antenatal survey data). As per ethics and local consultation processes, women who identified as Aboriginal and/or Torres Strait Islander during the CATI were offered the choice of undertaking the survey with a female Aboriginal interviewer.

Data Collection Procedures

Both the CATI and web-based surveys were developed in REDCap (Research Electronic Data Capture; Vanderbilt University) electronic data capture tools [23]. Survey consent and responses were also stored in REDCap which acted as the central survey database. All survey items were developed and based on local, state, and national health surveys with postpartum women [24,25] and surveys conducted in similar health settings (ie, antenatal services) to assess self-reported acceptability and care by the health service [22]. The surveys were reviewed by child and family health nurses, dietitians, Aboriginal health care workers, and end users (mothers and Aboriginal and Torres Strait Islander women) and pilot-tested prior to use.

Outcome Measures

Women were asked the following questions in this survey: Aboriginal and/or Torres Strait Islander origin; country of birth; residing postcode, current employment status (full-time, part-time, casual, paid or unpaid maternity leave, unemployed, home duties, student, retired, full-time carer, unable to work due to health problems); timing of their return to work after birth (in months); the child's date of birth. The survey items were adapted from previous surveys with postpartum women [25] and the Australian Infant Feeding Study [24]. Maternal education status, first or subsequent pregnancy status, and maternal age were not collected in this survey as they were previously collected via the initial antenatal survey with women or medical record data [22]. Participants were asked about their perceived stress via the "perceived stress scale" [26]. The tool is a validated 10-item scale that asks participants to rate their feelings and thoughts in the last month on a 5-point Likert scale from 0 (never) to 4 (very often). For example, the first item asks "In the last month, how often have you been upset because of something that happened unexpectedly?"

Participants were asked about whether they had accessed CFHN services in the first six months since the birth of their baby (yes or no) and the location of the visit (home or clinic).

Preferences and Acceptability of Technology-Based Support for Child and Family Health Services

Questions around the acceptability of perceived models of care were developed using a 5-point Likert scale (strongly agree to disagree) and were informed using previous surveys with women attending antenatal services [22]. To assess the perceived acceptability for various technology-based CFHN service provision models, mothers were asked: "Can you tell me if you strongly agree, agree, neither agree or disagree, disagree or strongly disagree with receiving information from the health service to support the health of you and your baby for each of these models of technology?" Where five digital delivery models (accessible within current NSW health care systems) were listed (1) SMS text message, (2) website, (3) telehealth services, (4) phone, (5) email, and women were prompted to indicate their acceptability for each option listed. To assess preferences for health-related topics, mothers were asked "Please tell me whether you believe it would be okay to receive support and advice on these topics via technology-based services. You can respond with strongly agree, agree, neither agree or disagree, disagree or strongly disagree." A list of 11 health-related topics (informed by key Blue Book topics aligned with focus areas of CFHN service provision) were given as options for this question including (1) breastfeeding or bottle feeding, (2) growth checks and immunization reminders, (3) introduction to solids (including timing, portion and type of foods), (4) fussy eating, (5) sleep and settling, (6) age and stage developmental milestones, (7) healthy growth, (8) healthy eating, (9) mental health, (10) social support, (11) parent groups or networks, and women were able to select all response options that applied. Preferences for the timing of the receipt of technology-based support were assessed by asking: "In addition to usual care, if the health service was to provide families with information and support via technology about feeding your baby, when would be the ideal time to receive this information." Women were instructed to select all response options that applied, including (1) 1st trimester, (2) 2nd trimester, (3) 3rd trimester, (4) 0-6 months after birth, and (5) 7-12 months after birth.

Characteristics Associated With Perceived Acceptability of Technology-Based CFHN Models of Care

We explored if there were any differences in acceptability by technology-based models of CFHN support by characteristics hypothesized to influence acceptability and use of digital health interventions [13] such as maternal age, maternal education, socioeconomic area, geographical remoteness, current employment status, first pregnancy, Aboriginal or Torres Strait Islander origin, perceived stress, and CFHN service access (in first 6 months post birth).

Data Analysis

All data were analyzed using the statistical software package SAS (version 9.3; SAS Institute). Descriptive statistics were used to describe the (1) characteristics of the sample, (2) the proportion of women accessing child and family health services in the first 6 months, (3) acceptability of receipt of technology-based support from child and family health services, and (4) appropriate timing of information receipt. Data regarding the characteristics of the sample are presented categorically. Maternal age and timing of return to work after birth were trichotomized where maternal age was categorized as "18-24 years," "25-34 years," and "≥35 years" and women's timing of return to work after birth was categorized as "0-3 months," "4-6 months," and ">6 months." Condensed response categories were created for (1) Aboriginal or Torres Strait Islander Origin ("Aboriginal and/or Torres Strait Islander" or "Neither Aboriginal or Torres Strait Islander" and "don't know"), (2) maternal education ("high school or less" or "tertiary education or more"), and women's current employment status including "employed" (full-time, part-time, or casual); "maternity leave" (paid or unpaid) or "unemployed" (home duties, unemployed, retirees, or full-time carers). Women's residential postcode was used to determine socioeconomic areas using the 2016 socioeconomic indexes for areas [27], which were dichotomized at the median into areas of "most disadvantage" or "least disadvantage." Women's residential postcode was also used to determine geographical remoteness ("major cities" or "regional or remote") using the Access/Remoteness Index of Australia [28]. Women's perceived stress was determined using the 10-item perceived stress scale [26] where scores were assigned ranging from 0 to 4 for each respective question. The score for each question was then summed to provide a total score of 40. "Low stress" was defined as a score ranging from 0 to 13, "moderate stress" was defined as a score ranging from 14 to 26, and "high stress" was defined as a score of 27 to 40. Child age at the time of survey completion is presented continuously (mean, SD). Women's reported acceptability of CFHN via varying models of technology was dichotomized into "acceptable" (agreed or strongly agreed) and "not acceptable" (strongly disagree, disagree, or neutral).

Logistic regression models were created to assess associations between maternal characteristics [(1) Aboriginal and/or Torres Strait Islander status, (2) age, (3) education, (4) socioeconomic status, (5) geographical remoteness, (6) employment status, (7) first pregnancy, (8) perceived stress, and (9) use of CFHN services] and a measure of the acceptability (agree or strongly agree) of technology. Separate logistic regression models were undertaken for each of the five technology models [(1) website, (2) telehealth, (3) telephone, (4) SMS text message, and (5) email], exploring 45 crude logistic regression models in total. Both crude (unadjusted) and models adjusted for all 9 participant characteristics are presented.

In the instance where regression models were unable to produce an odds ratio (OR; if 100% of the group were in one comparison arm), a Haldane-Anscombe correction [29] was applied, whereby the data was weighted in order to add 0.5 to each cell frequency. Statistical significance was set at *P*<.05.

Results

Characteristics of Sample

A total of 356 (50% response rate) women participated in the study. While most of the characteristics between the consenting and nonconsenting sample were similar, self-reported Aboriginal and/or Torres Strait Islander status was significantly (*P*=.03) higher within the nonconsenting sample (n=36, 11.6%) compared with the consenting sample (n=23, 6.6%). The majority (n=315, 88%) of consenting study participants were born in Australia with 57% (n=202) of participants residing in major cities and 43% (n=154) of participants in regional or remote locations. Aboriginal and/or Torres Strait Islander women represented 7% (n=23) of the sample. Most of the women were between the ages of 25 and 34 years old (n=242, 68%), had completed tertiary level education or higher (n=250, 71%), and were on maternity leave (n=140, 39%). Of those that were currently employed (n=140), just over half (n=79, 56%) returned to work between 4 and 6 months after birth. The majority of women (n=205, 58%) had perceived stress scores rated as “low” at the time of the survey. The full characteristics of the sample are presented in Table 1.

Table 1. Characteristics of women who participated in the survey.

Characteristics	Value (N=356)
Aboriginal and/or Torres Strait Islander[a], n (%)	
Yes	23 (7)
No or don’t know	325 (93)
Maternal age (in years), n (%)	
18-24	45 (13)
25-34	242 (68)
≥35	69 (19)
Maternal education[a], n (%)	
High school or less	100 (29)
Tertiary education or more	250 (71)
Country of birth, n (%)	
Australia	314 (88)
United Kingdom	4 (1)
New Zealand	7 (2)
India	6 (2)
Other	24 (7)
Socioeconomic area[b], n (%)	
Most disadvantaged	222 (62)
Least disadvantaged	134 (38)
Remoteness[c], n (%)	
Major Cities	202 (57)
Regional or remote	154 (43)
Employment status at the time of the survey	
Employed	140 (39)
Maternity leave (paid or unpaid)	140 (39)
Unemployed	76 (21)
Return to work after birth (in months; n=140), n (%)	
0-3	31 (22)
4-6	79 (56)
>6	30 (21)
First pregnancy, n (%)	
Yes	143 (41)
No or don’t know	208 (59)
Age of baby (in weeks), mean, SD	31.2 (3.1)
Perceived stress[a], n (%)	
Low stress	205 (58)
Moderate stress	132 (37)
High stress	18 (5)

[a] There were missing data for this survey item and the denominator does not total 356 (ie, the women did not respond to the item or skipped the question).

[b] Defined by residential postcode using the 2016 Socioeconomic Indexes for Areas.

[c] Defined by residential postcode using the Access/Remoteness Index of Australia.

A total of 89% (n=305) of women reported accessing CFHN services in the first 6 months following their child's birth, with 86% (n=262) of visits occurring in the home and 58% (n=177) of women having visited a clinic.

Preferences and Acceptability of Technology-Based Support From Child and Family Health Services

As shown in Table 2, the majority of women "strongly agreed or agreed" that receiving information from the health service via technology would be acceptable (range: 82%-92%; Cronbach α=0.66), with "website" being rated as the most accepted (n=315, 92%). Most women "strongly agreed or agreed" with being provided with information on all health topics via technology (range: 90%-98%). The most accepted topics were "growth checks and immunization reminders" (n=335, 98%), "healthy eating" (n=333, 97%), and "introduction to solids" (n=331, 97%). Women reported a preference to receive information about feeding their baby in the 3rd trimester of pregnancy (n=173, 50%) or 0-6 months after birth (n=201, 59%).

Table 2. Women who agree or strongly agree to receipt of CFHN[a] support via technology-based services during the first 6 months (in addition to usual CFHN care), and timing preferences for provision of support.

Variable	Value (N=343), n (%)
Mode of technology support rated as "acceptable"[b]	
Website	315 (92)
Telehealth	306 (89)
Telephone	295 (86)
Email	287 (84)
SMS text message	282 (82)
Acceptability of health topics delivered via technology[b]	
Growth checks and immunization reminders	335 (98)
Healthy eating	333 (97)
Introduction to solids (timing, portion, and types of foods)	331 (97)
Breastfeeding or bottle-feeding	323 (94)
Sleep and settling	322 (94)
Healthy growth	323 (94)
Mental health	322 (94)
Fussy eating	317 (92)
Social support	316 (92)
Age and development milestones	314 (92)
Parent groups or networks	308 (90)
Timing of information receival[c]	
1st Trimester of pregnancy	34 (10)
2nd Trimester of pregnancy	55 (16)
3rd trimester of pregnancy	173 (50)
0-6 months after birth	201 (59)
7-12 months after birth	33 (10)

[a] CFHN: Child and Family Health Nursing.

[b] "Acceptability" was defined as "agree" or "strongly agree" with receipt of technology-based information.

[c] Women were instructed to select all that apply.

Associations With Perceived Acceptability of Technology-Based CFHN Models of Care

While the acceptability of technology-based CFHN services was high for participants overall, some associations were found between maternal characteristics and the acceptability of support provided by technology-based CFHN services (Tables 3-5 and Tables S1 and S2 in Multimedia Appendix 1). Website acceptability was significantly associated with employment (*P*=.01), where women had higher odds of reporting website acceptability if they were employed (adjusted OR 3.30, 95% CI 1.22-8.91) or on maternity leave (adjusted OR 5.06, 95% CI 1.61-15.91) compared to women who were unemployed. For telephone acceptability, women who had received a "high school education or less” had higher odds of agreeing or strongly agreeing that support provided by telephone would be acceptable compared to women who had received “tertiary education or higher” (adjusted OR 2.64, 95% CI 1.07-6.51; *P*=.03). Additionally, women who reported it was their first pregnancy had lower odds of telephone acceptability compared to those that had a previously reported pregnancy (adjusted OR 0.37, 95% CI 0.18-0.76; *P*=.007). For email acceptability, women who had received “high school education or less” had higher odds of reporting email support as acceptable compared to those who had a “tertiary education or higher” (adjusted OR 2.90, 95% CI 1.20-7.00; *P*=.02). Similarly, women who had accessed a CFHN service in the first 6 months since birth had a higher odds (adjusted OR 2.44, 95% CI 1.07-5.53; *P*=.03) of reporting email support as acceptable compared with those that had not accessed a CFHN service. Women’s age was also associated with email acceptability (*P*=.04), where women aged 25-34 years reported higher acceptability of email support (n=206, 87%) compared to women aged 18-24 years (n=32, 76%) and those 35 years and older (n=49, 75%). There were no significant differences between maternal characteristics and telehealth or SMS text messaging acceptability.

Table 3. Association between participant characteristics and those who perceive the website as an acceptable (agreed or strongly agreed) mode of receiving health support (n=315).

Characteristics	Website acceptability, n (%)	Crude analysis		Adjusted analysis	
		OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value
Aboriginal or Torres Strait Islander, or both (n=311)[b]			.39		.59
Yes	20 (87)	0.57 (0.16-2.06)		0.69 (0.17-2.74)	
No	291 (92)	1 (reference)		1 (reference)	
Age of women (in years)			.52		.36
18-24	38 (90)	0.46 (0.10-2.17)		0.34 (0.06-2.04)	
25-34	215 (91)	0.50 (0.14-1.72)		0.40 (0.11-1.45)	
35+	62 (95)	1 (reference)		1 (reference)	
Education (n=310)[b]			.76		.24
High school or less	89 (93)	1.15 (0.47-2.82)		1.85 (0.66-5.20)	
Tertiary or higher	221 (92)	1 (reference)		1 (reference)	
Socioeconomic area			.35		.35
Most disadvantaged	197 (93)	1.45 (0.67-3.15)		1.57 (0.61-4.01)	
Least disadvantaged	118 (90)	1 (reference)		1 (reference)	
Remoteness			.71		.66
Major cities	180 (90)	0.86 (0.39-1.90)		0.80 (0.31-2.11)	
Regional or remote	135 (92)	1 (reference)		1 (reference)	
Employment			.006[c]		.01[c]
Employed	127 (93)	3.01 (1.22-7.42)		3.30 (1.22-8.91)	
Maternity leave	127 (95)	4.51 (1.64-12.44)		5.06 (1.61-15.91)	
Unemployed	61 (82)	1 (reference)		1 (reference)	
First pregnancy (n=311)[b]			.65		.70
Yes	129 (93)	1.20 (0.53-2.72)		1.20 (0.48-3.01)	
No or don't know	182 (91)	1 (reference)		1 (reference)	
Perceived stress (n=314)[b]			.68		.89
Low stress	182 (93)	1.73 (0.36-8.35)		1.10 (0.20-6.06)	
Moderate stress	117 (91)	1.30 (0.26-6.38)		0.88 (0.16-4.93)	
High stress	15 (88)	1 (reference)		1 (reference)	
Used CFHN[d] services			.24		.30
Yes	282 (92)	1.86 (0.66-5.21)		1.78 (0.59-5.37)	
No or don't know	33 (87)	1 (reference)		1 (reference)	

[a] OR: odds ratio.

[b] Indicates that some characteristic data is missing for women reporting websites as acceptable (n=315 in total).

[c] Indicates a significant result.

[d] CFHN: Child and Family Health Nursing.

Table 4. Association between participant characteristics and those who perceive telephone as an acceptable (agreed or strongly agreed) mode of receiving health support (n=295).

Characteristic	Telephone acceptability, n (%)	Crude analysis		Adjusted analysis	
		OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value
Aboriginal or Torres Strait Islander, or both (n=291)[b]			.87		.72
Yes	20 (87)	1.11 (0.32-3.88)		1.27 (0.34-4.73)	
No	271 (86)	1 (reference)		1 (reference)	
Age of women (in years)			.27		.52
18-24	36 (86)	0.50 (0.14-1.76)		0.76 (0.17-3.35)	
25-34	199 (84)	0.45 (0.17-1.19)		0.57 (0.20-1.64)	
35+	60 (92)	1 (reference)		1 (reference)	
Education (n=291)[b]			.08		.03[c]
High school or less	88 (92)	2.06 (0.92-4.59)		2.64 (1.07-6.51)	
Tertiary or higher	203 (84)	1 (reference)		1 (reference)	
Socioeconomic area			.67		.77
Most disadvantaged	181 (85)	0.87 (0.46-1.65)		1.12 (0.53-2.35)	
Least disadvantaged	114 (87)	1 (reference)		1 (reference)	
Remoteness			.15		.15
Major cities	174 (88)	1.56 (0.85-2.88)		1.69 (0.82-3.45)	
Regional or remote	121 (83)	1 (reference)		1 (reference)	
Employment			.61		.27
Employed	114 (84)	0.81 (0.36-1.82)		0.93 (0.39-2.24)	
Maternity leave	117 (88)	1.14 (0.49-2.66)		1.71 (0.65-4.52)	
Unemployed	64 (86)	1 (reference)		1 (reference)	
First pregnancy (n=292)[b]			.004[c]		.007[c]
Yes	111 (80)	0.39 (0.21-0.75)		0.37 (0.18-0.76)	
No or don’t know	181 (91)	1 (reference)		1 (reference)	
Perceived stress (n=294)[b]			.85		.66
Low stress	170 (87)	1.40 (0.38-5.21)		1.84 (0.44-7.64)	
Moderate stress	110 (85)	1.24 (0.33-4.73)		1.96 (0.46-8.44)	
High stress	14 (82)	1 (reference)		1 (reference)	
Used CFHN[d] services			.26		.25
Yes	260 (85)	0.50 (0.15-1.68)		0.48 (0.13-1.69)	
No or don’t know	35 (92)	1 (reference)		1 (reference)	

[a] OR: odds ratio.

[b] Indicates that some characteristic data is missing for women reporting telephone as acceptable (n=295 in total).

[c] Indicates a significant result.

[d] CFHN: Child and Family Health Nursing.

Table 5. Association between participant characteristics and those who perceive email as an acceptable (agreed or strongly agreed) mode of receiving health support (n=287).

Characteristic	Email acceptability, n (%)	Crude analysis		Adjusted analysis	
		OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value
Aboriginal or Torres Strait Islander, or both (n=283)[b]			.07		.07
Yes	16 (70)	0.42 (0.16-1.07)		0.39 (0.14-1.07)	
No	267 (84)	1 (reference)		1 (reference)	
Age of women (years)			.03[c]		.04[c]
18-24	32 (76)	1.04 (0.42-2.59)		0.77 (0.23-2.54)	
25-34	206 (87)	2.24 (1.13-4.43)		2.06 (0.98-4.33)	
35+	49 (75)	1 (reference)		1 (reference)	
Education (n=282)[b]			.03[c]		.02[c]
High school or less	87 (91)	2.28 (1.07-4.86)		2.90 (1.20-7.00)	
Tertiary or higher	195 (81)	1 (reference)		1 (reference)	
Socioeconomic area			.05[c]		.13
Most disadvantaged	184 (87)	1.79 (1.00-3.18)		1.70 (0.85-3.41)	
Least disadvantaged	103 (79)	1 (reference)		1 (reference)	
Remoteness			.26		.76
Major cities	161 (82)	0.71 (0.39-1.29)		0.89 (0.43-1.85)	
Regional or remote	126 (86)	1 (reference)		1 (reference)	
Employment			.63		.56
Employed	117 (86)	1.31 (0.61-2.84)		1.38 (0.58-3.27)	
Maternity leave	109 (82)	0.97 (0.46-2.04)		0.96 (0.40-2.34)	
Unemployed	61 (82)	1 (reference)		1 (reference)	
First pregnancy (n=283)[b]			.91		.76
Yes	116 (83)	0.97 (0.54-1.74)		0.90 (0.44-1.81)	
No or don’t know	167 (84)	1 (reference)		1 (reference)	
Perceived stress (n=286)[b]			.18		.24
Low stress	169 (86)	2.61 (0.85-7.99)		2.93 (0.84-10.22)	
Moderate stress	105 (81)	1.82 (0.59-5.66)		2.43 (0.68-8.61)	
High stress	12 (71)	1 (reference)		1 (reference)	
Used CFHN[d] services			.03[c]		.03[c]
Yes	260 (85)	2.35 (1.09-5.08)		2.44 (1.07-5.53)	
No or don’t know	27 (71)	1 (reference)		1 (reference)	

[a] OR: odds ratio.

[b] Indicates that some characteristic data is missing for women reporting email as acceptable (n=287 in total).

[c] Indicates a significant result.

[d] CFHN: Child and Family Health Nursing.

Discussion

Principal Findings

This study describes the acceptability of technology-based models of CFHN support to families in the first 6 months postpartum and identifies maternal characteristics that may influence the acceptability or adoption of such technology-based models. Our findings indicate most mothers (90%-98%) would find receiving information on key health topics via technology-based platforms acceptable. While there was high acceptability across a range of maternal characteristics, employment status, education level, and age were significantly associated with maternal acceptability of receiving various types of digital support and should be considered when developing technology-based models of CFHN support or care.

The technology platform that the highest proportion of mothers found acceptable for receiving health information was websites (n=315, 92%), followed by telehealth (n=306, 89%), telephone (n=295, 86%), email (n=287, 84%) and SMS text messaging (n=282, 82%). Given that mothers universally (ie, >80%) reported these technology-based platforms as acceptable, these findings suggest that various models of technology-based support would be suitable for providing families with child health and parenting support. This finding is largely consistent with the wider published literature, indicating that pregnant women and new mothers believe that the use of digital platforms, such as websites or SMS text messages, is a preferable and appealing method for receiving health information due to the convenience of the delivery models [30,31].

Almost all mothers surveyed in this study indicated that they would like to receive information related to growth checks and immunizations (n=335, 98%), healthy eating (n=333, 97%), and the introduction of solids (n=331, 97%). However, at least 90% of mothers indicated an interest in another eight topics including breastfeeding or bottle feeding, sleep and settling, and healthy growth, highlighting that new mothers are interested in accessing information across a broad spectrum of health topics related to their babies. Approximately 50% of mothers indicated a preference for receiving health information during the 3rd trimester and 59% of mothers in the first 6 months after birth. This finding is consistent with previous qualitative research that found mothers were most open to receiving parenting information closer to or after the baby was born, but not while in the hospital [30]. The 3rd trimester and first 6 months after birth when the mother is home with her newborn represents a highly receptive period for providing mothers with supportive, relevant, and reliable child health and parenting information.

Early motherhood represents a period in which women are interested in accessing a wide range of parenting information. Increasingly, the use of digital media sources represents an opportunity for women to access information that is of relevance to them, and at times that is convenient. Specifically, qualitative data has indicated that mothers tend to favor digital media during early motherhood, as they valued that the information was: (1) immediate (ie, quick Google search), (2) regular (ie, regular release of information without their intervention), (3) detailed, (4) entertaining (ie, relatable content or means of alleviating boredom), (5) customized, (6) practical (ie, how to), (7) professional, (8) reassuring, and (9) unbiased (ie, noncommercial) [32]. However, the most acceptable and equitable digital or technology mode for supporting mothers to assess child health and parenting information during this time remains unclear.

To the authors’ knowledge, very few studies have previously examined the association between the acceptability of various technology-based models of CFHN care with maternal characteristics [33,34]. Our findings indicated that websites had higher odds of being acceptable if the mother was employed or on maternity leave. An Australian study conducted in 2010 by Wen et al [35] found that lower-income households and less educated mothers tended to have lower rates of internet access for accessing health information. These findings suggest a possible inequity of websites for providing child health and parenting information, however, the spread of smartphones and internet access over the past decade has likely reduced this potential inequity [35]. In addition, we found higher odds of telephone and email support being acceptable if the mother had received a “high school education or less” compared with women who received a “tertiary education or higher.” Email was also more acceptable if the mother had accessed the CFHNs in the first 6 months following the birth, and if the mother was 25-34 years old. Maternal characteristics were not significantly associated with the acceptability of telehealth or SMS text messaging modalities, suggesting that CFHN support offered through these platforms may be more equitably accessed by mothers, however, further research exploring this topic is timely.

Limitations

Limitations of this research include the cross-sectional nature of the study and possible selection bias (influenced by a 50% response rate), which may limit the generalizability of these findings. Additionally, the sampling of mothers may have been slightly skewed to include mothers who are more engaged with CFHN services, as 89% (n=305) of mothers in the sample accessed CFHNs in the first 6 months following birth, which is higher than HNE-wide CFHN service attendance (<70%). However, the survey question used to capture this data did not ask if mothers attended all scheduled CFHN service visits in the first 6 months, therefore participant engagement with CFHN services may appear artificially high, as other characteristics of the sample are similar to that of the broader HNE region [36], with approximately 62% of mothers aged between 25 and 34 years and 91.5% from English speaking backgrounds [37]. Although previous research has demonstrated high acceptability and feasibility for delivering health advice to women using mobile apps [38], this research did not explore the acceptability of mobile apps given the well-known technological issues often experienced with the development and upkeep of mobile apps [39]. Rather, this research focused only on technology-based platforms that are already readily available within the health service. As such gaps remain in our understanding of mother acceptability for a range of possible technology platforms for delivering CFHN care, outside of those assessed in this study. Additionally, some of the regression analyses conducted for this study produced wide confidence intervals, suggesting a level of uncertainty in some of the associations and should be considered when interpreting the findings.

Conclusions

The findings of this study indicate that mothers are interested in using technology to access information related to a variety of child health and development topics, specifically within the first 6 months post partum. Technology-based models of providing this support to mothers, alongside CFHN services were found to be highly acceptable among new mothers, however, maternal characteristics, including employment status, education level, and age, were found to significantly modify maternal acceptability of technologies including websites, telephone, and email. Despite mothers indicating an appetite for receiving age and stage-relevant health and development information via technology-based approaches, future research is warranted to ensure technology-based models of CFHN care are accessed equitably by mothers.

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Authors' Contributions

TD, JKJ, ALB, and CL had full access to the data in the study and took responsibility for the integrity of the data and the accuracy of the data analysis. TD, LW, NH, SY, DG, JW, MK, and RS contributed to the concept and design. TD, JKJ, ALB, LW, NH, SY, DG, JP, PC, SR, JW, MK, MH, and RS contributed to the acquisition, analysis, and interpretation of data. TD, JKJ, ALB, and RS drafted the manuscript. LW, NH, CL, SY, DG, JP, PC, SR, MH, JW, and MK critically revised the manuscript. TD and CL conducted the statistical analysis.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional tables.
[DOCX File , 18 KB - pediatrics_v7i1e59191_app1.docx]

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Abbreviations

CATI: computer-assisted telephone interview
CFHN: Child and Family Health Nursing
HNE: Hunter New England
NSW: New South Wales
OR: odds ratio
REDCap: Research Electronic Data Capture
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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Feasibility of Sexual Health and Contraceptive Web Services for Adolescents and Young Adults: Retrospective Study of a Pilot Program on Reunion Island

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Abstract

Background: Sexual health indicators for adolescents and young adults (AYAs) aged between 13 and 25 years are particularly poor on Reunion Island. Access to accurate information as well as sexual health and contraceptive services are vital to maintaining sexual well-being. Teleconsultations offer a promising approach to addressing the sexual health and contraceptive needs of AYAs who are more susceptible to engaging in unprotected sexual intercourse. However, the literature on digital sexual health services for this demographic group is limited.

Objective: This study aims to describe the feasibility of a pilot sexual health and contraceptive teleconsultation web service used by AYAs on Reunion Island.

Methods: A descriptive, retrospective study was conducted at the Reunion Island University Hospital Center using a convenient sample. Eligible participants were informed about the program through various communication channels, including seminars for health care professionals, radio broadcasts, posters, flyers, press articles, videos, and social media posts. AYAs accessed a web-based platform named SEXTUOZE from December 15, 2021, to September 30, 2022, that offered sexual health information and teleconsultations. Data collected included participant and teleconsultation characteristics, patient satisfaction, and the quality of completeness of medical records.

Results: A total of 22 teleconsultations were scheduled and 7 were completed, all via synchronous video communication (duration: median 35 min). Overall, 4731 sessions were generated on the SEXTUOZE website. Reasons cited for accessing the web services were to seek sexual health advice (8/22, 36%), receive an initial birth control prescription (12/22, 55%), and inquire about condom prescriptions (2/22, 9%).

Conclusions: While teleconsultation use for sexual health was initially low, it rose toward the end of the study period. Considering all elements of the implementation theory, future research should design interventions that not only are more operative and tailored but also ensure their adoption and sustainability in various health contexts.

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KEYWORDS

sexual health; adolescent; young adults; web application; contraception prescription; contraception; teleconsultation; telemedicine; youth; usage; e-consultation; web based

Introduction

Adolescent pregnancy, defined as pregnancy in adolescents and young adults (AYAs) younger than 20 years, is a global public health concern occurring in high-, middle-, and low-income countries [1]. According to the World Health Organization, complications in pregnancy are the leading cause of death for girls aged 15 to 19 years [2]. These pregnancies are influenced by various interconnected factors, including sociocultural norms, lack of sexual education, poor economic conditions, and relationship dynamics, as well as limited access to reproductive health services. Lack of access to and use of contraceptive methods has been considered a key factor [1]. Social and family pressures, as well as media influences, also play a significant role [3].

On Reunion Island, a French overseas department situated in the Indian Ocean, unwanted pregnancies are a significant concern [4]. In 2022, according to the French National Institute of Statistics and Economic Studies (INSEE), 4.3% of births involved mothers younger than 20 years, a rate almost 3 times higher than that of mainland France (1.7%) [5]. The abortion rate was 13%, double that of mainland France [6]. Abortion rates were also high among young people aged 20 to 24 years, with 26.9% in metropolitan France and the overseas territories [6]. Moreover, data from the regional health observatory in 2019 reported that only half of sexually active AYAs aged 15 to 17 years used contraception during their first sexual encounter [7].

For young women aged 15 to 25 years who had already had their first sexual intercourse, a survey reported that 56% used a contraceptive method other than condoms and that a lack of knowledge and negative perceptions of contraception, along with the family taboo surrounding sexuality, contributed to it [7]. Some AYAs were aware of various contraceptive methods; however, their fragmented understanding of how to obtain them prevented the effective prevention of unwanted pregnancies [8]. de Pirey et al [9] presented that nearly a quarter of Reunionese minors who had an abortion or gave birth in 2009 never used any contraceptive method and that 42% did not use any contraceptive method in the month their pregnancy began. This study also reported that these minors had difficulties in accessing contraception, citing financial or confidentiality issues [9].

Sexual health resources available to AYAs on Reunion Island are substantial; however, they may be hindered by the mountainous geography and the isolated nature of many villages [10]. Patient access to sexual health services, particularly for AYAs who have scheduling constraints such as attending school or who do not drive, may be significantly impacted. This phenomenon may also be aggravated by the heterogeneous distribution of health care services on the island [10]. There are 3 free drop-in sexual health centers (known as the Centres Gratuits d'Information, de Dépistage et de Diagnostic [CeGIDD]) and 10 family planning and education facilities (Centres de Planification et d'Éducation Familiale [CPEF]) located on the island, which offer free birth control consultations and sexually transmitted illness (STI) screenings for AYAs. Contraception is free of charge and can be provided without informing the parents of minors [10]. Moreover, digital coverage extends to 80% of the territory, and in 2017, a total of 78% of the population older than 15 years were reported to have internet access at home [11].

Telemedicine activities, such as teleconsultations, are a promising approach to improving access to health care services [12]. Telemedicine is the use of telecommunications technology to provide medical care, consultations, and health education remotely. It can include services such as web-based doctor visits, remote monitoring of patients, digital transmission of medical data, and the provision of health information via electronic communication. The aim of telemedicine is to enhance the accessibility and quality of health care, particularly for individuals in remote or underserved areas, by overcoming the physical distance between patients and health care providers [12].

In gynecologic care, telemedicine may provide an innovative solution for improving access to sexual health services [13-15]. Globally, teleconsultations allow access to contraceptive care [16], birth control advice [17], medication-induced abortions [18], and the management of STIs [19]. However, access to sexual health care and contraceptive methods faces several contemporary challenges, particularly concerning teleconsultation services for AYAs. Literature has reported the frequency of internet connection failures, lower acceptability of such services, confidentiality, and data security concerns among a younger audience while confronted by the lack of data on the number and satisfaction of teleconsultations carried out [20]. Patients consulting gynecologists via digital health services in Australia reported satisfaction with their experience, finding it useful, time-saving, and cost-efficient [21]. In another study, although face-to-face care was preferred, digital health services for AYA contraceptive needs were perceived as both acceptable and accessible by most patients [19]. A study on young adults examined how AYAs used contraceptive methods over time, based on telemedicine consultations with health care professionals [22]. The implementation of teleconsultations for sexual and reproductive health in isolated regions, such as Reunion Island, presents a unique opportunity to overcome geographical and sociocultural barriers. Few studies have explored the impact of such solutions in insular contexts, providing valuable insights into the adaptation and implementation of these services in similar regions around the world. The objective of this study was to evaluate the feasibility of a sexual health teleconsultation website focused on providing detailed information and issuing contraceptive prescriptions for AYAs on Reunion Island.

Methods

Study Design

A retrospective single-center analysis of a sexual health pilot program implemented at the University Hospital of Reunion Island was conducted from December 15, 2021, to September 30, 2022. In June 2020, the pilot program consisted of two phases: (1) designing a website and teleconsultation platform (SEXTUOZE) within a Symphony Framework environment, and (2) evaluating the feasibility of the teleconsultations. A 24-month budget was allocated to complete the project; 14 months were required for the website development due to administrative, technological, and institutional issues, leaving only 10 months for testing with AYAs. The platform was developed by a team comprised of midwives, nurses, doctors, and the primary investigator, in collaboration with the development team. Due to time constraints, AYAs were not invited to participate in the setup process. Multimedia Appendix 1 details how SEXTUOZE worked. The implementation of the teleconsultation platform responded to a governmental request as part of the sexual health strategy in France [23]. The study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.

Publicity

Information about the pilot study and SEXTUOZE was disseminated through seminars for 150 health care professionals, radio broadcasts, posters, flyers, news articles, videos, and social media posts. Two hundred students attended the presentations at their schools. Content was shared on 2 social media networks (Facebook and Instagram) under the hashtag #Sextuoze. Participating nurses and midwives managed the sites after specific training. Weekly publications and daily stories were posted throughout the 10-month study period, following specific hospital guidelines. The various media campaigns provided information about the digital health services, their mission, and how they worked to encourage AYAs to use sexual health and contraceptive web-platform services.

Sampling and Recruitment

We used convenience sampling, including all AYAs aged 15 to 25 years residing on Reunion Island, who accessed the SEXTUOZE teleconsultation platform during the study period. Potential participants were informed about the program through various communication channels, including seminars for health care professionals, radio broadcasts, posters, flyers, press articles, videos, and social media posts (Facebook and Instagram).

Study Intervention

The teleconsultations concerned information and education about sexuality (including prevention of STIs, the morning-after pill, birth control, and prevention of sexist behavior and sexual violence) as well as birth control (including first-time prescriptions for young females and condoms). The 3-month follow-up after birth control initiation (as per French Health Authority guidelines) was also offered. AYAs had the opportunity to participate in teleconsultations with midwives using a computer or smartphone. Teleconsultations were available 6 days a week from Monday to Friday (6 AM to 7 PM) and on Saturday from 6 AM to noon. A total of 1000 consultation slots were offered during the study period. Once an account was created, AYAs had direct access to the appointment scheduling system and could register for the time slot that suited them. Appointments up to 2 hours before a teleconsultation were possible. A teleconsultation was free of charge and adhered to privacy and confidentiality laws. Patients received a link via email both 1 day prior and again a few minutes before their appointment. Teleconsultations could be carried out with the patient alone or in the company of a primary caregiver. At the end of each teleconsultation, participants were invited to answer a Likert-scale satisfaction question: “On a scale of 1 to 5, how would you rate your overall satisfaction with this teleconsultation? (1: very dissatisfied; 2: dissatisfied; 3: neutral; 4: satisfied; 5: very satisfied).” After 24 hours, participants received an online satisfaction evaluation form as well.

Study Variables

The study variables examined included scheduled teleconsultation appointments, the total number of completed teleconsultations, the mean duration of teleconsultations, website traffic, patient satisfaction, and the quality and completeness of the medical files.

Data Collection

An Excel (Microsoft Corporation) file was created for data to store account creation and appointment scheduling information. Patient characteristics, including age, sex, socio-professional data, contraceptive prescription, medical history, and satisfaction, were extracted from their electronic medical records.

Statistical Analysis

Descriptive statistics were expressed in numbers and percentages, including the median. Statistical analyses were performed using SAS (version 9.4; SAS Institute Inc).

Ethical Considerations

In accordance with French regulations, we received informed consent from each patient (by telephone) before accessing their medical files. This process ensured that participants understood the study’s objectives, the nature of the data collected, and their rights to confidentiality. This study was approved by the Research Ethics Committee of the University Hospital of Bordeaux, France (reference number: CER-BDX 2023 - 74) and was registered with the National Institute of Health Database (#F20220518181737).

Results

Website Traffic

Overall, 4731 sessions were recorded on the platform, including visits, whether to consult information on sexual health and contraception or to explore the teleconsultation services offered (Figure 1). Out of these sessions, 69 unique users created an account on the platform to access the teleconsultation services, among which 22 scheduled a teleconsultation appointment. The mean number of monthly sessions was 473 sessions per month, with the highest at 789 sessions at the start of the study and the lowest at 287 sessions in June 2022 (Figure 2). These variations may have been related to both the general and targeted messaging of communication campaigns. Presentations in schools, combined with the distribution of posters and flyers, were the most effective means of promotion, as indicated by the increase in website traffic. Radio broadcasts did not seem to positively influence website traffic (Figure 3).

Figure 1. Study flowchart.

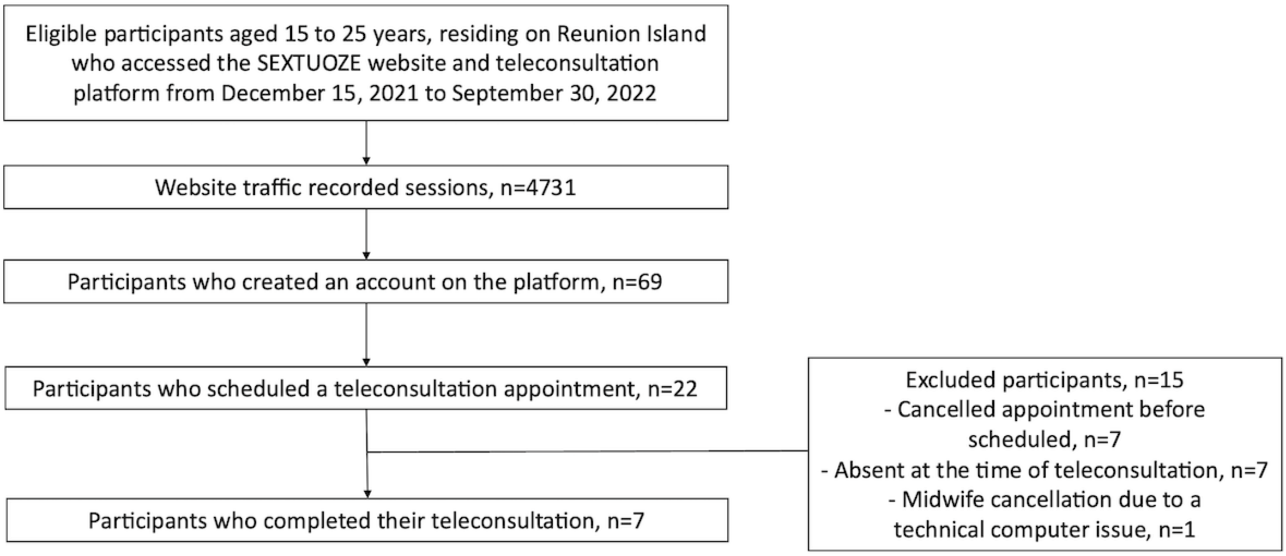


Figure 2. Monthly website traffic data from December 2021 to September 2022 on Reunion Island.

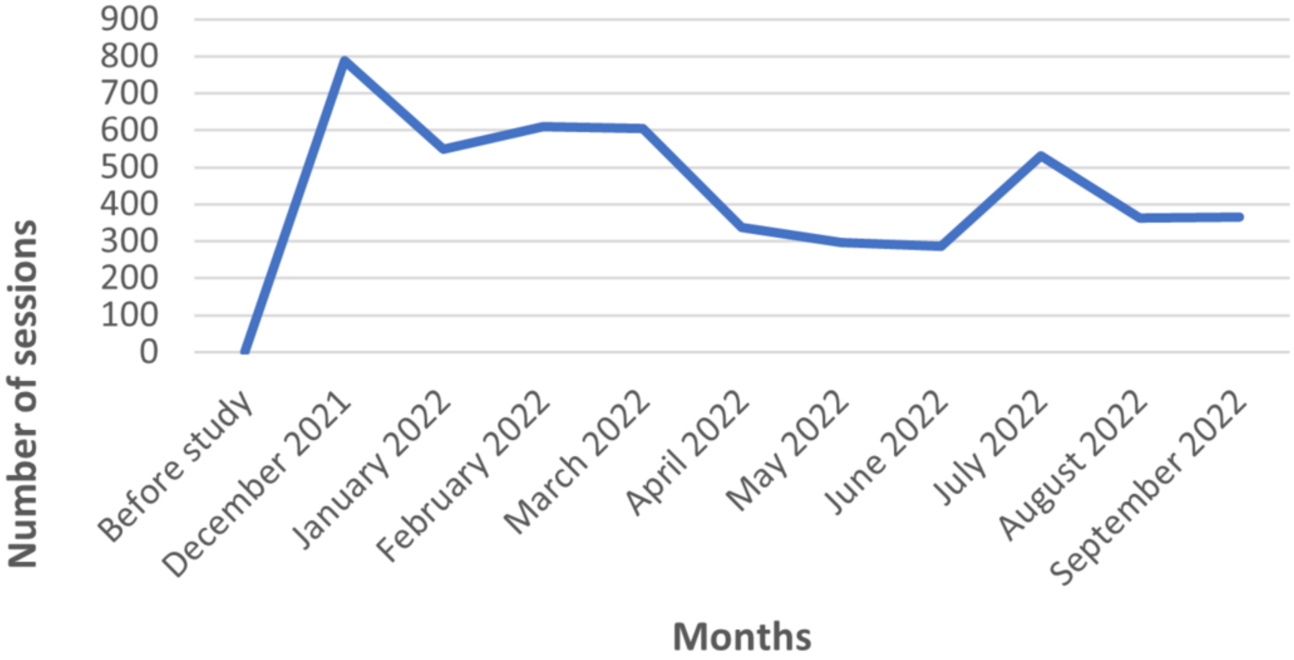
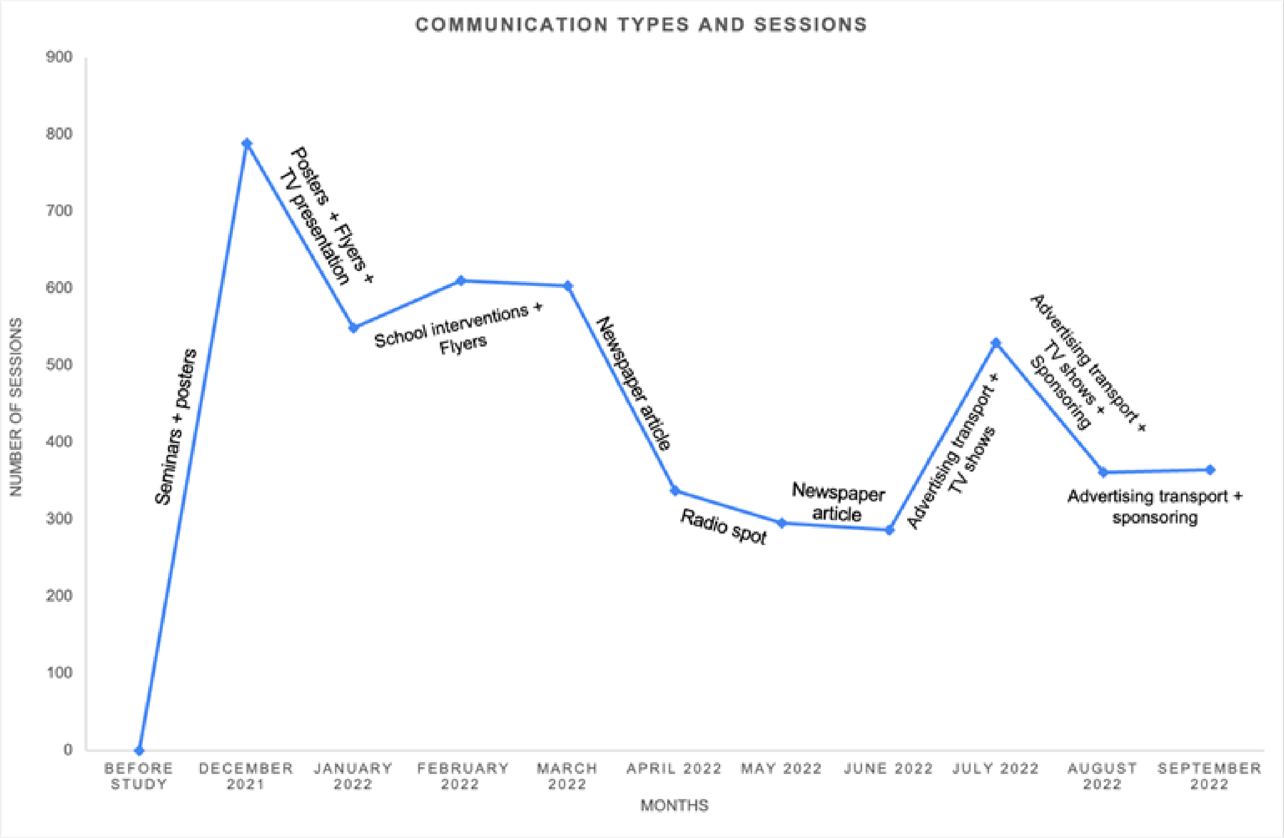


Figure 3. Impact of communication campaign on website traffic. The campaign was to promote the use of a teleconsultation platform for sexual health services to adolescents and young adults residing on Reunion Island.



Sexual Health and Contraceptive Teleconsultations

A total of 22 AYAs scheduled a teleconsultation appointment. Of these, 7 (32%) AYAs completed their consultation, 7 (32%) AYAs canceled before the scheduled date, 7 (32%) AYAs were absent at the time of teleconsultation, and in one case, a midwife canceled due to a technical computer issue. Among the scheduled consultations, 55% (n=12) were for an initial birth control prescription, while 36% (n=8) were for sexual health advice. Consultations related to inquiring about condom prescriptions represented 9% (n=2) of cases. No birth control follow-up consultation was scheduled. Completed teleconsultations were conducted via videoconferencing and lasted for a median duration of 35 minutes. Among the 7 patients who completed teleconsultation, the median age was 18 years, and all were females who resided in the northern and southern regions of Reunion Island. Various birth control methods were prescribed, including pills, implants, patches, and intrauterine devices (Table 1).

Table . Patient and teleconsultation use characteristics.

Variables		Value
Age (years; N=7), median (IQR)		18.0 (15.0-24.0)
Sex (female), n (%)		7 (100)
Education level		
	Secondary (high school)	—[a]
	Tertiary (university)	—
Region of residence		
	Northern region of Reunion Island	—
	Southern region of Reunion Island	—
Living with primary caregiver/parent		—
Teleconsultation duration, median (IQR)		35.0 (25.0-60.0)
Reason for teleconsultation		
	Sexual health counseling	—
	First contraception prescription	—
Contraception prescribed		—
Type of prescribed contraception		
	Intrauterine device	—
	Implant	—
	Pill	—
Experience of teleconsultation, n (%)		
	Very satisfactory	5 (71)
	Satisfactory	2 (29)

[a] —: Confidential.

Patient Satisfaction

Participants revealed high levels of self-perceived satisfaction with the use of teleconsultation for contraceptive care. Most AYAs expressed positive feedback, with 5 out of 7 reporting that they were very satisfied and 2 out of 7 indicating they were satisfied with their teleconsultation experience. It should be noted that the satisfaction forms sent online were not returned by any of the teleconsultants.

Quality and Completeness of Medical Files

The survey on the use of teleconsultation for contraceptive care among AYAs demonstrated complete compliance with the required information submission. All necessary data for the teleconsultations were successfully provided by the participants, ensuring that the process was thorough and efficient.

Discussion

Principal Findings

To our knowledge, this is the first study to assess the feasibility of a sexual health and contraceptive teleconsultation platform on Reunion Island. Establishing this platform necessitated the collaboration of a multidisciplinary team to navigate administrative, technological, and institutional challenges. While the number of completed teleconsultations was low, website traffic results indicated a notable interest in digital health care. The low use of teleconsultations for obtaining contraception was also observed in an American study by Yarger et al [22], wherein only 6% of 1630 young adults declared teleconsultation use. A lack of collaboration between researchers and stakeholders, particularly AYAs, to gather information on their needs and determine the optimal approach to implement and communicate interventions may explain the low use of teleconsultations observed in our study. Active participation of stakeholders, including children, parents, and health care providers, at all stages of developing a health intervention is essential to increase the effective use of health care interventions [24,25]. Co-design, as defined by Sanders and Stappers [26], involves collective creativity throughout the design process and can potentially lead to the development of more engaging, satisfying, and useful interventions for potential end users. Moreover, cocreation, practiced at the early front end of the design development process, can have positive, long-term effects. Involving AYAs in the co-design of the platform, according to cocreation principles, may have improved outcomes. Despite efforts to promote the program and sexual health and contraceptive websites to both health professionals and the general public, very few AYAs were informed about the program, which was crucial to reaching them.

Social media networks such as Instagram and Facebook social media networks were used to inform the target group about SEXTUOZE during the study period because these platforms are widespread among AYAs and are considered to be important tools in promoting sexual health [27,28]. On the other hand, when combined with other distribution channels, they did not result in providing significant awareness among AYAs. This finding aligns with existing literature, such as a study by Lim et al [29], which indicated that many young adults in Australia were not comfortable accessing health information through social media channels. In hindsight, our communication strategy may not have been sufficiently captivating or motivating to achieve the expected results. Employing a community manager may have been more effective in developing a successful strategy.

Considering that sexual behavior is a sensitive matter that can lead to social stigma, it is well established that confidentiality is a key element in optimally functioning sexual and reproductive health care services [30]. Confidentiality protection encourages AYAs to autonomously seek care and share sensitive information necessary for providing appropriate care [31]. Studies have shown that many AYAs are unaware of the specific privacy safeguards concerning the transmission of sexual health care information in place [32,33]. However, the understanding of confidentiality may vary according to age, with young adolescents being less aware of their right to confidentiality [33]. It is essential to make it clear to young adults that their privacy will be ensured, even when it is through digital communication. This is especially relevant given that most countries are moving toward integrated health care models with electronically accessed information that connects existing health care provider structures, regional clinical result databases, and the sharing of patient records [34]. For example, a study conducted in the United States found that 88% of adolescents were more inclined to seek sexual health services if they were assured of their privacy and confidentiality [35]. This underscores the significance of transparent communication regarding privacy policies and the implementation of robust data protection measures. Such measures are crucial for fostering trust and encouraging AYAs to use these services without fear of exposure or judgment.

Analyzing the causes behind why participants dropped off at different stages (such as canceling the scheduled appointment and not showing up) allowed us to identify specific friction points. For example, technical issues and a lack of familiarity with teleconsultations were 2 such reasons in this study. On Reunion Island, among those aged 15 to 44 years, 9 out of 10 have high-speed internet at their residence. However, those residing in the highlands of the island are less well equipped, with only 70% having internet access at home and 58% having high-speed internet [11]. By addressing these obstacles, we can propose targeted solutions to improve service adoption in the future. This analytical approach, which focused on optimizing user processes, can be applied to other contexts and teleconsultation use services, providing valuable insights to enhance the efficiency and acceptability of digital health solutions.

Limitations

Our study had several limitations. First, the small sample size limited the generalizability of our findings. The low number of completed teleconsultations may not have represented the broader population of AYAs on Reunion Island. Second, self-selection bias may have influenced the results, since those who chose to participate might have differed from those who did not in terms of motivation and access to digital resources. Third, the short duration of the evaluation period may not have been sufficient to capture the full potential and challenges of implementing the teleconsultation service. Changes in behavior take time and are a complex and iterative process that individuals who are aware of best health practices do not always succeed in adjusting [36]. Last, the lack of returned satisfaction forms restricted our understanding of patient experiences and satisfaction. Future research should aim to include larger and more diverse samples to enhance the generalizability of findings. Longitudinal studies would be beneficial to assess the long-term impact and sustainability of teleconsultation-based sexual health services. Additionally, strategies to improve awareness and engagement, such as involving community managers and leveraging popular social media platforms such as TikTok, should be explored. Ensuring digital literacy and addressing barriers to internet access are crucial for equitable implementation. For example, implementing community-based digital literacy programs could help bridge the digital divide. Moreover, maintaining robust confidentiality and privacy measures will be essential to building trust and encouraging the use of teleconsultation services among AYAs. Policy makers should consider supporting teleconsultation initiatives through funding and regulatory frameworks to ensure their sustainability and effectiveness.

Our study also may have highlighted several key lessons that can be used for future initiatives. First, stakeholder engagement is critical for the success of teleconsultation services. Involving AYAs in the design process could have enhanced the usability and acceptance of the platform. Second, effective time management is crucial to ensure timely development and evaluation. Our pilot program had a budget allocated for 24 months to develop and evaluate the platform. However, due to unforeseen administrative and public procurement obstacles, the development phase took longer than initially planned (14 mo) instead of the projected 6 months. Consequently, we were left with only 10 months to conduct the evaluation. Therefore, delays in development can significantly reduce the time available for evaluation and optimization. Third, a well-thought-out awareness and engagement campaign is essential for encouraging the target population to use the services. Robust data confidentiality and protection measures are also necessary to build trust and encourage use among AYAs.

Conclusion

Our study demonstrates the feasibility and challenges of implementing a teleconsultation platform for sexual health in an isolated region. SEXTUOZE was functional and authorized prescriptions for contraception and sexual health advice and information; however, the demand for teleconsultations was low, and no follow-up or request for emergency contraception was made. By identifying friction points and proposing improvements, we provide valuable insights that can be applied to other similar contexts. This innovative approach, both conceptually and empirically, can contribute to the international body of literature and may underscore the importance of future research to develop more effective, tailored, and sustainable interventions.

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Data Availability

Data supporting the results or analyses presented in this manuscript can be found in the medical records.

Authors' Contributions

DR and NB developed the research project concept and design. DR obtained funding and managed the research project with all professionals. DR, NB, and EC analyzed data. DR, NB, EC, and CM wrote the manuscript. All authors approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Functions of the sexual health website and teleconsultation platform (SEXTUOZE) used on Reunion Island.
[PNG File, 197 KB - pediatrics_v7i1e52557_app1.png]

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Abbreviations

AYA: adolescent and young adult
CeGIDD: Centres Gratuits d’Information, de Dépistage et de Diagnostic
CPEF: Centres de Planification et d’Éducation Familiale
INSEE: Institute of Statistics and Economic Studies
STI: sexually transmitted illness
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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Original Paper

Cocreating First Steps, a Toolkit to Improve Adolescent Sexual and Reproductive Health Services: Qualitative Human-Centered Design Study With Hispanic and Black Adolescent Mothers in New York City

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Abstract

Background: Adolescent voices are frequently excluded from sexual and reproductive health (SRH) research. Despite progressive policies and access to SRH care, adolescents in New York City who live in neighborhoods with high poverty and those who identify as Black or Hispanic experience poor SRH outcomes, including high rates of unplanned pregnancies and sexually transmitted infections.

Objective: This qualitative study aims to guide Black and Hispanic adolescent mothers in identifying problem areas in SRH care and cocreate health service recommendations with input from health care stakeholders to address those problems and improve SRH experiences.

Methods: Through ethnographic interview methods, adolescent mothers in New York City shared their experiences from before pregnancy through parenting and identified problem areas in adolescent SRH services and education. Data were analyzed inductively and using situational analysis. Adolescent participants attended 2 cocreation workshops. In the first workshop, they confirmed interview findings, set priorities, and created rough prototypes. Following the first workshop, health care providers were interviewed to inform refinement of the rough prototypes. Adolescents further developed prototypes in the second cocreation workshop and named the resulting toolkit.

Results: A total of 16 adolescent mothers participated in 47 interviews, and 10 (63%) participants attended at least 1 cocreation workshop. They highlighted deficiencies in sexual health education and emphasized the roles of health care providers and parents, rather than schools, in improving it. Adolescent participants designed recommendations for adolescents and health care providers to support quality conversations between adolescents, parents, and health care providers and created a preappointment checklist to help young patients initiate conversations with health care providers. Young participants stressed that sex education should address topics beyond sexually transmitted infections and pregnancy, such as emotional health and relationships. They created guidelines for health care providers outlining communication strategies to provide respectful, unbiased care and contraceptive counseling that encourages adolescent autonomy. Participants shared specific suggestions for how to support young parents respectfully. Health care stakeholders recommended adding information on confidential care; supporting lesbian, gay, bisexual, transgender, and queer youth; and focusing on improving communication between health care providers and patients rather than creating educational materials. In the second workshop, adolescent participants revised the prototypes based on feedback from health care stakeholders and named the toolkit of recommendations First Steps.

Conclusions: This study highlighted the important roles that parents and health care workers play in adolescent sexual health education. Cocreated toolkits offer a practical approach for health care providers to engage adolescents and their parents in meaningful, adolescent-centered conversations that can promote health, safety, and well-being.

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KEYWORDS

adolescent; reproductive health; sexual health; cocreation; co-design; human-centered design

Introduction

Background

Much of the research on adolescent sexual and reproductive health (SRH) is deficit-focused, aiming to change individual behaviors. This deficit model, which focuses on challenges, rather than strengths, can perpetuate beliefs that certain groups, particularly young people of color and those living in marginalized communities, need to be rescued or saved by members of the oppressing community [1,2]. Such practices minimize the lived experiences and expertise of youth and can perpetuate cycles of poor health outcomes [1], by failing to acknowledge the root causes of health inequities, such as racism, segregation, and inequitable health policies [1,2].

Adolescent participation in SRH research is vital, given the rising rates of sexually transmitted infections (STIs) [3] and the significant racial, ethnic, geographic, and socioeconomic disparities among pregnant and parenting adolescents [4]. However, few research studies include adolescents in roles that harness their wisdom about their SRH needs and experiences. There is a need for strengths-based research approaches that engage adolescents as experts to not only improve SRH outcomes but also to address the root causes of the sustained and widening inequities.

Adolescent SRH outcomes in New York City (NYC) expose stark health inequities. Youth living in NYC neighborhoods experiencing high poverty and those who identify as Black or Hispanic experience the highest rates of pregnancy, childbirth, and STIs [5,6]. In NYC, non-Hispanic Black adolescents report pregnancies at rates 4 times higher than non-Hispanic White adolescents and 7 times higher than Asian adolescents [6]. Similar disparities are present in birth data, with Hispanic or Latinx adolescents giving birth at a rate 4 times higher than Asian adolescents and 3 times greater than non-Hispanic White adolescents.

Adolescent childbirth and parenting are associated with poor social, educational, and health outcomes for young parents and their children. Pregnant adolescents are at high risk of complications such as pre-eclampsia and labor and delivery concerns, including hemorrhage requiring blood transfusion [7]. Infants born to adolescent parents are more likely to have low Apgar scores and require assisted ventilation and intensive care [7]. Parenting adolescents have lower chances of graduating from high school and report high periods of joblessness [8,9].

Adolescents are generally at high risk of STIs, and social determinants of health including poverty and discrimination increase this risk for marginalized adolescents [10,11]. In NYC, Black adolescents and those living in neighborhoods with high poverty experience chlamydia and gonorrhea infections at the highest rates [5]. STIs are often undetected due to low rates of testing and many sexual partners experiencing asymptomatic infections [10]. Data on STI testing prevalence among adolescents in NYC is limited; however, nationally, just 20.4% of sexually active adolescents reported being tested in the last 12 months [11].

STIs are associated with adverse outcomes, including cancer, pelvic inflammatory disease, and infertility, and many STIs require lifelong treatment [12]. Female adolescents are at a higher risk for certain infections such as chlamydia related to normal biological changes associated with development [13]. Pregnant and parenting adolescents are at higher risks of STIs [13], as they are less likely to consistently use STI prevention behaviors, such as condom use [14,15].

Adolescent SRH research in the United States has focused on increasing knowledge about sexual health [16,17], increasing contraceptive use [18-21], and developing decision support tools to guide contraceptive method choice [22-24]. Many studies have found modest or no effects on sexual health outcomes. As the adolescent pregnancy rate decreases, disparities persist, and those experiencing pregnancy are more likely to develop an STI, indicating a significant gap in SRH education and health care.

Few studies have investigated adolescent family planning experiences or behaviors beyond encouraging the consistent and correct use of a contraceptive method, and even fewer have investigated this phenomenon in parenting adolescents who are at an increased risk for repeat pregnancies and STIs [25,26]. This approach to mitigating adolescent pregnancy is situated in a research approach where health care providers and researchers design models of care to address predetermined problems based on their expertise [27] and measure success using outcomes such as contraceptive uptake or STI rate. Research approaches that de-emphasize factors beyond these clinical outcomes, such as satisfaction with care, are of particular concern for adolescents who will experience age-appropriate life course changes that can affect their SRH decisions and preferences over time.

The studies that have investigated adolescent SRH with a more flexible and creative approach found that adolescent SRH decisions are dynamic and influenced by numerous factors and relationships, beyond the evidence-based effectiveness focus of providers [28-30]. For instance, one randomized controlled trial found that individually tailored motivational interviewing that allowed for flexible conversations about concerns beyond contraception, between participants and nurse interventionists, significantly reduced the rate of repeat adolescent pregnancy

[31]. Adolescents are capable of describing their distinct health care needs, but they often receive care in health service settings designed for adults or preadolescent children [32]. Their voices are often not included in health services design due to barriers to their participation in research [33].

Aims

There is a need to expand on the studies that support adolescent-centered health services and to use research approaches that are inclusive, collaborative, strengths-based, and creative to facilitate adolescent participation in the design of their SRH care. To meet this need and address the wide and sustained SRH inequities, this study aimed to (1) use ethnographic and design research to guide adolescent mothers to identify problem areas in SRH care and (2) cocreate recommendations to improve SRH education and services with both health care stakeholders and adolescent parents to improve SRH experiences. Adolescent mothers are an ideal population to participate in cocreation to improve SRH for the broader adolescent population based on their experiences with the SRH care and education systems at key time points before, during, and after an adolescent pregnancy.

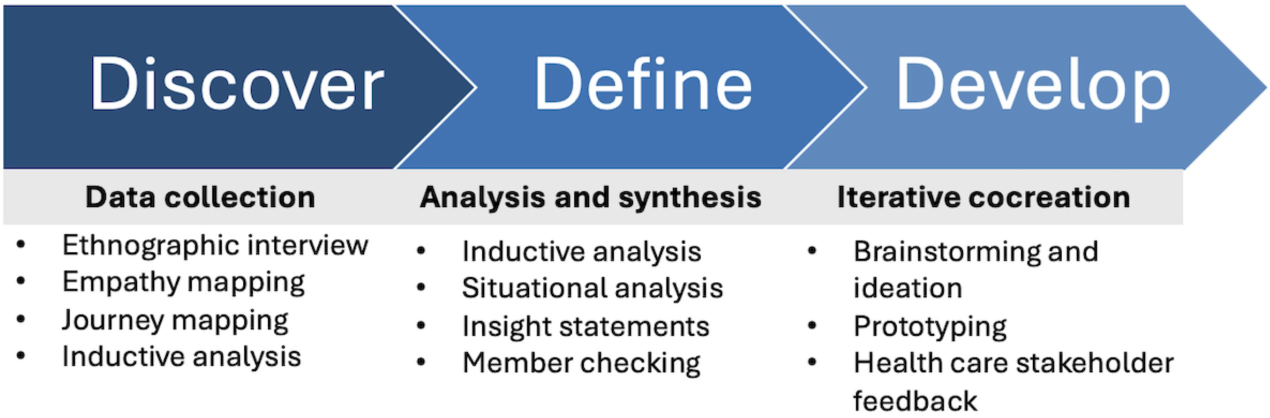
Methods

Overview

This study presents findings from a qualitative human-centered design (HCD) study with a sample of adolescent mothers living in NYC. HCD is a research methodology in health care that considers the expertise of stakeholders, and more specifically beneficiaries of health services, essential to the problem-solving and solution-generating processes [34]. HCD uses iterative processes where researchers are deeply immersed in a specific context and take a facilitator's role to support all stakeholders, whose expertise is recognized as central, in defining and reframing problems as well as creating and refining solutions [35-37]. HCD is an appropriate method to investigate persistent problems and disparities that are not improved by existing interventions [27]. It is a promising approach to addressing health disparities where the needs of vulnerable and marginalized populations may not be met by traditional research approaches [38].

HCD follows a phased process where researchers and stakeholders first investigate and define problems before they prototype and evaluate solutions. The Double Diamond, more recently called the Framework for Innovation, is a visual representation of the iterative processes used in HCD. Problem-solving and innovation in the Double Diamond framework are divided into 4 phases: discover, define, develop, and deliver [39]. In the discover phase, researchers and designers use ethnographic methods to develop a deep understanding of the experiences and contexts of service users. In the define phase, a problem is defined and redefined based on data from the discover phase and input from stakeholder groups. In the develop phase, prototypes are created to address the problems identified in the define phase and feedback is elicited to improve the prototypes. In the deliver phase, the final product is put into practice and evaluated for its impact on outcomes. This paper reports on this project's discover, define, and develop phases. Figure 1 displays a process diagram that shows the methods of data collection, analysis, and cocreation in each of the 3 phases.

Figure 1. Process diagram.



Positionality

The first author (LG) conducted all study procedures as part of a doctoral dissertation. She is a cisgender White woman who is bilingual (Spanish and English), bicultural by heritage (Hispanic Costa Rican and White Italian heritage), and works as a maternal–child home visiting nurse. Coauthors served as mentors with expertise in health services research (AS), adolescent sexual health (YL), and HCD research (ALF).

Theoretical Framework

HCD elevates the voices of stakeholders if carried out in its ideal, participatory form where studies acknowledge the context, culture, and political nature of complex problems. Fayard and Fathallah [40] suggested that researchers need to apply a critical stance to recognize the expertise of stakeholders, consistently reflect on positionality and the researcher's influence on the study, and maintain a commitment to a political viewpoint that reflects the goals and needs of the participants and their communities.

To adopt this critical stance, we used intersectional feminist theory to guide data collection, analysis, and researcher reflexivity. Intersectional feminism considers the intensified effects of overlapping racism, classism, and other forms of oppression on marginalized women [41-43]. This framework encouraged continual consideration of the power matrix that adolescent parents in NYC face, including the health and socioeconomic disparities sustained by racism, poverty, and societal judgment.

Participants and Recruitment

We recruited adolescent participants from a home visiting program for first-time parents, from a childcare program located in NYC public schools, and through snowball sampling. Participants were eligible if they were aged <20 years, lived in NYC, had English or Spanish proficiency, and had ever experienced a live birth. We recruited health care stakeholders for the develop phase by contacting members of an adolescent health special interest group of a professional organization focused on SRH and a nursing health services research collaborative. Health care stakeholders were eligible if they were licensed registered nurses (RNs), physicians, nurse practitioners, or physician assistants. We expanded inclusion criteria to include students in a degree-granting program for these health care roles to include the views and opinions of trainees with recent experiences in health education. We continued recruitment efforts until meaning saturation was achieved per Hennink et al [44], where authors developed an understanding of the various dimensions of single codes and an overall understanding of the data in both Spanish and English.

Ethical Considerations

LG translated consent forms and all study materials into Spanish, and a native speaker confirmed translations. All study procedures and materials in English and Spanish were approved by the New York University institutional review board (FY2023-7308). New York State Public Health law considers parents aged <18 years to be adults and allows them to make health decisions for themselves and their children without parental consent. Consistent with this law, all participants, regardless of age, provided written informed consent. The consent form included specific language about the mandated reporting of suspected child abuse and neglect and the procedures to do so. In addition, participants were made aware that the research team could provide them with resources for physical health; mental health; and educational, parenting, and other needs.

All participants were aware that their participation was voluntary and could be revoked at any point during the study, and declining would not affect their relationship with their referral source. Participants received US $30 cash or gift card incentive for completing each interview, up to 3 total. Before cocreation sessions, participants were reminded of the group-based nature of the workshops and that they did not need to share their names or other identifying information with the group and could keep their cameras off. Adolescent participants received a US $50 cash or gift card incentive for cocreation workshop, up to 2 workshops.

Discover Phase

Overview

The discover phase used multiple qualitative data collection tools to support immersion into the adolescent context and to build rapport and trust with participants. LG conducted all data collection following a 3-section semistructured interview guide, composed of ethnographic interview questions (section 1), card sorting (sections 1 and 2), empathy mapping (section 3), and journey mapping (section 3). Participants could elect to complete data collection in up to 3 research encounters to offer flexibility for scheduling. All participants chose the location of interviews, including an online option on Zoom (Zoom Video Communication, Inc). Participants completed a demographic survey and reported contraceptive history.

Ethnographic Interview

Ethnographic interviews are appropriate data collection techniques during the discover phase of HCD studies as they are exploratory and conversational and build trust with participants [45]. We used both descriptive and structural ethnographic interview questions to encourage participants to use their own language and describe how they organized their thinking about sex education, family planning, and sexual activity. The interview guide included specific questions about birth control and contraceptive counseling at time points from before their pregnancies through parenting.

Card Sorting

Design researchers use card sorting to build rapport through interactive activities that can ease participant discomfort in discussing sensitive topics such as sex [46,47]. Card sorting helps researchers understand and visualize how and why participants organize or categorize knowledge related to a phenomenon. In card sorting, we asked participants to group people in their lives who either should or should not speak to adolescents about sexual health and to rank the trustworthiness of sexual health information sources.

Mapping

Design researchers use empathy mapping [48] to uncover a person’s unspoken beliefs by dividing a page into 4 sections: do, say, think, and feel. Participants completed 4 total maps, 2 from their perspectives as adolescents and 2 regarding how they believe adults would fill out maps about adolescents. In total, 2 maps focused on adolescents generally and 2 focused on parenting adolescents. They completed each map by answering the questions, (1) “What do adolescents/parenting adolescents do/say/think/feel about sex and family planning? and (2) “What do adults do/say/think/feel about adolescent/parenting adolescent sex and family planning?”

Journey mapping [48] displays the steps people take and the emotions accompanying those actions when engaging with a service. Participants reflected on experiences receiving sex and family planning counseling before, during, and after pregnancy and described positive or negative moments along the journey. Templates and examples of completed card sorts, empathy maps, and journey maps are available upon request.

Data Analysis

Data analysis co-occurred with data collection. Data were analyzed inductively, first through open coding and later using focused coding to categorize findings [49]. Situational analysis derived from grounded theory [50] identified influential people, objects, and organizations that affect adolescent sexual decision-making. Findings specific to situational analysis are published in a separate manuscript [51]. Findings were synthesized into insight statements or short statements that capture the important motivations, tensions, and perspectives that encompass an HCD problem [52]. Interviews were audio recorded on a password-protected recorder, anonymized, and professionally transcribed. Audio recordings were deleted after transcription was completed and transcripts were confirmed for accuracy. Transcripts were read multiple times for immersion into the data and were analyzed using Atlas TI (ATLAS.ti Scientific Software Development GmbH). Spanish language transcripts were coded in Spanish. Analyses were confirmed through team-based discussions and through member checking, where participants offered feedback or confirmed the researcher's findings. Reflexivity and reflection on positionality were achieved through memoing and by discussing with research mentors (AS, YL, and ALF), with the first author paying specific attention to emotional and physical responses during interviews and analyses.

Define Phase

Overview

In the define phase of an HCD study, a problem is defined and redefined based on data from the discover phase and inputs from stakeholder groups. We invited participants with English proficiency who completed at least 1 interview segment to attend the first group cocreation workshop conducted on Zoom to maximize young participants' ability to attend. Spanish-speaking workshops will be conducted in a future study, given limited resources and a smaller sample.

Workshop 1: Define

LG started the first workshop by providing a positionality slide and facilitating a group discussion on rules for participation, including agreeing to maintaining confidentiality, respecting others' comments, and being open to learning new things. The first half of workshop 1 focused on supporting adolescent participants to define the key problems in SRH care and prioritize which problems to address through cocreation.

As the first step to defining the problems, LG presented insight statements. Participants had opportunities to share feedback on insight statements and suggest changes to statements if they disagreed. Together, adolescents and LG transformed insight statements into design opportunities or short statements that summarized the challenges and encouraged participants to think broadly about solutions.

Develop Phase

In the develop phase, researchers and stakeholders create and refine solutions to design opportunities. The research team selected a toolkit to design multiple solutions that could be tailored to a specific context.

Workshop 1: Develop

Using a virtual whiteboard and guided by the design opportunities, the group individually and then collectively brainstormed a list of important content areas a messaging toolkit for health care providers and adolescents should address. LG encouraged participants to think about general sexual health and education and address specific contraceptive counseling needs as identified in insight statements. A second whiteboard was created considering how participants imagined the toolkit recommendations could be used. After brainstorming a range of ideas, LG presented 2 personas and accompanying scenarios for the development of rough toolkit prototypes. We created personas or fictional characters that represented different service users' needs, experiences, pain points, and goals. LG refined rough prototypes after the first workshop based on the group's goals and feedback during workshop discussions.

Health Care Professionals' Feedback

LG conducted interviews using a semistructured interview guide to elicit feedback on prototypes developed with adolescents participating in workshop 1 with health care professionals, including RNs, pediatricians, and obstetrician-gynecologists. In addition to these interviews, LG led a group discussion in a graduate-level nursing SRH course. LG provided a summary of the findings from the discover and define phases and introduced different versions of the prototypes from the first workshop. The interview guide asked health care professionals to share feedback on the content of the prototype; the strengths, weaknesses, and usefulness of the prototype in their practice; and how they imagined the toolkit could be disseminated and used in the future. Consistent with the develop phase, versions of the toolkit were created and refined according to providers' feedback to be shared with adolescent stakeholders in a subsequent workshop.

Workshop 2

In workshop 2, LG summarized health care stakeholders' feedback on the toolkit for the adolescent participants. Discussions focused on reviewing feedback on the proposed length, toolkit content, and the primary audience. During the group discussion, LG and participants continued to iterate on and refine the prototypes. The final 15 minutes of the workshop were spent naming the toolkit, brainstorming ways to use the toolkit, and discussing future directions for the project.

Results

Overview

A total of 16 adolescent participants signed written informed consent. Demographics are presented in Table 1.

Table 1. Interview and cocreation workshop participant characteristics (N=16).

Participant characteristics	Participants, n (%)
Age (y)	
14	1 (6)
15	1 (6)
16	1 (6)
17	5 (31)
18	5 (31)
19	3 (19)
Race or ethnicity	
Black	3 (19)
Both Black and Hispanic	4 (25)
Hispanic	9 (56)
Interview language	
English	12 (75)
Spanish	4 (25)
Highest education completed	
<9th grade	2 (12)
9th grade	4 (25)
10th grade	3 (19)
11th grade	5 (31)
High school diploma	1 (6)
High school equivalency	1 (6)
Birthplace	
United States	12 (75)
Dominican Republic	2 (12)
Ecuador	2 (12)
Years living in the United States for foreign-born individuals	
1	1 (6)
2-5	2 (12)
>5	1 (6)
Neighborhood income below the federal poverty level (%)	
<20	1 (6)
20-24.9	8 (50)
25-29.9	6 (38)
>30	1 (6)
Insurance	
Medicaid	13 (81)
Private insurance	2 (12)
Uninsured	1 (6)
Contraceptive history	
Condoms	12 (75)
Withdrawal	10 (63)
Natural family planning or fertility awareness	9 (56)

Participant characteristics	Participants, n (%)
Oral contraceptive pill	6 (38)
Implant	6 (38)
Injection	4 (25)
Patch	3 (19)
Ring	0 (0)
Intrauterine device	0 (0)
Emergency contraception	3 (19)

All participants identified as cisgender women or girls with a median age of 17.5 (IQR 17-18) years. Most participants were interviewed in English (12/16, 75%), insured by Medicaid (13/16, 81%), and had not received a high-school diploma (14/16, 88%). Participants identified as Black (3/16, 19%), both Black and Hispanic (4/16, 25%), or Hispanic (9/16, 56%). Contraceptive histories varied, with most participants having used condoms (12/16, 75%). The implant (6/16, 38%) and oral contraceptive (6/16, 38%) were the most common hormonal methods. In total, 10 (63%) of the 16 participants attended at least 1 cocreation workshop, with 9 (56%) attending each workshop and 8 (50%) attending both workshops.

Discover Phase

Overview

Participants completed 47 (98%) of 48 interview segments, with 11 (69%) of the 16 participants having at least 1 in-person interview that was conducted at their homes, schools, or a community organization. The remaining interviews took place on Zoom where mapping exercises were completed using Google Slides. The interview segment duration ranged from 22 to 63 minutes. We saw no differences in interview quality by length, language, age of participant, or virtual versus in-person setting.

Sex Education Needs

Participants described lacking quality sex education at school, in their homes, and with health care providers. Despite living in a large city with progressive reproductive health policies around contraception and abortion, most participants received no sex education in their school or received a single class period as part of a health class that addressed other topics such as nutrition and substance use. At the same time, many shared that school is not the best place for young people to learn about sex due to the group setting and concerns that school staff do not have the training and resources necessary to provide up-to-date information.

In card sorting, all participants agreed that parents or other trusted adults in a young person's life such as an older cousin or aunt should be speaking to adolescents about sexual health. However, in their experiences, participants said that most adults overreacted or were judgmental and uncomfortable in these conversations. Participants saw parental disapproval of sexual activity as a universal experience for all young people. In the interviews, they reflected on their experiences and wished that their parents had understood normative adolescent development, which could have created a safe environment for conversations about sexual activity and safety. On the other hand, some participants grew up in families where adolescent sex or pregnancy was seen as acceptable or inevitable, which changed the way sexual health was discussed in their homes.

In addition to parents, all participants believed that health care professionals should be educating young people about sex because of their education and training in the health care space. Some believed that health care workers could bridge the SRH communication gap between parents and their children. Many shared that pediatricians did not assess for sexual activity or did so briefly only to move on from the topic if a young patient said they were not sexually active. Instead, participants shared that they began to learn about sexual health in more detail after they discovered their pregnancy and that at this time point, they found health care providers to be judgmental and paternalistic, especially around birth control. Almost all participants experienced coercive contraceptive counseling, with providers pressuring them to long-acting reversible contraception (LARC) and providing biased counseling that did not address the side effects. Providers with the LARC-first mentality dismissed participants' desires to use other less effective methods, discouraged LARC removal, and diminished participants' trust.

Contraceptive Use

Many participants shared that they did not want to use contraception, even when actively avoiding pregnancy. Discussions about side effects took place in interviews with every participant. Many had personally experienced negative side effects, including mood changes, weight gain, and undesired vaginal bleeding or menstrual changes. Some participants described feeling uncomfortable with the idea of LARC methods being placed inside their bodies and disliking needles as reasons to decline the injection. While most participants had used condoms at least once, many described them as difficult to use consistently because of issues with partners, skin irritation, and not having or using them in the moment of sexual activity.

Define Phase Workshop 1

During the first cocreation workshop, LG shared findings from interviews with participants in the form of insight statements and asked them for feedback and validation. Insight statements and quotes from interviews that represent each statement are provided as a Multimedia Appendix 1.

Insight statements focused on desiring adults, especially parents, to understand and accept normative adolescent sexual activity, recognizing insufficient sex education in school, and requesting that parents and health care professionals take on roles to educate adolescents about sex. Three specific insight statements guided cocreation activities, as follows: (1) young people do not have a way to learn about sex and contraception that includes their parents (or an adult they trust) and health care providers (who have the knowledge and training), (2) young people who do not want to become pregnant do not use birth control; and (3) health care providers put pressure on young people, especially young parents, to use birth control, and it affects how they counsel their patients. They do not accept “no” as an answer the first time. Using “how might we” questions, LG transformed insight statements into design opportunities to guide cocreation.

Develop Phase

Workshop 1: Develop (Brainstorming Toolkit Content)

In workshop 1, the group discussed the goal of creating recommendations to help adolescents, parents, and health care providers have high-quality conversations about sexual health and contraception. The first cocreation activity asked participants to consider what SRH content should be included in the recommendations. Using sticky notes on a web-based whiteboard (Figure 2), participants brainstormed the topics they felt were important to include in sex education that would be used by adolescents, health care professionals, parents, and trusted caregivers. After initial brainstorming, the group categorized and grouped sticky notes into 3 content areas: contraceptive-specific content, general sex education, and other.

Figure 2. Workshop 1 content brainstorming categorized. Formatting and spelling in the figure represent the tool as it was created during the session. STD: sexually transmitted disease.

What education should be included about sex?		What education should be included about birth control?		What other topics should be included?		How should our suggestions be available to people? How could they be used by doctors/nurses, parents, and young people?	
STDs	Protection	Different types	List all the options	How to talk to someone you're having sex with about condoms	Emotional attachment - changes to relationship after sex	School - guidance counselor	Clinic- talking to a doctor
Sex is a choice, consent	Condoms	Side effects	Birth control failure	Confidentiality		School with a teacher	Pamphlet or flyer in waiting room
baby	Planning for or preventing a pregnancy	someone that tells you that is okay to take care of yourself / use protection	The cost if you don't have insurance	How to talk to your parents or people you trust about sex			
It's okay to wait	be careful with who you have sex	Hearing from people with the real experience	Plan B				

To address general sexual health issues, participants wanted content that addressed STIs, condoms, planning for or preventing pregnancy, choosing an intimate partner, and consent. Participants shared important topics specific to contraception, including a list of all the birth control options available and recognition of the birth control failure rate. Participants asked for the content to address emergency contraception specifically. Along with a complete list of all contraceptive options, participants wanted honest descriptions of side effects and desired testimonies of real people’s positive and negative experiences using a specific method. Workshop participants discussed the importance of having an adult who will not judge a young patient who wants to use contraception.

In addition to general sexual health and contraception content, participants asked for specific information related to emotional health, especially around how the relationship with a partner can change after having sex. They suggested 2 content areas about communication, including tips for how to talk to a partner about condom use and ways to talk to parents or other trusted adults about sex.

Workshop 1: Personas and Prototyping

LG created 2 personas (Multimedia Appendix 2) based on interview data to reflect participants’ challenges and experiences. One persona was a sexually inexperienced cisgender girl aged 14 years, Alyssia, who was in a new relationship and considering sexual activity with a new partner aged 15 years. She had a close relationship with her mother, but when they talked about sex, her mother used generic messages such as “If you do that, be safe.” She had 2 goals, first to learn about sex from her pediatrician whom she trusts and second to open a communication channel with her mother to be able to talk about these topics without her mother becoming angry or uncomfortable. At a recent routine pediatric screening, her pediatrician did not mention sexual health and she was too shy to ask for sex education.

Workshop participants brainstormed recommendations and advice to share with Alyssia and her pediatrician to help Alyssia meet her goals. Participants believed that it was the pediatrician’s job to conduct a sexual health assessment and to present sexual health as a normal conversation point. They also stressed that even if a pediatrician was using the "right words" that support normative sexual activity to introduce sexual health, young patients would need to feel that the checkup was in a safe and judgment-free environment. Participants introduced the idea of a preappointment checklist as a way for Alyssia to alert the pediatrician about sensitive topics that she wanted to discuss. They felt that this would be a way to ensure the pediatrician made time for sexual health discussions or could connect Alyssia with someone else at the clinic to continue the conversation if they ran out of time. They suggested that the checklist should include physical sexual health topics such as STIs and birth control, along with relationship and emotional health content. Participants brainstormed ways for Alyssia to have a productive appointment with her pediatrician. First, they stressed the importance of Alyssia's pediatrician being responsible for starting the conversation about sex. Second, they shared that private conversations and an understanding of confidential care with the option to include a parent or trusted adult are the best ways for a young person to feel comfortable.

The second persona was Vanessa, a cisgender girl aged 17 years. She was a sexually active patient presenting to the gynecologist to start birth control. She expressed a desire to use the oral contraceptive pill, but the gynecologist disagreed and focused counseling on the intrauterine device and the implant. Vanessa wanted to learn more about the pill and avoid pregnancy. Workshop discussions about Vanessa's case focused on designing recommendations for health care providers to improve contraceptive counseling experiences.

First, participants discussed what guidelines the gynecologist could follow to improve this encounter. They shared that health care providers need to be accepting of a patient's requests while also doing their job using questions such as, "What makes you interested in the pill?" They suggested that health care providers need to begin contraceptive counseling sessions with broad and open-ended questions such as "What birth control methods did you have in mind?" rather than assuming that a young patient wants a long-acting method. They emphasized the importance of Vanessa feeling safe during the appointment and feeling comfortable speaking about her SRH needs.

The group responded to a final set of questions about how health care providers should speak to and support young parents. In terms of contraceptive counseling, participants wanted to be treated the same as adult pregnant or parenting patients and given respect and autonomy. Many shared that they wanted health care providers to care about them as a person and a parent, rather than a young person at risk of a subsequent poor outcome. Others shared that the assumption that a young mother is sexually active and desires birth control or will not be able to abstain from sexual activity is harmful and leads to a loss of trust in the health care provider.

Following this workshop, LG organized prototyped recommendations into separate "recommendations toolkits" for adolescents and health care workers. LG created an electronic mock-up of rough prototyped toolkits using the Canva software (Canva Pty Ltd).

Health Care Stakeholder Feedback

Prototype feedback interviews ranged from 20 to 40 minutes with 10 health care professionals, including RNs (n=6, 60%), pediatricians (n=3, 30%), and obstetricians-gynecologists (n=1, 10%). Nurses in a graduate-level SRH class in NYC (8/10 students, 80%) also provided feedback. While most (7/10, 70%) RN and obstetric stakeholders had practice experience in the NYC area, pediatric providers represented more geographic diversity, with experiences from New England, the southeastern United States, and the West Coast represented. When reviewing the prototypes, they believed that the content requested by the adolescent participants was appropriate and could help health care providers understand adolescents' needs. Health care stakeholders were unsurprised that young parents felt judged and had negative experiences with SRH providers. To address these negative experiences, they suggested that the toolkit could focus on improving adolescent-health care provider communication, rather than duplicating preexisting educational resources. However, health care provider participants shared 1 concern about adding to the cognitive burden placed on primary care providers to serve as sex educators, given their limited time and resources.

They recommended adding information on the ability to provide confidential SRH care to minors and information on inclusive and respectful care of sexual and gender-diverse youth, including normalizing the use of pronouns. Pediatricians suggested adding practical tips for health care stakeholders to conduct routine sexual health appointments with adolescents, such as adding conversation starters or reviewing the steps of a sexual health assessment. They believed that the previsit checklist could be helpful, both for young patients and health care providers to prioritize sensitive topics and to consider including or excluding parents or supportive adults based on a young patient's request. LG iterated on the prototype versions after interviews to present to participants in workshop 2 for additional revisions.

Workshop 2

In the second workshop, adolescent participants discussed health care stakeholders' suggestions to improve communication between health care workers and adolescents, rather than recreating educational materials. Participants agreed, and cocreation workshop 2 focused on refining the toolkit made for health care providers.

First, LG shared health care stakeholders' questions about how to help young patients feel safe to have sexual health discussions with them. Participants shared that the most important aspect of a conversation was that it was nonjudgmental and that health care providers addressed them with respect by giving them time and attention, not following checklists, or being focused on the computer. Participants shared that hearing personal stories from a health care provider about their own life or the experiences of their patients or friends can help a person to feel comfortable and humanize SRH education and counseling. Participants shared that many young patients do not know that they can receive SRH care confidentially and that this may affect their trust in a health care provider.

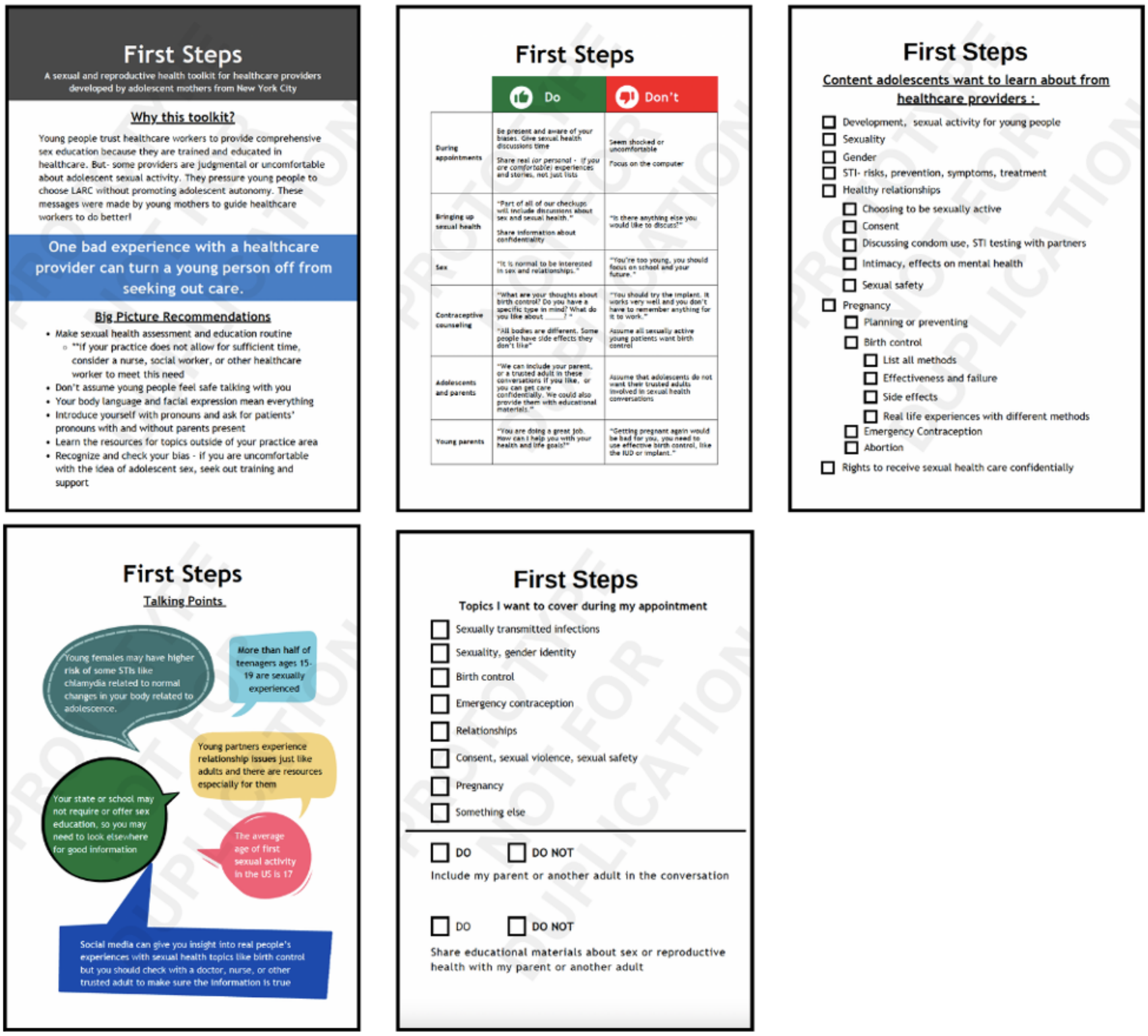
Participants discussed the proposed preappointment checklist and felt that it could encourage autonomy by motivating adolescents to set appointment goals and priorities. They also responded positively to the checklist having talking points related to specific SRH topics. The group reviewed the list of topics on the checklist, and participants opted to add consent and sexual violence aspects, which were not included in the sex education they had received at school or home. Finally, the group brainstormed a list of appointment “dos and don’ts” to provide concrete recommendations to guide health care providers to find the words needed to conduct sexual health assessments.

At the end of the workshop, participants took time to name the toolkit. The group agreed on First Steps as they felt that the guidelines that they had created were building blocks for health care providers to improve their SRH care to adolescents. Following the workshop, LG continued to refine the toolkit using the Canva design software and reviewed the toolkit with coauthors while considering plans for future refinement, dissemination, and implementation.

Final Toolkit

The final toolkit is a 5-page document (Figure 3), with each page functioning as a stand-alone sheet that could inform care. The first page introduces the creation of the toolkit with adolescent mothers and their motivation to participate in the project based on their prior experiences with poor care. This first page offers big-picture recommendations for health care providers working with adolescent patients, including making sexual health assessment routine, recognizing biases, and considering body language and facial expression as components of a safe space.

Figure 3. Toolkit final prototype.



First Steps

A sexual and reproductive health toolkit for healthcare providers developed by adolescent mothers from New York City

Why this toolkit?

Young people trust healthcare workers to provide comprehensive sex education because they are trained and educated in healthcare. But- some providers are judgmental or uncomfortable about adolescent sexual activity. They pressure young people to choose LARC without promoting adolescent autonomy. These messages were made by young mothers to guide healthcare workers to do better!

One bad experience with a healthcare provider can turn a young person off from seeking out care.

Big Picture Recommendations

- Make sexual health assessment and education routine
  - **If your practice does not allow for sufficient time, consider a nurse, social worker, or other healthcare worker to meet this need
- Don't assume young people feel safe talking with you
- Your body language and facial expression mean everything
- Introduce yourself with pronouns and ask for patients' pronouns with and without parents present
- Learn the resources for topics outside of your practice area
- Recognize and check your bias - if you are uncomfortable with the idea of adolescent sex, seek out training and support

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	Do	Don't
During appointments	Be present and aware of your biases. Give sexual health discussions time Share real *(or personal - if you are comfortable)* experiences and stories, not just lists	Seem shocked or uncomfortable Focus on the computer
Bringing up sexual health	“Part of all of our checkups will include discussions about sex and sexual health.” Share information about confidentiality	“Is there anything else you would like to discuss?”
Sex	“It is normal to be interested in sex and relationships.”	“You’re too young, you should focus on school and your future.”
Contraceptive counseling	“What are your thoughts about birth control? Do you have a specific type in mind? What do you like about ______? ” “All bodies are different. Some people have side effects they don’t like”	“You should try the implant. It works very well and you don’t have to remember anything for it to work.” Assume all sexually active young patients want birth control
Adolescents and parents	“We can include your parent, or a trusted adult in these conversations if you like, or you can get care confidentially. We could also provide them with educational materials.”	Assume that adolescents do not want their trusted adults involved in sexual health conversations
Young parents	“You are doing a great job. How can I help you with your health and life goals?”	“Getting pregnant again would be bad for you, you need to use effective birth control, like the IUD or implant.”

First Steps

Content adolescents want to learn about from healthcare providers :

☐ Development, sexual activity for young people
☐ Sexuality
☐ Gender
☐ STI- risks, prevention, symptoms, treatment
☐ Healthy relationships
  ☐ Choosing to be sexually active
  ☐ Consent
  ☐ Discussing condom use, STI testing with partners
  ☐ Intimacy, effects on mental health
  ☐ Sexual safety
☐ Pregnancy
  ☐ Planning or preventing
  ☐ Birth control
    ☐ List all methods
    ☐ Effectiveness and failure
    ☐ Side effects
    ☐ Real life experiences with different methods
  ☐ Emergency Contraception
  ☐ Abortion
☐ Rights to receive sexual health care confidentially

First Steps

Talking Points

Young females may have higher risk of some STIs like chlamydia related to normal changes in your body related to adolescence.

More than half of teenagers ages 15-19 are sexually experienced

Young partners experience relationship issues just like adults and there are resources especially for them

Your state or school may not require or offer sex education, so you may need to look elsewhere for good information

The average age of first sexual activity in the US is 17

Social media can give you insight into real people's experiences with sexual health topics like birth control but you should check with a doctor, nurse, or other trusted adult to make sure the information is true

First Steps

Topics I want to cover during my appointment

☐ Sexually transmitted infections
☐ Sexuality, gender identity
☐ Birth control
☐ Emergency contraception
☐ Relationships
☐ Consent, sexual violence, sexual safety
☐ Pregnancy
☐ Something else

☐ DO ☐ DO NOT
Include my parent or another adult in the conversation

☐ DO ☐ DO NOT
Share educational materials about sex or reproductive health with my parent or another adult

The second page displays a table with the “dos and don’ts” for various categories, including introducing sex, contraceptive counseling, and working with young parents. Dos include offering both confidential private care and the inclusion of parents or trusted adults at appointments, sharing real people’s experiences, including their own experiences, and providing contraceptive counseling that supports adolescent autonomy. Don’ts address coercive contraceptive counseling approaches, shaming young patients for being sexually active, and assuming that all adolescent participants would like their SRH care to be kept private from their parents.

The third page offers talking points that can help normalize sexual health behavior and offer educational information about various factors that affect adolescents' decisions and behaviors. The fourth page presents a list of SRH topics that adolescent participants wanted health care workers to be able to provide education or resources about. The preappointment checklist is the toolkit's final page. The checklist includes a list of topics adolescents can use to alert health care providers of the SRH content they want to learn about and includes options to request the involvement of a parent or trusted adult either during an appointment or through educational materials.

Discussion

Principal Findings

This study used HCD and cocreation techniques with adolescent mothers and health care stakeholders to design a toolkit to help health care providers deliver high-quality, adolescent-centered SRH care. Using HCD supported us in acknowledging the importance of adolescents' agency and recognizing their expertise as necessary components to develop health services that are meaningful and useful. Using HCD not only guided adolescent participants to identify the SRH problems they have seen and experienced but also generate solutions that are relevant to their experiences and needs [53]. While still subject to bias and power dynamics, HCD and other participatory approaches can address common concerns in research where interventions designed by experts in a field can lead to the development of culturally unsafe interventions that are ineffective or even harmful [54].

Comparison With Prior Work

Our findings are consistent with previous literature, and through the HCD approach, these findings supported the cocreation of the First Steps toolkit. Participants described insufficient SRH education, and many believed that they did not have the knowledge they needed when they were contemplating engaging in sexual activity or discovered that they were pregnant. Similar to our participants, the SRH education that adolescents received depends on the norms and values in their homes and schools, with some favoring comprehensive sex education and others endorsing abstinence-only education or avoiding the topic [55-58].

In cocreation workshops, adolescents brainstormed ways to fill the gaps left by insufficient sex education. While participants described parents as responsible for communicating with their children about SRH, they acknowledged that some parents may not have the comfort or knowledge to do so. Instead, they identified health care workers as responsible adults with the knowledge and training to educate them, and potentially their parents, on SRH. At the same time, participants shared that their experiences with health care workers were judgmental or coercive, putting pressure on them to use a specific birth control method and focusing on risk rather than their overall health or well-being. These findings are consistent with literature examining adolescent experiences with health care providers where young patients have experienced or feared the health care provider's judgment about their sexual health behaviors [59] or counseling that was biased due to their age [60]. Researchers have begun to recognize contraceptive coercion at the hands of health care providers, realizing that counseling methods such as tiered-effectiveness counseling are at odds with reproductive justice tenets [61]. First Steps not only confirmed these findings but also offered suggestions and actionable practice changes to address longstanding reproductive health concerns and amplified the importance of reproductive autonomy.

Toolkit recommendations focused on content areas that adolescents believed should be included in SRH education, guidance to health care workers on how to discuss sex with young patients, and a previsit checklist that could help adolescent patients alert health care staff that there are specific SRH topics they would like to discuss at a checkup. Many of these concepts are not new to the SRH literature, including respecting adolescent patients as capable of making autonomous decisions [62,63] and the importance of trust and nonjudgmental care [63,64]. However, the First Steps toolkit provides tangible recommendations for health care providers to improve health service delivery created by adolescents in their language and based on their needs and expertise. Beyond modules or training, the toolkit offers an actionable change to practice that can be implemented in diverse contexts. The toolkit can be paired with the few existing education-focused interventions that support the engagement of both parents and health care providers, such as Families Talking Together, a sex education program for Black and Latino youth aged 10 to 14 years [65].

First Steps addresses adolescent–health care provider communication, filling a gap in research where studies typically focus on increasing SRH knowledge, exploring experiences, or testing interventions designed by health care providers and researchers as the experts. First Steps, on the other hand, is innovative having been created through the phases of HCD with both adolescents and health care stakeholders, focusing on improving SRH service experiences and adolescent communication with trusted adults. The toolkit enables health care providers and researchers to use existing education resources while strengthening their relationships with adolescents and the trusted adults in their lives.

Strengths and Limitations

This study engaged an underresearched population, adolescent mothers, to share their experiences and participate in redesigning SRH service delivery through cocreation. The use of HCD methods allowed for considerable time in the field and immersion into the adolescent context, while the workshops brought participants together to share their experiences and expertise. This study's most significant strengths are cocreation and the design of a tangible deliverable that uses adolescent mothers' words to recommend actionable SRH practice and education changes. Adolescent mothers are frequently overlooked in research; however, our findings, participant retention, and the toolkit deliverable collectively exemplify their wisdom and commitment to the health and well-being of their communities.

Varied data collection techniques, member checking, and additional confirmation of insight statements during group sessions strengthened the credibility of the findings. LG is an experienced home visitor with >10 years of experience working with young parents and their infants and toddlers. However, she was the sole researcher conducting interviews and facilitating cocreation workshops, which may have led to biases in analyses and interpretations. This bias was mitigated as much as possible through group-based discussions, reflection through memoing, and discussion of LG's positionality with participants.

The adolescent participants are reflective of the adolescent parenting population in NYC in terms of race, age, and ethnicity; however, their experiences and recommendations to improve practice may not meet the needs of nonparenting adolescents, those from rural communities, or those with different heritage backgrounds, potentially limiting the transferability of the findings. The geographic diversity of health care stakeholders and the participatory HCD approach may have helped to mitigate the effect of this limitation. Similarly, all participants identified as cisgender women or girls, and their SRH experiences and proposed care solutions may not meet the needs of sexual and gender-diverse adolescents. Owing to resource constraints, LG did not recruit enough Spanish-speaking participants to conduct separate cocreation workshops with those participants; however, their perspectives from interviews were included in cocreation discussions and generally matched the perspectives of English-speaking participants.

Implications

Methods such as HCD can guide researchers to conduct studies that support adolescents in identifying problems and creating solutions. Elevating the voices and expertise of adolescent mothers addresses a gap in research, where adolescents who are already parents are under-studied in favor of prevention programs focused on nulliparous adolescents. This study provides methodological guidance to conduct a multilingual HCD study that includes virtual and in-person interviews and a cocreation component with adolescents. Future research can support adolescents, including those who are already parents, to design sexual health education and assessments that are adolescent-centered and foster a sense of safety. Replication of the earliest phases of the project will ensure that toolkit recommendations meet the needs of diverse populations, including adolescents from rural communities, immigrants from regions and countries not represented in this study, and sexual and gender-diverse adolescents.

Health care providers can use the toolkit and introduce the preappointment checklist to their patients to normalize sexual health discussions, support parent involvement if desired, and situate themselves as sexual health educators. Additional research to further refine the prototype and consider how to best evaluate the toolkit in practice is needed and planned for future study. Health care providers working in geographically diverse settings, particularly those in states that restricted access to SRH services and education, will have unique and important insights that can inform the creation of multiple versions of the toolkit for use in diverse health services contexts, including school-based health centers.

There are opportunities for continuing education and interdisciplinary collaboration in pediatric care settings. Such practices support specialization in the various SRH topics that adolescents described as important to their overall SRH knowledge besides STIs and pregnancy, including relationship and emotional health. Adolescent health care sites can consider adding mental health providers, RNs, or other health care workers to deliver holistic SRH care and education without adding additional practice burdens on primary care providers.

Conclusions

Despite decades of commitment from researchers, policy makers, and health care providers seeking to increase adolescent SRH knowledge and improve access to services, poor outcomes still persist and health disparities continue to widen. There is a need to address adolescent SRH concerns from the perspectives of adolescents themselves and to value and recognize their lived experiences as essential to the development of health services. This HCD study exemplifies adolescents' wisdom, creativity, and abilities to be the designers of their own SRH care. The study supports adolescent participation in the redesign of health services and education in the United States and offers health care stakeholders the opportunity to reflect on the care they provide, with actionable and constructive practice changes that can improve SRH education, service experiences, and ultimately, outcomes.

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Authors' Contributions

LG participated in the conceptualization, design, and implementation of the study, including analysis, manuscript preparation, and revision, as a part of a doctoral dissertation. LG secured the study funding. Coauthors YL, ALF, and AS participated in the design and implementation of the study, supervision, and contributed to reviewing and editing the manuscript. All authors approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Insight statements and corresponding quotes.
[DOCX File , 22 KB - pediatrics_v7i1e60692_app1.docx]

Multimedia Appendix 2
Personas and scenarios.
[DOCX File , 840 KB - pediatrics_v7i1e60692_app2.docx]

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Abbreviations

HCD: human-centered design
LARC: long-acting reversible contraception
NYC: New York City
RN: registered nurse
SRH: sexual and reproductive health

STI: sexually transmitted infection

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An Electronic Teen Questionnaire, the eTeenQ, for Risk Behavior Screening During Adolescent Well Visits in an Integrated Health System: Development and Pilot Implementation

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Abstract

Background: Screening for risk behaviors is a routine and essential component of adolescent preventive health visits. Early identification of risks can inform targeted counseling and care. If stored in discrete fields in the electronic health record (EHR), adolescent screening data can also be used to understand risk behaviors across a clinic or health system or to support quality improvement projects.

Objective: Goals of this pilot study were to adapt and implement an existing paper adolescent risk behavior screening tool for use as an electronic data capture tool (the eTeenQ), to evaluate acceptance of the eTeenQ, and to describe the prevalence of the selected risk behaviors reported through the eTeenQ.

Methods: The multidisciplinary project team applied an iterative process to develop the 29-item eTeenQ. Two unique data entry forms were created with attention to (1) user interface and user experience, (2) the need to maintain patient privacy, and (3) the potential to transmit and store data for future use in clinical care and research. Three primary care clinics within a large health system piloted the eTeenQ from August 17, 2020, to August 27, 2021. During preventive health visits for adolescents aged 12 to 18 years, the eTeenQ was completed on tablets and responses were converted to a provider display for teens and providers to review together. Responses to the eTeenQ were stored in a REDCap (Research Electronic Data Capture; Vanderbilt University) database, and for patients who agreed, responses were transferred to an EHR flowsheet. Responses to selected eTeenQ questions are reported for those consenting to research. At the conclusion of the pilot, the study team conducted semistructured interviews with providers and staff regarding their experience using the eTeenQ.

Results: Among 2816 adolescents with well visits, 2098 (74.5%) completed the eTeenQ. Of these, 1811 (86.3%) agreed to store responses in the EHR. Of 1632 adolescents (77.8% of those completing the eTeenQ) who consented for research and remained eligible, 1472 (90.2%) reported having an adult they can really talk to and 1510 (92.5%) reported feeling safe in their community, yet 401 (24.6%) reported someone they lived with had a gun and 172 (10.5%) reported having had a stressful or scary event that still bothered them. In addition, 157 (9.6%) adolescents reported they were or wondered if they were gay, lesbian, bisexual, pansexual, asexual, or other, and 43 (2.6%) reported they were or wondered if they were transgender or gender diverse. Of 11 staff and 7 providers completing interviews, all felt that the eTeenQ improved confidentiality and willingness among adolescents to answer sensitive questions. All 7 providers preferred the eTeenQ over the paper screening tool.

Conclusions: Electronic capture of adolescent risk behaviors is feasible in a busy clinic setting and well accepted among staff and clinicians. Most adolescents agreed for their responses to risk behavior screening to be stored in the EHR.

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KEYWORDS

electronic data capture; data capture; privacy; security; adolescent health; risk behavior screening; screening; acceptance; primary care; adolescent; adolescents; electronic health record; risk behavior; risk; risky; behavior; behaviors; behaviour; behaviours; digital health; eHealth; teenage; teens; teen; teenager; teenagers; children; young adults; youth; online health; web data; online data; user experience; interview; interviews; qualitative

Introduction

Adolescence is a period of rapid and complex transitions. Biological maturity often precedes psychosocial maturity and the choices made during this period can have both immediate and long-term health consequences. While many adolescent risk behaviors are transient or experimental, habits and unhealthy coping strategies with origins in adolescence may persist into adulthood [1,2]. In addition, limit-testing behaviors explored during adolescence can increase risk for injury and can contribute to long-term morbidity and mortality [3].

Routine risk behavior screening of adolescents is an important part of providing comprehensive and equitable care to this age group and it is a recommended best practice by the American Academy of Pediatrics [4,5]. Early recognition and response to high-risk adolescent behaviors can help to maintain youth on a healthy trajectory. Standardized questionnaires assessing adolescent risk behaviors have been found to help shift the focus of primary care visits from data gathering to discussion and counseling around sensitive topics. Furthermore, use of standardized questionnaires can improve organization and efficiency during the visit [6].

Many primary care practices rely on paper adolescent screening tools. However, these tools are often not completed by patients and results of the paper screening are inconsistently recorded in the electronic health record (EHR), making it difficult to monitor individual or population-level risk behaviors over time [7]. Electronic data capture for adolescent risk behavior screening has several potential advantages over paper screening and is generally preferred by adolescents [8-10], including those engaging in high-risk behaviors [9,11].

Nevertheless, barriers to adoption of electronic risk behavior screening tools remain, including clinical and institutional inertia and concerns regarding confidentiality of patient-reported risk behaviors collected on electronic tablets or similar devices [12]. In addition, risk behavior screening in primary care through paper or electronic methods may prolong visits and crowd out time for addressing other acute health issues.

In this pilot project, we adapted a paper-based adolescent risk behavior screening tool, the Adolescent and Young Adult Teen Questionnaire [13], which was developed by the Minnesota Department of Health and is currently in use in our health system as a paper screening tool at all primary care clinics, for use as an electronic data capture tool, the eTeenQ. We then pilot-tested the eTeenQ at 3 primary care clinics within our large, integrated, Midwestern health system, with goals of evaluating patient and clinician acceptance of the eTeenQ and describing the prevalence of selected adolescent risk behaviors as reported through the eTeenQ.

Methods

Adaptation of the Paper Risk Screening Tool for Electronic Data Capture as the eTeenQ

The multidisciplinary project team, which included 2 primary care physicians, 1 project manager, and 2 members of the HealthPartners Institute software engineering team, applied an iterative process over a 4-month period to adapt a paper risk behavior screening tool, the Adolescent and Young Adult Teen Questionnaire, for use as an electronic data capture form to be completed at the point of care on an electronic tablet. Two unique data entry forms were created with attention to (1) user interface and user experience (UI/UX), (2) the need to maintain patient privacy, and (3) the potential to transmit and store data for future use in clinical care and research. Additional considerations that affected the overall design of the eTeenQ included the need for the system to be stable, process responses quickly, and require limited ongoing maintenance. The overall architecture of the eTeenQ is shown in Multimedia Appendix 1.

The first electronic, web-based form created allowed clinic staff at check-in to enter the patient medical record number (MRN) and then to confirm the patient identity (Multimedia Appendix 2). The GetPatientDemographics application programming interface (API) from Epic Systems was used to identify the correct patient. The second electronic, web-based form created enabled adolescent patients to complete the 29-item fixed-response questions on safety, physical activity, diet and body image, school, self-harm, gender identity, sexual identity, and sexual activity that comprise the Adolescent and Young Adult Teen Questionnaire (Multimedia Appendix 3). The second form contained additional questions for adolescents to consent for their survey responses to be used for research and stored in the EHR, as described below. The eTeenQ forms were developed in REDCap (Research Electronic Data Capture; Vanderbilt University). REDCap is a secure web application used for building and managing online databases and surveys [14].

At the point of care, responses to the eTeenQ are converted to a provider display and adolescents and their primary care providers review responses together on the tablet during the visit. As shown in Multimedia Appendix 4, the provider display highlights eTeenQ “positive screens” or responses requiring attention during the visit. In real time, eTeenQ responses are stored in a REDCap secure external database [14]. For patients who consented to have their data stored in the EHR, after completing the eTeenQ and pressing Submit, a copy of their eTeenQ responses was automatically saved. The SetSmartDataValues API from Epic Systems was used to securely transfer the data from REDCap to custom discrete data elements created in the EHR for the project.

Additional security was integrated to the build of the tool to prevent the use of the tool outside the health system’s intranet. Software use and data transfer were closely monitored throughout the project, and the tablet firmware was maintained.

Setting and Population for Pilot Implementation

HealthPartners Care Group includes a multispecialty group practice of more than 1800 physicians, 8 hospitals, 55 primary care clinics, 22 urgent care locations, 24 dental clinics, and numerous specialty practices in Minnesota and western Wisconsin. The care group uses a common EHR (Epic; Epic Systems Corporation). Adolescents aged 12 to 18 years receive primary care within the care group from physicians trained in pediatrics, family medicine, or internal medicine, as well as from advanced practice providers, including nurse practitioners and physician assistants.

In June 2018, all 55 primary clinics within HealthPartners Care Group implemented comprehensive screening for well-being and risk behaviors among adolescents aged 12 to 18 years during well visits. At the time of check-in, patients and their parents were each handed a letter that described policies related to confidential care for adolescents and notified them that the adolescent would be completing a paper questionnaire for teens (based on the Adolescent and Young Adult Teen Questionnaire [13] developed by the Minnesota Department of Health). The letter provided at check-in also advised the adolescents and their parents that during the visit the parent would be asked to leave the room so the provider could review responses to the paper questionnaire in private with the adolescent. After the visit, the paper questionnaire was shredded, and it was at the discretion of the clinician to document any patient responses or discussion related to the risk behaviors identified in the EHR.

This pilot implementation of the eTeenQ took place at 3 clinics within the HealthPartners Care Group. Clinic A, located in a small town in Minnesota, had 27 pediatricians participate during the period from January 18, 2021, to August 27, 2021; clinic B, located in a metropolitan area of St Paul, Minnesota, had 5 pediatricians participate during the period from January 18, 2021, to August 27, 2021; clinic C, located in a Minneapolis suburb, had 3 pediatricians and 8 family medicine clinicians participate during the period from August 17, 2020, to August 27, 2021.

All patients aged 12 to 18 years and presenting for a preventive health or well visit with a participating primary care provider at a pilot site during the study period were eligible to participate. Eligible visits were identified through current procedural terminology (CPT) codes for these preventive health visits: 99384, 99394, 99385, and 99395; they were also identified through the *International Classification of Diseases, 10th Revision–Clinical Modification (ICD-10-CM)* codes Z00.121, Z00.129, Z00.00, and Z00.01.

Training and Support

All staff and providers at the 3 pilot sites attended lunchtime in-person or virtual training(s) regarding the pilot test and implementation of the eTeenQ. At each clinic, an operational staff member and a provider were designated as site champions and points of contact for the research team. Throughout the pilot study, research staff regularly connected by phone, email, or in person with the clinic site champions to obtain informal feedback about the intervention, including identification and triage of any challenges with workflow, technology, or confidentiality.

Pilot Clinic Workflow for the eTeenQ

Successful implementation of the eTeenQ required careful attention to clinic workflow. Electronic tablets were preloaded with a link to the eTeenQ data capture form. As shown in Multimedia Appendix 2, at the time of registration staff opened this link and entered the patient's MRN. After a verification process to confirm that the MRN corresponded to the correct adolescent patient, the tablet was handed to the patient along with instructions to complete the eTeenQ on their own, without input from parents or other guardians (Multimedia Appendix 2). After completing the eTeenQ, patients completed 2 additional questions regarding permission to import the eTeenQ data into the EHR and permission for responses to the eTeenQ to be accessed for research. Patients were instructed to hand the electronic tablet to the rooming staff so it could be reviewed by the clinician in advance and discussed during the confidential portion of the visit.

Prior to entering the patient room, the clinician reviewed the data on the tablet. Any survey responses that would generally require attention during the visit were highlighted on the provider display in order to facilitate efficiency (Multimedia Appendix 3).

Evaluating Use of the eTeenQ and Responses

Use of the eTeenQ was assessed by comparing the total number of adolescent preventive health visits at the 3 participating sites during the pilot period to the number of completed eTeenQ surveys stored in the REDCap database. For those consenting for their data to be used in research, eTeenQ responses were linked to administrative data (eg, age, sex, race/ethnicity, and insurance type) as recorded in the EHR. Selected responses were compared by age group (12-14 years vs 15-18 years) with the chi-square test with a 2-sided $P<.05$ as the threshold for significance. All analyses were conducted in SAS (version 9.4; SAS Institute).

Obtaining Feedback From Providers and Clinic Staff at Pilot Sites

At the conclusion of the pilot, the study primary investigator (SN) conducted brief in-person or virtual semistructured interviews with participating clinic providers and staff to understand their experiences using the eTeenQ. Questions for clinic staff included the following: "How did this pilot go?" "How did it work to hand out the tablets at the front desk to adolescents to complete the eTeenQ before the visit?" "Can you tell me about any difficulties with the technology or workflow?" "What ideas do you have about improvements we should make to the workflow or technology before spreading across primary care?" and "Do you have any additional feedback regarding this pilot?"

Questions for providers included the following: "How did this pilot go?" "Can you tell me about any difficulties with the technology or workflow?" "How did it work to review the Teen Questionnaire on a tablet?" "As compared to prior to the pilot, how did use of the eTeenQ impact visit efficiency?" "As compared to prior to the pilot, how did use of the eTeenQ impact quality of care?" "As compared to prior to the pilot, how did use of the eTeenQ impact adolescent clinician communication?" "As compared to prior to the pilot, how did use of the eTeenQ impact parent-clinician communication?" "As compared to prior to the pilot, how did use of the eTeenQ impact adolescent confidentiality?" "Did you make changes to clinical care or documentation as a result of the data reviewed on the tablet during the visit?" "Were you able to find the results of the eTeenQ in Epic, after the visit?" "How satisfied are you with electronic capture of eTeenQ data on a tablet?” (3-point scale for responses) and “Do you have a preference for how adolescent risk behavior screening should be administered at your clinic in the future?”

The study primary investigator took notes during the semistructured interviews. These notes were reviewed by the full study team to identify common themes regarding perceptions, preferences, and actual use of the eTeenQ.

Ethical Considerations

This study was reviewed and approved by the HealthPartners Institutional Review Board (A19-123). Implementation of the eTeenQ at pilot sites was approved with a waiver of informed consent. Adolescent consent for eTeenQ survey responses to be used for research and to be stored in the EHR was obtained as described below.

Adolescents consented for their eTeenQ responses to be used for research by reading the following prompt and then answering the consent question on the tablet:

> *We are asking all teens who complete the Teen Questionnaire on a tablet for permission to group their answers together in a large database. This data will be used to better understand the health of teens in our clinics and to improve care for teens in the future. We will not include your name or other information about you in the database. This study is voluntary. That means you can tell us that you do not want us to use your answers to the questionnaire for research. This will not affect your care today or in the future. We expect up to 1000 adolescents to participate in this study.*
>
> *Do you give permission to use your answers to this questionnaire for research?*

Adolescents consented for their eTeenQ responses to be stored in their EHR by reading the following prompt and then answering the consent question on the tablet*:*

> *The information in this questionnaire is confidential. It will be used by the doctors and nurses taking care of you to provide the best care possible. In the occasion that your parent or guardian requests a copy of your entire medical record, it is possible they may see the answers you provided on this form. If you report that you intend to harm yourself or to harm others, we are required to intervene on your behalf.*
>
> *Do you give permission to save this information in your medical record so that it can be used to help take care of you at future medical appointments?*

Results

Evaluating Use of the eTeenQ

During the pilot period, among 2816 eligible adolescents with well visits, 2098 (74.5%) completed the eTeenQ. Of the 2098 adolescents who completed the eTeenQ, 1653 (78.8%) consented to have their data used for research and 1811 (86.3%) agreed to have their data stored in the EHR. After excluding 21 responses due to incorrect MRN linkage to the EHR or because the patient had an a priori research opt-out recorded in their EHR, the final analytic sample included 1632 adolescents; 818 (50.1%) were female and the mean age was 14.5 (SD 1.8) years. (Figure 1, Table 1)

Figure 1. Flowsheet of study eligibility and consent for data to be used in research. EHR: electronic health record; MRN: medical record number.

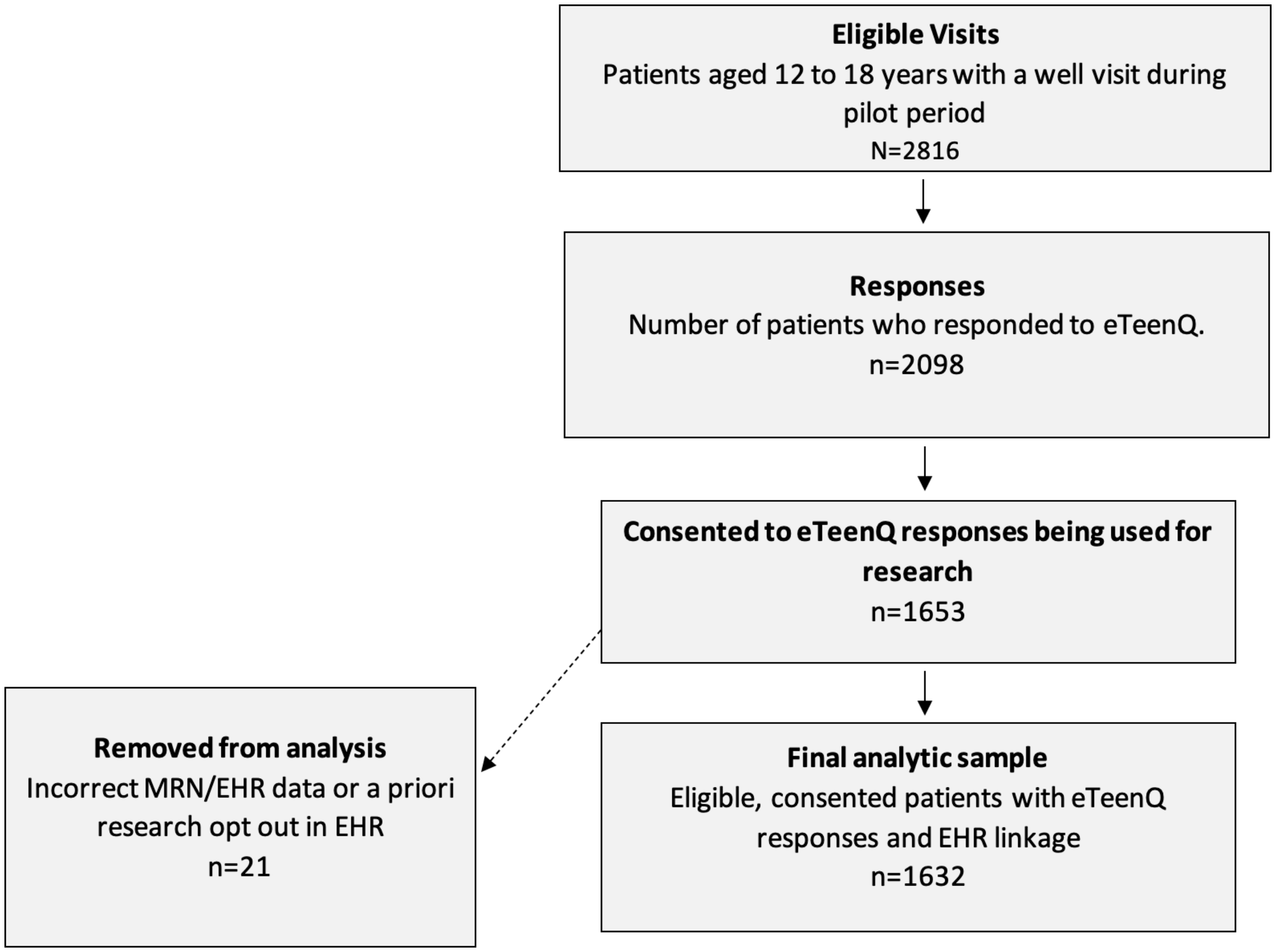

Table . Characteristics of sample (n=1632).

Characteristics		Values
Site, n (%)		
	Clinic A	997 (61.1)
	Clinic B	231 (14.2)
	Clinic C	404 (24.8)
Age (years), mean (SD)		14.5 (1.8)
Sex, n (%)		
	Female	818 (50.1)
	Male	814 (49.9)
Race/ethnicity, n (%)		
	White	1224 (75)
	Black/African American	139 (8.5)
	Asian	72 (4.4)
	Native Hawaiian or Pacific Islander	60 (3.7)
	American Indian or Alaska Native	4 (0.3)
	Other (or multiple)	74 (4.5)
	Unknown	59 (3.6)
	Hispanic	70 (4.3)
Insurance type, n (%)		
	Commercial	1284 (78.7)
	Public	340 (20.8)
	Missing	8 (0.5)

Overall data quality was good. Of 1632 respondents in the analytic sample, 1562 (95.7%) responded to all 29 questions in the eTeenQ. The most common question skipped was “How often do you use marijuana?” but this was only left incomplete for 10 (0.6%) respondents.

Across all 1632 teen respondents, 1472 (90.2%) reported having an adult they can really talk to and 1510 (92.5%) reported feeling safe in their community, yet 401 (24.6%) reported someone they lived with had a gun and 172 (10.5%) reported having had a stressful or scary event that still bothered them. In addition, 263 (16.1%) reported missing 7 or more days of school and 196 (12%) reported their grades were worse than they used to be. In addition, 157 (9.6%) responded they were or wondered if they were gay, lesbian, bisexual, pansexual, asexual, or other, and 43 (2.6%) reported they were or wondered if they were transgender or gender diverse. Risk behaviors were more common among older adolescents (aged 15-18 years; n=774) as compared to younger adolescents (aged 12-14 years; n=858). For example, 137 (17.7%) of older adolescents reported ever having had any kind of sex (with anyone of any gender) as compared to 9 (1%) of younger adolescents ($P<.001$). Similarly, 133 (17.2%) of older adolescents reported ever having used alcohol and 94 (12.1%) reported ever having used marijuana, as compared to 25 (2.9%) and 11 (1.3%), respectively, reporting use among younger adolescents ($P<.001$ for comparisons by age group).

Feedback From Providers and Clinic Staff at Pilot Sites

Across the 3 pilot clinics, 18 providers and clinic staff provided feedback through semistructured interviews. All felt that their adolescent patients liked using the tablets for completing the eTeenQ. They believed that patients were more honest with their responses using the tablet and noted more “positive screens” than when screening for adolescent risk behaviors on paper. They felt the tablets enhanced privacy and they particularly liked the provider display on the tablet that highlighted the “positive screens” or topics to address during the visit.

Challenges with the eTeenQ reported during interviews included isolated interruptions of Wi-Fi connectivity and confusion about which tablet belonged to which adolescent when 2 or more siblings with well visits were in the same examination room. In addition, adolescents occasionally clicked past the provider display screen, and the provider was then unable to review the eTeenQ responses on the tablet. Despite these occasional minor difficulties, primary care providers felt that the eTeenQ improved the quality of care they were able to provide and enhanced adolescent confidentiality. When asked their screening preference going forward, paper vs electronic, all respondents chose electronic.

Discussion

Principal Results

In this pilot study conducted in 3 busy community-based clinics within a large health system, we demonstrated that a paper adolescent risk screening tool can be converted for use as an electronic form; that adolescents were generally adherent to completing electronic risk screening on tablets at the time of preventive health visits, with a majority agreeing to have their responses stored in the EHR; and that implementation of the eTeenQ was feasible and well accepted by providers. Furthermore, the conversion of adolescent questionnaire responses to an intuitive provider display may have improved identification of risk behaviors requiring attention or further discussion during the visit. Storage of eTeenQ responses in a discrete field in the EHR can allow clinicians or researchers to evaluate adolescent risk behaviors across a clinic or geographic region, and ultimately can be used to design and implement targeted quality improvement projects.

Limitations

Several limitations to this pilot study should be noted. First, the participating clinics were not randomly selected. These clinics were motivated sites and had site champions who were engaged partners throughout the pilot. The successful adaptation and implementation of the eTeenQ at our pilot sites may not be generalizable to other clinics or health systems. A second limitation was that while adolescents complete several questionnaires at their preventive health visits, due to limitations in scope and budget, in our pilot only the eTeenQ was completed electronically. Thus, teens were filling out forms both electronically and on paper, which was cumbersome for staff and patients. Third, as a pilot project, we were not able to optimize all aspects of UI/UX, and the transfer of the data from REDCap to the EHR required a manual trigger following patient consent. If widely implemented, we would encourage additional modifications to the display and updates to the architecture to allow eTeenQ responses to flow seamlessly, in real time, into the EHR, and the incorporation of all adolescent screening tools for completion through electronic data capture. Further enhancements should also support completion of risk behavior screening in the days prior to preventive health visits. Fourth, as a small pilot study, our assessment of provider and staff acceptance of the eTeenQ was based on brief semistructured interviews and did not include formal qualitative analyses.

Comparisons With Prior Work

Findings from this pilot study were consistent with prior research, which has demonstrated that adolescents appear to more accurately report and be more willing to disclose sensitive information when questioned electronically vs on paper or in person [15,16]. In a pilot study conducted in 2015 in an academic adolescent clinic in Seattle, teens aged 13 to 18 years reported they preferred an electronic screen to a paper version. Prior studies have also noted that adolescents also perceive their visits as more confidential, feel they are listened to more carefully, and report they are more satisfied with their visit when computerized screening is used, as compared to other approaches to adolescent risk behavior screening [17]. Our study adds to the literature, as we conducted this work outside of an academic setting in 3 community-based clinics.

A potential benefit of electronic data capture is that forms can be easily modified and can include additional skip patterns or branching logic to support additional targeted data collection. For example, for those responding "yes" or "sometimes" to the eTeenQ single screening question regarding gender identity, "Are you or do you wonder if you are transgender or gender diverse?" in future iterations additional questions could then display allowing the patient to specify their gender identity [18].

We are not aware of prior research on adolescent preferences for storing sensitive information in the EHR. Prior to conducting this pilot, health system leaders had assumed that adolescent patients would not want their responses to adolescent risk screening stored in the EHR, as there would be a potential risk for disclosure to parents or others accessing their medical records. As such, we were surprised to find that 86% of adolescents consented to store their eTeenQ responses in the EHR. Recording of eTeenQ responses in discrete fields in the EHR is critical for follow-up of risk behaviors at future visits. If not documented, important health information revealed through risk behavior screening may be lost and not available at a patient's next medical encounter. In addition, adolescents may assume that communication between care teams occurs in the EHR and may not reveal vital sensitive information during a subsequent visit.

Conclusions

The use of electronic data capture for adolescent risk screening in primary care is feasible for collecting sensitive information in busy, community-based primary care settings. Most adolescents were agreeable to having their data stored in the EHR, and staff and primary care providers preferred electronic to paper screening. Providers felt that electronic screening enhanced confidentiality and that the eTeenQ improved the quality of care overall.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Architecture of the eTeenQ and data transfer.

[PNG File, 1069 KB - pediatrics_v7i1e47355_app1.png]

Multimedia Appendix 2

Check-in workflow for the eTeenQ.

[PNG File, 68 KB - pediatrics_v7i1e47355_app2.png]

Multimedia Appendix 3

First 7 questions of the eTeenQ for adolescents to complete, as displayed on a tablet.

[PNG File, 130 KB - pediatrics_v7i1e47355_app3.png]

Multimedia Appendix 4

Provider display of eTeenQ responses, with positive results highlighted in blue.

[PNG File, 512 KB - pediatrics_v7i1e47355_app4.png]

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Abbreviations

API: application programming interface
CPT: current procedural terminology
EHR: electronic health record
***ICD-10-CM*:** *International Classification of Diseases, 10th Revision–Clinical Modification*
MRN: medical record number
REDCap: research electronic data capture
UI/UX: user interface and user experience

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mHealth Apps in the Digital Marketplace for Pediatric Patients With Cancer: Systematic Search and Analysis

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Abstract

Background: The substantial increase in smartphone ownership has led to a rise in mobile health (mHealth) app use. Developing tailored features through mHealth apps creates a pathway to address the health care needs of pediatric patients with cancer and their families who have complex care needs. However, few apps are designed specifically to integrate with pediatric cancer care.

Objective: This study reports a systematic search and analysis of mHealth apps available on the Apple App (iOS) and Google Play (Android) stores designed for pediatric cancer through a list of features that serve (1) patients, (2) caregivers, or (3) both audiences.

Methods: Following PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines, we reviewed apps for pediatric patients with cancer and caregivers available as of January 30, 2024. We searched the Apple App and Google Play stores with a list of keyword combinations focusing on pediatric cancer care. The inclusion criteria were (1) specifically apps targeted toward pediatric patients with cancer, their families, or both; (2) available in either app store; and (3) available in English. Apps were assessed using the Mobile Application Rating Scale (MARS). The MARS is a quality assessment for mHealth apps, including components of engagement, functionality, aesthetics, and informational quality (5-point Likert scale items—1: low and 5: high quality).

Results: In total, 22 apps were identified and 17 of those apps were available on both platforms. The most popular features (n=12) were resource sharing, symptom tracking, reminders, care team connections, journaling, community support, medication tracking, data visualizations, and appointment tracking. Features and interfaces were designed for caregivers (n=9) more frequently than the patients (n=7) while a subset of apps created options for both users (n=6). A total of 16 apps received positive reviews (mean 4.4, SD 0.59; Min=3.1, Max=5.0). A small subset (n=3) achieved over 5000 downloads; however, the majority (n=15) had fewer than 500. More than half (n=12) of the apps were not available in English. Apps requested access to a range of device functionalities to operate (mean 2.72, SD 3.13; Min=0, Max=10). Out of 22, a total of 17 apps were publicly accessible. The mean MARS scores for the apps ranged from 1.71 (SD 0.75) to 4.33 (SD 0.82). Overall, apps scored high on functionality (mean 3.72, SD 0.54) but low on engagement (mean 3.02, SD 0.93).

Conclusions: Our review highlights the promising yet underdeveloped potential of mHealth apps in pediatric oncology care, underscoring the need for more inclusive, comprehensive, and integrative digital health solutions. Future developments should actively involve key stakeholders from the pediatric oncology community, including patients, families, and health care professionals, to ensure the apps meet specific needs while addressing linguistic and cultural barriers.

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KEYWORDS

mHealth; mobile health; mobile application; mobile apps; digital health; digital technology; digital intervention; smartphones; cancer; oncology; pediatric cancer; paediatric cancer; pediatric oncology; paediatric oncology; systematic analysis; systematic analyses; review; mobile phone

Introduction

Approximately 400,000 children are diagnosed with cancer each year internationally, and the incidence continues to rise annually [1]. Fortunately, treatment advances have also resulted in significant improvements in survival rates [2,3]. Despite these significant advances, pediatric cancer remains a leading cause of death among children [4]. The management of pediatric cancer is complex and requires multidisciplinary care that involves ongoing monitoring, management of physical or psychological symptoms, and social support for families. This includes community resources, symptom management, rehabilitation, and access to educational content for patients and their families. Digital interventions, such as mobile health (mHealth) apps, have the potential to meet these needs in real time while eliminating barriers like the distance from a medical center, lifestyle demands (eg, work and school), and mental health stigma [5].

mHealth apps are software apps designed to run on mobile devices, such as smartphones and tablets [6]. The significant increase in mobile or smartphone ownership has simultaneously led to a rise in the use of mHealth apps. Furthermore, the global proliferation of mobile devices among the younger demographic underscores the feasibility of mHealth apps for pediatric patients with cancer. Recent statistics indicate that technological access is substantial among the adolescent cohort [7]. Approximately 95% of adolescents possess or at least have access to smartphones and 90% have access to a desktop or laptop computer in the United States. Notably, almost half (46%) of this demographic reported to be online almost constantly [7]. mHealth apps offer a range of health-related services and resources, such as tracking symptoms, providing medication reminders, and connecting patients with health care professionals [5,8]. The use of mHealth apps in the context of pediatric cancer is an emerging field that holds great potential for improving the management and outcomes of this disease [5,9]. mHealth can provide valuable support for families dealing with pediatric cancer, including access to emergency contact information, educational resources, and social support networks [10]. Some apps also provide pediatric cancer families with tools to improve psychosocial well-being and health outcomes [11]. Additionally, these apps can help health care professionals to monitor and track patient progress more efficiently while providing more personalized care [12].

Despite the increasing number of mHealth apps developed for patients with cancer, there is a lack of literature on pediatric cancer regarding the mHealth apps available on the market. To our knowledge, a limited literature has focused on mHealth apps for caregivers of pediatric patients with cancer [5,9]. One of the early investigations highlighted cancer apps for adolescent and young adult patients with cancer with their functionalities for symptom tracking, pain management, monitoring, and medication management [13]. Looking at the broader literature, the studies mostly reported findings on a specific mHealth app, which might be focusing on electronic medical diaries for mood, symptom and treatment tracking [14], care after cancer treatment [15], pre-rehabilitation support [16], and posttreatment medical adherence [17]. In addition, newer mHealth technologies have leveraged wearable technologies for tracking physical activity [18,19], social media behaviors [19,20], web-text messaging for weight management [21], and gamification of monitoring symptoms to address cancer-associated pain through self-guidance [22,23].

mHealth apps for pediatric patients require further investigation to explore the potential benefits collectively. Therefore, a broader perspective (beyond the apps available in the current literature) is required to understand the current state of the mHealth apps. In line with that, the evaluation of those apps further contributes to the current state of the app market in pediatric oncology care. The aim of this systematic search is (1) to investigate currently available mHealth apps designed specifically for pediatric oncology in mobile app repositories (Google Play store and Apple App store); (2) to analyze the features and cost of services provided; and (3) to conduct a descriptive analysis to inform developers, designers, and clinician scientists. Our study aims to evaluate pediatric cancer–specific mHealth apps that ultimately improve psychosocial and health outcomes in vulnerable populations.

Methods

Overview

We performed an observational, cross-sectional, descriptive study of all smartphone apps associated with pediatric cancer available on the iOS (Apple App store) and Android (Google Play store) platforms. We only evaluated apps available in these 2 online stores.

Ethical Considerations

Institutional review board approval was not obtained as this is not human subjects research per our institutional policy and does not require institutional review board approval.

Mobile App Search

The methodology used was based on the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) system (see Checklist 1 for the PRISMA checklist) [24]. The search was conducted on January 2024 by a researcher (DIJ), accessing app stores via mobile devices (Apple iPhone SE and Google Pixel 4a). The review used a series of keyword combinations (n=116) through the Apple App store and Google Play store. The search terms included “pediatric,” “kid,” “teen,” “youth,” “adolescent,” “child,” “infant,” “little,” “minor,” “onco-,” “teenager,” “young,” “blood,” “bone,” “leukemia,” “lymphoma,” “oncology,” “tumor,” and “cancer.”

Inclusion Criteria

The coauthors (MSSF, MAS, ES, and DIJ) reviewed apps for eligibility. For inclusion in the review, apps met the criteria, which are (1) specifically related to supporting pediatric patients with cancer or families; (2) available in the Apple App store or Google Play store (Android) as of January 30, 2024; and (3) available in English (not exclusively). Free apps (no cost), apps for a fee and free trial apps (freemium), and subscription service apps were included. Apps that functioned as multi-institutional patient portals were excluded for being too broad to be considered a service for pediatric oncology care. A total of 196 apps were identified in both app stores. At the screening round, 159 apps were excluded due to not meeting our inclusion criteria based on store descriptions. Then, the eligible apps (n=37) were assessed for full inclusion (downloading and reviewing the apps). At this stage, we excluded 15 additional apps as they were identified as not being specific to the target population (n=7), not having an English interface (n=1), or were no longer available in either app store by the time the researchers initiated the analysis (n=7).

Data Collection and Analysis

Data were collected on the variables of descriptions, app rating (out of 5), number of reviews, total cost of services, intended user demographic, file size, supported languages, app privacy and data access requests, latest updates, and the app features from the app stores. App features were determined by reading the app description, reviewing snapshot images provided in the store, downloading the apps from each store on one of the mobile devices (Apple iPhone SE or Google Pixel 4a), and reviewing the original publisher's website post or press release. Each app was categorized by the level of access required before using the app (no account required, log in via account, closed sign-ups, and shutdown). A secure set of credentials was used for "login via account" apps. Data were recorded on a Microsoft Excel sheet for analysis (see Multimedia Appendix 1).

App Quality Assessment

We used the Mobile Application Rating Scale (MARS), which is a 23-question assessment of mHealth interventions, to measure apps in 5 domains including engagement, functionality, aesthetics, and information (see Textbox 1) [25]. We used information from the store page and in-app information to evaluate the population of eligible apps. We included 17 apps for MARS evaluation. Apps unavailable for download or that had special access requirements (not publicly available; n=5) were not evaluated. To measure credibility (the legitimacy of the app publisher) and evidence (scientific reports on the test or trial of the app) subcategories in the MARS, apps were cross-verified with external sources from the store page and in-app info, such as the developer's company page or ClinicalTrials.gov (as suggested by MARS guidelines). A total of 2 researchers evaluated the apps using the MARS instrument and resolved any disagreements via discussion and consensus. Finally, we reported the descriptive results. All included apps were available in the Apple App store but not in the Google Play store (n=5). For those available in both stores, we observed no difference in the user interface; therefore, apps were downloaded and tested on an iPhone SE for the quality assessment. Please see Multimedia Appendix 2 for the MARS scoring for each app.

Textbox 1. Mobile Application Rating Scale (MARS) domains.

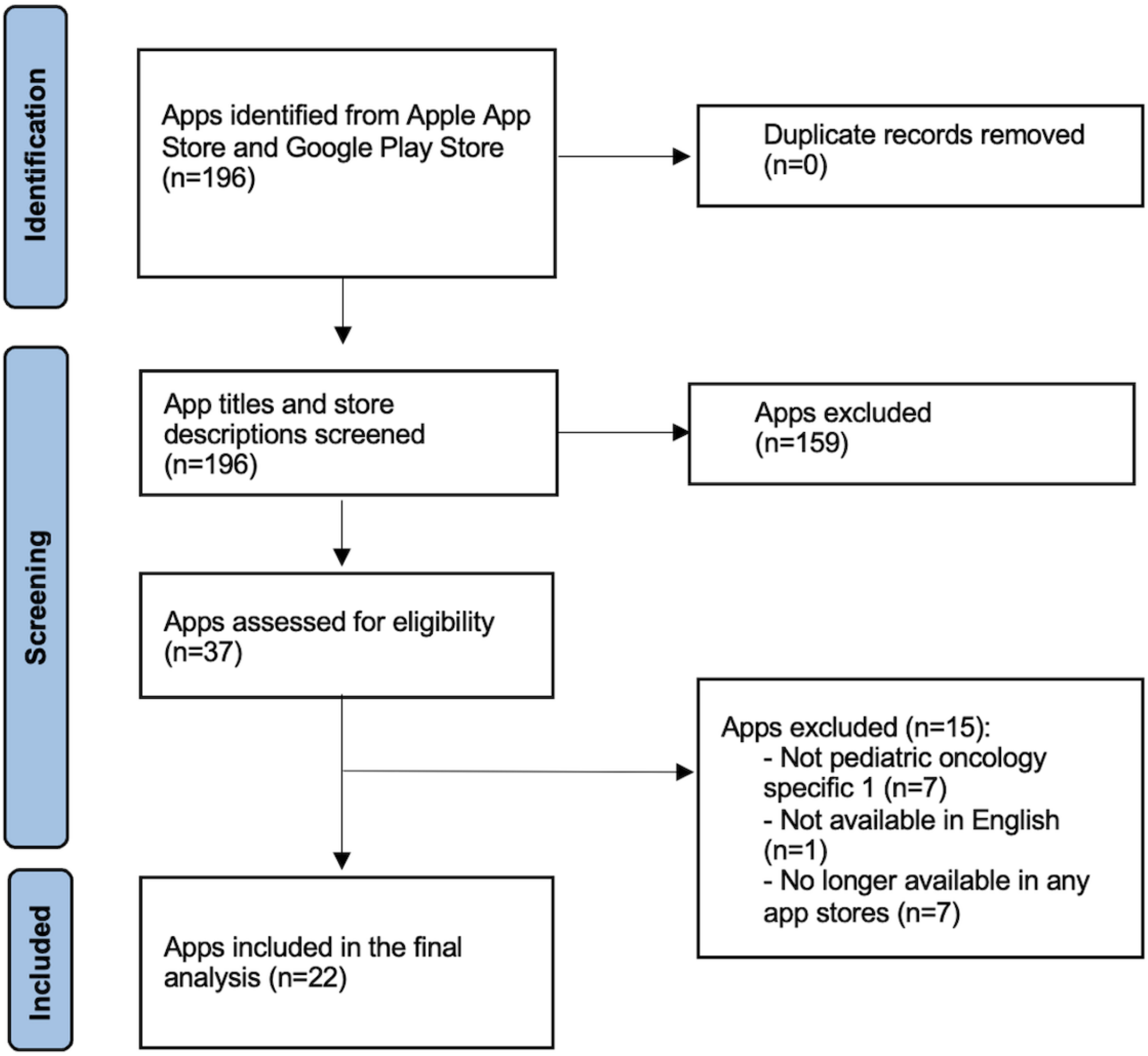
- Engagement: This domain measures how appealing, flexible, and well-targeted an apps for the target audience. This may include techniques for entertainment (ie, gamification), app features (ie, sound, content, notifications), and applicability between caregiver and pediatric patient age groups.
- Functionality: This measures basic app functions, ease of use, navigational difficulty, and gestural components. This may include how quickly buttons and menus react to user inputs. Additionally, this measures how logically consistent device-specific interactions are, such as taps, swipes.
- Aesthetics: This assesses the layout, graphical design, and visual appeal of the app. This may include quality of graphics or size of the visuals.
- Information: This domain evaluates the quality, quantity, and credibility of information within the app. This includes understanding the source of the content such as the developer and sponsor from their linked store page as well as scientific literature.

Results

Overview

In total, 22 apps were included in this review of pediatric cancer apps within the digital marketplace. Figure 1 illustrates the PRISMA flow diagram of the review. Most apps were available in both the Google Play (Android) and Apple App stores and shared the same features for both Android and iOS users (see Multimedia Appendix 1). Therefore, our report is based on consolidated data (Google Play or Android and Apple App store) for each app. More specifically out of 22 apps, 17 of them were available on both marketplaces. The remaining 5 apps were exclusively present on the Apple App store either because the Google Play store (Android) version was taken down or was never created. No apps were exclusively available on the Google Play store.

Figure 1. PRISMA flow diagram. PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses.



App Features

We grouped and summarized the features of the apps by frequency (see Table 1). The resource and information feature was the most frequent property (n=17, 77%). This feature allows users to access guidebooks and video course material related to pediatric cancer. Following that, the symptom tracking feature (n=12, 55%) allowed users to log journal entries or short reports on their immediate symptoms. Reminders (n=10, 45%) let users customize push notifications for important treatment-related events. Connections to care teams, journaling, and community support (n=9, 41%) provided speed-dial options for oncological health care, a logging feature for clinical guidance, and a social component to connect with other pediatric patients with cancer or caregivers directly. Medication tracking and data visualization or graphs (n=8, 36%) saved or described dosage instructions and created pictures to describe variables over time such as medication adherence. The ability to share data, appointment tracking, and health activity data (n=6, 27%) presents a repository for users to save important documents to send pictures to a health care team; schedule upcoming medical appointments on the app calendar; and record basic aerobics, mindfulness activities, and nutritional habits. Integration with other health apps (n=2, 9%) allowed the platform to access other downloaded health and fitness data tracking apps in the patient or caregiver’s phone, such as Apple Health or the Fitbit App (Google).

Most apps (n=16) were free to use and publicly available. “Tracker, Reminder - CareClinic” had additional in-app purchases (up to US $60 total) that expanded on the existing features of the software.

Table . Apps and feature distribution.

App names	App features												
	Symptom tracking	Medication tracking	Appointment tracking	Information or resources	Push notification reminders	Data visualization or graphs	Ability to share data	Journaling	Connection to care team	Health activity data tracking	Integration with other health apps	Community support	Multiple language support
COG KidsCare	✓	✓	✓	✓	✓		✓	✓	✓				✓
Cancer.Net Mobile	✓	✓		✓		✓			✓				
My Cancer Tracker	✓	✓	✓			✓	✓	✓					
CancerAid	✓	✓	✓	✓				✓	✓			✓	
NET Cancer Health Storylines	✓	✓		✓	✓	✓		✓		✓	✓		
Pain Squad[a]	✓				✓								
iThrive Beyond Peds Cancer[a]	✓			✓	✓								
HomeTown Cancer Predisposition	✓		✓	✓	✓	✓				✓			
Heroes Circle[a]												✓	
The Breath Brake App[a]												✓	
Kids' Guide to Cancer				✓								✓	✓
The Lounge at MSK				✓			✓		✓			✓	✓
BE-LONG beating Cancer Together				✓	✓		✓		✓			✓	✓
Tracker, Reminder - CareClinic	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓		

App names	App features												
	Symptom tracking	Medication tracking	Appointment tracking	Information or resources	Push notification reminders	Data visualization or graphs	Ability to share data	Journaling	Connection to care team	Health activity data tracking	Integration with other health apps	Community support	Multiple language support
Outcomes4Me Cancer Care	✓	✓	✓	✓	✓	✓			✓			✓	
iaya				✓				✓				✓	
I'll explain it to you[a]				✓									✓
FORTEe Get Strong				✓						✓			
AYABytes	✓			✓	✓	✓		✓		✓			
Our Journey with Cancer				✓				✓	✓				
LLS Coloring with Kids				✓									
OncoPower	✓	✓		✓	✓	✓	✓	✓	✓	✓		✓	
Frequency, n (%)	12 (55)	8 (36)	6 (27)	17 (77)	10 (45)	8 (36)	6 (27)	9 (41)	9 (41)	6 (27)	2 (9)	9 (41)	5 (23)

[a] Only available in Apple App store.

App Quality Assessment

For each app, we calculated the mean and SD values of MARS scores under 4 categories (Table 2). In addition, we report "objective score," which represents the mean value of 4 categories. Functionality (mean 3.66, SD 1.05) scored the highest among the 17 apps following aesthetics (mean 3.51, SD 1.02), information (mean 3.49, SD 0.80), and engagement (mean 3.02, SD 1.05). See Multimedia Appendix 2 for detailed scoring in each category.

Table . App evaluations with the Mobile Application Rating Scale[a].

App names	Engagement, mean (SD)	Functionality, mean (SD)	Aesthetics, mean (SD)	Information, mean (SD)	Objective score, mean (SD)
COG KidsCare	3.80 (0.98)	4.50 (0.50)	4.33 (0.47)	4.67 (0.75)	4.33(0.82)
My Cancer Tracker	3.00 (1.10)	4.25 (0.43)	4.00 (0.82)	3.17 (0.69)	3.50 (0.96)
CancerAid	2.60 (1.36)	4.25 (0.83)	3.67 (0.94)	4.17 (1.07)	3.67 (1.29)
Net Cancer Health Storylines	4.00 (1.10)	4.50(0.87)	4.00 (0.00)	4.20 (0.75)	4.18 (0.86)
Pain Squad	4.00 (0.63)	4.75 (0.43)	4.00 (0.82)	4.14 (0.99)	4.21 (0.83)
HomeTown Cancer Predisposition	1.60 (0.80)	4.00 (0.71)	3.00 (0.82)	4.00 (1.22)	3.06 (1.39)
Heroes Circle	1.80 (0.75)	1.50 (0.50)	2.33 (0.47)	2.25 (0.43)	1.94 (0.66)
The Breath Brake App	1.80 (0.75)	1.75 (0.83)	1.67 (0.47)	1.60 (0.80)	1.71 (0.75)
Kid’s Guide to Cancer	2.80 (1.33)	3.75 (1.30)	5.00 (0.00)	4.00 (0.89)	3.76 (1.31)
BELONG Beating Cancer Together	4.40 (0.80)	5.00 (0.00)	4.33 (0.94)	3.40 (1.02)	4.24 (1.00)
Tracker, Reminder – CareClinic	4.60 (0.49)	2.50 (0.50)	4.67 (0.47)	3.00 (1.41)	3.65 (1.28)
Outcomes4ME Cancer Care	3.00 (0.89)	4.75 (0.43)	4.00 (0.82)	4.33 (1.11)	4.00 (1.11)
I’ll explain it to you	1.80 (0.98)	4.75 (0.43)	2.33 (0.47)	4.00 (1.26)	3.24 (1.52)
FORTEe Get Strong	3.20 (1.17)	2.25 (0.43)	2.67 (0.47)	2.67 (0.75)	2.72 (0.87)
Our Journey with Cancer	1.40 (0.80)	3.00 (0.00)	2.00 (0.00)	3.40 (0.49)	2.47 (0.98)
LLS Coloring for Kids	4.60 (0.49)	4.25 (0.43)	3.67 (0.94)	3.67 (0.75)	4.06 (0.78)
OncoPower	3.00 (1.41)	3.50 (0.50)	3.00 (0.82)	2.80 (1.60)	3.06 (1.26)
Average score	3.02	3.72	3.45	3.50	3.40

[a] Objective score reflects average of 1 through 4 for each app.

Audience Categories

Apps were split into 3 groups based on their intended audience. In the first group, apps that focused on a pediatric population, between the ages of 0 and 17 years (n=7), used activities designed to interest the younger demographic to convey valuable information or make certain features more accessible from a medical literacy perspective. In the second group, apps that focused on caregivers, 18 years and older (n=9), were more likely to create direct connections to health care and generate data visualizations to translate numbers into meaningful interpretations. In the last group, the rest of the apps targeted both pediatric patients and caregivers (n=6). These apps proposed separate user accounts to differentiate parent and child, as well as the targeted features.

User Ratings and Reviews

The majority of apps (n=18) had user ratings publicly available for review and analysis. A total of 4 apps did not receive any user reviews or ratings (Hometown Cancer Predisposition, Kid’s Cancer Guide, AYABytes, and FORTEe Get Strong). These apps had between 1 and 100 posted reviews per app, whereas there were apps that received a high number of user ratings, such as “Tracker, Reminder - CareClinic” (n=3100) and “BELONG Beating Cancer Together” (n=5770). A total of 16 apps received high ratings (mean 4.4, SD 0.59; Min=3.1, Max=5.0).

Downloads and Storage

CancerAid, Cancer.Net Mobile, BELONG Beating Cancer Together, and My Cancer Tracker were downloaded by more than 5000 users. The rest of the apps were downloaded by fewer than 500 users. Apps required between 1.7 and 235.3 MB of storage for saving health-related information and app functionality (mean 67.03 MB, SD 58.38 MB).

Language Availability

To be included, apps were required to have an English option. The majority of the apps provided English exclusively (n=12). However, 10 apps provided multilanguage options including Spanish (n=4), French (n=4), Arabic (n=2), German (n=2), Chinese (n=2), Hebrew (n=1), Dutch (n=1), Italian (n=2), Hindi (n=1), Romanian (n=1), and Portuguese (n=1).

Data and Health Information Privacy

Apps typically request access to key hardware or software features built into the device to exercise the full length of capabilities designed into the mHealth app. These requests appear as pop-up notifications that require input before continuing to use the app (mean 2.72, SD 3.13; Min=0, Max=10). The types of requests across both app stores included approved access to the calendar, files, camera, microphone, location, user ID, device ID, Wi-Fi networks, contacts, and phone status. Based on our observation, none of the apps mentioned any type of encryption on the app store or in-app. Similarly, none of the apps provided 2-step verification options or similar security measures after account creation.

Discussion

Principal Findings

The principal findings of our systematic search and analysis study reveal a noticeable scarcity of pediatric oncology-specific mHealth apps in the digital marketplace, highlighting a critical gap in resources aimed at supporting pediatric patients with cancer and their families. Despite the growing prevalence of mHealth solutions in the broader health care landscape [26], our analysis underscores the underrepresentation of pediatric patients with cancer in this technological advancement [27]. Similarly, Jupp et al's [28] earlier review identified only 1 out of 28 qualifying oncology apps that specifically served pediatric patients.

The existing apps predominantly focus on educational resources, symptom tracking, and medication reminders. We observed that the adoption of these apps may rely on how well an app can both target specific diagnoses and remain applicable to the wider oncology audience. Therefore, high functionality may have come at the cost of aesthetics and engagement quality of the apps and lacking concise and quality information. While these features align with general needs within chronic illness management, they often lack the specificity and depth required for the complex care trajectories typical in pediatric oncology. This includes focusing on cancers more common in children than adults, implementing risk-based medical follow-ups, a systematic plan for lifelong surveillance, managing symptoms, addressing developmental delays or educational disruption, and mitigating long-term effects of treatment [29,30].

Quality Assessment

Of the objective domains, functionality scored the highest while engagement scored lowest on average. The prioritization of equipping patients and their caregivers with accessible tools is a strong theme among newer mHealth apps, especially in pediatric oncology. These health management apps can create the structure needed for caregivers and patients to monitor progress, which leads to better accountability and overall better patient outcomes [31]. However, the design of these apps often does not incorporate tactics to maintain attention or consistent usage, such as gamification, in the long term. This in combination with the lower information scores creates an obstacle to sustained adoption. An app may be highly functional and aesthetically professional but lacks specific flexibility and informative quality for caregivers, patients, or both.

Lower scores for engagement are consistent with other studies in the literature that used MARS for oncology app interventions [32]. Additionally, the developers' tendency to focus on implementation rather than building evidence-based features highlights a trend of understudied interventions on the market today [33]. Many of the apps included in this study either were minimally tested in a usability trial or were not rigorously tested at all. New users of these apps may find oncology mHealth apps helpful for minor tracking purposes like notifications but might find them problematic with evolving treatment plans, expanding diagnostic information, and available support groups in the area.

Target Population

Of the few apps currently available for pediatric cancer, apps were designed to target children and adolescent patients, caregivers, or both user populations. Apps designed for adolescents and young adults (AYA) with cancer are of interest since nearly two-thirds of AYAs within the United States report using an app for health behaviors, including medication reminders [34]. Several studies have reported the informational needs of AYAs in a cancer care app by highlighting features such as free-text diaries. The overarching goal of a cancer care app is expected to help monitor the impact of the disease and treatment in their day-to-day life and emotions [14]. Additionally, there is a need for personalized data to be adapted to a patient's specific condition, considering factors such as the type, history, and severity of cancer [27], as well as age-appropriate content that addresses topics like diagnosis, treatment options, sustaining social ties, and strategies to manage the illness [35]. These abilities help AYAs to be more independent with self-care, thus easing the transition to adulthood and long-term survivorship [36]. Additionally, more recent pediatric oncology literature has called out the gap in the child's voice, particularly in symptom assessment [37-39]. mHealth apps designed specifically for children could provide that opportunity to improve reporting standards.

Value of Apps in Patient Care

In our study, the majority of the apps focused on educational (information) resources for different user audiences. This aligns with Vaffis et al's [30] finding as mHealth apps focus on cancer as an important component of patient disease management. Moreover, this is an expected finding as pediatric cancer treatment requires complex treatment regimens, daily medications, intensive side effects, and symptom burden [40]. In addition, medication tracking, symptom tracking, and notifications for reminders are other major features. This matched with the need and also the major challenge to the oncological treatment plans, which is managing medication nonadherence or noncompliance. Missed treatments during home care are major causes of increased adverse outcomes including infection, relapse, and death in this vulnerable population [41]. Therefore, the apps have been aiming to address this vital issue via those critical features, aligning with earlier apps [13]. In addition, the literature presents evidence to support the efficacy of digital interventions in improving medication adherence, psychosocial well-being, and health outcomes in children and adolescents with chronic health conditions [5]. This indicates that mHealth apps aim to improve adherence, self-management and alleviating symptom burden could be essential to improving the use of the apps, and health outcomes.

Inclusivity

Furthermore, our findings highlight a significant language barrier, with more than half of the reviewed apps available exclusively in English. The accessibility of these digital interventions in alternative languages is a step toward closing the gap in care [42,43]. However, this has been an improvement as a review in 2017 cited that only 20% of all medication apps were offered alternative languages [36]. In addition, the digital divide between socioeconomic and ethnic groups reduces the availability of such resources to underserved populations including limited English proficiency patients and families [44,45]. New approaches via mobile apps should be considered, as these platforms can help with medical literacy and build self-care routines among patients and families [46,47]. In addition, developers and decision makers should consider device compatibility and dependency on cellular connectivity to reduce problems due to inconsistent service, limited storage, data plan requirements, or budget-friendly smartphones that are outside of the regularly maintained cycle of software updates [14,20,36]. Such an approach may support scalable, accessible, and affordable use.

Privacy and Security

Finally, data security and privacy are important as patients and families are storing and sharing personally identifiable information and confidential health information via apps. Health care institutions create guidelines for handling sensitive data; however, the privacy and security of personal health apps remain the responsibility of end users. Unfortunately, the Health Insurance Portability and Accountability Act (HIPAA) does not regulate third party apps or their services [48]. Other regulations such as the Children’s Online Privacy Protection Act (COPPA) have been a major piece of legislation for protecting child information from third-party organizations, yet it has limited protections with regard to health care information [49-51]. To ensure adequate protection, app stores hosting mHealth tools should have additional protocols to require justification for the necessity of accessing requested phone sensors and other sensitive health informatics (eg, camera, location, and microphone) [48].

Limitations

This review provided an overview of pediatric cancer-specific apps limited to the currently available apps in the Google Play and Apple App Store. We included these 2 common app stores because they are available in 2 major smartphone operating systems (iOS and Android) and are accessible by the majority of end users [52]. We have not included other stores, such as the Galaxy Store or Amazon Appstore, due to their limited user base and specific requirements for service (ie, the Amazon Appstore requires additional app installations) which may not be applicable for a broader audience of pediatric patients with cancer and caregivers. We focused on the US market for available apps as both app stores are regionally locked due to our physical location. In addition, we focused on apps available in the English language with additional language options. That limited our access to other apps that do not include English language as an option, or alternative apps for different regions or languages. We were not able to use content or sentiment analysis with all user comments because not all apps had a sufficient volume of comments to be analyzed. In addition, we have not received feedback from developers, patients, and clinicians about the apps during the study. This may have limited the study’s objectivity by not including their insights about the apps. Finally, the apps have a life cycle and are subject to change depending on developer updates and business or are not accessible and have restricted access. Some apps could be also removed from these stores for any reason, which may reduce the ability to evaluate these apps continuously and replicate this review with the same set of apps.

Future Works

Further research is suggested to investigate how developers create mHealth interventions through theory-based frameworks and collaborations (ie, co-design). Based on the MARS, we recommend future interventions to balance focus between extensive customizability and reliable intractability.

Additionally, future development efforts must prioritize the involvement of pediatric oncology stakeholders, including patients, families, and health care professionals, to ensure that the apps are not only technically sound but also deeply aligned with the specific needs, reducing linguistic and cultural barriers. We suggest a focus on evidence-based implementations and rigorous testing approaches for intervention, validation, adoption, and effectiveness. Going beyond, future research may expand how these apps are created from the developer’s perspective and ways to enable cross-disciplinary collaborations including patient and clinician stakeholders as well. Other avenues of research may also incorporate recent innovations in virtual reality, extended reality, and artificial intelligence to create more effective mobile and web apps.

Conclusions

Our study examined the landscape of mHealth apps for pediatric cancer. While mHealth apps hold promise for enhancing care and support for pediatric cancer treatment, our findings underscore the need for more inclusive, comprehensive, and integrated digital health solutions. The complexity of pediatric cancer is a multifaceted challenge, and mHealth apps can bridge the gaps to become a fundamental source of support for patients and caregivers from diagnosis to survivorship.

Conflicts of Interest

ES is an associate editor for the *Journal of Medical Internet Research*. The other authors declare no conflicts of interest.

Multimedia Appendix 1
mHealth app list.

[XLSX File, 43 KB - pediatrics_v7i1e58101_app1.xlsx]

Multimedia Appendix 2
Mobile Application Rating Scale scores.
[XLSX File, 13 KB - pediatrics_v7i1e58101_app2.xlsx]

Checklist 1
PRISMA checklist.
[DOCX File, 33 KB - pediatrics_v7i1e58101_app3.docx]

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Abbreviations

AYA: adolescents and young adult
COPPA: Children’s Online Privacy Protection Act
HIPAA: Health Insurance Portability and Accountability Act
MARS: Mobile Application Rating Scale
mHealth: mobile health
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Original Paper

Online Ambassador Visits for Hospitalized Children With Cancer: Qualitative Evaluation of Implementation

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Abstract

Background: Children with cancer or cancer-like disease risk treatment-related isolation, which can negatively impact their peer relationships and social competencies and exacerbate their loneliness. During the COVID-19 pandemic, increased online socialization became the new normal imposed by national isolation guidelines. To adhere to the treatment-related isolation guidelines, children with cancer were offered online classmate "ambassador" visits during hospitalization.

Objective: This study aimed to identify facilitators and barriers to online classmate "ambassador" visits during children with cancer's hospitalization through a qualitative descriptive process evaluation using the Consolidated Framework for Implementation Research.

Methods: From January to April 2022, we conducted 39 individual semistructured interviews with hospitalized children (n=16), their classmates (n=16), teachers from their schools (n=3), and study nurses (n=4) from involved hospitals. Most interviews (n=37, 95%) were conducted online using Microsoft Teams or Google Meet, while 2 (5%) interviews were conducted in person at the participants' residences. This approach allowed us to gain a broad understanding of the facilitators and barriers to online ambassador visits.

Results: We identified four themes: (1) working together, (2) ensuring participation, (3) staying connected, and (4) together online. The themes are described in terms of facilitators and barriers to online ambassador visits with 3 Consolidated Framework for Implementation Research domains: innovation, individuals, and the implementation process.

Conclusions: Addressing the social needs of hospitalized children through online visits with their classmates may be relevant when one-on-one meetings are problematic. The online visits are highly dependent on collaboration between study nurses and teachers and assessing the needs of the hospitalized children. While a high degree of adult engagement and a stable internet connection are pivotal, these online visits can promote much-needed social interaction between children across physical settings.

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KEYWORDS

Children; cancer; school-aged; peers; interaction; online; in-hospital; social; relationship; quality of life; intervention; qualitative

Introduction

In Denmark, 200 children aged between 0-18 years are diagnosed with cancer annually [1]. The positive advancement in treatment for childhood cancer has positively impacted the overall 5-year survival rates, which now exceeds an 80% chance for survival [2]. Although survival is expected for most children diagnosed with cancer, the treatment is often intense, involving chemotherapy, surgery, irradiation, and long periods of hospitalization [2,3]. As a result of the tough treatment, most children with cancer face long-term effects, which continue to plague them into their survivorship [3]. Childhood cancer survivors report long-term effects such as fatigue, impaired physical function, and poor cognitive function [4,5]. Furthermore, children with cancer and childhood cancer survivors also face social difficulties due to absenteeism from school, as well as leisure and social activities during treatment [6,7]. Consequently, their absence disrupts peer relationships, decreases social competencies, and increases feelings of loneliness [7,8]. Thus, treatment-related long-term effects combined with social isolation during treatment can hurt childhood cancer survivors' long-term well-being [3,8].

When returning to school after treatment, childhood cancer survivors often experience uncertainty and fear of losing their social relationships with classmates or peers [9,10]. It is, therefore, essential that children with cancer stay connected with school during hospitalization to maintain a sense of normalcy, develop social skills, and ensure successful re-entry after treatment [11-13]. A 2016 systematic review shows that school re-entry programs and peer education of classmates about cancer can further promote positive attitudes toward the child with cancer [14]. This positive classmate attitude was associated with greater motivation for interacting with the child with cancer and including them in social situations [14]. In 2013, a multimodal intervention called RESPECT (Rehabilitation Including Social and Physical Activity and Education in Children and Teenagers With Cancer) was designed to target and ameliorate children with cancer's physical, social, and academic functioning during hospitalization. The intervention included education of classmates about children with cancer and cancer treatment, visits by classmate "ambassadors" to the hospital, and establishing a link between the hospital and the child's school peer group through in-hospital supervised activity [15,16]. Previous research from the RESPECT study has shown that social interaction by hospitalized children with cancer can promote a sense of connectedness with their classmates while, in turn, motivating the classmates to support them [17-19].

Recently, technologies, including video conferencing and telepresence robots, have become viable options for socialization and schooling [20,21]. These technologies have been shown to positively impact homebound or hospitalized children's perceived social presence, academic behavior, and sense of normalcy [22-24]. As the COVID-19 pandemic shut down schools worldwide and the accompanying restrictions to physically isolate became inevitable, the need for technologies to support academic and social performance came to the forefront [25,26].

In response to the COVID-19 pandemic, hospitals and schools in Denmark prohibited in-person visits from March 2020 to April 2022, and the RESPECT study was forced to shift from in-person to online ambassador visits. We speculate that online visits may not be a better stand-alone option for school re-entry but could be seen as a supportive component. In some countries or settings, the online option may be more accessible than in-person visits, for example, a hospitalized child in isolation. However, it is still important to know the degree to which school re-entry programs and online ambassador visits complement each other and how online visits contribute. In this study, we aimed to identify facilitators and barriers to online ambassador visits for hospitalized children with cancer through a qualitative descriptive process evaluation using the Consolidated Framework for Implementation Research (CFIR). By identifying facilitators and barriers to online visits, this qualitative process evaluation intended to inform other health care professionals or professionals working closely with hospitalized children on what to be aware of when offering online visits to hospitalized children. Hopefully, our findings will inspire others to provide a social connection between hospitalized children and their peers.

Methods

Design

A qualitative descriptive process evaluation of online classmate "ambassador" visits was conducted with semistructured interviews after implementation. We used qualitative descriptive research to uncover the participants' experiences through their descriptions of the online ambassador visits. Qualitative descriptive research design has been predominantly used within health care research to provide direct descriptions of phenomena where the experiences are described from the participants' viewpoint [27]. In this study, qualitative descriptive research offers the opportunity to gather direct, rich descriptions of the online visits from the involved participants: hospitalized children, their ambassadors, their teachers, and the study nurses [27]. The knowledge gained from our participants' descriptions can be used to design future online psychosocial interventions for hospitalized children. The CFIR was used to interpret the participants' descriptions of facilitators and barriers to online visits [28]. As the meta-theoretical basis for the CFIR includes several implementation aspects, the CFIR provides a helpful framework for illuminating facilitators and barriers across 38 constructs within the five domains: (1) innovation, (2) outer setting, (3) inner setting, (4) individuals, and (5) implementation process [28]. The innovation domain refers to the proposed changes implemented and includes aspects of the intervention such as the innovation source and strength, evidence quality, relative advantage, adaptability, trialability, complexity, design, and cost [28]. The inner setting refers to the environment where the intervention is implemented, for example, hospital, school, city, etc. The inner setting domain includes team culture, compatibility, leadership engagement, and the implementation climate [28]. The outer setting domain refers to the context in which the intervention's inner setting exists and includes patient needs and resources, the level at which the implementing organization is connected with other organizations, peer pressure, and external policies and incentives [28]. The individuals domain refers to personal beliefs, knowledge, self-efficacy, and attributes that affect the intervention's implementation [28]. The implementation domain refers to activities and strategies used to implement the intervention, including planning, executing, reflecting, evaluating, and key intervention stakeholders, for example, opinion leaders, engagement, and project champions [28].

The RESPECT Study

The initial RESPECT study was a controlled intervention study implemented at the University Hospital of Copenhagen from 2012 to 2019. An in-depth description of the RESPECT intervention study, including inclusion and exclusion criteria for participation, is described elsewhere [15,29]. Based on qualitative results from the RESPECT study [17,19], it was decided to implement this study nationwide, offering (1) educational sessions for classmates on cancer and treatment and (2) facilitation of classmate "ambassador" visits during hospitalization as an integral part of the RESPECT implementation study (Textbox 1).

Textbox 1. Overview of the RESPECT (Rehabilitation Including Social and Physical Activity and Education in Children and Teenagers With Cancer) intervention study and the RESPECT implementation study.

The RESPECT intervention study. **Started in 2012. Ended in 2019.**

- Purpose: explore if involving healthy classmates at the hospital from the time of diagnosis and throughout treatment will improve the physical, educational, and social function of children with cancer, including facilitating their re-entry to everyday life after treatment.
- One intervention group from the pediatric oncology ward at the University Hospital of Copenhagen (Rigshospitalet).
- Three control groups from the pediatric oncology wards at Aarhus University Hospital, Aalborg University Hospital, and Odense University Hospital.

The RESPECT intervention study consists of:

- Educational sessions for classmates and teachers on childhood cancer, treatment, side effects, physical activity, and the RESPECT study in the school classroom by the study nurses.
- Supervised in-hospital physical activity. This component begins when the child with cancer or cancer-like disease is included in the RESPECT study.
- After the educational session, 2 classmates are elected as ambassadors in collaboration with the classmates, their parents, their teachers, and the study nurses.
- Classmate “Ambassador” visits during hospitalization. Ambassador visits are offered every 14th in-hospital stay day.

June 2019

- The national implementation of the RESPECT study began. The RESPECT intervention study changes to the RESPECT implementation study.

The RESPECT implementation study. Started in 2019. Ongoing.

- Purpose: to improve the social and educational well-being of children with cancer or cancer-like diseases during hospitalization, including facilitating their transition to everyday life after treatment.
- Offered at 4 Danish pediatric oncology wards: University Hospital of Copenhagen (Rigshospitalet), Aarhus University Hospital, Aalborg University Hospital, and Odense University Hospital.

The RESPECT implementation study consists of:

- Educational sessions for classmates and teachers on childhood cancer, treatment, side effects, physical activity, and the RESPECT study in the school classroom by the study nurses.
- After the educational session, 2 classmates are elected as ambassadors in collaboration with the classmates, their parents, their teachers, and the study nurses.
- Classmate “ambassador” visits during hospitalization. Online ambassador visits are offered every 14th in-hospital stay day.

March 2020

- COVID-19 pandemic hits Denmark, causing national lockdowns, including lockdowns at all 4 pediatric oncology wards and schools. No in-person ambassador visits are allowed. The RESPECT implementation study adapts to an online app format using Microsoft Teams (Microsoft) or Google Meet (Google).
- Online educational sessions for classmates and teachers on childhood cancer, treatment, side effects, and the RESPECT study by study nurses.
- Two classmates are chosen as ambassadors online in collaboration with the classmates, their parents, their teachers, and the study nurses.
- Online classmate “ambassador” visits during hospitalization. Online ambassador visits are offered every 14th in-hospital stay day.

Participation in the RESPECT Implementation Study

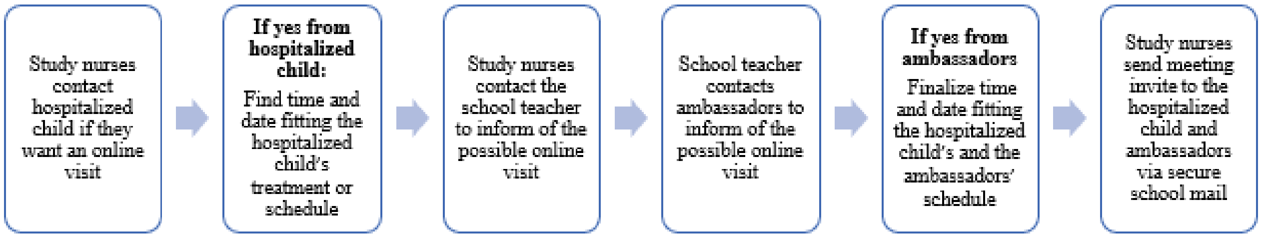
Study nurses invited hospitalized children to participate in the RESPECT implementation study if they were (1) school-aged (6-18 years old); (2) diagnosed with cancer or cancer-like diseases, for example, immune deficiency or severe aplastic anemia; (3) treated with chemotherapy, radiation, surgery, or hematopoietic stem cell transplantation; and (4) receiving cancer treatment at a pediatric oncology ward in Denmark. Classmates were introduced to an “ambassador” function during the educational session in the classroom and could apply for the role, which involved visiting the hospitalized child throughout the treatment trajectory or until the classmate no longer wished to hold the function.

The classmates were also informed of the practicality of the ambassador visits, such as being transported to and from the hospital, that the time duration of the ambassador visits was always on a school day between 9 AM and 3 PM, and what to expect as an ambassador visiting the hospital, for example, seeing children who are sick. If needed, ambassadors were replaced with new ones. Further, 2 ambassadors per hospitalized child were identified in collaboration with the classroom teacher, the hospitalized child, the hospitalized child’s parents, the ambassadors’ parents, and this study’s nurses. All ambassadors were screened by this study's nurses. The inclusion criteria for becoming an ambassador were (1) being a classmate to the hospitalized child and (2) possessing educational, emotional, and social competencies to support the hospitalized child. Children with cancer or cancer-like diseases and their classmates were excluded if they were (1) unable to speak Danish or (2) had severe mental disability.

The RESPECT Implementation Study During the COVID-19 Pandemic

To ensure that children with cancer stayed socially connected with their school classmates during the COVID-19 pandemic, the RESPECT implementation study adapted their in-person educational sessions and ambassador visits to a digital format using Microsoft Teams (Microsoft) or Google Meet (Google). Manuals or guidelines on how to organize or facilitate these online educational sessions or online ambassador visits were not developed before the initiation of the online visits. Guidelines were eventually developed simultaneously with conducting the online ambassador visits and based on experiences gained during the intervention. They were updated nationally during weekly meetings between this study's nurses and the principal investigator of the RESPECT study. The online visits were led by study nurses associated with the RESPECT implementation study. The online visits were offered via secure mail accounts and were scheduled by this study's nurses. These visits took place between 9 AM and 3 PM, with a frequency of 1 visit every 14th in-hospital day (Figure 1).

Figure 1. Preparation process for online ambassador visits.



The online ambassador visits took place during regular school hours. The teachers were responsible for assisting the ambassadors with setting up their equipment, for example, logging in to Microsoft Teams or Google Meet but they were not required to be present during the online visits. The hospitalized children decided if they wanted their parents or this study's nurse to be present during an online visit. In most cases, the parents did not participate but were present in the hospital room. The online visits did not have a fixed timeframe but ranged from 10 to 90 minutes, depending on the hospitalized children's well-being on the day and the motivation of hospitalized children and their ambassadors to continue the session. Equipment such as computers, telephones, or tablets facilitated the online visits. The hospitalized children and the ambassadors often used computers provided by the school but a mobile device with an internet connection and secure mail account to access Microsoft Teams or Google Meet was acceptable.

Participants and Recruitment

We recruited participants from the RESPECT implementation study for this study. All children with cancer or cancer-like diseases (hospitalized children), ambassadors, RESPECT study nurses, and teachers with experience in online ambassador visits were eligible to join this study. We used a convenience sample strategy to include the participants in this study. We strived to include participants representative from all of Denmark to provide nuanced descriptions of online visits. We included hospitalized children with cancer from 3 out of 4 hospitals that have a pediatric oncology ward. The criteria for inclusion of the hospitals were that the RESPECT implementation study must have been implemented and offered online visits during the COVID-19 pandemic.

The implementation of the RESPECT implementation study was scheduled for the fourth hospital but was postponed due to the COVID-19 pandemic. As a result, the fourth hospital did not meet our inclusion criteria. From the RESPECT implementation study, 123 hospitalized children were identified as eligible to participate in this study. Out of these, this study's nurses invited 34 hospitalized children to participate in this study. If the hospitalized child consented to participate, their ambassadors were also contacted regarding participation. Study nurses from the RESPECT study and schoolteachers were invited to participate if they had facilitated at least one online visit during the COVID-19 pandemic. Author NNB, a female PhD student without prior knowledge of the participants, contacted the invited participants by telephone regarding participation in this study. Of these 34 hospitalized children, 16 agreed to participate, as well as 16 of their ambassadors, 4 RESPECT study nurses, and 3 schoolteachers (Figure 2).

In total, 26 participants were from Zealand (University Hospital of Copenhagen), and 13 participants were from Jutland (University Hospital of Aarhus and University Hospital of Aalborg) in Denmark. The 16 hospitalized children (8 boys and 8 girls) were treated for leukemia (n=9), immune deficiency (n=3), extracranial solid tumors (n=2), tumors located in the central nervous system (n=1), or severe aplastic anemia (n=1). The hospitalized children and their ambassadors were aged between 7-16 (mean 10.5, SD 2.8) years. The hospitalized children participated in 4.5 (SD 3.5) online visits with a range of 1-12 online visits. Participant characteristics are presented in Table 1 below.

Figure 2. Recruitment process.

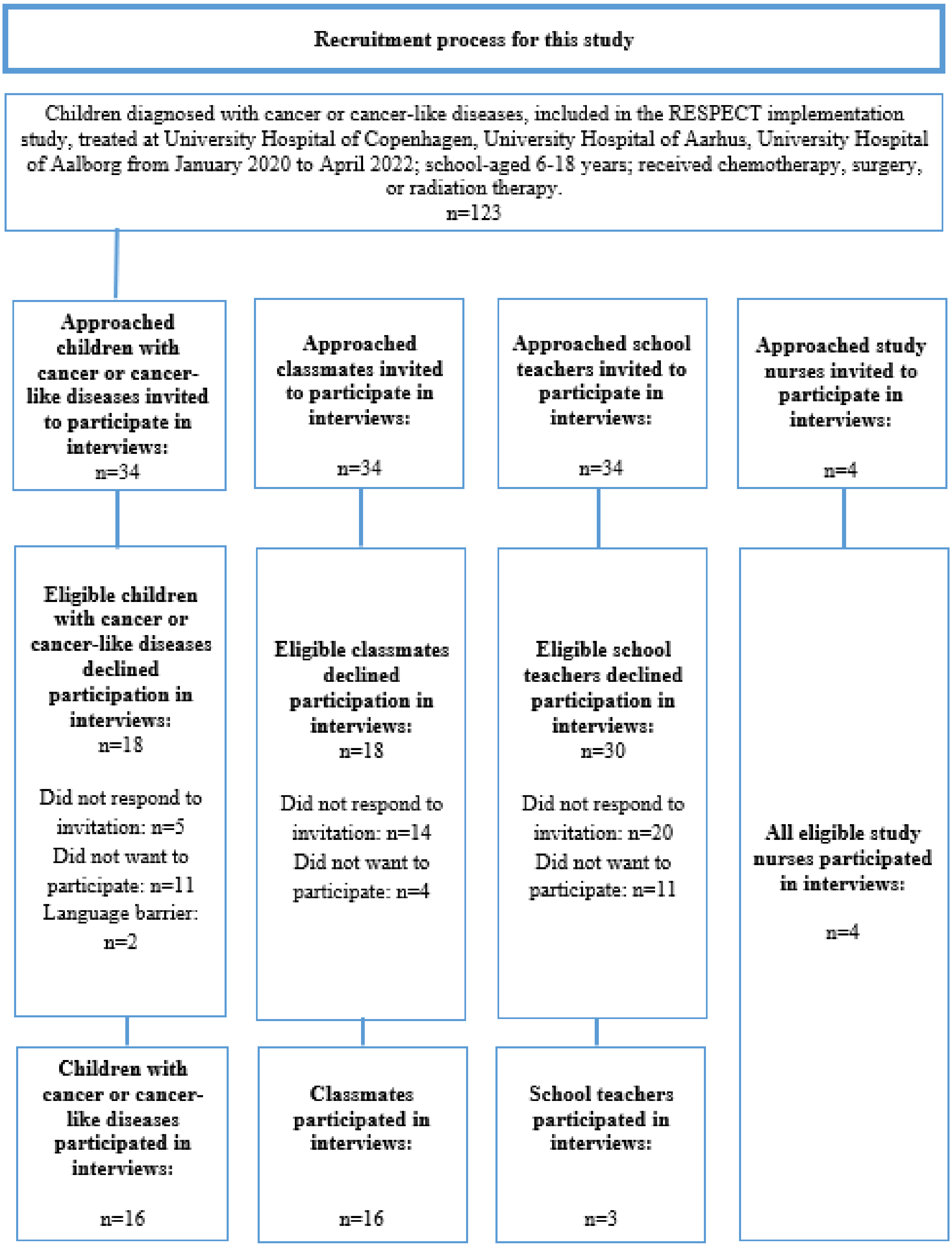


Table 1. Participant demographics. Note that ambassadors and schoolteachers are presented by region, not by hospital site, as they are not linked to the hospital.

Participant demographics	Children with cancer (n=16)	Ambassadors (n=16)	Study nurses (n=4)	Teachers (n=3)
Sex, n (%)				
Male	8 (50)	6 (38)	—[a]	1 (33)
Female	8 (50)	10 (62)	4 (100)	2 (67)
Type of cancer or cancer-like diseases, n (%)				
Leukemia	9 (56)	—	—	—
Tumors located in the central nervous system	1 (6)	—	—	—
Extracranial solid tumors	2 (12)	—	—	—
Immune deficiency	3 (19)	—	—	—
Severe aplastic anemia	1 (6)	—	—	—
Treatment, (%)				
Chemotherapy	16 (100)	—	—	—
Radiation therapy	2 (12)	—	—	—
Surgery	4 (25)	—	—	—
Hematopoietic stem cell transplantation	4 (25)	—	—	—
Age (years), median (range)				
Age at the time of diagnosis	9.5 (6-14)	—	—	—
Age at the time of data collection	10.5 (7-16)	10.5 (7-16)	—	—
Region and pediatric oncology ward, n (%)				
Zealand	—	11 (69)	—	2 (67)
University Hospital of Copenhagen	11 (69)	—	2 (50)	—
Jutland	—	5 (31)	—	1 93)
Aarhus University Hospital	2 (12)	—	1 (25)	—
Aalborg University Hospital	3 (19)	—	1 (25)	—

[a] Not available.

Ethical Considerations

The RESPECT implementation study is a part of the original RESPECT study (file H-20077439). The Danish Data Protection Agency (file P-2021-208) approved the RESPECT study. Participants provided written and informed verbal consent, and parents gave consent on behalf of their children under 15 years of age. All participants were informed of their right to withdraw from this study at any time. Participants were pseudonymized for privacy considerations.

Data Collection

In total, 4 semistructured interview guides were developed targeting the hospitalized children, ambassadors, teachers, and this study's nurses (Multimedia Appendix 1). These guides were designed to elicit participants' descriptions of online ambassador visits (including facilitators and barriers) and used open-ended questions to encourage reflection on their experiences [27]. The semistructured interviews were held from January to April 2022. Interviews were conducted by the first author (NNB), who introduced herself and this study's aim before starting each interview. NNB has experience in performing qualitative interviews as well as in interviewing children across age groups. Some of the younger children (n=4) preferred being interviewed with their parents present for emotional support. No parent contributed to the interviews. Most interviews (37/39, 95%) were conducted using Microsoft Teams or Google Meet, while 1 hospitalized child and 1 ambassador preferred being interviewed at home. All interviews were audio recorded and varied in duration from 8 to 55 (mean 15.6, SD 10.7) minutes.

Data Analysis

Interviews were transcribed verbatim by a student assistant using a transcription guide to ensure consistency. A Danish and English medical writer ensured that all descriptions were captured and interpreted correctly in English. A deductive analysis inspired by Braun and Clarke's [30] approach to Thematic Analysis was used. The data were organized and coded using NVivo coding software. Due to our qualitative descriptive research design, we aimed to stay as close as possible to the participants' descriptions of their experiences with online visits during the analysis process. CFIR was applied in the analysis as an interpretation tool to gain an in-depth understanding of facilitators and barriers to implementing online ambassador visits in a hospital setting. The analysis used the following steps: (1) the transcripts were read repeatedly until author NNB gained an in-depth understanding of the participants' descriptions of the online classmate visits; (2) author NNB coded the participants' descriptions into the CFIR domains; (3) authors NNB, MW, and HBL assigned the CFIR domains into overarching themes; (4) the themes were discussed and reviewed within the author group to ensure that the participant descriptions were rightfully captured within the CFIR domains and themes; and (5) themes were finalized after thorough discussion and agreement. All authors agreed on the final themes, and disagreements were discussed and resolved within the author group.

Results

Overview

We identified the following four themes from the participants' descriptions of the online ambassador visits: (1) working together, (2) ensuring participation, (3) staying connected, and (4) together online. The themes included facilitators and barriers to online ambassador visits within 3 CFIR domains: innovation, individuals, and the implementation process.

Working Together

Collaboration between the hospital and the school was an essential element when planning and facilitating online ambassador visits and included sharing information about the well-being and frame of mind of the children and technical support. Collaboration between the hospital and schools exemplifies the CFIR construct of "teaming" within the implementation process. This study's nurses experienced collaboration with teachers as demanding when the teachers were not keen to secure online visits. These experiences were often linked to technical problems faced by the teachers or to their limited time.

> *Having the resources can be challenging for the teachers. They often say no thanks to the online visits because they do not have the resources. The teachers want to participate, but the practicality [of it] can be problem[atic]* [Study nurse]

Time constraints and technical issues led some teachers to disregard online visits. They were also seen as barriers that negatively impacted collaboration. The hospitalized children and their ambassadors never mentioned collaboration between the hospital and the school. Rather, the hospitalized children explained that they had a close relationship with this study's nurses, which increased their willingness to participate in online visits. Collaboration between the hospitalized children and this study's nurses was seen as a facilitator for ensuring participation in the online visits and also fit into the CFIR construct of "teaming" within the implementation process.

> *Most times, it is me who gets to decide what activities we do, but the nurse is the one who knows about my overall plan with school and my treatment during the day. I think it is nice [that] the nurse helps me because sometimes I don't know what I want to talk about.* [Hospitalized child aged 12 years]

This study's nurses elaborated that they depended on the hospitalized children's collaboration to ensure that online visits occurred as intended, for example, ensuring social interaction. Collaboration between this study's nurses and the hospitalized children exemplifies the CFIR construct of "planning" within the implementation process. When planning online visits, this study's nurses identified their roles and responsibilities and defined the goals for success in collaboration with the hospitalized children.

Ensuring Participation

Online ambassador visits required some level of adaptability to ensure the participation of the hospitalized children and their ambassadors. The teachers explained that schools used different online apps, such as Microsoft Teams and Google Meet, designed for emergency teaching during the COVID-19 pandemic. This study's nurses adapted the setting of the online visits to fit each school's preferred apps.

The CFIR construct "adaptability" within the innovation domain refers to how the intervention can be modified and tailored to fit into the inner settings [31]. In this study, the inner settings are the hospitals and schools where online visits are implemented. Using the schools' preferred apps, this study's nurses ensured that the teachers did not have to learn new technologies and had easy access to online visits. Thus, adapting to the setting was seen as a facilitator for online visits. This study's nurses explained that they also adapted the content of online visits to ensure participation by the hospitalized children and their ambassadors.

> *…an unfocused, younger [or] sick child not feeling up to it or experiencing mood swings… that's when communication breaks down and [when] online visits become boring … that's when I terminate the [online ambassador] visit.* [Study nurse]

Adaptability of the content of online visits also included changing the duration of the visit to accommodate the hospitalized child's preferences and daily well-being. Adapting the content was described as a facilitator for the online visits. This study's nurses' decision regarding the duration of online visits was based on a "quality over quantity" value assessment. The children expressed that the timeframe for online visits was acceptable and that having a shorter timeframe did not impact their feelings of social connectedness.

This study's nurses explained that they often participated actively during online visits if the hospitalized child desired their participation. The older children preferred to be alone with their ambassadors, whereas the younger children preferred the study's nurses to take part in games or conversations.

> *I liked the privacy with my ambassadors during the [online] visits. I said to the nurse I wanted to be alone with my ambassadors so she started [Microsoft] Teams for me and then left. She [the nurse] came back when it was time to finish the visit.* [Hospitalized adolescent aged 14 years]

By assessing the needs of the intervention recipients, that is, the hospitalized children, this study's nurses ensured that online visits met their needs, which CFIR underscores as important when implementing an intervention [31]. The younger hospitalized children experienced that this study's nurses' participation, including offering games or conversation topics, helped them feel socially connected to their ambassadors. This resulted in the hospitalized children being more interested in repeating the experience; hence, the participating role of this study's nurse was seen as a facilitator of online visits.

> *…During the online visit, the two ambassadors started to play because they were physically together. I think they forgot [about] the hospitalized child. I tried to redirect their attention back to their ambassador visit, but I had to devise a game to keep them focused.* [Study nurse]

This study's nurses described the younger children as having problems sitting still or staying focused for long periods of time. If a study nurse was unsuccessful in redirecting the children's attention back to the visit, the visit would be terminated to ensure that any future online visits were perceived as positive experiences.

Staying Connected

The hospitalized children explained that they were happy to see their ambassadors during online visits, as they often felt isolated from their school and social activities. The ambassadors also felt isolated from their school class due to the COVID-19 pandemic lockdown. As such, online visits provided an opportunity for both groups to sustain social interactions.

> *I got an insight into what was happening at school; how everyone was doing, and stuff like that. Knowing all of that helped me [during my hospitalization].* [Hospitalized child aged 16 years]

The hospitalized children described receiving information from their ambassadors, for example, about new classmates, new teachers, or the latest gossip, provided them with a sense of social connectedness.

Likewise, some ambassadors expressed how they experienced a sense of social connectedness with the hospitalized child, as the visits provided the ambassador with news about the hospitalized child's life in the hospital. Understanding how the hospitalized children and their ambassadors experience connectedness during hospitalization is an example of the CFIR construct of "reflecting and evaluating" within the implementation process (ie, how successful the intervention is based on both qualitative and quantitative data) [31]. The ambassadors took great pride in their role and described it as being "information providers," as such, the link between the hospital and the school, and as "supportive peers." The most common task of the ambassadors was to share news from school.

> *She [the child with cancer] was happy that I told her [about what was going on in school]. She cheered up because I told her funny things like [the fact that] we got a new student in our class. She thought that was interesting.* [Ambassador aged 11 years]

This quote exemplifies how the ambassadors are happy to provide a sense of connectedness and social interaction as they perceive the hospitalized children's feedback on sharing information from the school as positive. According to the CFIR construct "innovation delivers" within the implementation process domain, locating and understanding priorities from the innovation delivers is vital when implementing an intervention [31]. As innovation deliverers, the ambassadors' motivation to participate in online visits stemmed from their desire to support the hospitalized child. The ambassadors also enjoyed receiving information about the everyday activities of the hospitalized children, reinforcing their feelings of social connectedness with the hospitalized children. However, the hospitalized children preferred receiving news and information from their ambassadors. Some of the teachers explained that choosing the right ambassadors to participate in online visits could enhance the social interaction experience.

> *Participating in online visits and socially interacting with each other can be difficult if they [the hospitalized child and their ambassadors] do not know each other. I think having [that] friendship before participating is important.* [Teacher 2]

If the hospitalized children and their ambassadors did not have preexisting relationships and had nothing in common to talk about, then social interaction would require more intervention by this study's nurse. As such, ambassador selection can be seen as an important facilitator of social connectedness during hospitalization.

Together Online

According to the construct "assessing context" within the implementation process, facilitators and barriers to implementing or delivering the intervention must be identified and assessed [31]. The hospitalized children and their ambassadors found the online ambassador visits favorable as they provided the opportunity to connect socially during hospitalization and the pandemic lockdown. However, both groups expressed that online visits could not replace in-person social interactions, including touching, playing physically together, or watching a movie together.

> *Being on Microsoft Teams is okay but not what I like. When you're together in person, you can do a lot of things like run around.* [Hospitalized child aged 9 years]

Despite having no experience with in-person ambassador visits, the children still expressed that they preferred in-person visits to online ones and that online visits were more favorable than no visits at all. This study's nurses described the online setting as a potential barrier to the children's social interaction, as communicating face-to-face online was intense for most of the children, resulting in the children being shy and not knowing what to talk about. Likewise, the ambassadors expressed that being limited to talking was boring as they would have preferred to do physical activities together with the hospitalized child.

> *I would have liked to visit her [the hospitalized child] in the hospital. It was a bit boring online because all we did was talk. If we had been together in the*

> *hospital, we could walk around or sit together* [Ambassador aged 11 years]

Some of the hospitalized children mentioned that their treatment-related physical changes made them conscious of their appearance during the online visits, and the setting amplified their consciousness about their altered appearance. Consequently, the hospitalized children participated in online visits without using the camera. Their ambassadors stated that they did not feel as socially connected without being able to see the hospitalized child on the screen. The hospitalized children explained that being together with their ambassadors was more important to them than their altered appearance, so much so that, in some cases, they felt relaxed enough to participate online using the camera. The teachers also described the online setting as a potential barrier for ambassadors to understand the hospitalized children's circumstances, including the severity of their disease or its treatment.

> *I think online visits can be difficult for the ambassadors because the setting is [similar to] watching a movie. Understanding the hospitalized child's treatment through a movie [lens] can be difficult.* [Teacher]

Another potential barrier often seen in the setting of online visits is having a poor internet connection. This study's nurses and teachers described how the hospital and school internet connections could fluctuate in terms of quality and negatively impact the integrity of the visits.

> *Sometimes, we canceled the online ambassador visits because of poor internet [connection]. That was a bit annoying because I had looked forward to seeing him [the hospitalized child]* [Ambassador aged 13 years]

Having a poor internet connection caused some ambassadors to feel discouraged that they could not keep their promise of social connectedness to the hospitalized children. Consequently, the hospitalized children and their ambassadors were not eager to participate in online visits when the internet was not fully functional.

Discussion

Overview

This qualitative process evaluation study aimed to identify facilitators and barriers to online ambassador visits during the hospitalization of children with cancer. Using qualitative descriptive research and CFIR, we gained an understanding of the online visit, including possibilities and difficulties faced by the hospitalized children, their ambassadors, schoolteachers, and study nurses. We found that the dominant facilitator was located within the construct of "teaming" in the implementation process domain, as the online visits required a high level of collaboration and adult facilitation. The main barrier was found within the "assessing context" construct in the implementation process domain, as the internet connection was considered a major barrier for online visits. Finally, further consideration should be given to the fact that, to date, online visits cannot provide the same level of social connectedness between children as physical visits.

In this study, close collaboration between this study's nurses and the teachers and close collaboration between this study's nurses and hospitalized children were seen as pivotal facilitators of online visits. However, strategies regarding implementation and collaboration are needed to specify the involvement of the various players associated with the intervention. CFIR suggests careful consideration of the individual's capability (interpersonal competence, knowledge, and skills to fulfill their role) and their motivation for fulfilling their role when implementing an intervention [31]. Based on our findings, we suggest that assessing the individuals' capability can potentially strengthen collaboration, as we found that identifying and outlining the roles of the individuals delivering the intervention and collaboration between this study's nurses and the hospitalized children formed the basis for successful integration of the online visits and led to strengthening feelings of social connectedness. Other studies suggest involving stakeholders, for example, health care professionals, teachers, and children, is vital to successful implementation [32-34]. However, based on our findings, strategies or guidelines on how to ensure collaboration when involving different stakeholders such as study nurses, teachers, hospitalized children, and ambassadors should be considered as we found that the collaboration between this study's nurses and teachers was not without challenges.

Another finding was that the hospitalized children had individual needs and preferences for the content of the online visits and the study's nurses' participation. Likewise, previous research suggests that pediatric interventions are not one-size-fits-all, and to ensure participation and involvement, there must be an element of individualization, that is, accommodating an individual's needs and preferences [35-37]. Our findings suggest that, depending on age, children interacted differently. Young-aged children were especially impacted, which was considered a potential barrier to online visits. Younger children needed more facilitation, and as such, this required more time commitment from this study's nurses. Interestingly, a study from 2013 reported similar findings, which included that time commitments were a barrier to their nurse-led videoconferencing intervention [38]. Considering that our study finding is similar to the study from 10 years ago, further research on how to accommodate time commitment issues should be actively pursued. We argue that setting achievable goals for each online visit should be required and that these goals should be discussed with all participating children. Regardless, research on actively involving intervention recipients in designing and adapting interventions for children is needed. When offering pediatric interventions, the adaptability of the intervention also requires consideration. In our study, both the setting and the content of the online visits were adaptable. This ensured participation and supported a feeling of being socially connected during the COVID-19 pandemic.

This study shows that online visits can lead to social connectedness between hospitalized children and their ambassadors. A central finding is that receiving new information during the visits supported the hospitalized children's feelings of social connectedness. Similarly, Pennant et al [39] found that hospitalized children and young adults benefited from social support during treatment, as social support was associated with feelings of “not being alone” and better coping strategies [40]. Our findings suggest that knowledge about each other and the children’s pre-existing relationships facilitated social interaction. Therefore, exploring the children’s motivation for participating in online visits could enhance feelings of social connectedness, limit the need for adult supervision, and thus reduce time consumption by this study’s nurses.

Lastly, it is important to note that this study’s nurses and teachers considered the online setting a barrier to social interaction. In contrast, the children proclaimed that the online setting presented an opportunity to interact socially and gave them a sense of connectedness. These findings align with previous research showing that videoconferencing technologies can strengthen friendships and relationships with peers and provide a sense of social presence for children with chronic diseases [24,38]. Although the online setting provided an opportunity to interact socially, our findings showed that the children preferred in-person visits to online visits as the online visits were perceived as boring in some situations. However, the online visits were better than no visits at all. Therefore, we suggest online visits may be a good option for hospitalized children in the absence of an in-person option but that in-person visits remain preferable. Furthermore, our findings show that a good internet connection is indispensable when offering online visits as a poor internet connection can impact the children’s motivation to participate and ultimately lead to negative views about social interaction online. Likewise, Weibel et al [24] found that poor internet connection and audio capabilities limited the children’s use of telepresence robots. Johannessen et al [41] also argued that having a poor internet connection is problematic for online dialogue. This is supported by previous research showing that poor internet quality is the primary source of technological difficulties when using online formats [42-44]. Although these studies report that poor internet connection is problematic for online social interaction or web-based interventions, none of the studies provide any solutions.

Limitations

Most (9/16, 56%) of the hospitalized children involved in this study were diagnosed with leukemia, and the remaining 7 (44%) children were diagnosed with other cancers or cancer-like diseases. Thus, further work is needed to explore whether this study’s findings are transferable to children with other diagnoses. Furthermore, only 3 (9%) of the 34 eligible teachers wanted to participate in this study, which limited variety in the description of online ambassador visits.

A central limitation of this study was that CFIR was not formally applied when developing the interview guides but only during data analysis. Consequently, we did not address constructs from the outer setting and inner setting domains. Hence, some key elements require further consideration. The online ambassador visits were part of an existing study offering in-person ambassador visits during hospitalization. This study has been ongoing since 2013, with several guidelines for in-person ambassador visits. Furthermore, this study’s nurses connected to this study were familiar with organizing and facilitating in-person ambassador visits, which may have impacted their readiness for change when the COVID-19 pandemic resulted in physical isolation across Denmark. Another example is how schools in Denmark changed from an in-person classroom teaching format to an online context during the COVID-19 pandemic. This impacted how the participants adapted to the online ambassador visits [45]. The schools’ readiness for change may also have impacted how the participants adapted to the online ambassador visits. Previous results from the RESPECT study show that children with cancer and their classmates are motivated to participate in in-person classmate visits [17,18,29]. Thus, we believe that the combination of an already existing organizational structure derived from our experiences with in-person ambassador visits and our knowledge of the classmates’ motivation to participate in in-person ambassador visits has enhanced this study’s nurses’ flexibility to adapt from the in-person to the online context. Therefore, we are unsure if implementing online ambassador visits in other settings may differ from ours.

Future Perspective

Emerging research highlights the importance of staying socially connected with peers and classmates during cancer treatment [37,39,46] and that there is a need for interventions that specifically target the relationship between children with cancer and their classmates [11,47,48]. Our study findings suggest that online visits with classmates or ambassadors can meet the hospitalized child’s need for social connectedness, albeit in-person visits are preferable for some children. Accordingly, online ambassador visits may prove valuable when in-person visits are not an option due to long distances and hospital isolation. However, the same finding also warns of the need to be aware of the children’s ages and individual preferences. Thus, it is advisable to assess and address the needs of the participating children, including the differences in needs across ages and individual preferences. While poor internet connection can negatively impact online social interaction, knowledge about how to accommodate internet consistency is limited. Future web-based interventions should consider establishing an appropriate internet connection to ensure participation. Based on our findings, we suggest that health care professionals offering online visits to hospitalized children align their expectations with those of the participating children regarding the purpose and context of the visits. This study’s findings may be transferable to other pediatric settings as knowledge about online visits and their facilitation during hospitalization can be applied across disease groups and cultures. However, research is needed to understand how to implement online visits in other contexts.

Conclusions

Hospitalized children and their ambassadors benefited from participating in the online ambassador visits as these visits contributed to enhanced social connectedness. This study’s findings showed that online social interaction between hospitalized children and their ambassadors is possible but requires being attentive to the individual needs of the hospitalized children and continuous collaboration between the hospital and school regarding organizing and facilitating. The online visits were pivotally reliant on sound internet connections. Including classmates during treatment should not be underestimated when addressing the social needs of hospitalized children. Future online psychosocial interventions can advantageously consider the collaboration between involved participations, sensitivity regarding individual preferences, and creating a stable internet connection when offering online visits during hospitalization.

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Authors' Contributions

HBL designed and implemented the RESPECT (Rehabilitation Including Social and Physical Activity and Education in Children and Teenagers With Cancer) intervention study. HBL and VS implemented the RESPECT implementation study. NNB created this study's design, recruited participants, conducted data collection and analysis, and prepared this paper. HBL and MW contributed to the analysis as well. CEW, PEB, MO, KBN, VS, and MKF all contributed to the preparation of this paper. All authors revised this paper critically to ensure intellectual content and approved the final version of this paper.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guides for hospitalized children, classmates (ambassadors), study nurses, and teachers.
[DOCX File , 27 KB - pediatrics_v7i1e53309_app1.docx]

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Abbreviations

CFIR: Consolidated Framework for Implementation Research
RESPECT: Rehabilitation Including Social and Physical Activity and Education in Children and Teenagers With Cancer

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Factors Affecting Usability and Acceptability of an Online Platform Used by Caregivers in Child and Adolescent Mental Health Services: Mixed Methods Study

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Abstract

Background: Young people and families endure protracted waits for specialist mental health support in the United Kingdom. Staff shortages and limited resources have led many organizations to develop digital platforms to improve access to support. myHealthE is a digital platform used by families referred to Child and Adolescent Mental Health Services in South London. It was initially designed to improve the collection of routine outcome measures and subsequently the "virtual waiting room" module was added, which includes information about child and adolescent mental health as well as signposting to supportive services. However, little is known about the acceptability or use of digital resources, such as myHealthE, or about sociodemographic inequalities affecting access to these resources.

Objective: This study aimed to assess the usability and acceptability of myHealthE as well as investigating whether any digital divides existed among its userbase in terms of sociodemographic characteristics.

Methods: A survey was sent to all myHealthE users (N=7337) in May 2023. Caregivers were asked about their usage of myHealthE, their levels of comfort with technology and the internet. They completed the System Usability Scale and gave open-ended feedback on their experiences of using myHealthE.

Results: A total of 680 caregivers responded, of whom 45% (n=306) were from a Black, Asian, or a minority ethnic background. Most (n=666, 98%) used a mobile phone to access myHealthE, and many had not accessed the platform's full functionality, including the new "virtual waiting room" module. Household income was a significant predictor of caregivers' levels of comfort using technology; caregivers were 13% more likely to be comfortable using technology with each increasing income bracket (adjusted odds ratio 1.13, 95% CI 1.00 - 1.29). Themes generated from caregivers' feedback highlight strengths of digital innovation as well as ideas for improvement, such as making digital platforms more personalized and tailored toward an individual's needs.

Conclusions: Technology can bring many benefits to health care; however, sole reliance on technology may result in many individuals being excluded. To enhance engagement, clinical services must ensure that digital platforms are mobile friendly, personalized, that users are alerted and directed to their full functionality, and that efforts are made to bridge digital divides. Enhancing dissemination practices and improving accessibility to informative resources on the internet is critical to provide fair access to all using Child and Adolescent Mental Health Services.

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KEYWORDS

child mental health; caregivers; digital technology; digital health; technology use; digital skill; digital literacy; digital divides; online systems; online survey; pediatric; mental health; usability; platform; survey; questionnaire; children; youth; adolescent; informal care; family care; acceptability; System Usability Scale; SUS; mobile phone

Introduction

Overview

In the United Kingdom, Child and Adolescent Mental Health Services (CAMHS) offer support for mental health difficulties among individuals under the age of 18 years. In April 2023, around 700,000 children and young people in England accessed mental health services [1]. Young people who are referred to CAMHS have to wait over 12 weeks before receiving treatment [2]. This can be a risky period for young people, with some experiencing deterioration in their mental health while awaiting treatment [3]. It can also lead to fragmented service delivery, since caregivers often contact other children's mental health agencies while waiting [4]. In addition, the longer a young person spends waiting, the more likely they are to miss their first appointment [5], and the less likely they are to engage in treatment [6], and these missed appointments further increase wait times [7].

As well as reducing waiting times, it is crucial to think about what CAMHS can provide to young people and their parents or carers while they are waiting for assessment or treatment. There is an increasing amount of attention on the potential for digital innovation in mental health services, which can entail delivering therapy and accessing resources via the internet. CAMHS settings are also increasingly considering how digital innovation can support caregivers' involvement [8]. However, it is essential to consider digital exclusion when discussing and designing digital innovations. Digital exclusion can occur when individuals are not able to access digital services; for example, they may not own a smartphone or computer [9], or lack interest in using technology [9]. More vulnerable groups are also more likely to be affected by digital exclusion, such as those who are older, unemployed, and more socially isolated [10].

Digital innovation can include internet-based portals that inform and engage service users [11]. The myHealthE platform was launched in 2021, as a digital solution to assist collection of caregiver-completed routine outcome measures for young people accessing CAMHS in South London [12]. In England, the National Health Service Outcomes Framework policy [13] recommend the use of routine outcome measures to assess the impact of their interventions in CAMHS [14]. myHealthE facilitates the collection of routine outcome measures from the point of referral, providing clinicians, caregivers and parents a useful way of assessing young people's current mental health symptoms as well as tracking progress over time [12]. Since myHealthE's staggered implementation in 2021, over 10,000 caregivers whose young people were referred to South London and Maudsley National Health Service Foundation Trust (SLaM) CAMHS have registered with the myHealthE platform.

In 2022, an extensive public user engagement campaign led by the South London Listens program highlighted the urgent need to provide a better pathway to access information for caregivers and young people while waiting for a CAMHS assessment. A recommendation from the campaign to create a "virtual waiting room" was taken forward by SLaM. After rapid consultation with senior managers, clinicians, and caregivers, a "minimal viable product" online module was developed. This new "virtual waiting room" module hosted new resources and signposting information selected by local CAMHS clinicians, which included, for example, a welcome video explaining the service, psychoeducation videos about low mood and anxiety, as well as external links to UK mental health charities like Mind. This new module was successfully integrated into the myHealthE platform in January 2023 [15]. Enrolled caregivers were then contacted twice (2 weeks apart) in January and February 2023, via personalized email messages to make them aware of the recent updates. Before this update, caregivers reported in a previous small-scale evaluation that myHealthE was generally easy-to-use [12]. No larger scale investigation of its accessibility has since been conducted.

The aim of this study was, first, to conduct a large-scale baseline assessment of the usability and acceptability of the myHealthE platform as well as of its new "virtual waiting room" module. This study also aimed to investigate whether differences in sociodemographic characteristics reveal any digital divides among the caregivers who use myHealthE.

Research Questions

1. How often, using which devices, and for what purposes are caregivers accessing the myHealthE platform?
2. Are sociodemographic characteristics (ie, age, ethnicity, marital status, and household income) associated with a digital divide, namely, (1) levels of comfort with the internet and technology and (2) perceived usability of the myHealthE platform?
3. How has the myHealthE platform and the inclusion of a virtual waiting room module been received by caregivers?

Methods

Ethical Considerations

This project was given approval by SLaM CAMHS Audit and Service Evaluation Committee on April 13, 2023 (Project #236). The project involved a voluntary survey sent to current the current userbase of myHealthE. Participation was anonymous since caregivers did not provide their names on completion and there was no way to link data in order to identify participants. No compensation was provided.

Participants and Procedures

On May 5, 2023, a text message was sent to all caregivers registered with the myHealthE site containing a link to the online voluntary survey hosted on Qualtrics. The survey was kept open for 6 weeks. There were a total of 29 questions on the survey, displayed on 6 pages. The participants were able to go back and change their answers. The participants saw a bar at the top of the screen indicating their progress through the survey. No incentives for completion were offered. IP addresses were checked to ensure there were no identical addresses.

Measures

Sociodemographic Characteristics

The participants were asked their age range, gender, ethnicity, marital status, and household income.

Access of and Attitudes Toward myHealthE

To answer Research Question 1, participants were asked what kinds of digital devices they own and they were asked a single choice question on how frequently they access the myHealthE site, and a multiple choice question on what their reasons were for doing so. They were asked when they first signed up to myHealthE to determine whether they had seen myHealthE before its "virtual waiting room" update in January 2023. For the participants that had signed up to myHealthE before 2023, they were asked if they noticed a change, and then whether they felt the update had improved the myHealthE platform. All participants were asked how helpful and how easy they found it to access the myHealthE resources. The participants were also asked 2 open-ended questions: (1) “Can you give any recent examples of a positive experience of using myHealthE?” and (2) “Do you have any ideas on ways it can be improved?”

The participants were then asked two questions rated on 5-point Likert scales from “very comfortable” to “very uncomfortable”: (1) How comfortable do you feel using technology? and (2) How comfortable are you with accessing the internet? The data for levels of comfort with (1) the internet and (2) technology were polarized rather than normally distributed, and therefore a binary variable was created by grouping the participants who answered “very comfortable” and “slightly comfortable” into one variable and the ones who answered “very uncomfortable” and “slightly uncomfortable” into one variable. Those who answered “neither uncomfortable nor comfortable” were excluded from the analysis.

The System Usability Scale (SUS) was used to measure participants’ views on the usability of the myHealthE platform [16]. It contains 10 items rated on a Likert scale from “Strongly disagree” to “Strongly agree.” It has been shown to have good reliability and face validity [17]. A total of 5 items are phrased in agreement (eg, “I thought the system was easy to use”) and five are phrased in disagreement (eg, “I thought there was too much inconsistency in this system”). The word “system” was replaced with “myHealthE” for this study. Half of the items were reverse-coded so that a higher response indicated a more positive view of the usability of the myHealthE platform. The responses to the items from the SUS questionnaire were converted numerically so the responses to each item ranged from 0 to 4. Then scores were summed and multiplied by 2.5 so that total scores ranged from 0 to 100.

Analysis

Quantitative Data

We conducted statistical analyses to investigate the association between sociodemographic characteristics, levels of comfort with the internet and technology, and perceived usability of myHealthE (Research Question 2).

To examine these digital divides, we conducted a multiple linear regression, with SUS scores as the outcome variable and sociodemographic characteristics of age, gender, ethnicity, marital status, and household income as predictor variables. Gender, ethnicity, and marital status were treated as categorical variables, while age and household income were treated as ordinal variables. Those who were widowed were removed from the marital status variable due to small cell counts (n=3). Similarly, multiple logistic regression models were conducted with levels of comfort with (1) the internet and (2) technology as outcome variables, and the same sociodemographic characteristics as predictor variables. Threshold for statistical significance was set at .05. Complete case analysis was used.

Qualitative Data

The qualitative feedback was analyzed using reflexive thematic analysis [18] to answer Research Question 3. Feedback to both open-ended questions was merged and read through twice and then coded to capture the smallest meaningful unit of information. Then codes were grouped conceptually to create initial themes. These initial themes were compared to the original data and redefined and redeveloped until a final set of themes and subthemes were generated and discussed within the research team. This set of themes and subthemes captured how the authors interpreted participants’ feedback to the two questions, with a focus on both participants’ experience with the myHealthE platform as well as digitalization in general.

Results

The survey was sent out to 7337 users of myHealthE, and a total of 680 individuals responded, giving a 9.27% response rate.

Demographics

There was a total of 680 participants, of whom 552 (81.2%) completed the survey and 128 (18.8%) provided partial data. The majority of respondents were female, and most were aged in their 30s or 40s. The participants were ethnically diverse: White British was the majority ethnic group (341/644, 53%) followed by Black British or Black African or Caribbean (126/644, 19.6%). The most common marital status was single (274/630, 43.5%; Table 1).

Table . Sociodemographic characteristics.

Characteristics[a]		Participants, n (%)
Gender (n=675)		
	Women	644 (95.4)
	Men	31 (4.6)
Age (years) (n=664)		
	25 and younger	17 (2.6)
	26 - 30	34 (5.1)
	31 - 35	107 (16.1)
	36 - 40	125 (18.8)
	41 - 45	168 (25.3)
	46 - 50	119 (17.9)
	51 - 55	70 (10.5)
	56 - 60	24 (3.6)
Ethnicity (n=644)		
	White British	341 (53)
	Black British or Black African or Caribbean	126 (19.6)
	Any other White background	77 (12)
	Mixed or multiple ethnic groups	56 (8.7)
	Asian or Asian British	27 (4.1)
	Other ethnic group	17 (2.6)
Marital status (n=630)		
	Single	274 (43.5)
	Married or civil partnership	254 (40.3)
	Divorced or dissolved civil partnership	59 (9.4)
	Separated	40 (6.3)
	Widowed	3 (0.5)
Household income (n=519) [b]		
	Below £10,000	128 (24.7)
	£10,001-£20,000	124 (23.9)
	£20,001-£30,000	81 (15.6)
	£30,001-£40,000	48 (9.2)
	£40,001-£50,000	31 (6)
	£50,001-£60,000	31 (6)
	Above £60,000	76 (14.6)

[a] Data were missing for gender (5/680, 0.7%), age (16/680, 2.4%), ethnicity (36/680, 5.3%), marital status (50/680, 7.4%), and household income (161/680, 23.7%).

[b] Conversion rate: British £1=US $1.26732.

myHealthE Access and Usage

The participants were asked what type of internet-enabled devices they owned (Table 2). Over 98% (647/659) owned a smartphone, and 53.4% (352/659) exclusively owned a phone. One percent (8/640) stated they did not own any internet-enabled device. Table 2 describes the frequency of access and reasons for using myHealthE. The majority of participants used myHealthE less than once a month, and a third used myHealthE once a month. Most (528/640, 82.5%) only used myHealthE for one purpose, with the main reason cited as completing outcome measures (575/640, 89.8%).

Table . myHealthE access and usage.

myHealthE access and usage		Responses, n (%)
Type of device (n=659) [a]		
	iPhone	396 (60.1)
	Android phone	274 (41.6)
	Laptop	239 (36.3)
	iPad or tablet	168 (25.5)
	PC	65 (9.9)
	I don’t own any devices	8 (1.2)
Number of devices owned (n=651)		
	1	353 (54.2)
	2	148 (22.7)
	3	112 (17.2)
	4	33 (5.1)
	5	5 (0.8)
Frequency of myHealthE usage (n=640)		
	Less than once a month	367 (57.3)
	Once a month	230 (35.9)
	Once a week	37 (5.8)
	Multiple times a week	6 (0.9)
Number of reasons for using myHealthE (n=640)		
	1	528 (82.5)
	2	70 (10.9)
	3	28 (4.4)
	4	14 (2.2)
Reasons for using myHealthE (n=640)		
	Completing questionnaires	575 (89.8)
	Looking at information about CAMHS	109 (17)
	Looking at resources on myHealthE	54 (8.4)
	Looking at other organizations	40 (6.3)
	Other reason	41 (6.4)

[a] Participants could select multiple options in response to type of device and reasons for using myHealthE. Data were missing for type of device (21/680, 3.1%), number of devices (29/680, 4.3%), frequency of myHealthE usage (40/680, 5.9%), and reasons for using myHealthE (40/680, 5.9%).

The myHealthE “Virtual Waiting Room” Module

Very few of the 585 participants who had been registered with the myHealthE site before the update had noticed the “virtual waiting room” update (62/537, 11.5%), and many were not sure whether myHealthE had improved following the update (Table 3). Excluding the “not sure” response option, more participants thought that the update had improved myHealthE than made it worse. Everyone was asked whether they found the new resources helpful and whether they found the resources on the “virtual waiting room” module easy to access. Slightly more participants stated they found the resources more helpful than unhelpful. However, many participants subsequently indicated that had been unaware of the new “virtual waiting room” module resources.

Table . myHealthE “virtual waiting room” update.

Questions on myHealth update[a]		Responses, n (%)
Which year did you first use myHealthE? (n=637)		
	2021	115 (18.1)
	2022	205 (32.2)
	2023	95 (14.9)
	I don’t know	222 (34.9)
Did you notice the update to the myHealthE site? (n=537)		
	Yes	62 (11.5)
	Not sure	253 (47.1)
	No	222 (41.3)
Do you feel the new update improved the myHealthE site? (n=277)		
	Much improved	37 (13.4)
	Somewhat improved	51 (18.4)
	Neither improved nor worsened	37 (13.4)
	Somewhat made worse	2 (0.7)
	Made much worse	2 (0.7)
	Not sure	148 (53.4)
Do you find the resources on myHealthE helpful? (n=601)		
	Very helpful	22 (3.7)
	Somewhat helpful	165 (27.5)
	Neither helpful nor unhelpful	275 (45.8)
	Somewhat unhelpful	35 (5.8)
	Very unhelpful	104 (17.3)
Do you find the resources on myHealthE easy to access? (n=601)		
	Very easy	90 (15)
	Slightly easy	64 (10.6)
	Neither easy nor difficult	142 (23.6)
	Slightly difficult	13 (2.2)
	Very difficult	6 (1)
	I did not know about these resources	286 (47.6)

[a] All participants (n=680) were presented with the question "Which year did you first use myHealthE?" Only those who answered “2021,” “2022“ or “I don't know” were presented with the question "Did you notice the update to the myHealthE site?" (n=585). Only those who answered “yes“ or “not sure” were presented with the question "Do you feel the new update improved the myHealthE site?" (n=315). Data were missing for ”Which year did you first use myHealthE?” (43/680, 6.3%), ”Did you notice the update to the myHealthE site?” (48/585, 8.2%), ”Do you feel the new update improved the myHealthE site?” (38/315, 12.1%), ”Do you find the resources on myHealthE helpful?” (79/680, 11.6%), and ”Do you find the resources on myHealthE easy to access?” (79/680, 11.6%).

Digital Divides

Levels of Comfort With Technology and the Internet

The participants were asked how comfortable they were with technology and with the internet in general. The majority of participants were slightly (130/659, 19.7%) or very comfortable (261/659, 39.6%) using technology and slightly (88/659, 13.4%) or very comfortable (337/659, 51.1%) using the internet, but around a quarter of participants were slightly (64/659, 9.7%) or very uncomfortable (132/659, 20%) using technology and slightly (39/659, 5.9%) or very uncomfortable (127/659, 19.3%) using the internet.

System Usability Scale

For 128 participants, at least one of their responses to the SUS was missing, so they were removed from analyses of SUS. The mean overall SUS score was 62.4 (SD 15.0) with the median score as 60 (IQR 50-72.5), meaning most participants found myHealthE neither easy nor difficult to use, with a slight skew toward participants finding it easy.

Examining the Association Between Sociodemographic Factors and Digital Divides

A multiple regression was run with SUS score as the outcome variable and age, gender, ethnicity, marital status, and household income as predictor variables. None of these sociodemographic characteristics were found to be statistically significantly associated with SUS score except those whose marital status was “separated” when compared with those who were “married.” (Table 4). However, a similar difference was not found for those who were “single” or “divorced.”’

Multiple logistic regressions were run with internet comfort and technology comfort as the outcome variables (uncomfortable vs comfortable) and age, gender, ethnicity, marital status, and household income as predictor variables (Table 5). Household income was a statistically significant predictor of how comfortable participants were with the internet and technology, with higher income being associated with higher levels of comfort. When compared with married participants, single and divorced participants were less likely to be comfortable with using technology; however, there was not a significant difference when modeling internet comfort.

Table . Multiple linear regression analysis between each sociodemographic characteristic (predictor) and System Usability Scale score (outcome), n=461.

Covariate and response category	Estimate (SE)	*P* value
Age	−0.74 (0.54)	.17
Gender		
Female	Ref[a]	Ref
Male	−6.76 (4.05)	.10
Ethnicity		
White British	Ref	Ref
Black British or Black African or Caribbean	−1.88 (2.07)	.36
Any other White background	1.67 (2.59)	.52
Mixed or multiple ethnic groups	2.51 (2.59)	.33
Asian or Asian British	−0.99 (4.01)	.81
Other ethnic group	−1.79 (4.66)	.70
Marital status		
Married	Ref	Ref
Single	−0.48 (1.93)	.80
Divorced	−1.52 (2.91)	.60
Separated	−6.52 (3.07)	.03
Household income	0.36 0.42)	.39

[a] Ref: reference.

Table . Multiple logistic regression analysis between sociodemographic characteristics (predictors) with (1) level of comfort with the internet (outcome; "uncomfortable" is the reference category), n=442 and (2) level of comfort with technology (outcome; "uncomfortable" is the reference category), n=444.

Covariate and response category	Levels of comfort with the internet			Levels of comfort with technology		
	Adjusted odds ratio (95% CI)	Standard error	*P* value	Adjusted odds ratio (95% CI)	Standard error	*P* value
Age	1.04 (0.89 - 1.21)	0.078	.63	1.05 (0.91 - 1.22)	0.075	.52
Gender						
Female	Ref[a]	Ref	Ref	Ref	Ref	Ref
Male	1.29 (0.37 - 4.43)	0.630	.69	1.53 (0.45 - 5.17)	0.623	.50
Ethnicity						
White British	Ref	Ref	Ref	Ref	Ref	Ref
Black British or Black African or Caribbean	1.57 (0.89 - 2.76)	0.288	.12	1.44 (0.84 - 2.48)	0.276	.19
Any other White background	2.17 (0.95 - 4.99)	0.423	.07	1.52 (0.72 - 3.19)	0.379	.27
Mixed or multiple ethnic groups	1.96 (0.91 - 4.21)	0.391	.09	1.73 (0.83 - 3.60)	0.374	.14
Asian or Asian British	1.85 (0.50 - 6.90)	0.672	.36	3.22 (0.69 - 15.10)	0.789	.14
Other ethnic group	0.49 (0.15 - 1.58)	0.601	.23	0.34 (0.10 - 1.15)	0.617	.08
Marital Status						
Married	Ref	Ref	Ref	Ref	Ref	Ref
Single	0.58 (0.34 - 1.01)	0.278	.05	0.48 (0.28 - 0.82)	0.276	.007
Divorced	0.87 (0.37 - 2.04)	0.434	.76	0.43 (0.19 - 0.95)	0.410	.04
Separated	1.03 (0.41 - 2.57)	0.469	.96	0.47 (0.20 - 1.11)	0.438	.09
Household income	1.18 (1.04 - 1.34)	0.065	.01	1.13 (1.00 - 1.29)	0.063	.04

[a] Ref: reference.

Understanding Attitudes Toward myHealthE

There were 142 responses to the question asking about positive experiences and 138 responded to the questions on ideas for improvement. The thematic analysis generated 3 themes and 8 subthemes (Table 6).

Table . Themes and subthemes.

Themes and subthemes	Illustrative quotations
Digitalization results in less personalization	
Digitalization reduces human contact	“A human should talk to me.” “I don’t know if anybody reads the information collected.”
The content isn’t personalized towards me and my child	“Make it personal. You have my details.” “Some questions are about my child’s behavior at school but he doesn’t attend school.”
Barriers to participation in a digital world	“Every time I check for updates to our case I have to reset my password.” “There should [be] good communication through the post!!!”
A platform with opportunities	
Room for improvement; introduce more functionality	“Add a medical record scroll down menu containing child’s all reports.” “…a way to communicate or leave a message that can’t be included in a questionnaire.”
Give us more information and support	“Update on local group meetings.” “Tools to assist parents or webinars for accessing tools and services”.
Lack of awareness; missed opportunities	“I wasn’t aware of these new resources mentioned in the questions above. So I recommend promoting those more.”
Digitalization brings insight and usability	
Data collation gives information and hope to caregivers	“Completing the questionnaires and seeing the results over time helps me understand my son’s progression.” “It always prompts me and updates me of progress, so I know I haven’t been lost in the system.”
MyHealthE has good usability	“Easy to fill questionnaire.” “Useful links to access support.”

Digitalization Results in Less Personalization

This theme captured how among all the benefits of digitalization, caregivers also were left with a lack of personal connection around their child’s journey with health services. This theme contained 3 subthemes.

Digitalization Reduces Human Contact

Respondents highlighted how they wanted themselves or their child to have contact with a real person. Caregivers felt that it was their right to be able to speak to someone about their child’s welfare: “A human should talk to me,” and some noted that the format of myHealthE made them feel “disconnected from [their children’s] care.” Caregivers wanted more to come from their completion of questionnaires like having “someone who contacts parents or carers after every test to discuss the results.” Caregivers seemingly struggled to see the direct benefit to their child from their completion of questionnaires, and feared that the information they were providing was not being used: “I don’t know if anybody reads the information collected.” Some caregivers were left with a negative emotional impact on themselves: “I don’t know why I bother filling it in as even though I see how in the red and in desperate need of help my son is, he does not get any help.”

The Content Isn’t Personalized Toward Me and My Child

Caregivers seemed to find that myHealthE felt generic and not tailored toward their or their child’s needs. Suggestions of personalization included using caregiver’s and children’s names and other details: “Make it personal. You have my details.” Caregivers felt they could not fully capture the difficulties that their child and their family had been experiencing in just one questionnaire: “Box ticking does not give a full picture of what is happening.” There was also a sense that some questionnaires were not appropriate in terms of age, disability, and school attendance: “my son is a teenager (16) and for me answering questions about sharing toys in school or playing with kids has no sense for me”; “Some questions are about my child’s behavior at school but he doesn’t attend school.”

Barriers to Participation in a Digital World

Respondents highlighted their difficulties with accessing the platform: “can never log in… so unsubscribed”; “can’t access the site”; “every time I check for updates to our case I have to reset my password” and with completing the questionnaires: “The forms weren’t fillable on my tech.” Caregivers also struggled to use some of the functionality on the platform: “unable to input my child’s new school.” One respondent also highlighted how digital information is not their preferred method of communication: “there should [be] good communication through the post!!!”

A Platform With Opportunities

This theme depicted how caregivers identified numerous ways in which myHealthE could be improved and it also seemed that the survey itself had highlighted potential benefits of the platform of which respondents were not previously aware. This theme contained 3 subthemes.

Room for Improvement; Introduce More Functionality

Respondents noted that the site had reduced functionality on mobile phones, and one respondent suggested an app: "I struggled to remember where to logon. I [wish] there was an app?" One caregiver also noted it would be valuable to be able to "share to print on android phone." Users also highlighted the benefits of integration of information from other platforms with myHealthE: "Booking a GP appointment through the app"; "add a medical record scroll down menu containing child's all reports."

Some respondents had ideas for how the information from routine outcome measures could be better used: "It would be nice if the information collected [could be] used towards building up reports for the assessment team to have a better understanding to that child." Caregivers asked for more information about the questionnaires: "state where and who the information from the questionnaires go to." Respondents also felt that they needed: "a way to communicate or leave a message that can't be included in a questionnaire."

Give Us More Information and Support

Caregivers wanted more "information on help is available"; one suggestion being information about what is available locally: "update on local group meetings." Caregivers seemingly wanted to know how they could help their child: "tools to assist parents or webinars for accessing tools and services."

Lack of Awareness; Missed Opportunities

For some respondents, the survey had alerted them to the existence of resources on the myHealthE site: "I wasn't aware of these new resources mentioned in the questions above. So I recommend promoting those more." A suggestion was made to "send parents/carers a link or text about it or even create a flyer."

Digitalization Brings Insight and Usability

This theme captured how users of myHealthE also noted its benefits. It contained 2 subthemes.

Data Collation Gives Information and Hope to Caregivers

Once caregivers on myHealthE complete a questionnaire, they can see their data summarized, as well as seeing any changes from their previous questionnaire. Respondents noted that they like the visualization: "it's interesting to see the questionnaire results overtime in a graph." Caregivers noted that they enjoyed how their child's scores had change: "at the end you see improvement or difficulties. It really picks up on how our home life is at the moment" and that viewing these data also helped them make insight into their child: "completing the questionnaires and seeing the results over time helps me understand my son's progression." The questionnaires also seemed to give caregivers hope: "It always prompts me and updates me of progress, so I know I haven't been lost in the system."

myHealthE Has Good Usability

There were also a number of strengths of the myHealthE platform that were noted by caregivers. Some respondents found it easy to use: "easy to fill questionnaire"; "logging in and answering questionnaires was easy." Caregivers also highlighted its helpfulness: "it helped me to get more info about how to get help for my child." Numerous examples of the myHealthE platform were also highlighted as positive: "very helpful and useful information; "useful links to access support"; "simple explanation of resources."

Discussion

Principal Findings

This study surveyed 680 caregivers of young people waiting for treatment in CAMHS to determine the acceptability and use of myHealthE, as well as investigating any digital divides. It found that the majority of caregivers were accessing myHealthE exclusively using a phone, and most accessed the platform less than once a month. Caregivers were not accessing the full functionality of the myHealthE platform, including its new "virtual waiting room" module. Caregivers gave recommendations on how myHealthE could be improved, including ensuring the site is personalized. This study also showed that household income is a significant predictor of digital divides.

How Often, Which Devices, and for What Purposes Are Caregivers Using myHealthE?

The majority of caregivers indicated that they were only using their phones to access the digital world. Therefore, platforms like myHealthE must ensure they have been designed with mobile use in mind to maximize their accessibility. Any current and future development of digital resources for CAMHS populations must focus on testing new platforms via this medium.

The participants did not use myHealthE particularly frequently, with the majority using it less than once a month. This is not surprising, however, since up until the "virtual waiting room" module was launched, the only use for the system was to complete outcome measures which caregivers were alerted to once every three months. Caregivers were alerted to the new "virtual waiting room" update by text message; however, this survey has demonstrated this was not sufficient, since many were not aware of the full functionality of the platform. This study has, therefore, highlighted the need for developers of digital platforms to establish users' baseline awareness of a platform's features. It gives motivation for continual improvement and an increase in dissemination of features on platforms like myHealthE to promote awareness of and engagement with digital resources.

Does a Digital Divide Exist Between the Caregivers Who Access myHealthE?

We did not find strong evidence for associations between sociodemographic characteristics and System Usability Scale scores. However, we found household income to be a predictor of comfort with the internet and technology, with higher income predicting greater levels of comfort. Household income is an indicator of social deprivation and vulnerability, a known source of digital divide [10]. It is important to note that we still found this to be a factor, even within a sample of individuals whose level of comfort with the internet and technology was sufficiently high to own a device and complete an online survey. There was also some evidence that individuals who were single or divorced were less comfortable with technology compared to married individuals.

It is important to note that this study investigated digital divides using an online survey, meaning it is possible that other sociodemographic characteristics would have been found to predict usability and comfort if a nondigital survey was used. For example, despite ethnicity not being found to be a significant predictor of responses to the SUS or levels of comfort with the internet or technology, it is a known factor in literature concerned with digital divides, and must continue to be addressed in the development of digital platforms [19]. In addition, other variables not measured by this study, such as education level, have been found to influence digital divides [20]. Future studies should continue to investigate digital divides using study designs with a range of data collection methods, and should consider investigating the interaction between sociodemographic variables such as household income and ethnicity.

How Has myHealthE and Its New "Virtual Waiting Room" Module Been Received by Caregivers?

Respondents' views on digitalization were polarized. Its pitfalls were made clear and there was a general sense of depersonalization. Caregivers felt that the platform was generic and not tailored toward their family. Positive aspects included the visualization of change in their child's score on outcome measures. Suggestions from caregivers included using their names and their young people's names in notifications. Customizability has also been named as a recommendation by participants in other studies of digital platforms [21]. Digital platforms in mental health settings could also improve their user experience by tailoring questionnaires and content to suit certain mental health presentations, neurodiversity, and different age ranges of children.

The System Usability Scale measured participants' views on the usability of myHealthE. The average score was 62.4, which represents "high marginal" acceptability [22] and is lower than the previous evaluation of myHealthE using SUS, which found that a sample of 8 participants rated it at 78 [12]. However, this study had a much larger sample size, and it is likely therefore to be more representative of the true response of the myHealthE userbase. It is essential that digital platforms use measures like the SUS to evaluate their usability in a standardized manner; however, this is not currently common practice [23].

Caregivers were asked whether they thought myHealthE had been improved by the "virtual waiting room" update in January 2023, which expanded the platform from exclusively collecting routine outcome measures, to also including information about CAMHS, mental health resources, and information on other organizations. Only 11.5% (62/537) of respondents indicated they had noticed the update to the site. This demonstrates that the two alerts sent to caregivers were not sufficient to notify them of this update. Therefore, despite efforts being made to build and populate the new "virtual waiting room' module, insufficient effort had been made to promote awareness of and engagement in these resources. Therefore, digital platforms should consider a variety of methods to notify their userbase of updates, such as using both text and email as well as suggesting users visit new webpages when they are on the site.

Strengths and Limitations

This study is the first evaluation of the myHealthE platform in its current form using both quantitative and qualitative analyses, and has resulted in specific recommendations for the improvement of all digital platforms used by CAMHS populations.

A major limitation of this study is that, by using an online survey, our ability to measure digital divides was limited, and likely affected by sampling and response bias. The appraisal of comfort with the internet and technology are particularly likely to be overestimated, since by the study's design, participants were all able to respond to an online survey using an internet-enabled device. In addition, fewer than 10% of myHealthE's total userbase responded to the survey, indicating that our results are likely representative of those who are more motivated to complete online surveys. Another limitation was the lack of male respondents. This limitation stems from the underlying electronic health record system in SLaM, which permits only one contact detail for a primary caregiver to be listed, and female caregivers are often preferentially recorded in these fields. Therefore, findings relating to gender should be interpreted with caution.

Conclusions

This study provides a baseline assessment of the acceptability and usability of the myHealthE platform. It provides useful guidance for all health care providers for children and young people on developing online resources for caregivers and young people waiting to access mental health services. It also considered barriers to accessing these platforms. We found that although there was, in general, good acceptability and usability of myHealthE, there were still numerous recommendations made by users and opportunities for improvements. For example, this study highlighted the importance of ensuring digital platforms are mobile friendly. It also highlighted potential gaps between development and dissemination of new information to service users; it is not simply enough to create new materials, we must ensure that service users are fully informed. Finally, it is essential that platforms like myHealthE are not solely designed for individuals with high digital literacy, but also consider how individuals might be being excluded through digitalization. Bridging digital divides, particularly those observed among different sociodemographic groups, such as different income levels, is crucial.

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Conflicts of Interest

None declared.

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Abbreviations

CAMHS: Child and Adolescent Mental Health Services
NIHR: National Institute for Health and Care Research
SLaM: South London and Maudsley National Health Service Foundation Trust
SUS: System Usability Scale

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Social Media Exposure and Other Correlates of Increased e-Cigarette Use Among Adolescents During Remote Schooling: Cross-Sectional Study

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Abstract

Background: Little is known about the role of exposure to e-cigarette–related digital content, behavioral and mental health factors, and social environment on the change in adolescent e-cigarette use during COVID-19 shelter-in-place orders and remote schooling.

Objective: The aim of the study was to examine changes in adolescent e-cigarette use during shelter-in-place and remote schooling in association with exposure to e-cigarette–related digital content and other correlates: stronger e-cigarette dependence, feeling lonely, inability to socialize, e-cigarette use to cope with shelter-in-place, and the number of family members aware of participants' e-cigarette use.

Methods: A cross-sectional survey conducted between August 2020 and March 2021 included 85 California adolescents (mean age 16.7, SD 1.2 years; 39/85, 46% identified as female and 37/85, 44% as Hispanic) who reported e-cigarette use in the past 30 days. Multivariable penalized logistic regressions determined associations adjusted for age, race and ethnicity, and mother's education. The outcome of increased e-cigarette use was defined as more frequent use of e-cigarettes of the same or stronger nicotine or tetrahydrocannabinol concentration.

Results: Almost all respondents (83/85, 98%) reported using social media more since shelter-in-place, and 74% (63/85) reported seeing e-cigarette digital content. More than half (46/85, 54%) reported increased e-cigarette use during shelter-in-place. Most individuals who increased use were exposed to e-cigarette digital content (38/46, 83%) compared to those who did not increase e-cigarette use (25/39, 64%), but the association was nonsignificant after adjusting for demographics (adjusted odds ratio [AOR] 2.34, 95% CI 0.71 - 8.46). Respondents who felt lonely (AOR 3.33, 95% CI 1.27 - 9.42), used e-cigarettes to cope with shelter-in-place (AOR 4.06, 95% CI 1.39 - 13.41), or had ≥2 family members aware of participants' e-cigarette use (AOR 6.42, 95% CI 1.29 - 39.49) were more likely to report increased e-cigarette use.

Conclusions: Almost all participants reported using social media more during shelter-in-place, with many respondents reporting increased e-cigarette use, and significant associations with loneliness and use to cope with shelter-in-place. Future interventions should consider leveraging digital platforms for e-cigarette use prevention and cessation and address the mental health consequences of the COVID-19 pandemic.

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KEYWORDS

adolescents; social media use; e-cigarette use; mental health; COVID-19 shelter-in-place orders; remote schooling; smoking; vape; e-cigarette implications; COVID-19; anxiety; depression

Introduction

Background

In 2021, 3.3% of middle and 14.1% of high school students in the United States reported e-cigarette use in the past 30 days [1]. Feelings of anxiety, depression, or stress (43.4%) and the use of e-cigarettes by friends (28.3%) are commonly cited reasons for adolescent e-cigarette use [2]. Harmful effects on the developing brain and lungs [3] and a higher risk of addiction to nicotine and other drugs [4,5] are some of the adverse health outcomes associated with youth e-cigarette use [6,7]. In addition to nicotine e-cigarettes, the 2021 Monitoring the Future national survey [8] revealed past 30-day use of tetrahydrocannabinol (THC) cannabis e-cigarettes among 4.7% of 8th graders, 12.4% of 10th graders, and 18.3% of 12th graders; and studies in adolescents have shown concurrent use or couse of both nicotine and cannabis [9-12]. Such use of nicotine and THC vaporizers is worrisome due to the hazardous health effects of not only nicotine [13-15] but also THC use [16-18] and potentially elevated health risks associated with couse of both products [19,20].

e-Cigarette use among US adolescents remains a concern [1,21] despite declines in prevalence from 2020 to 2021 [22,23]. The decrease in adolescent use might be related, among other factors [24-26], to the increased public awareness about COVID-19 [23,27,28] and the impact of shelter-in-place orders in the early stage of the pandemic [28,29] (hereafter referred to as “shelter-in-place”). At the same time, both quantitative [28] and qualitative [30] studies reported *increased* youth e-cigarette use due to boredom, stress, or as a distraction during shelter-in-place [23].

A meteoric rise of social media use and prolonged screen time accompanied the COVID-19 pandemic [31]. Frequency of social media use is positively correlated with exposure to e-cigarette–related digital content that, in its turn, is associated with positive attitudes toward e-cigarette use [32]. Observational [33-39] and experimental [40,41] studies have shown that social media use and exposure to social media content (eg, advertisements or posts) are associated with increased willingness and intention to use e-cigarettes [40], increased curiosity [41] and odds of experimental [41,42] and subsequent [38] e-cigarette use among e-cigarette naïve adolescents, greater perceived norms [40] and benefits of e-cigarettes [42], lower perceived danger [39,40], and more positive attitudes toward e-cigarettes among youths and adolescents [40]. Increased prevalence of adolescent cannabis use has also been associated with exposure to social media cannabis marketing [43].

Goal of This Study

The need to reduce exposure to e-cigarette–related digital content on social media to prevent tobacco initiation has been raised [44,45], but little is known about the effect of exposure to e-cigarette–related digital content on the change in e-cigarette use among adolescents using tobacco.

To our knowledge, this cross-sectional study is the first to assess the association between exposure to e-cigarette–related digital content on social media and increased e-cigarette use during the unique time frame of shelter-in-place and remote schooling among California adolescents currently using e-cigarettes. Prior research has shown that e-cigarette use is associated with secondhand smoke exposure among family and friends and a pro–e-cigarette social environment [46-48] as well as with mental health and psychological distress [49-52]. Thus, we also aimed to determine potential correlates of increased e-cigarette use during shelter-in-place, including the level of e-cigarette dependence, feeling lonely, inability to socialize during shelter-in-place, e-cigarette use to cope with shelter-in-place, and awareness of family members of participants’ e-cigarette use.

Methods

Study Design and Recruitment

This was a cross-sectional study with a convenience sample of adolescents (N=85) who provided their responses to a web-based survey between August 2020 and March 2021. The eligibility criteria included being a middle or high school student in California before California started shelter-in-place on March 19, 2020 [53] and who reported current (past 30-day) use of any e-cigarette products containing nicotine (eg, disposable or pod-based) or THC (eg, marijuana vaporizers and “weed pens”).

SIS International Research recruited adolescent participants by reaching out to their research panels and by posting the study screener on the web. To qualify for the study, adolescents had to be ages 13 - 18 years, attending middle or high school in California, and using e-cigarettes at the start of the COVID-19 pandemic. SIS verified adolescents’ age and demographics by reviewing supporting documentation. The research team pilot-tested the survey questionnaires, which were administered anonymously on the Qualtrics platform (Qualtrics, Provo, UT) and designed to take approximately 20 minutes to complete.

Ethical Considerations

The study was approved by the University of California, San Francisco Institutional Review Board (20 - 31136). In the first few months of the study, adolescents provided assent, and a parent or legal guardian provided informed consent, but subsequently, adolescents were later allowed to consent for themselves, consistent with California law, which allows adolescents to consent to medical treatment for substance abuse. Participants received a US $20 gift card incentive. Each participant was assigned a unique survey identification number, and SIS kept their identities confidential. To validate entries of deidentified data, the research team manually checked each completed survey based on geolocation, duration of survey completion, quality of responses to open questions, as well as demographic data (age, gender, and race). Among 126 entries received, 97 were valid responses. We then eliminated 12 duplicate observations for 9 participants, retaining only the response with a longer survey duration time. The final analytic sample included 85 participants with valid responses, who completed the survey between August 12, 2020, and March 4, 2021, during remote schooling; shelter-in-place orders in California were lifted effective June 15, 2021 [54].

Measures: Outcome and Exposure of Interest

The survey items assessing changes in the frequency of use and concentration of e-cigarettes had the potential to directly demonstrate the impact of shelter-in-place by asking: “Overall, have you changed HOW MUCH you vape since the Shelter-in-Place rules?” and “Overall, has the STRENGTH of your vape changed since the Shelter-in-Place rules?” Given the significant correlation between the 2 variables (77.7% of overall agreement in responses, Cramer $V \chi^2_1$=0.59; P<.001), we used an aggregate outcome: increased e-cigarette use during shelter-in-place. This was a binary variable (yes or no) defined as a self-reported increase in the frequency of e-cigarette use *and* an increase or no change in the nicotine or THC concentration in the e-cigarettes used (Table S1 in Multimedia Appendix 1). Thus, selecting the response “taking more frequent hits or by using more days a month” and also reporting increased strength or no change in the concentration of e-cigarettes were classified as having increased e-cigarette use. Inconsistent changes in the frequency and concentration of e-cigarettes (eg, weaker concentration but more frequent use and vice versa, n=8) were not counted as an increase [55].

Exposure to e-cigarette digital content on social media was coded as a binary variable (yes or no) defined as affirmative responses to the following question: “At any point during Shelter-in-Place have you viewed vape advertisements or vaping digital content on any social media sites?” Both “not sure” and “no” responses were coded as “no exposure.”

Correlates and Covariates

e-Cigarette Use

The survey included images and provided examples of e-cigarette brands in questions about lifetime and past 30-day use of disposable (eg, Puff Bar), pod- or cartridge-based (eg, JUUL), or other types of nicotine e-cigarettes (eg, mod-based e-cigarettes, e-hookahs, and e-cigars) and THC vaporizer products (eg, Evolab).

We assessed e-cigarette dependence using the 4-item e-cigarette dependence scale (EDS) [56], with a possible range from 0 to 16 (Cronbach α=0.87) [57]. The survey also included questions about tobacco use among those who lived with the respondents (eg, a family member or a friend), which we further dichotomized for logistic modeling: any family member or friend versus nobody, the number of people who lived with the respondents (in categories: alone, 1 - 2, 3, and ≥4), how many family members and who (eg, a parent and a sibling) were aware that respondents used e-cigarettes (in categories: 0, 1, and ≥2), as well as reasons why respondents reported increased or decreased e-cigarette use during shelter-in-place (eg, being bored, lonely, and stressed).

Social Media Use

Participants reported whether they used social media more since shelter-in-place (yes or no) and what types of apps or websites respondents used in the past 30 days; we then derived the number of web-based platforms or apps used by respondents. Social media intensity was measured with 6 survey items (Cronbach α=0.83) adapted from the Facebook Addiction Scale by Andreassen et al [58] rating agreement with statements about social media use on a 5-point Likert scale from 1=never to 5=always; we used the average score similar to past research (Table S2 in Multimedia Appendix 1) [59].

COVID-19 and Coping With Shelter-in-Place Orders

Respondents reported whether they had been tested positive for COVID-19 and the methods used to cope with shelter-in-place (eg, using e-cigarettes and social media). We measured anxiety over COVID-19 using agreement with 6 statements on a Likert scale: 1=strongly disagree to 5=strongly agree and calculated the average score of the 6 items (Cronbach α=0.77; Table S2 in Multimedia Appendix 1).

Psychological Distress

We used the Kessler 6 Scale to measure shelter-in-place–related psychological distress over the past 30-day recall period (scores ranged from 0 to 24) [60,61]. We summed the score values and classified those with score ≥13 as severe psychological distress during shelter-in-place [60]. Respondents also reported other possible concerns they felt during shelter-in-place and how often they felt lonely (dichotomized to all or most of the time vs less often or never).

Sociodemographic Characteristics

The participants provided data about their age (in years); school grade as of fall 2020: high school (grades 9 - 12) or middle school (grades 6 - 8); self-identified sex; race and ethnicity that were combined to create a four-level covariate representing those who were (1) non-Hispanic African American or Black, (2) non-Hispanic White, (3) non-Hispanic other race, and (4) Hispanic, of any race; as well as mother’s highest level of educational attainment as a proxy for socioeconomic status [27]—a four-level variable: (1) General Education Development test or high school degree or lower, (2) some college, (3) some graduate or professional degree, and (4) unknown.

Statistical Analysis

All analyses were conducted using SAS software (version 9.4; SAS Institute). Two-sided P values ≤.05 were deemed statistically significant. Descriptive statistics included frequencies and proportions for categorical variables, means and SDs or medians and the IQRs (25th and 75th percentiles) for normally and nonnormally distributed continuous variables, respectively. As suggested to be a superior method to handle small sample and sparse data [62], we conducted bivariate and multivariable penalized logistic regressions with profile-likelihood CIs for nonlinear models [63] to assess unadjusted and adjusted odds ratios (AORs and odds ratio) with 95% CIs. In penalized logistic regression modeling, the likelihood is “penalized” by half of the logarithm of the determinant of the information matrix [62].

We assessed adjusted associations of increased e-cigarette use during shelter-in-place with exposure to e-cigarette content on social media and with other predictors of interest that were significant on α=.10 in unadjusted models. We adjusted all multivariable models for potential confounding factors, similar to prior research: age, race and ethnicity, and mother’s educational attainment [27,28,64]. Complete case analysis (n=84) was used in all models because of the small amount of missing data (n=1, 1%). We found no substantial collinearity in the models. Because of the exploratory nature of our study, we report all results that reached statistical significance [65]. We also present supplement models with results significant at $P \le .007$ (ie, .05/7) using Bonferroni correction (Tables S4-S10 in Multimedia Appendix 1).

Sensitivity Analyses

First, we reran all penalized multivariable logistic regression models while excluding 3 respondents who had reported 0 days and times of e-cigarette use in the past 30 days in the final survey. These data contradicted their prior responses about current e-cigarette use in the screening questionnaire (ie, which violates the eligibility criteria).

Second, we carried out traditional multivariable logistic regression models with normal-based Wald CIs to compare results with the primary analysis that used penalized regression modeling with profile-based CIs. For the third and fourth sensitivity analyses, we carried out multivariable logistic regression models (penalized and traditional for comparison) to assess correlates of 2 separate outcome variables: increased frequency of e-cigarette use and increased concentration of e-cigarettes used.

Results

Respondent Characteristics

Most participants were high school students (80/85, 94%), many identified as male (45/85, 53%) and Hispanic (37 of 85, 44%), and the mean age was 16.7 (SD 1.2) years (Table 1). One (1%) respondent was 19 years of age but was still in high school and, thus, was included in the analysis. Many reported that their mothers had at least some college education (37/85, 44%) and had received or were obtaining a graduate or professional degree (18/85, 21%).

Table . Respondent characteristics (N=85).

Characteristic or behavior	Values[a]
Demographic characteristics	
Age (n=84) (years), mean (SD)	16.7 (1.2)
School grade, n (%)	
High school (9th-12th)	80 (94)
Middle school (6th-8th)	5 (6)
Self-identified sex, n (%)	
Female	39 (46)
Male	45 (53)
Other or nonbinary	1 (1)
Race and ethnicity, n (%)	
African American or Black and non-Hispanic	13 (15)
Hispanic	37 (44)
White and non-Hispanic	26 (31)
Other race[b] and non-Hispanic	9 (11)
Mother’s educational attainment, n (%)	
GED[c] or high school or lower	25 (29)
Some college degree	37 (44)
Some graduate or professional degree	18 (21)
Unknown	5 (6)
e-Cigarette use before and during shelter-in-place orders	
Ever-use of e-cigarette products in the lifetime, n (%)	
Disposable	82 (96)
Pod-based	71 (84)
THC[d]	75 (88)
Other	68 (80)
e-Cigarette dependence (range 0 - 16), median (IQR)	9 (4-11)
Change in the frequency of e-cigarette use during shelter-in-place, n (%)	
More days per month or more hits per day	51 (60)
Fewer days per month or fewer hits per day	28 (33)
No change	6 (7)
Change in the concentration of e-cigarettes used during shelter-in-place, n (%)	
Stronger	38 (45)
Weaker	23 (27)
No change	24 (28)
Tobacco or THC use among coresidents, n (%)	
Nobody	21 (25)
Family member or friend	64 (75)
Family members only	34 (40)
Friends (nonfamily members) only	22 (26)
Family and Friends	8 (9)
People you live with, n (%)	

Characteristic or behavior	Values[a]
Alone	3 (4)
1 - 2	18 (21)
3	31 (36)
≥4	33 (39)
Who knows that you use e-cigarettes? n (%)	
A parent	46 (54)
A sibling	40 (47)
A grandparent	7 (8)
Another relative	15 (18)
No one	12 (14)
Family members who know you use e-cigarettes, n (%)	
0	10 (12)
1	49 (58)
≥2	26 (31)
Social media use	
Using social media more since shelter-in-place, n (%)	83 (98)
Social Media Intensity score (range 1 - 5), median (IQR)	3.5 (2.7 - 3.8)
Saw e-cigarette digital content on social media, n (%)	63 (74)
Apps used in the past 30 days (n=74), n (%)	
Facebook	42 (57)
Instagram	58 (78)
Snapchat	50 (68)
TikTok	45 (61)
Twitter	44 (59)
WhatsApp	35 (47)
YouTube	51 (69)
Other[e]	4 (5)
Apps used (n=74, range 1 - 8), median (IQR)	4 (3-6)
COVID-19 status and coping with shelter-in-place orders	
Diagnosed with COVID-19, n (%)	7 (8)
Anxiety over COVID-19 (range 1 - 5), median (IQR)	3.8 (3.3 - 4.2)
How are you coping with shelter-in-place? n (%)	
Being on social media	76 (89)
Facetiming	24 (28)
Streaming videos	29 (34)
Watching television	46 (54)
Playing videogames	48 (56)
Reading	14 (16)
Using e-cigarettes	56 (66)
Drinking alcohol	24 (28)
Having sex	9 (11)
Exercising	27 (32)

Characteristic or behavior	Values[a]
Meditating	17 (20)
Other[f]	3 (4)
I am not coping	5 (6)
Psychological and emotional distress	
Feeling lonely all or most of the time, n (%)	35 (41)
Psychological distress (n=84)[g], n (%)	
Severe (≥13)	39 (46)
Not severe (<13)	45 (53)
Other concerns endorsed, n (%)	
Stuck at home with my family all the time	49 (58)
Frustrated that my routine or plan has been disrupted	45 (53)
Not sure when my life will go back to normal	51 (60)
Spending more time on social media	32 (38)
Worried about COVID-19	33 (39)
Not able to meet up or hang out with the people I want to	42 (49)
Angry about the current state of politics	25 (29)
Other[h]	4 (5)

[a] Results may not add up to 100% or may exceed 100% because of rounding.

[b] Includes Alaskan Native or American Indian or multiracial, Asian or Native Hawaiian, or Pacific Islander, non-Hispanic.

[c] GED: General Education Development test.

[d] THC: tetrahydrocannabinol.

[e] Includes Among Us, Discord, Teams, and Zoom.

[f] Includes responses such as “going outside, work, or drugs.”

[g] One participant had missing values and an unpredictable sum of scores.

[h] Includes responses such as “having before-lockdown problems, no friends, mental health, or web-based learning is difficult.”

e-Cigarette Use

All respondents reported past 30-day use of nicotine e-cigarette products, and 68 of 85 (80%) reported past 30-day use of THC vaporizers; 75 of 85 (88%) had ever used THC vapor products. The average and median EDS scores were 8.3 (SD 4.4) and 9 (IQR 4 - 11), respectively. Three-quarters of the respondents (64/85, 75%) reported household e-cigarette use among people with whom they lived. Many (51/85, 60%) increased the frequency of e-cigarette use, and the main reasons among 48 (of 51) respondents who reported were (1) being bored (n=32, 67%), (2) stressed (n=27, 56%), (3) lonely (n=21, 44%), and (4) having other people around who used e-cigarettes (n=12, 25%; Table S3 in Multimedia Appendix 1). Many (38/85, 45%) said that e-cigarettes they used were of stronger concentration, and 46 of 85 (54%) reported increased frequency of e-cigarette use of the same or stronger concentration during shelter-in-place (Table S1 in Multimedia Appendix 1).

Social Media Use

Almost all participants said that they used social media more since shelter-in-place (83/85, 98%), and the intensity of social media use was moderately high (median 3.5 of 5, IQR 2.7 - 3.8). Many reported seeing e-cigarette advertisements or other digital content on social media during shelter-in-place (63/85, 74%). Of 85 respondents, 74 (87%) named a total of 11 social media platforms or apps they had been using in the past 30 days (median 4, IQR 3 - 6; range 1 - 8). Almost all of those 74 reported past-month use of at least 2 social media platforms (n=73, 99%), and 48 (65%) said they used at least 4 platforms. The top 5 web-based platforms listed by the 74 respondents were Instagram (n=58, 78%), YouTube (n=51, 69%), Snapchat (n=50, 68%), TikTok (n=45, 61%), and Twitter (n=44, 59%).

COVID-19 and Coping With Shelter-in-Place Orders

The level of anxiety over COVID-19 was moderately high among the respondents (median 3.8 of 5, IQR 3.3 - 4.2). Participants (N=85) reported 14 ways how they coped with shelter-in-place; the top 5 were examined in subsequent regression analyses: being on social media (n=76, 89%), using e-cigarettes (n=56, 66%), playing videogames (n=48, 56%), watching television (n=46, 54%), and streaming videos (n=29, 34%).

Psychological and Emotional Distress

Many participants reported feeling lonely (35/85, 41%), and the average level of psychological distress was 12 (SD 5.1), with 46% (39/84) reporting severe psychological distress.

Participants (N=85) also endorsed the following concerns: not being sure when life would go back to normal (n=49, 58%), being "stuck at home" with their family all the time (n=49, 58%), being frustrated that their routine or plan has been disrupted (n=45, 53%), being unable to meet up or hang out with the people they wanted to (n=42, 49%), and being worried about the COVID-19 (n=33, 39%).

Correlates of Increased e-Cigarette Use

The association between increased e-cigarette use during shelter-in-place and exposure to e-cigarette–related digital content on social media was borderline significant (odds ratio 2.58, 95% CI 0.98 - 7.13; *P*=.06) in the unadjusted analysis (Table 2) and nonsignificant (AOR 2.34, 95% CI 0.71 - 8.46; *P*=.19) after controlling for demographics (Figure 1 and Table S4 in Multimedia Appendix 1). Among the other 6 predictors assessed in the adjusted modeling (Figure 1 and Table S4 in Multimedia Appendix 1), 3 were positively associated with increased e-cigarette use: having ≥2 family members (vs no one) who were aware about participants' e-cigarette use (AOR 6.42, 95% CI 1.29 - 39.49; *P*=.04), using e-cigarettes to cope with shelter-in-place (AOR 4.06, 95% CI 1.39 - 13.41; *P*=.02), and feeling lonely (AOR 3.33, 95% CI 1.27 - 9.42; *P*=.02). Older participants were more likely to report increased e-cigarette use based on all models (Table S4 in Multimedia Appendix 1).

Table . Unadjusted associations of increased e-cigarette use with demographic and behavioral characteristics: results from unadjusted penalized logistic regression models (N=85).

Variable (responses)	Increased (n=46)	Did not increase (n=39)	OR[a] (95% CI)	*P* value
Demographic characteristics				
Age (n=84) (years), mean (SD)	17.1 (1.2)	16.17 (1.1)	2.03 (1.35 - 3.31)	.002
In high school (9th-12th), n (%)	45 (98)	35 (90)	3.85 (0.67 - 39.62)	.20
Self-identified sex, n (%)				
Female	24 (52)	15 (38)	1.80 (0.77-4.32)	.19
Male	21 (46)	24 (61)	Reference	—[b]
Other or nonbinary[c]	1 (2)	0 (0)	—	—
Race and ethnicity, n (%)				
African American or Black and non-Hispanic	10 (22)	3 (8)	1.91 (0.48 - 9.03)	.39
Hispanic	15 (33)	22 (56)	0.44 (0.16 - 1.19)	.12
White and non-Hispanic	16 (35)	10 (26)	Reference	—
Another race[d] and non-Hispanic	5 (6)	4 (10)	0.78 (0.18 - 3.52)	.75
Mother's educational attainment, n (%)				
GED[e] or high school or lower	12 (26)	13 (33)	0.60 (0.18 - 1.99)	.42
Some college degree	21 (46)	16 (41)	0.85 (0.27 - 2.59)	.78
Some graduate or professional degree	11 (24)	7 (18)	Reference	—
Unknown	2 (4)	3 (8)	0.47 (0.06 - 3.00)	.46
e-Cigarette use				
e-Cigarette dependence (range 0 - 16), median (IQR)	10 (7 - 11)	7 (3-11)	1.12 (1.02 - 1.25)	.03
Who knows that you use e-cigarette? n (%)				
A parent	28 (61)	18 (46)	1.79 (0.77 - 4.25)	.19
A sibling	26 (57)	14 (36)	2.27 (0.97 - 5.49)	.07
A grandparent	4 (9)	3 (8)	1.10 (0.25 - 5.23)	.90
Another relative	9 (20)	6 (15)	1.31 (0.44 - 4.10)	.64
No one	4 (9)	8 (21)	0.39 (0.11 - 1.30)	.15
Family members who know you use e-cigarettes, n (%)				
0	3 (7)	7 (18)	Reference	—
1	26 (57)	23 (59)	2.42 (0.64 - 10.93)	.23
≥2	17 (37)	9 (23)	3.95 (0.93 - 19.71)	.08
Tobacco or THC[f] use among people with whom you currently live, n (%)				
Family member or friend	36 (78)	28 (72)	1.40 (0.53 - 3.75)	.50
Nobody	10 (22)	11 (28)	Reference	—
People you live with, n (%)				
Alone	3 (7)	0 (0)	4.56 (0.36 - 648.0)	.40
1 - 2	11 (24)	7 (18)	Reference	—

Variable (responses)	Increased (n=46)	Did not increase (n=39)	OR[a] (95% CI)	*P* value
3	15 (33)	16 (41)	0.61 (0.19 - 1.92)	.42
4+	17 (37)	16 (41)	0.69 (0.22 - 2.14)	.54
COVID-19–related factors				
Diagnosed with COVID-19, n (%)	2 (4)	5 (13)	0.35 (0.06 - 1.56)	.22
Anxiety over COVID-19 (range 1 - 5), median (IQR)	3.9 (3.5 - 4.2)	3.8 (3.3 - 4.2)	1.07 (0.62 - 1.87)	.81
Strongly willing to be vaccinated against the COVID-19 infection, n (%)	35 (76)	26 (67)	1.57 (0.62 - 4.06)	.35
How are you coping with shelter-in-place? n (%)				
Being on social media	42 (91)	34 (87)	1.51 (0.40 - 6.01)	.56
Streaming videos	18 (39)	11 (28)	1.61 (0.66 - 4.04)	.31
Watching television	6 (57)	20 (51)	1.23 (0.53 - 2.88)	.64
Playing videogames	29 (63)	19 (49)	1.77 (0.76 - 4.22)	.20
Using e-cigarettes	36 (78)	20 (51)	3.31 (1.34 - 8.59)	.01
Social media				
Social Media Intensity (range 1 - 5), median (IQR)	3.5 (2.7 - 3.8)	3.3 (2.3 - 3.8)	1.22 (0.77 - 1.96)	.40
Using social media more since shelter-in-place, n (%)	45 (98)	38 (97)	0.85 (0.07 - 10.74)	.91
Saw e-cigarette digital content on social media, n (%)	38 (83)	25 (64)	2.58 (0.98 - 7.13)	.06
Apps used in the past 30 days (n=74), n (%)				
TikTok	25 (66)	20 (56)	1.52 (0.61 - 3.88)	.38
Instagram	30 (79)	28 (78)	1.07 (0.36 - 3.19)	.91
Facebook	23 (61)	19 (53)	1.36 (0.55 - 3.41)	.51
Twitter	25 (66)	19 (53)	1.70 (0.68 - 4.33)	.27
Snapchat	25 (66)	25 (69)	0.85 (0.32 - 2.22)	.75
WhatsApp	21 (55)	14 (39)	1.91 (0.77 - 4.83)	.17
YouTube	24 (63)	27 (75)	0.58 (0.21 - 1.54)	.29
Other[g]	2 (4)	2 (5)	0.95 (0.14 - 6.44)	.96
Apps used in the past 30 days (n=74), median (IQR)	4 (3-7)	4 (3-5)	1.12 (0.86 - 1.46)	.41
Emotional and psychological distress				
Feeling lonely all or most of the time, n (%)	18 (50)	9 (26)	4.15 (1.68 - 10.91)	.003
Psychological distress (n=84), [h] **n (%)**				
Severe (13+)	17 (47)	15 (43)	1.23 (0.53 - 2.90)	.64
No severe psychological distress (<13)	19 (53)	20 (57)	Reference	—
Other concerns endorsed, n (%)				

Variable (responses)	Increased (n=46)	Did not increase (n=39)	OR[a] (95% CI)	*P* value
Stuck at home with my family all the time	27 (59)	22 (56)	1.10 (0.47 - 2.58)	.83
Frustrated that my routine or plan has been disrupted	28 (61)	17 (44)	1.98 (0.85 - 4.73)	.12
Not sure when my life will go back to normal	28 (61)	23 (59)	1.08 (0.46 - 2.56)	.86
Spending more time on social media	23 (50)	9 (23)	1.25 (0.53 - 3.00)	.62
Worried about COVID-19	19 (41)	14 (36)	0.73 (0.31 - 1.69)	.46
Not able to meet up or hang out with people	21 (46)	21 (54)	3.21 (1.30 - 8.40)	.02
Angry about the current state of politics	16 (35)	9 (23)	1.74 (0.69 - 4.59)	.26

[a] OR: odds ratio.

[b] Not applicable.

[c] Excluded from logistic regression.

[d] Alaskan Native or American Indian or multiracial, Asian or Native Hawaiian, or Pacific Islander, non-Hispanic

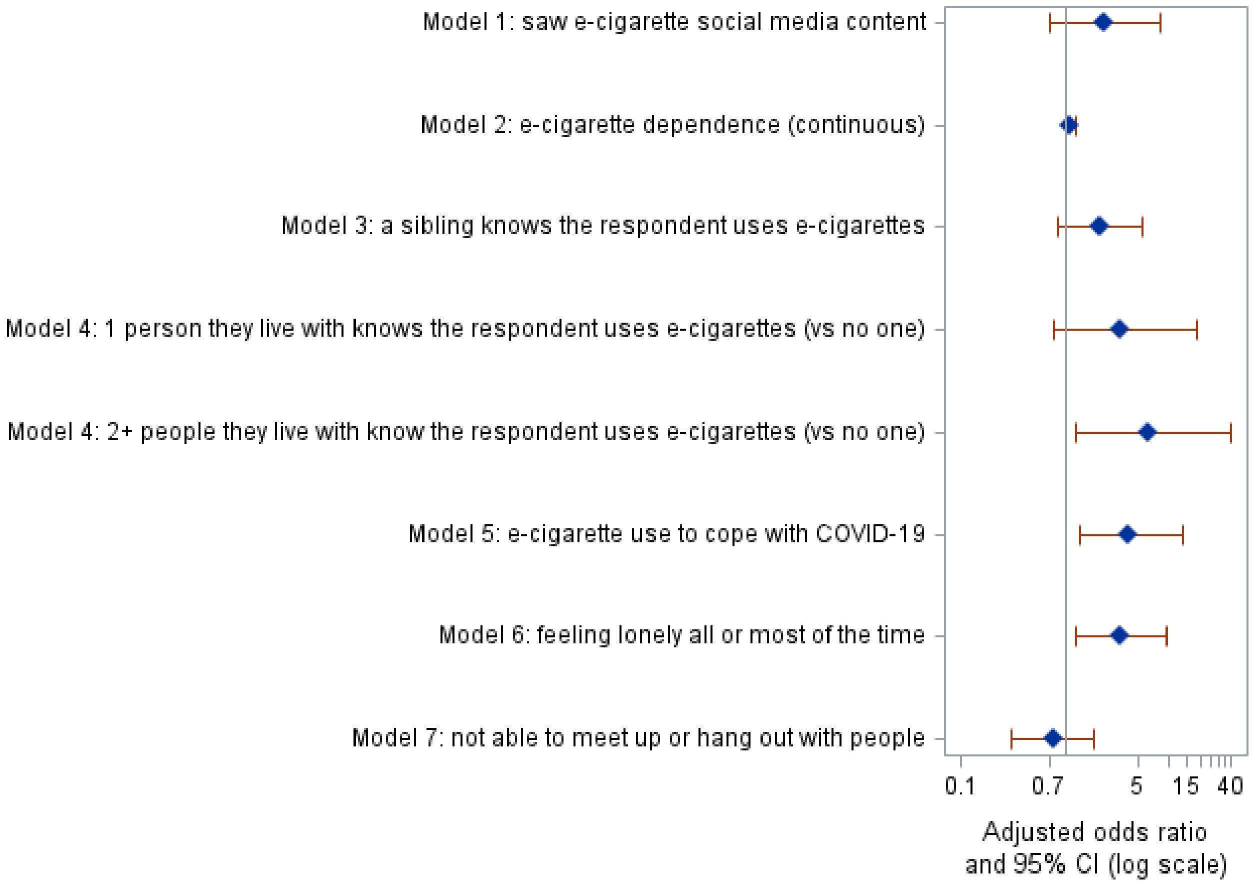
[e] GED: General Education Development test.

[f] THC: tetrahydrocannabinol.

[g] Includes the following: Among Us, Discord, Teams, and Zoom.

[h] One participant was excluded due to missing values and an unpredictable sum of scores.

Figure 1. Forest plot based on results of 7 adjusted penalized logistic regressions with self-reported increased adolescent e-cigarette use during shelter-in-place as the outcome (n=84). Results shown are adjusted odds ratios and their 95% confidence intervals (CIs) for the main predictors of interest in each of the 7 models assessed. All models were adjusted for age, race and ethnicity, and mother's highest level of educational attainment.



Sensitivity Analyses

Results of the first sensitivity analysis (Table S5 in Multimedia Appendix 1), while excluding 3 observations with inconsistent data on past 30-day e-cigarette use (n=81), confirmed our primary findings. Results from the second sensitivity analysis to compare traditional versus penalized logistic regression models showed similar findings in terms of the directionality and the significance of the associations assessed. The only exception was a statistically significant association in the traditional logistic regression for increased use and e-cigarette use dependence (AOR 1.13, 95% CI 1.01 - 1.28; *P*=.04; Table S6 in Multimedia Appendix 1), whereas this result had borderline significance in the primary analysis (AOR 1.12, 95% CI 1.00 - 1.25; *P*=.06; Table S4 in Multimedia Appendix 1).

The third sensitivity analysis of correlates of increased frequency of use revealed consistent results with the primary findings for increased e-cigarette use (Tables S7 and S8 in Multimedia Appendix 1). The fourth sensitivity analysis of correlates of increased concentration of e-cigarettes used also showed similar results, except for no or borderline significant associations with increased age in both penalized and traditional logistic regressions, and consistently positive associations with increased e-cigarette use dependence and lower odds for increased concentration among those who were limited in social interaction during shelter-in-place (Tables S9 and S10 in Multimedia Appendix 1).

Discussion

Principal Findings

This cross-sectional study of 85 California adolescents using e-cigarettes revealed many increased social media use during shelter-in-place (83/85, 98%), often as a way of coping with shelter-in-place (76/85, 89%). We found that a larger proportion of respondents who reported increased e-cigarette use (vs those who did not) also viewed e-cigarette–related social media digital content during shelter-in-place (38/46, 82% vs 25/39, 64%), but differences were not statistically significant likely due to the small sample size. Comparable to prior research [66,67], the average EDS score in our sample was 8.3 (SD 4.4). Consistent with national [8,21,25] and California surveys [68], and in accordance with previous studies [46,49,50,69], older adolescents, those who used e-cigarettes to cope with shelter-in-place, and those who had ≥2 family members being aware of participants' e-cigarette use were more likely to report changes of increased e-cigarette use during shelter-in-place. A novel finding of our study was that loneliness was associated with increased e-cigarette use, in contrast with prior studies that found no significant differences [70] or associations with decreased e-cigarette use [71] among young people during the COVID-19 pandemic. We found only one prepandemic study suggesting a higher risk of e-cigarette use initiation among tobacco-naïve adolescents with high internalizing problems, including loneliness [49].

Comparison With Prior Work

Our hypothesis that the exposure to e-cigarette–related digital content would impact adolescent e-cigarette use during shelter-in-place was based on previous studies, which were mainly focused on tobacco-naïve youths [36,38], compared tobacco users to nonusers [33,72], or were conducted before the COVID-19 pandemic. In contrast, our survey was done during the unique time and settings of shelter-in-place orders and remote schooling, and the sample was restricted to adolescents who were currently using e-cigarettes. However, we lacked data on the type of advertisement or digital content that the respondents had seen on social media. Being exposed to both pro- and anti–e-cigarette use digital content [73] could have shifted the results toward the null. These findings warrant future research with a larger sample to better understand whether different types of exposure to e-cigarette content on social media may have different impacts on current consumers of e-cigarettes or on tobacco-naïve youths, including after the COVID-19 pandemic.

The risk of adolescent e-cigarette use can vary by the type and frequency of web-based venues used [36]. Camenga et al [38] found that Facebook advertisements increased cigarette use in the cohort of e-cigarette–naïve youths. Exposure to cannabis advertisements on Facebook, Instagram, and Twitter was also associated with increased past-year cannabis use among adolescents [43]. Unlike past research before the COVID-19 pandemic, we did not see any differences in the odds of increased e-cigarette use associated with the use of specific social media platforms during shelter-in-place. This could likely be explained by increased overall social media use among adolescents during shelter-in-place and a high proportion of respondents who used multiple existing social media platforms (up to 8 web-based platforms or apps) in our study. Further, our survey rather asked about the use of web-based platforms in general and not about exposure to e-cigarette–related content viewed on specific social media sites.

By providing trustworthy and relevant content [74], social media can become an effective channel for the implementation and promotion of intervention measures to prevent both cannabis and nicotine e-cigarette use and couse among adolescents. Although data to support the effectiveness of web-based e-cigarette cessation interventions among adolescents are lacking [75,76], past research has shown feasibility [77,78] and successes [79] of web-based interventions for smoking prevention among adolescents and young adults and viability of recruitment of young adults through social media in e-cigarette use cessation [80]. However, given the increased social media use among young people in recent years and especially during the COVID-19 pandemic, improved regulations are needed to make social media use safer for adolescents [81]. In addition to the protection of personal data, such regulations should also be designed to prevent abilities of advertisers to use social media algorithms and marketing strategies for manipulating adolescent users into viewing e-cigarette advertisement or other pro–e-cigarette content [82].

Secondhand smoke exposure among family or friends and a pro–e-cigarette social environment can increase the risk for e-cigarette use initiation [46] and susceptibility to both cigarette [48,69] and e-cigarette use [47,48]. Despite not being statistically associated with increased e-cigarette use during shelter-in-place, 64 of 85 (75%) of our respondents reported household e-cigarette use among their coresidents; and those who increased e-cigarette use were significantly more likely to report 2 or more family members who were aware of participants' e-cigarette use. These findings raise questions regarding potential approval or indifference and lack of concern toward adolescent e-cigarette use among family members and their nearest social environment. Future research is recommended to assess attitudes and perceived harms among relatives or coresidents of adolescents and its impact on e-cigarette use.

Mental health problems and psychological distress may increase the risk for e-cigarette use initiation [49,50] and current use [12,51,52]. The elevated risk of adolescent e-cigarette use has been associated with internalizing (eg, feeling lonely and depressed) and externalizing (eg, conduct disorder) problems [49,51] and perceived stress [51]. The prevalence of mental health conditions among adolescents during the lockdown and social isolation period of the COVID-19 pandemic accelerated the youth mental health crisis [83,84], resulting in increased rates of anxiety and depressive symptoms [52,85] and suspected suicidal attempts [86]. A survey of Utah youths showed an increase in psychological distress indicators before versus after the COVID-19 pandemic period from an average level of 7.8 to 8.8 and revealed a positive association between psychological distress and e-cigarette use [52]. Compared to the Utah study, the average level of psychological distress among our respondents was higher (mean 12, SD 5.1), suggesting that many adolescents were experiencing at least moderate mental distress [87]; over 45% screened for severe psychological distress (39/84, 46.4%). Unlike the Utah survey that included both tobacco users and nonusers [52], our study restricted to e-cigarette users found that no differences of reporting increased e-cigarette use during shelter-in-place by the level of psychological distress [49,50].

Another novel aspect of the study is the measurement of cannabis vaporizer use during shelter-in-place. Earlier studies among US youths have found that 30.6% of those who had ever used e-cigarettes reported THC and nicotine couse [88]. In our survey, 88% (75/85) reported ever-use and 80% (68/85) reported past 30-day use of THC vaporizers in addition to nicotine e-cigarettes, highlighting a high prevalence of couse among those who had used nicotine e-cigarettes in the past month. Our study included adolescents residing in California, which was the first state to legalize medical cannabis in 1996 and adult recreational cannabis sales since 2018 [89], although some authors claim no effect of such regulations on adolescent use [90]. Concerns regarding mental health and the increased risk of psychological distress during shelter-in-place among adolescents using both substances underscore the need for further studies of tobacco and cannabis couse among adolescents with mental health symptoms [12,52].

Limitations

First, this survey had a descriptive, cross-sectional study design; causal inferences may not be derived. However, several key features of the survey design, including eligibility criteria, the time frame, and the language used in the questionnaire, have the potential to directly demonstrate the impact of shelter-in-place on the associations assessed. Second, the potential for generalizability of the study results outside California may be limited, as this was a sample of California adolescents only. However, the sample matches the demographic characteristics of California, with 44% (37/85) of our respondents identified as Hispanic, which aligns with prior California surveys in 2018 [68] and 2020 [91] that reported 47% and 52% participants of Hispanic ethnicity, respectively. Third, due to the small sample size, statistical power to detect significant differences was limited. Fourth, these were self-reported data, collected through web-based questionnaires during the COVID-19 lockdown and remote schooling, when adolescents could have been more closely monitored by their parents or guardians. Fifth, the survey did not ask about whether the respondents were aware of e-cigarette, or vaping product, use-associated lung injury. The increased public awareness regarding the harmful health effects of e-cigarettes associated with the 2019 e-cigarette, or vaping product, use-associated lung injury outbreak [92] might have contributed to the 2020 - 2021 decrease in the youth e-cigarette use [26].

Conclusions

Participants exposed to e-cigarette digital content had twice the odds of reporting increased e-cigarette use during shelter-in-place, but the results were not statistically significant in the adjusted analysis. Given almost all participants reported using social media more during shelter-in-place and associations of increased e-cigarette use with loneliness and coping with shelter-in-place, future e-cigarette use interventions should consider leveraging of digital platforms while addressing the mental health consequences of the COVID-19 pandemic.

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Data Availability

The datasets generated during this study are available from the principal investigator (VG) on reasonable request.

Authors' Contributions

VP and VG shaped the research question with guidance and support from PML. VP conducted data analysis, provided and interpreted the results, and drafted the manuscript. PML and BH-F provided resources for the development of questionnaires. VG developed the study design and questionnaires, supervised data collection and the findings, administered the project, and led funding acquisition. All authors revised and approved the final version of the manuscript.

Conflicts of Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. BH-F is a paid expert scientist in some litigation against the e-cigarette industry and an unpaid scientific advisor and expert regarding some tobacco-related policies. No other authors have any conflicts to disclose.

Multimedia Appendix 1
Supplementary information.
[DOCX File, 67 KB - pediatrics_v7i1e49779_app1.docx]

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Abbreviations

AOR: adjusted odds ratio
EDS: e-cigarette dependency scale
THC: tetrahydrocannabinol

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Original Paper

Development of MyREADY Transition BBD Mobile App, a Health Intervention Technology Platform, to Improve Care Transition for Youth With Brain-Based Disabilities: User-Centered Design Approach

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Abstract

Background: Transition from pediatric to adult health care varies and is resource intensive. Patient-centered health information technology (HIT) interventions are increasingly being developed in partnership with patients.

Objective: This study aims to develop an internet-based mobile app intervention for patients with brain-based disabilities to improve transition in care readiness.

Methods: The app was designed for patients aged 15 to 17 years with brain-based disabilities having the ability to use a mobile app. A multidisciplinary team, an industry partner, and a patient and family advisory council was assembled. We hypothesized that existing tools could be migrated into the app to address education, empowerment, and navigation. We used cognitive learning theory to support chapters targeting transition in care skill sets. We used the agile iterative methodology to engage stakeholders.

Results: We developed a novel MyREADY Transition HIT platform. An electronic mentor supported cognitive learning with messaging, quizzes, rewards, and videos. We used gaming to guide navigation through a fictitious health care city. Adapting existing tools was achieved by the patient and family advisory council requesting personalization. Our iterative design required time-consuming back-end technology management. Developing the platform took 24 months instead of our grant-approved 12 months, impacting the onset of the planned trial within the allotted budget.

Conclusions: A novel patient-centered HIT platform to improve health care transition was successfully developed in partnership with patients and industry. Careful resource management was needed to achieve timely delivery of the end product, flagging the cautious planning required to deliver HIT tools in time for the much-needed trials informing their clinical application.

Trial Registration: ClinicalTrials.gov NCT03852550; https://clinicaltrials.gov/study/NCT03852550

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KEYWORDS

patient-centered care; patient engagement; mobile app; health IT; health care transition; mobile phone

Introduction

Background

A growing number of adolescents with pediatric-onset health conditions have survived to adulthood owing to advances in medical care [1,2]. The Society of Adolescent Medicine defines *health care transition* as "a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented health care systems" [3-6]. Despite published guidelines, the resource-intensive process of transition in care at the point of care varies widely between institutions and health care systems [2,3,7,8].

Transition in care is largely policy-driven rather than patient-centered [9,10]. Variably between jurisdictions, transition in care is usually mandated to occur when a patient is aged between 18 and 21 years, irrespective of transition readiness [11-13]. However, among youth with chronic conditions, age correlates poorly with transition readiness [14]. Similar to other chronic conditions, brain-based disabilities (BBDs) such as autism, cerebral palsy, epilepsy, fetal alcohol spectrum disorder, and spina bifida require transition in care interventions to improve their outcomes [8]. Youth with BBD report barriers to transition in care, including inadequate support, information, and preparation, resulting in difficulty in navigating adult care systems [3,8,15,16].

Although there are various definitions of patient-centered care, core concepts uniformly highlight the central role that patients and families should play in health care delivery. The Institute of Medicine defines patient-centered care as "care that is respectful and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions" [17]. Systematically, elements include respect for patient preferences, psychosocial support, information, education, and access. Patient-facing mobile apps offer a promising approach to supporting health care transition by educating, engaging, and empowering youth and their families to manage their own health in collaboration with their health care providers [18].

Objective

The Readiness in Youth for Transition Out of Pediatric Care (READYorNot) BBD trial will test a health information technology (HIT) intervention in a randomized controlled trial (RCT) that aims to improve transition readiness in youth with BBD [19]. In this study, we describe the development of the mobile app that serves as the intervention in the READYorNot BBD trial [19]. The app was created to deliver educational content through an internet-based gamified interface, designed to engage and empower youth with BBD to navigate health care transition. Adolescents with chronic diseases have been shown to benefit from strategies that promote independence with health care management [12]. In line with these findings, our goal was to develop an internet-based patient-facing and patient-centered mobile app for youth with BBD to improve transition readiness. We report the design approach of partnering with patients and industry to develop a novel patient-centered HIT platform to improve health care transition. We targeted 3 cognitive pillars of transition in care: education, empowerment, and health care system navigation. In this paper, we illustrate (1) methodological principles relative to technology design, (2) a stakeholder engagement process that incorporates principles of patient-centered care, and (3) content development and strategies to reinforce learning. The subsequent RCT [19] will test the effect of the mobile technology developed by our team on transition readiness as a primary end point.

Methods

We developed the MyREADY Transition BBD app as a stage of the READYorNot BBD trial (RCT; ClinicalTrials.gov NCT03852550) [19].

Patient Population

This project was conducted within the Child Health Initiatives Limiting Disability–Brain Research Improving Growth and Health Trajectories (CHILD-BRIGHT) pan-Canadian network. The CHILD-BRIGHT projects focus on optimizing the health and well-being of infants, children, and youth with brain-based developmental disabilities [20]. Eligibility for enrollment in the READYorNot BBDs RCT [19] included patients who are aged between 15 and 17 years; have a diagnosis of autism spectrum disorder, cerebral palsy, epilepsy, fetal alcohol spectrum disorder, or spina bifida; have cognitive ability to provide informed consent; have the ability to read and understand English or French; have access to the internet and a smartphone, iPad, tablet, or desktop computer; and have a TRANSITION-Q score of >40 to benchmark the minimum threshold for transition readiness based on our earlier work [21]. In our app development, we decided on a target population of BBDs, including conditions that originate before an individual reaches the age of 18 years; that continue or can be expected to continue indefinitely; and that constitute a substantial impairment in three or more areas of major life activity including (1) self-care, (2) receptive and expressive language, (3) learning, (4) mobility,

(5) self-direction, (6) capacity for independent living, and (7) economic self-sufficiency. In addition, we considered the most prevalent BBDs among adolescents who were followed in the Canadian recruitment sites who would participate in our subsequent trial designed to test the efficacy of the mobile app. For the trial, we developed a detailed diagnostic reference document for recruitment; for example, adolescents with spina bifida occulta without any neurological loss and spina bifida of any type that has not resulted in hydrocephalus and developmental disability were excluded. The rationale for targeting individuals aged 15 to 17 years stems from several key considerations. This age group represents a cohort that is typically approaching the transition from pediatric to adult health care services, making them particularly relevant for the intervention's focus on transition support. By targeting adolescents who are nearing the transition period, we can ensure that they have ample opportunity to engage with the intervention and benefit from the support provided by the app. By selecting adolescents who are close to transition but still within a developmental stage conducive to learning and adaptation, we aim to maximize the effectiveness and impact of the intervention on their transition readiness and outcomes.

Methodological Principles Relative to Technology Design and Development

We assembled a multidisciplinary team of technology developers (HIT platform design); transition psychologists (content development); and stakeholders (patients, family members, and clinicians). The HIT team (AM, RR, and AV-DL) included technology experts, patient-centered care experts, health services researchers, and industry partners. We partnered with 360Medlink, a software company with experience in the development of multimedia solutions in the health care industry [22]. The transition psychology and informational content team (AHK, KA, CBF, BG, AV-DL, AM, and JWG) included clinical psychologists and transition experts in BBD who led the development of the educational content. The stakeholder engagement team (JWG, RR, SS, BG, AM, and AV-DL) included experts in developmental pediatrics and neurology and patient engagement to lead the stakeholder engagement activities and reports. Detailed information on the expertise and demographics of the teams is shown in Table 1.

To maintain continuous responsivity to feedback from stakeholders, we adhered to principles of Agile software development [23,24]. This programming approach enables dynamic collaboration with users as illustrated in Figure 1. The 3 teams communicated weekly to make iterative adjustments to the app based on feedback. We tested proposed solutions in subsequent consultations and repeated this process until a final solution was reached. An example of a storyboard reiteration is shown in Figure 2.

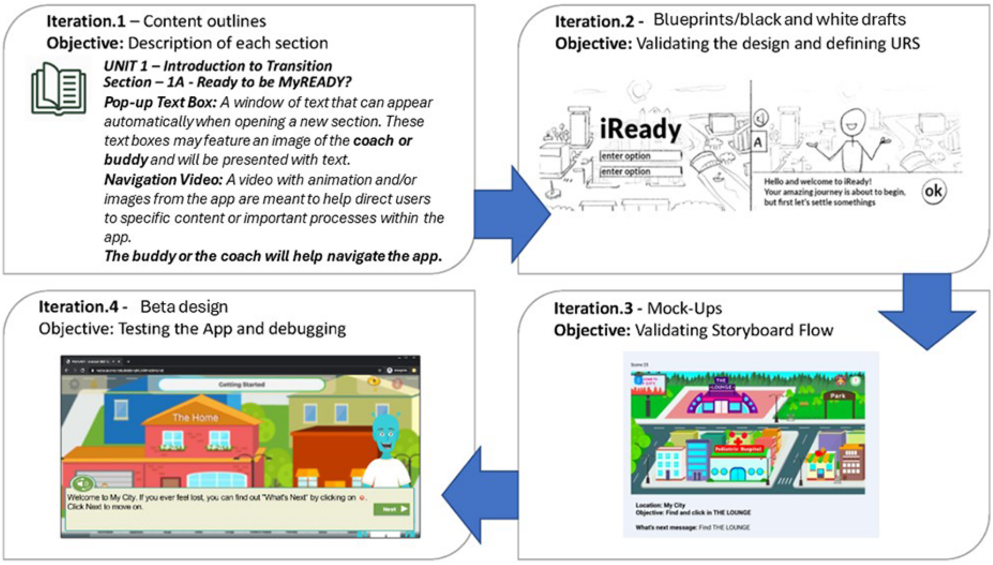
Table 1. Description of the multidisciplinary teams.

Team	Values
Health information technology (n=7)	
Age (y), range	
Technology project manager	40-55
Health services researchers	45-60
Industry partner team	25-50
Sex, n (%)	
Female	2 (29)
Male	5 (71)
Expertise, n (%)	
Technology project manager	1 (14)
Health services researchers	2 (29)
Industry partner team	4 (57)
Psychology content development (n=9)	
Age (y), range	
Lead clinical psychologists	40-60
Trainees	25-35
Sex, n (%)	
Female	7 (78)
Male	2 (22)
Expertise, n (%)	
Lead clinical psychologists	2 (22)
Project managers	2 (22)
Health services researchers	2 (22)
Trainees	3 (33)
Stakeholder engagement (n=6)	
Age (y), range	25-55
Sex, n (%)	
Female	4 (67)
Male	2 (33)
Expertise, n (%)	
Experts in developmental pediatrics and neurology and health services researchers	2 (33)
Patient-centered care expert	1 (17)
Qualitative data analyst	1 (17)
Project managers	2 (33)
Patient and family advisory council (n=9)	
Age (y), range	17-60
Sex, n (%)	
Female	5 (56)
Male	4 (44)
Expertise, n (%)	
Adolescents in transition	1 (11)
Young adults at posttransition stage	3 (33)

Team	Values
Parents	5 (56)

Figure 1. Description of agile iterative methodology. The figure provides a visual illustration of the agile iterative methodology applied to the life cycle of concept, app, and content development. URS: user requirement specification.

Figure 2. Interface development showing progress from descriptions to wireframes to final version. The figure illustrates the interface developmental process. All the design elements (buildings, rooms, objects, mentor, and accessories); logo; and the content (mentor messages, videos, and challenges) followed this developmental 4-step process. URS: user requirement specification.

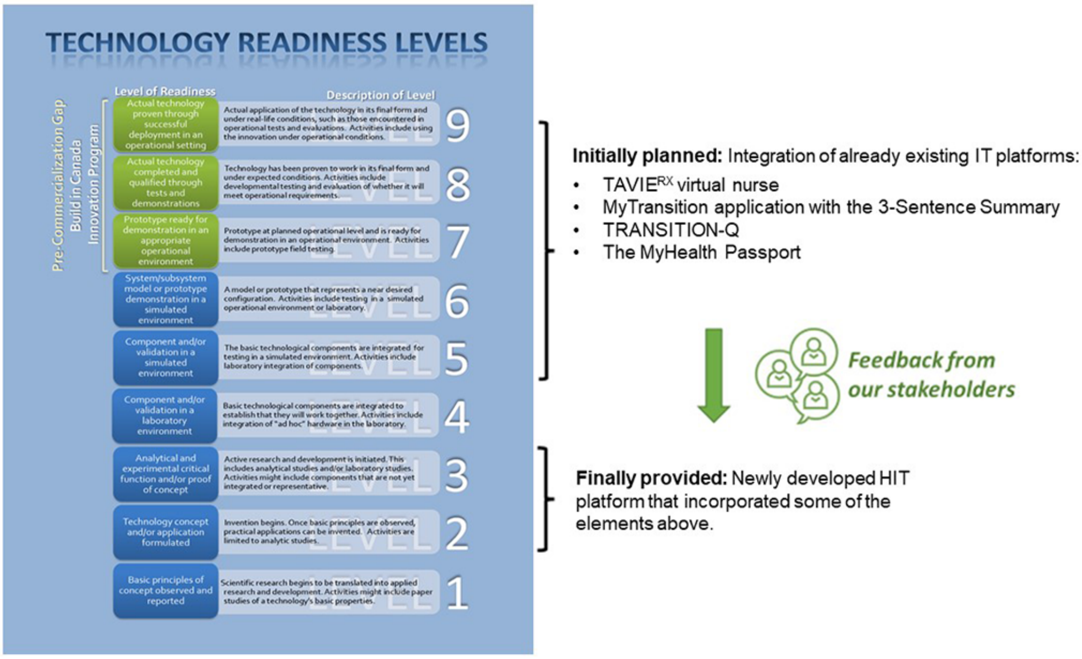


UNIT 1 – Introduction to Transition
Section – 1A - Ready to be MyREADY?
Pop-up Text Box: *A window of text that can appear automatically when opening a new section. These text boxes may feature an image of the* ***coach or buddy*** *and will be presented with text.*
Navigation Video: *A video with animation and/or images from the app are meant to help direct users to specific content or important processes within the app.*
The buddy or the coach will help navigate the app.

Stakeholder Engagement Process

App development was a collaborative process involving a series of research and stakeholder engagement activities. We used a participatory approach that incorporated stakeholder engagement and created an app that was patient centered and aimed for the highest probability of effectively meeting the needs of the BBD population. Our approach to eliciting feedback and making decisions was grounded in the principles of collaboration, transparency, and pragmatism to ensure that stakeholder input was carefully considered and incorporated wherever feasible [25]. We hypothesized that elements of existing patient-facing HIT tools could be leveraged to create a novel population-specific app. We reviewed patient-facing apps that could be adapted to meet our needs, including the TAVIE virtual nurse platform designed to improve patients' health knowledge and self-efficacy through guided need-specific content [26]. We evaluated existing BBD transition tools, including the MyTransition app [27], which includes resources to support health care transition including a 3-sentence summary to teach adolescents a concise method of summarizing their medical condition [28]; TRANSITION-Q, a validated scale for measuring skills needed to manage one’s own health care [21]; and the MyHealth Passport, a web-based tool developed by the Good2Go Transition Program [29] of the Hospital for Sick Children in Toronto [30]. We hypothesized that we could incorporate existing tools for the app development based on a technology readiness level between 5 and 6 of 9 levels, a method used to assess the maturity of technology relative to acquisition readiness [31] (Figure 3). We planned a 12-month pre-RCT development phase aiming to achieve a technology readiness level of 8, meaning that the app technology has been proven to work in its final form and under expected conditions and is now ready to be deployed and tested in real-life situations [31].

Figure 3. Description of technology readiness levels. The figure defines technology readiness levels used to predict the process from innovation concept to commercialization. HIT: health information technology. The left panel of the figure (Technology Readiness Levels) is a copy of the version available at https://buyandsell.gc.ca/initiatives-and-programs/build-in-canada-innovation-program-bcip/program-specifics/technology-readiness-levels.



Level of Readiness	Description of Level	
Actual technology proven through successful deployment in an operational setting	Actual application of the technology in its final form and under real-life conditions, such as those encountered in operational tests and evaluations. Activities include using the innovation under operational conditions.	9
Actual technology completed and qualified through tests and demonstrations	Technology has been proven to work in its final form and under expected conditions. Activities include developmental testing and evaluation of whether it will meet operational requirements.	8
Prototype ready for demonstration in an appropriate operational environment	Prototype at planned operational level and is ready for demonstration in an operational environment. Activities include prototype field testing.	7
System/subsystem model or prototype demonstration in a simulated environment	A model or prototype that represents a near desired configuration. Activities include testing in a simulated operational environment or laboratory.	6
Component and/or validation in a simulated environment	The basic technological components are integrated for testing in a simulated environment. Activities include laboratory integration of components.	5
Component and/or validation in a laboratory environment	Basic technological components are integrated to establish that they will work together. Activities include integration of "ad hoc" hardware in the laboratory.	4
Analytical and experimental critical function and/or proof of concept	Active research and development is initiated. This includes analytical studies and/or laboratory studies. Activities might include components that are not yet integrated or representative.	3
Technology concept and/or application formulated	Invention begins. Once basic principles are observed, practical applications can be invented. Activities are limited to analytic studies.	2
Basic principles of concept observed and reported	Scientific research begins to be translated into applied research and development. Activities might include paper studies of a technology's basic properties.	1

Initially planned: Integration of already existing IT platforms:

- TAVIE^{RX} virtual nurse
- MyTransition application with the 3-Sentence Summary
- TRANSITION-Q
- The MyHealth Passport

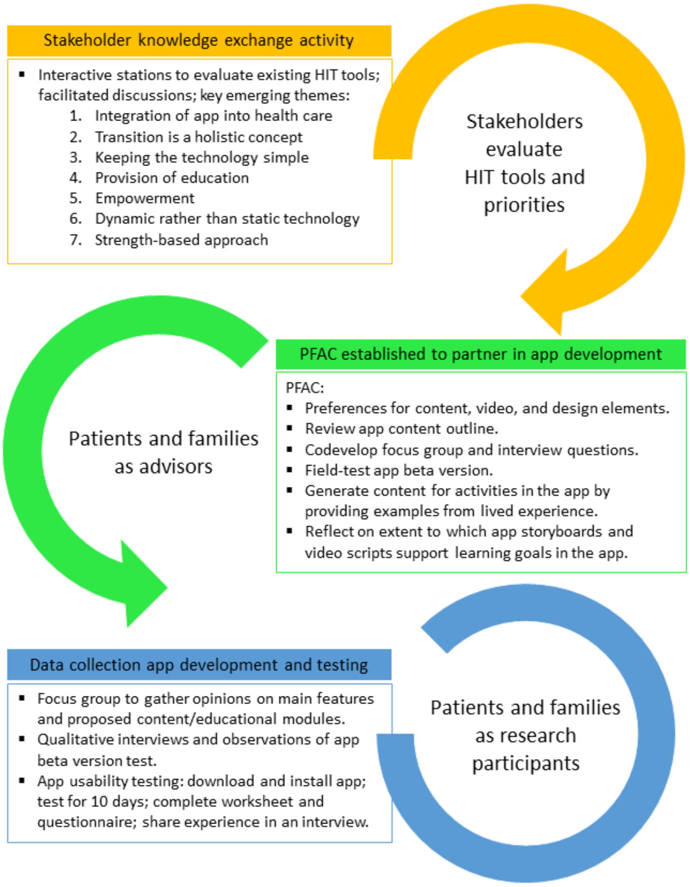
Feedback from our stakeholders

Finally provided: Newly developed HIT platform that incorporated some of the elements above.

We adopted a patient-oriented research methodology, engaging key stakeholders (youths with disabilities, families, and clinicians) and integrating their input throughout the design and development process. We hosted a stakeholder knowledge exchange activity to interact with existing HIT tools and discuss priorities before beginning app development. We formed a patient and family advisory council (PFAC) comprising a group of stakeholder partners including 1 adolescent in transition, 3 young adults at posttransition stage, and 5 parents who partnered with us on key discussions and decision-making. Among the adolescents and young adults, 2 were male and 2 were female. These youth and parent partners had a collective lived experience of cerebral palsy, autism spectrum disorder, stroke with hemiplegia, mental health conditions, prematurity with chronic health conditions, rare disorders, and complex medical needs. We hosted regular meetings with the PFAC to garner input about the concept and discuss the contents of the app. We conducted a focus group to help inform and finalize the proof-of-concept beta version of the app. We observed and interviewed adolescents and young adults and parents during an app beta version test. Adolescents, young adults, parents, and clinicians later participated in app usability testing by downloading and installing the app, testing it for 10 days, completing a worksheet and questionnaire, and sharing their experience during a qualitative interview to field-test the acceptability of the tool principally at the patient and family level and point of care to adjust and optimize the intervention tool before the subsequent clinical trial phase.

The user requirement specification list was created collaboratively by the HIT team described in Table 1. This collaborative effort drew upon extensive experience in similar health care and pharmaceutical projects, as well as adherence to best practices in app development within the health care sector. The list captured the functional and nonfunctional requirements of the app, thereby guiding its development and ensuring its alignment with stakeholder needs and regulatory standards (details in Multimedia Appendix 1). To finalize the inclusion of the user requirements, after consultation with the PFAC, 4 members from each of the psychology content development team and the stakeholder engagement team were asked to adjudicate the final inclusion or exclusion of the technical specification. The list was shared among all the stakeholders to define the minimum viable product for the app [32,33]. The process of stakeholder engagement is illustrated in Figure 4 and described in Multimedia Appendix 2.

Figure 4. Illustration of the stakeholder engagement process and activities. HIT: health information technology; PFAC: patient and family advisory council.



Stakeholder knowledge exchange activity

- Interactive stations to evaluate existing HIT tools; facilitated discussions; key emerging themes:
  1. Integration of app into health care
  2. Transition is a holistic concept
  3. Keeping the technology simple
  4. Provision of education
  5. Empowerment
  6. Dynamic rather than static technology
  7. Strength-based approach

PFAC established to partner in app development

PFAC:
- Preferences for content, video, and design elements.
- Review app content outline.
- Codevelop focus group and interview questions.
- Field-test app beta version.
- Generate content for activities in the app by providing examples from lived experience.
- Reflect on extent to which app storyboards and video scripts support learning goals in the app.

Data collection app development and testing

- Focus group to gather opinions on main features and proposed content/educational modules.
- Qualitative interviews and observations of app beta version test.
- App usability testing: download and install app; test for 10 days; complete worksheet and questionnaire; share experience in an interview.

Content Development

The transition psychology and informational content team designed preliminary content tailored to the specific needs of the BBD population. In alignment with what we learned from our research and stakeholder engagement activities, the goals were education and self-management through guided activities [15,34]. We tailored the content directly to youth while remaining mindful of the needs and expectations of other stakeholders including parents or guardians and health care providers [16].

Grounded in the principle of cognitive learning theory [35], we framed the learner as an active participant engaging with information from internal and external sources. Information was presented via a gamified interface in which a user navigates through a learning environment with the support of a guide and visits various areas of the learning environment to move through the content at a self-directed pace; this fosters motivation and intervention adherence while moving through educational sessions and achieving specific learning objectives.

The content and format of the chapters were developed systematically based on the core values and principles that emerged from stakeholder consultations and subjected to the user requirement specification list and minimum viable product criteria. Principles of social learning theory emphasized environmental and cognitive factors as well as the importance of modeling positive behavior, informed the development of a visual depiction of a city that the user learns to navigate, and included a mentor to guide users through the content. We incorporated quizzes, mentor dialogue, educational videos, as well as challenges and activities during each session. We created opportunities for self-evaluation, including a visual progress bar, a sliding scale for self-assessment of transition readiness, and checkpoints. We included a toolbox of transition resources for users, enabling access to key information about their health condition and treatment plan, thereby facilitating patient-provider communication. We cocreated multimedia content working with Spectrum Productions [36], a nonprofit social enterprise employing individuals on the autism spectrum, to film conceptual and testimonial videos with patient-actors.

Ethical Considerations

Hamilton Integrated Research Ethics Board (HiREB 2952) approval was obtained. For components of the study where patients and families were engaged as research participants (focus group, formative usability test, and summative usability test), adolescent participants provided assent and parents or caregivers provided consent for the participation of their child and themselves. We adhered to local, national, regional, and international laws and regulations regarding protection of personal information, privacy, and human rights.

Results

Technology Readiness Level and Elements

The app was developed from June 2017 to June 2019, and the English language version was launched in iOS and Android versions in the App Store and Google Play, respectively, on June 19, 2019. This was 12 months longer than (ie, twice as long as) the anticipated time in the funded grant application. Although the resources used in our preliminary design served as a starting point for development, feedback from our stakeholders motivated the creation of a completely newly developed HIT platform, reducing the technology readiness level from 5 to 6 at the onset of our study to a level of 2 to 3 as characterized in Figure 3.

The READYorNot BBD intervention includes 3 elements: the MyREADY Transition BBD mobile app, a content library containing the transition curriculum, and a back-end platform that manages the data and features of the user interface. To minimize time requirements and costs, the app was developed in Unity, a cross-platform tool, that works primarily with iOS and Android devices as well as with internet browsers. The final app comprises 985 storyboards or scenes; 88 testimonial and 46 conceptual videos; and 47 reward-driven challenges in English and in French.

Content management capabilities include indexing, search and retrieval (search boxes on the forms and reports of the indexed data by attributes such as publication dates, keywords, or population); content hierarchy with unlimited depth and size and an integrated file manager for video with multiple language support; format management (ensuring that content and videos fit the format and structure required for download); revision control (enabling content version management, including duplication and edition after initial publication); and publishing (which pushes the content in a digestible and preformatted way via the app user interface).

On the back-end platform, the app is run by a content management system that administers the users' information, journey completion (progression and adherence), and perceived value data. The content management system was designed using open-source resources, including the MySQL relational database, allowing for greater flexibility and customization as well as more timely development and scalability, while minimizing the costs associated with using branded solutions [37]. The content management system automatically pushes notifications to users based on predefined content deployment rules as well as user activity and enables administrators to access a dashboard containing user analytics reports. The content management system supports several administrative features in an easy-to-use interface, including onboarding, offboarding, secure authentication of users' access, monitoring users' data and activity, and push notifications to enhance users' adherence.

The dashboard (initially supported by Sisense data analytics software [Sisense] and currently by Microsoft Power-BI [Microsoft Corp]) contains user demographics, device type, operating system, user progression, and perceived value as well as options for data exportation. The dashboard incorporates preconfigured graphs and reports that can be filtered by key performance indicators.

The app requires an internet connection during the initial download and setup and for certain features (eg, video playback and voiceover). To ensure that users maintain access to the content, we designed the app to function offline if necessary. To do so, we optimized the balance between maximizing offline availability of key features and minimizing the download size.

Customization and Personalization of the App Based on Stakeholder Engagement

Key emerging themes from the stakeholder engagement process described in Figure 4 included the importance of viewing transition as a holistic concept, the need to keep the technology simple, and the central role of education. To increase the patient-centered focus of the app, in response to the PFAC, we incorporated features that were customized to the population with BBDs as well as options to personalize the experience of using of the app based on preferences and needs. True to the process of engagement, we also incorporated features to maximize adherence. The key features that were enhanced through customization or personalization are summarized in Multimedia Appendix 3. Features that can be both customized and personalized include privacy settings and notification, mentor appearance, text-to-speech and volume control, choice of language, color contrast and animation, and tailored resources.

Content Output

The content is deployed in five educational chapters: (1) Introduction to Transition; (2) Knowledge is Power; (3) Communication is Key; (4) Time to Take Charge; and (5) The Other Side (ie, adult care). Up to 19 sequential educational sessions are distributed along the chapters as illustrated in Figure 5. The subdivision of the educational curriculum into multiple sessions ensures that the content delivery is optimized to the attention span of youth with BBD. Each session contains between 40 and 55 scenes and includes an average of 7 videos covering conceptual material and testimonials from adolescents with BBD. The learning environment is presented in the context of a "Journey in the City," an internet-based environment that reinforces learning through gamification.

The transition curriculum is delivered through a gamified user experience in which the content of each session is provided through a combination of activities including challenges, games, and quizzes. These activities are designed to maintain the user's interest by introducing problem-solving elements and allowing users to collect rewards upon completion. The sessions have a recursive structure, and their predictable nature allows the user to easily navigate through the content. Each session begins at the same location and guides the user to a new location to access the main content and activity of that session as illustrated in Figure 6. The sessions conclude by guiding the user back to the start location while providing a summary of the key concepts learned and an opportunity to collect a reward.

Throughout their journey, the user is accompanied by a mentor that guides them through the learning environment, progressively introducing each educational activity, delivering informational messages, reminders, and motivational reinforcements. The user can build a relationship with the mentor, which simulates contact with a peer who has been through the transition process and facilitates learning by modeling positive behavior [3,38]. Users can customize the mentor's appearance as they accumulate rewards by completing activities.

Figure 5. Content scheme and session environment. Content scheme and session environment as user advances through the “Journey in the City,” an internet-based environment that reinforces learning through gamification. In the app, the user navigates through a simulated city (“My City”) by engaging with a series of internet-based buildings, each containing a thematic educational session. The user’s navigation is based in "the lounge," which acts as the starting point for each session.

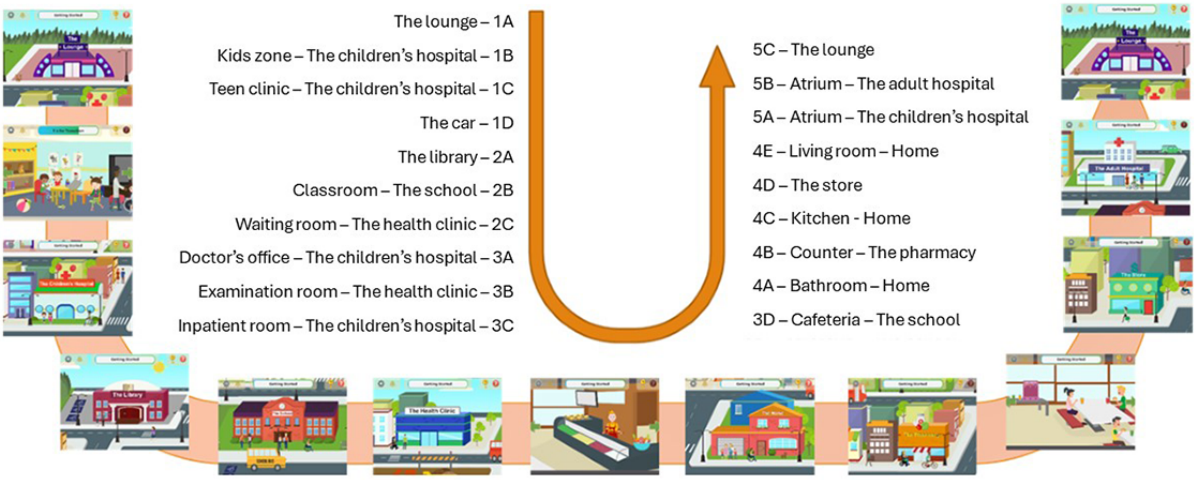
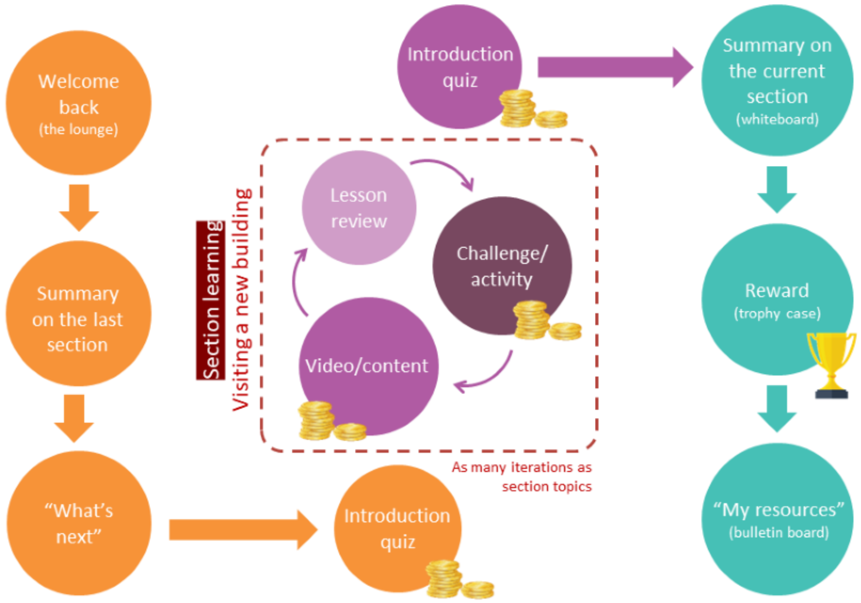


Figure 6. Workflow and recursive structure of educational sessions. The sessions have a recursive structure, and their predicable nature is intended to facilitate navigation through the content. Each session begins at the same location and guides the user to a new location to access the main content and activity of that session. The sessions conclude by guiding the user back to the start location while providing a summary of the key concepts learned and an opportunity to collect a reward.



Discussion

Principal Findings

In this study, we describe our experience developing a novel digital platform (MyREADY Transition BBD app) that delivers educational content through an internet-based gamified interface designed to engage and empower adolescents with BBD to navigate health care transition. To our knowledge, this is the first HIT intervention intended to improve transition readiness for youth with BBD. We hypothesized that existing tools could be migrated into the app to address education, empowerment, and navigation. Stakeholder feedback led us to create a custom-designed platform. Furthermore, although the development of the transition curriculum incorporated principles of cognitive and social learning theory, we found that the educational content needed to be delivered in a way that captivated the users. This led us to adopt gaming features and internet-based multimedia expression of contents to harness learning styles of youth with BBD. Finally, perhaps the most challenging but also rewarding aspect of our iterative design process was the rigorous incorporation of stakeholder engagement, requiring a back-end technology management platform that was cumbersome and required labor-intensive hands-on support. Our experience provides insight for other app developers, health care providers, and researchers about the process and efforts needed to develop apps for youth with special needs.

Youth with lifelong health conditions exhibit substantial variability in transition readiness [11-13]. Since policy-driven transfer of care is variable, we sought to develop an intervention that improves transition readiness. There is an increasing need to support the process of health care transition in a way that is adaptive to the demands of the adult health care system [4]. As an increasing number of HIT platforms designed to meet care gaps for specific populations are being developed in partnership with patients and industry, adjustment of time, budget, and expectations need to be carefully managed to achieve timely delivery of high-quality end products. The gaming elements, multimedia features, and journey-like processes throughout the app were designed to foster engagement and adherence to the educational curriculum [39]. Throughout the content development, stakeholders highlighted the need to deliver the transition curriculum using a strategy that is adapted to the learning requirements of youth with BBD [12]. This required a creative approach that merges the principles of cognitive and social learning theory with contemporary gamification strategies [40] and evidence on health intervention technology preferences among youth [12,41,42]. We incorporated several gaming elements into the app, including an internet-based environment, objective-based learning modules, challenges, and rewards [39]. In tandem with this, the mentor simulates peer-supported social learning, which has been identified as an important facilitator for learning among youth with BBD [3,38]. Gamification has the potential to reinforce learning and increase engagement with the transition curriculum [43-45].

Patient-centered, patient-facing mobile apps offer a promising approach to supporting health care transition by educating, engaging, and empowering youth and their families to manage their own health in collaboration with their health care providers [18]. Our project aligns with translational research design methods where the philosophy for using patient-centered design is to understand the needs of the people at the center of the research. Designing research in this way, based on an understanding of the needs and knowledge of user-centered design principles, aims to reduce the gap between research and its application. Our efforts to understand the users at the center of the project are evident both in our research approach and in our iterative methods to develop the app based on stakeholder feedback. Gelinas et al [46] provided recommendations from a Delphi panel regarding the oversight of patient-centered outcomes research, including the recommendation to use a formal taxonomy of patient involvement in research to disambiguate and distinguish between 3 broad roles patients may take, namely, study personnel, advisor, and research participant. In our project, we engaged patient and family stakeholders as advisory members in some instances and as research participants in other instances. We used these complementary approaches to garner input during the app development and usability testing process and to embed patients and families as formal advisors in key discussions and decision-making. We applied this user-centered, participatory approach by design to create a patient-centered app with a high probability of effectively meeting the needs of the population with BBDs. Many of the content and design decisions were made in collaboration with the READYorNot PFAC. The PFAC for this project was diverse and included both caregivers and youth in various stages of transition, some of whom transitioned to adult care during their time on the project. Having input from those currently living the transition experience allowed the app to be shaped in real time by youth's changing perspectives. While these partnerships were invaluable to the success of our app development, it is understandably difficult to recruit and retain youth to be involved in research; it requires time and flexibility in order to build a working relationship that may not be feasible in some circumstances. Researchers who are finding it challenging to engage youth may choose a consultation service such as the Child and Youth Advisory Council through Alberta Health Services or the National Youth Advisory Panel within the CHILD-BRIGHT network. Use of consultation services can be complementary to the other partnership activities, as there is often a need to use a suite of engagement tools when engaging youth with busy schedules.

We used an iterative technology methodology to incorporate stakeholders' feedback. It was difficult to adapt existing tools due to our commitment to personalization and customization of app features guided by our PFAC. Our iterative design required time-consuming back-end technology management. Developing the platform took 24 months instead of our grant-approved 12 months, impacting the planned trial onset within the allotted budget. An increasing number of HIT tools are being developed to meet care gaps [42,47,48]. Many of these tools are designed for patients with specific health conditions but may not be tailored to the needs and characteristics of specific populations, which can negatively impact adherence [49]. We aimed to design a patient-centered HIT intervention for youth with BBD, a population with a range of specific health conditions as well as specific usability needs, which posed unique design challenges [50,51]. Although numerous public funding agencies are calling for patient partners in research design and implementation, guidelines that estimate the impact of this engagement on achieving study deliverables are scant. Moreover, industry partners, pivotal to the success of product development, are to date, ill-equipped to handle the excess labor required to achieve this. Thus, despite the potential benefits of stakeholder engagement, the implementation of these partnerships remains challenging for HIT tool development, as it involves additional logistical considerations, significantly more time and funding, and careful management of stakeholders' expectations and responsibilities. As such, the co-design process requires a shift away from traditional health research processes and timelines.

In our study, we define *education* as the provision of information and resources aimed at enhancing participants' understanding of various aspects related to their health care and transition process. This includes imparting knowledge about their medical condition and health care rights and responsibilities, as well as empowering them with skills to effectively advocate for their needs within the health care system. Empowerment refers to the process of equipping individuals with the confidence, skills, and self-efficacy to actively participate in decisions regarding their health and health care. This involves fostering a sense of autonomy, self-advocacy, and self-management, empowering participants to take ownership of their health and well-being. Health system navigation encompasses the ability to navigate and access health care services effectively in Canada, including understanding how the health care system operates, accessing appropriate services and resources, and overcoming the barriers to care. These domains were selected based on their significance in facilitating successful transitions to adult health care and improving health outcomes among adolescents with chronic conditions.

Limitations

We achieved our goal although the time required to create the app exceeded the time that we planned initially. We chose to design a mobile app to be used by youth rather than parents or clinicians. While the latter are also important stakeholders in supporting health care transitions, youth are at the forefront of this process and stand to benefit the most from this type of intervention. With respect to the design process, several features that were suggested during the stakeholder consultations were omitted from the app due to budget, feasibility, and time constraints, leading to challenges with balancing the needs and expectations of stakeholders against the complexity of the resulting platform. A related challenge was to manage the contrasting timelines of the overarching research project and the software development. Finally, the effectiveness of this app in improving transition outcomes is yet to be evaluated. We did not systematically measure stakeholder engagement and satisfaction with our design approach of partnering with patients and industry to develop the app. However, we have published a commentary on navigating meaningful engagement and lessons learned from partnering with youth and families [52].

We recognize it is a limitation that the app is accessible only to people with a smart device or a computer with a navigator and internet access. While we have designed an offline mode, an internet connection is still required for initial download of the app, and a continuous internet connection is essential for accessing videos and text-to-speech features and synchronization with the content management system. Once we have completed the RCT and determined which components of the intervention have the highest probability of improving transition readiness, we will incorporate those in the future iterations of the intervention and explore how to maximize the accessibility of the app. Moreover, future iterations of the platform may incorporate measures to mitigate disparities in access to technology and internet services and digital literacy, thus aligning with broader goals of promoting health equity. Despite the limitation, mobile apps are a complementary approach to reducing care gaps, addressing health inequities by improving access to resources and support that may not be available in the clinical environment.

The importance of experimental implementation cannot be overstated. Although implementation science has made great advances in the use of digital technologies to advance knowledge translation and improve self-management and adherence, rigorous clinical trials need to measure their impact on well-specified outcomes. The process of engagement of patients as partners in research needs to be well characterized and accounted for in research planning. The MyREADY Transition BBD app will be implemented and tested in the READYorNot BBD trial, an ongoing cluster RCT, which began recruitment in June 2020 in 4 regions across Canada [19]. The objective of this trial is to assess the impact of this innovative tool on transition readiness among youth with BBD. The trial is designed to include 264 adolescents aged 15 to 17 years with BBD who meet minimum health and technology literacy criteria in order to potentially benefit from this intervention. We will collect and analyze data pertaining to the usability and patient experience of the app as well as how the app operates to further optimize the intervention. We hope that this intervention will be used by youth with BBD and be endorsed by health care providers and experts in Canada and elsewhere.

Conclusions and Future Directions

The MyREADY Transition BBD mobile app delivers educational content through an internet-based gamified interface, which was designed to engage and empower youth with BBD to navigate health care transition. The impact of this app on transition readiness and outcomes is being measured with an ongoing trial, the results of which will guide future development of apps for youth with special needs and steps toward dissemination. This intervention has the potential to improve transition outcomes during health care transition from pediatric to adult health care systems. Our process has the potential to inform other researchers tackling the growing need for HIT tools to support patients and families transitioning through the health care system. Technology platforms developed in partnership with patients and industry can be patient centered, but careful resource management is needed to achieve timely delivery of end products for the much-needed trials that will inform their application in clinical practice.

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Authors' Contributions

JWG is the second corresponding author of this paper and can be reached at gorter@mcmaster.ca.

Conflicts of Interest

None declared.

Multimedia Appendix 1
User requirement specification creation.
[DOCX File , 33 KB - pediatrics_v7i1e51606_app1.docx]

Multimedia Appendix 2
Description of the process of stakeholder engagement.
[PDF File (Adobe PDF File), 470 KB - pediatrics_v7i1e51606_app2.pdf]

Multimedia Appendix 3
Description of MyREADY Transition BBD app's key customization and personalization features.
[DOCX File , 20 KB - pediatrics_v7i1e51606_app3.docx]

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Abbreviations

BBD: brain-based disability
CHILD-BRIGHT: Child Health Initiatives Limiting Disability–Brain Research Improving Growth and Health Trajectories

HIT: health information technology
PFAC: patient and family advisory council
RCT: randomized controlled trial
READYorNot: Readiness in Youth for Transition Out of Pediatric Care

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Digital Gaming and Exercise Among Youth With Type 1 Diabetes: Cross-Sectional Analysis of Data From the Type 1 Diabetes Exercise Initiative Pediatric Study

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Abstract

Background: Regular physical activity and exercise are fundamental components of a healthy lifestyle for youth living with type 1 diabetes (T1D). Yet, few youth living with T1D achieve the daily minimum recommended levels of physical activity. For all youth, regardless of their disease status, minutes of physical activity compete with other daily activities, including digital gaming. There is an emerging area of research exploring whether digital games could be displacing other physical activities and exercise among youth, though, to date, no studies have examined this question in the context of youth living with T1D.

Objective: We examined characteristics of digital gaming versus nondigital gaming (other exercise) sessions and whether youth with T1D who play digital games (gamers) engaged in less other exercise than youth who do not (nongamers), using data from the Type 1 Diabetes Exercise Initiative Pediatric study.

Methods: During a 10-day observation period, youth self-reported exercise sessions, digital gaming sessions, and insulin use. We also collected data from activity wearables, continuous glucose monitors, and insulin pumps (if available).

Results: The sample included 251 youths with T1D (age: mean 14, SD 2 y; self-reported glycated hemoglobin A_{1c} level: mean 7.1%, SD 1.3%), of whom 105 (41.8%) were female. Youth logged 123 digital gaming sessions and 3658 other exercise (nondigital gaming) sessions during the 10-day observation period. Digital gaming sessions lasted longer, and youth had less changes in glucose and lower mean heart rates during these sessions than during other exercise sessions. Youth described a greater percentage of digital gaming sessions as low intensity (82/123, 66.7%) when compared to other exercise sessions (1104/3658, 30.2%). We had 31 youths with T1D who reported at least 1 digital gaming session (gamers) and 220 youths who reported no digital gaming (nongamers). Notably, gamers engaged in a mean of 86 (SD 43) minutes of other exercise per day, which was similar to the minutes of other exercise per day reported by nongamers (mean 80, SD 47 min).

Conclusions: Digital gaming sessions were longer in duration, and youth had less changes in glucose and lower mean heart rates during these sessions when compared to other exercise sessions. Nevertheless, gamers reported similar levels of other exercise per day as nongamers, suggesting that digital gaming may not fully displace other exercise among youth with T1D.

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KEYWORDS

exercise; exercises; exercising; physical activity; physical activities; digital game; digital games; gaming; electronic game; electronic games; computerized game; computerized games; pediatric; pediatrics; child; children; youth; adolescent; adolescents; teen; teens; teenager; teenagers; diabetes; diabetic; DM; diabetes mellitus; type 2 diabetes; type 1 diabetes; TD1; TD2; mobile phone

Introduction

Type 1 diabetes (T1D) is a common chronic medical condition among children [1]. It is characterized by a loss of endogenous insulin production in the pancreas and an inability to self-regulate blood glucose levels. The daily treatment for T1D includes vigilant glucose monitoring, carbohydrate counting, and intensive insulin delivery, with the goal of trying to achieve near-normal glucose levels [2]. Additionally, it is important for youth living with T1D to participate in regular physical activity and exercise as part of achieving a healthy lifestyle [3]. Current clinical recommendations guide youth living with T1D to achieve at least 60 minutes of moderate- to vigorous-intensity physical activity daily [4], which are the same recommended duration, intensity level, and frequency of physical activity as those recommended for youth without T1D [5,6]. However, results of a recent meta-analysis showed that many youth living with T1D do not meet the minimum recommended levels of physical activity and may even be less physically active than peers without T1D [7].

For all youth, regardless of disease status, minutes of physical activity compete with other daily activities, including school, extracurricular activities, sleep, meals, and socializing [8]. Playing digital games is another popular leisure activity for many youth [9]. Digital games represent any game that is played by using an electronic device. In 2021, it was estimated that the typical US teenager spent almost 2 hours per day playing digital games [10]. Although there is an emerging body of research examining whether playing “serious digital games” could be an effective method of preventing disease in youth [11-14], studies have also explored whether digital games could be displacing other physical activities and exercise among youth [15], thereby potentially contributing to poorer health outcomes [10]. To date, the association between digital games and daily physical activity minutes among youth with T1D has received no attention.

The Type 1 Diabetes Exercise Initiative Pediatric (T1DEXIP) study is a real-world observational study of physical activity and glycemic levels in youth living with T1D from across the United States [16]. The study collected youth-specific (eg, age, insulin regimen, and hypoglycemia fear) and event-specific (eg, type, duration, and intensity of activity) data that were hypothesized to influence the acute glycemic response to physical activity in youth living with T1D. In this study, we used data from the T1DEXIP study to (1) examine characteristics of youth-identified digital gaming sessions versus nondigital gaming exercise sessions (other exercise) and (2) test whether youth with T1D who played digital games regularly (at least 30 min/day; ie, gamers) engaged in less other exercise than youth who did not play digital games (ie, nongamers). Moreover, related to our second aim, we examined whether gamers identified more barriers to physical activity and fear of hypoglycemia than nongamers. We sought to be the first to examine these important factors for youth living with T1D to inform the pediatric diabetes literature and guide in-clinic exercise consultations among youth living with T1D.

Methods

Ethical Considerations

The Jaeb Center for Health Research Institutional Review Board approved all study-related materials prior to participant recruitment. We obtained parent informed consent and participant assent electronically before screening and data collection. Data collection lasted from October 6, 2021, to December 17, 2022. We identified youth’s data by using a study-specific identification number. We compensated youth up to US $100 for their participation.

Procedures

We recruited participants from pediatric diabetes centers across the United States and through diabetes community conferences, workshops, and web-based platforms. Eligible youth were aged 12 to 17 years, had a T1D diagnosis, were on an intensive insulin regimen (open-loop insulin pump, hybrid closed-loop pump, or multiple daily injections), and spoke English. Youth and parents completed web-based surveys. For 10 days, youth logged any exercise session that lasted >10 minutes, any digital gaming activities, 3 days of food intake, and insulin dosing (multiple daily injections only) in a study-specific version of the Bant Diabetes smartphone app (University Health Network and the Hospital for Sick Children). To objectively measure blood glucose levels, insulin use, and physical activity, we collected continuous glucose monitor (CGM), insulin pump (if available), and wrist-worn activity tracker (Garmin vívosmart 4; Garmin International Inc) data from youth.

Measures

Youth completed a study-specific demographic and medical history survey to report their age, race, ethnicity, sex, contact information, and diabetes history (including duration of T1D, insulin delivery method, previous occurrences of severe hypoglycemia or diabetic ketoacidosis, and most recent glycated hemoglobin A_{1c} [HbA_{1c}] level). To measure youth’s perceptions of barriers to physical activity, they completed the Barriers to Physical Activity in Type 1 Diabetes (BAPAD1) scale [17]. The BAPAD1 scale is a 12-item survey that was validated for use in youth living with T1D. BAPAD1 scale items include general barriers to physical activity (ie, bad weather and school schedule), as well as potential diabetes-specific barriers (ie, risk of hypoglycemia or hyperglycemia). Youth responded to items by using a 7-point Likert scale (1: extremely unlikely; 7: extremely likely), with higher scores indicating the perception of more barriers to physical activity. To measure youth’s fear of hypoglycemia, they completed the Hypoglycemia Fear Survey-Child version (HFS-C) [18,19]. This 25-item survey, which was validated for youth with T1D, measures hypoglycemia fear based on the youth’s level of worry about hypoglycemia and use of hypoglycemia avoidance behaviors. The HFS-C uses a 5-point Likert scale (0: never; 4: almost always). Higher scores on the HFS-C reflect greater levels of hypoglycemia fear. To measure parents’ fear of their child experiencing hypoglycemia, parents completed the Hypoglycemia Fear Survey-Parent version (HFS-P) [19,20]. This is also a 25-item survey, which was designed to measure fear based on the parent’s level of worry about hypoglycemia and use of avoidance behaviors. The HFS-P uses the same response scale as the HFS-C. Higher scores on the HFS-P also reflect greater levels of parent-reported hypoglycemia fear.

Statistical Analysis

Analyses compared exercise characteristics during digital gaming sessions and other exercise sessions, changes in glucose during digital gaming sessions and other exercise sessions, and mean heart rates during digital gaming sessions and other exercise sessions. An additional analysis compared digital gaming sessions to walks and low-intensity exercise sessions. The calculation of changes in glucose during a digital gaming session and an other exercise session required a CGM reading at the start and end of the session, and mean heart rate calculation required at least 15 minutes of heart rate readings. Analyses also evaluated participant characteristics, exercise characteristics, average changes in glucose during other exercise sessions, and mean heart rates during other exercise sessions for gamers versus nongamers. We completed the analyses by using SAS software, version 9.4 (SAS Institute Inc).

Results

Sample Characteristics

Our sample included 251 youths with T1D. Overall, youth were aged a mean of 14 (SD 2) years; they reported a mean HbA_{1c} level of 7.1% (SD 1.3%), a mean diabetes duration of 5.3 (SD 2.9) years, and a mean physical activity level of 2.7 (SD 0.6) on the Physical Activity Questionnaire [21]; and 105 (41.8%) youths were female. Youth logged 123 digital gaming sessions and 3658 other exercise (nondigital gaming) sessions over the 10-day period (Table 1). Types of other exercise sessions that youth reported included walking, basketball, gym class, playing with friends, cycling, running and jogging, swimming, baseball and softball, soccer, and volleyball.

Table . Comparison of digital gaming and other exercise sessions.

		Digital gaming exercise sessions	Other exercise sessions
Number of exercise sessions		123	3658
Exercise duration (min), median (IQR)		60 (35-115)	40 (20-75)
Glucose at start of exercise (mg/dL), mean (SD)		154 (61)	163 (66)
Change in glucose (mg/dL), mean (SD)		–3 (54)	–15 (58)
Heart rate during exercise (beats/min), mean (SD)		99 (18)	109 (16)
Exercise time of day, n (%)			
	Night (12 AM to <6 AM)	0 (0)	21 (0.6)
	Morning (6 AM to <12 PM)	15 (12.2)	914 (25)
	Afternoon (12 PM to <6 PM)	53 (43.1)	1984 (54.2)
	Evening (6 PM to <12 AM)	55 (44.7)	739 (20.2)
Exercise intensity, n (%)			
	Low	82 (66.7)	1104 (30.2)
	Medium	39 (31.7)	2150 (58.8)
	High	2 (1.6)	404 (11)

Characteristics of Gaming Versus Other Exercise Sessions

The median duration of digital gaming and other exercise sessions was 60 (IQR 35-115) minutes and 40 (IQR 20-75) minutes, respectively. Prior to digital gaming, youth's mean glucose level was 154 (SD 61) mg/dL, and prior to other exercise sessions, youth's mean glucose level was 163 (SD 66) mg/dL. Youth's mean glucose change was –3 (SD 54) mg/dL during digital gaming and –15 (SD 58) mg/dL during other exercise sessions. When compared to other exercise sessions, during digital gaming, the percentage of glucose time in range (70-180 mg/dL) was higher, and youth experienced slightly less hyperglycemia and hypoglycemia (Figure 1). Youth's mean heart rate was 99 (SD 18) beats per minute (BPM) during digital gaming and 109 (SD 16) BPM during other exercise sessions. Youth's mean heart rate during sedentary periods that occurred at the same time as digital gaming but on different days was 90 (SD 12) BPM. Youth described a greater percentage of digital gaming sessions as low intensity (82/123, 66.7%) when compared to other exercise sessions (1104/3658, 30.2%); however, youth described digital gaming as similar in intensity to walking (Table 2). Additionally, when compared to walking and low-intensity exercise, youth had less changes in glucose and lower mean heart rates during digital gaming, digital gaming sessions had longer durations, and digital gaming was more likely to take place during the evening.

Figure 1. Glucose metrics for digital gaming and other exercise sessions. The percentages on the right of each bar indicate the average percentage of time spent in each glucose category. The numbers to the left of each bar specify glucose levels in mg/dL.

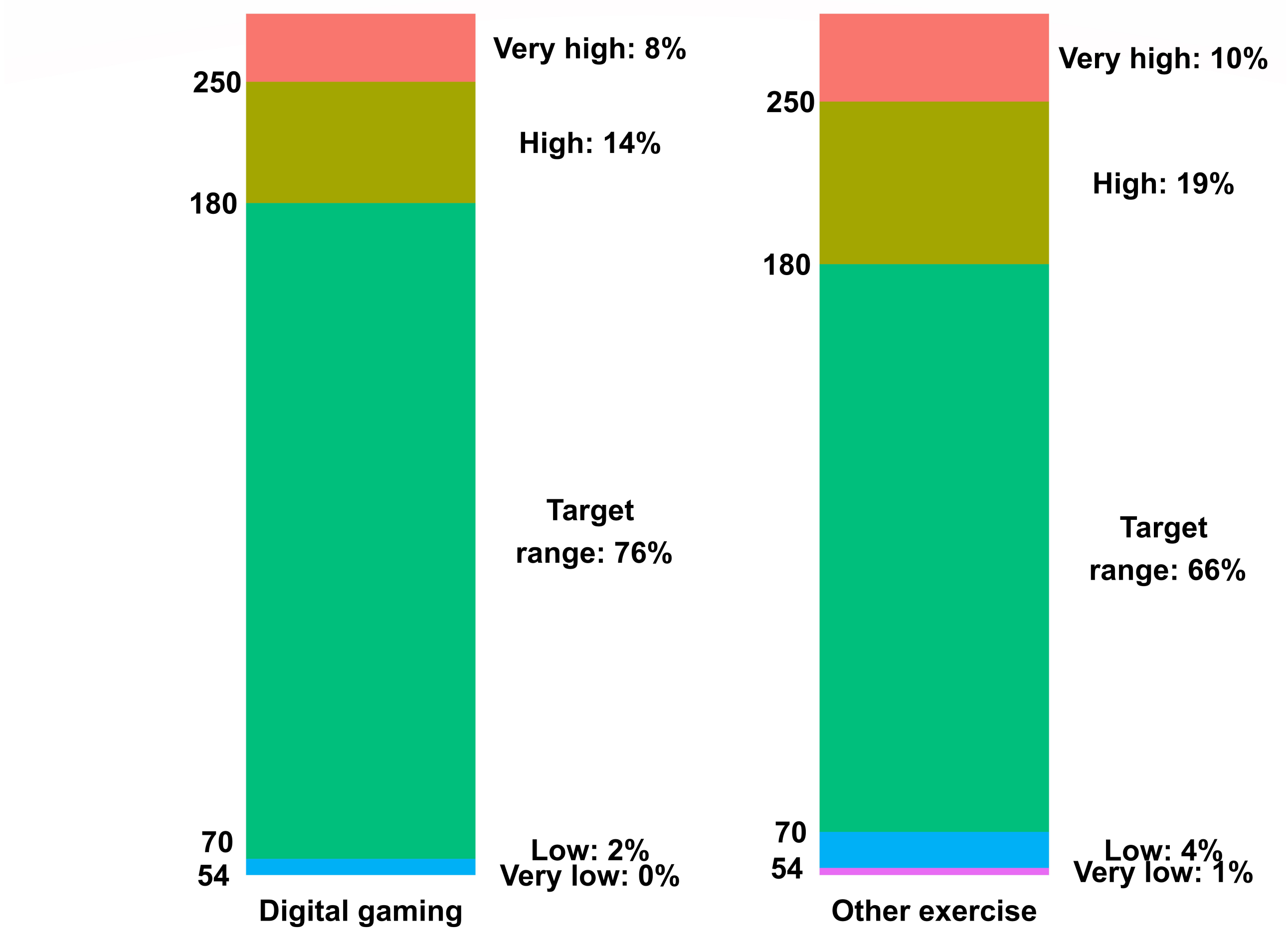

Table . Digital gaming versus walking versus low-intensity exercise.

		Digital gaming exercise sessions	Walking	Low-intensity exercise
Number of exercise sessions		123	975	503
Exercise duration (min), median (IQR)		60 (35-115)	30 (15-45)	40 (25-60)
Glucose at start of exercise (mg/dL), mean (SD)		154 (61)	168 (68)	162 (66)
Change in glucose (mg/dL), mean (SD)		–3 (54)	–16 (53)	–16 (54)
Heart rate during exercise (beats/min), mean (SD)		99 (18)	107 (15)	106 (15)
Exercise time of day, n (%)				
	Night (12 AM to <6 AM)	0 (0)	0 (0)	2 (0.4)
	Morning (6 AM to <12 PM)	15 (12.2)	266 (27.3)	121 (24.1)
	Afternoon (12 PM to <6 PM)	53 (43.1)	527 (54.1)	258 (51.3)
	Evening (6 PM to <12 AM)	55 (44.7)	182 (18.7)	122 (24.3)
Exercise intensity, n (%)				
	Low	82 (66.7)	601 (61.6)	503 (100)
	Medium	39 (31.7)	367 (37.6)	0 (0)
	High	2 (1.6)	7 (0.7)	0 (0)

Comparing Gamers to Nongamers

Our sample included 31 gamers and 220 nongamers who were similar in age, insulin regimen, HFS-C total score, HFS-P total score, and BAPAD1 scale score (Table 3). In contrast, we observed a greater percentage of male youths (26/31, 83.9%) in our gamer sample versus our nongamer sample (120/220, 54.5%). Gamers recorded 86 (SD 43) minutes of other exercise per day, whereas 80 (SD 47) minutes were reported by nongamers (Table 4). A follow-up correlation confirmed that there was no association between minutes of digital gaming and minutes of other exercise per day among gamers. The average glucose level at the start of other exercise sessions was 167 (SD 73) mg/dL for gamers versus 163 (SD 66) mg/dL for nongamers, and the mean glucose change during other exercise sessions was –17 (SD 60) mg/dL versus –15 (SD 58) mg/dL, respectively. Exercise characteristics and mean heart rates during other exercise sessions were similar for gamers and nongamers.

Table . Participant characteristics for gamers and nongamers.

		Gamers (n=31)	Nongamers (n=220)
Age (y), mean (SD)		14 (2)	14 (2)
Sex, n (%)			
	Female	5 (16.1)	100 (45.5)
	Male	26 (83.9)	120 (54.5)
BMI percentiles (%), mean (SD)		69 (27)	61 (27)
Insulin modality, n (%)			
	Multiple daily injections	4 (12.9)	34 (15.5)
	Open-loop pump	12 (38.7)	64 (29.1)
	Hybrid closed-loop pump	15 (48.4)	122 (55.5)
HFS-P[a] total score, mean (SD)		46 (13)	41 (13)
HFS-C[b] total score, mean (SD)		38 (18)	38 (13)
BAPAD1[c] scale score, mean (SD)		1.9 (0.9)	2.1 (1.0)
Minutes of digital gaming exercise per day, median (IQR)		19 (6-35)	0 (0-0)
Percentage of days with digital gaming exercise, median (IQR)		20 (10-40)	0 (0-0)
Minutes of other exercise per day, mean (SD)		86 (43)	80 (47)
Percentage of days with other exercise, median (IQR)		80 (70-100)	80 (70-90)

[a] HFS-P: Hypoglycemia Fear Survey-Parent version.

[b] HFS-C: Hypoglycemia Fear Survey-Child version.

[c] BAPAD1: Barriers to Physical Activity in Type 1 Diabetes.

Table . Summary of other exercise sessions for nongamers and gamers (percentages were calculated by using the number of other exercise sessions as the denominator).

		Gamers (n=31)	Nongamers (n=220)
Number of other exercise sessions		468	3190
Exercise duration (min), median (IQR)		40 (20-70)	40 (20-80)
Minutes of exercise per day, mean (SD)		86 (43)	80 (47)
Glucose at start of exercise (mg/dL), mean (SD)		167 (73)	163 (66)
Change in glucose (mg/dL), mean (SD)		–17 (60)	–15 (58)
Heart rate during exercise (beats/min), mean (SD)		111 (16)	108 (16)
Exercise time of day, n (%)			
	Night (12 AM to <6 AM)	4 (0.9)	17 (0.5)
	Morning (6 AM to <12 PM)	101 (21.6)	813 (25.5)
	Afternoon (12 PM to <6 PM)	275 (58.8)	1709 (53.6)
	Evening (6 PM to <12 AM)	88 (18.8)	651 (20.4)
Exercise intensity, n (%)			
	Low	131 (28)	973 (30.5)
	Medium	308 (65.8)	1842 (57.7)
	High	29 (6.2)	375 (11.8)

Discussion

In this study's cohort of physically active youth with T1D, digital gaming sessions lasted longer and were more likely to be described as low intensity, relative to activities such as walking, playing sports, and other physically active social activities that youth engaged in on a regular basis. We also found differences in mean heart rates, changes in glucose, and glucose metrics during digital gaming versus during other exercise sessions. The slightly higher percentage of glucose time in range (70-180 mg/dL) during digital gaming versus other exercise sessions could have been due to the lower starting glucose levels and the little change in glucose during digital gaming. Although the mean heart rate during digital gaming was lower than that during other exercise sessions, it was higher than that during sedentary periods that occurred at the same time as digital gaming but on different days, which is consistent with existing data [22]. Also consistent with existing evidence are youth's perceptions of digital gaming intensity. In an accelerometry study, researchers characterized digital gaming as similar in intensity to walking or light jogging [23]. However, our study of free-living exercise among youth with T1D offers new results; we reported differences in changes in glucose during exercise and differences in mean heart rates when comparing digital gaming sessions, walking, and low-intensity exercise. We believe that these novel results can help to inform in-clinic exercise consultations among youth with T1D, as youth, parents, and health care professionals may otherwise be unaware of how these activities, particularly digital gaming, may impact glucose levels and heart rates in youth [24,25].

Youth with T1D who reported digital gaming also participated in other exercise. Moreover, comparing daily minutes of other exercise between our gamers and nongamers revealed no differences. This result is consistent with a Dutch study of youth without T1D, which found that the time youth spent playing digital games did not replace the time spent in other physical activities [15]. When comparing gamers to nongamers, there were no differences in hypoglycemia fear or perceived barriers to physical activity. In general, adolescents with T1D report few barriers to physical activity [26], and only hypoglycemia avoidance behaviors [27] appear to be associated with their physical activity.

As an important limitation, this analysis of T1DEXIP study data was likely underpowered to detect differences. Gamers accounted for only 12.4% (31/251) of our sample, which was lower than expected, and this could be an indication of underreporting. Relatedly, because the T1DEXIP study recruited a physically active sample of youth with T1D, it is possible that daily minutes of other exercise may not generalize to typical youth living with T1D. Therefore, we need future research to confirm our study results in a large sample of youth with T1D who report more diverse levels of daily physical activity. It would also be valuable to recruit a large sample of youth with T1D based on their digital gaming habits to determine if minutes of other exercise sessions differ for youth with T1D who self-identify as novice gamers and those who self-identify as avid gamers. We acknowledge the limitation of a possible Hawthorne effect. Youth who participated in the T1DEXIP study were aware that we were interested in examining the associations between their daily physical activity and glycemic levels; therefore, it is possible that they may have altered their gaming and exercise frequencies during the 10-day observation window. Strengths of this study include its real-world observational design and the large number of exercise sessions captured within a large sample of youth with T1D. We also believe that our methods are strong because we used validated surveys and, when available, objective and noninvasive data sources (eg, CGMs, Garmin wearables, and insulin pumps) [28].

In conclusion, for a physically active sample of youth with T1D, our results identified some differences in the duration and intensity of digital gaming versus other exercise sessions, as well as some differences in the mean heart rates and glucose changes during digital gaming versus other physical activity sessions, and suggested that playing digital games may not displace daily minutes spent engaged in other exercise for youth with T1D who are regular gamers. In light of the similarity in daily minutes spent engaged in other exercise between youth with T1D who identify as gamers and those who identify as nongamers, it is possible that interventions for promoting physical activity among youth with T1D should focus on reducing the impact of other barriers to physical activity (eg, hypoglycemia risk and sedentary screen time) rather than target digital gaming.

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Data Availability

The data sets generated by the Type 1 Diabetes Exercise Initiative Pediatric (T1DEXIP) study are available on the Vivli platform [29].

Authors' Contributions

SRP wrote the first draft and reviewed and edited the manuscript. SB conducted statistical analyses and wrote and edited the manuscript. RLG, PC, MAC, JLS, and MCR contributed to discussions and reviewed and edited the manuscript.

Conflicts of Interest

SRP reports receiving grants from the Leona M. and Harry B. Helmsley Charitable Trust, the National Institutes of Health (NIH), and the Jaeb Center for Health Research, as well as an honorarium from the American Diabetes Association outside the submitted work. RLG, SB, and PC report no conflicts of interest. MAC is the chief medical officer of Glooko, Inc, and has received research support from Dexcom and Abbott Diabetes Care. Children’s Mercy Kansas City has received grants or contracts for MAC from the NIH, the Leona M. and Harry B. Helmsley Charitable Trust, JDRF, the Emily Rosebud Foundation, Eli Lilly, the Jaeb Center for Health Research, Tolerion, and Garmin. JLS serves, or has served, on advisory panels for Bigfoot Biomedical, Cecelia Health, Insulet Corporation, Medtronic Diabetes, StartUp Health Diabetes Moonshot, and Vertex. JLS has served as a consultant to Abbott Diabetes, Bigfoot Biomedical, Insulet, Medtronic Diabetes, and Zealand Pharma. Yale School of Medicine has received research support for JLS from Abbott Diabetes, the Jaeb Center for Health Research, JDRF, Insulet, Medtronic, the NIH, and Provention Bio. MCR serves on the following advisory panels: Zealand Pharma A/S, Zucara Therapeutics, and Indigo Diabetes. MCR acts as a consultant for the Jaeb Center for Health Research and has given lectures sponsored by Dexcom, Inc; Novo Nordisk; and Sanofi. He is also a shareholder, or holds stocks in, Supersapiens and Zucara Therapeutics.

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Abbreviations

BAPAD1: Barriers to Physical Activity in Type 1 Diabetes
BPM: beats per minute
CGM: continuous glucose monitor
HbA_{1c}: glycated hemoglobin A_{1c}
HFS-C: Hypoglycemia Fear Survey-Child version

HFS-P: Hypoglycemia Fear Survey-Parent version
T1D: type 1 diabetes
T1DEXIP: Type 1 Diabetes Exercise Initiative Pediatric

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Original Paper

Understanding Adolescents’ Experiences With Menstrual Pain to Inform the User-Centered Design of a Mindfulness-Based App: Mixed Methods Investigation Study

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Abstract

Background: Digital interventions are increasingly popular for the provision of nonpharmacological pain interventions, but few exist for adolescents with menstrual pain. User-centered design involves incorporating users across phases of digital health intervention design, development, and implementation and leads to improved user engagement and outcomes. A needs assessment is the first step of this approach.

Objective: The goal of this study was to conduct a needs assessment to understand menstrual pain management needs and preferences and mindfulness experiences, preferences, and knowledge of adolescents with menstrual pain to inform the future development of an app for managing menstrual pain.

Methods: We used an explanatory sequential mixed method design that included a survey followed by focus groups. Adolescents aged 13-17 years completed a survey (n=111) and participated in focus groups (n=16). Data were analyzed using descriptive statistics and thematic content analysis and synthesized to provide specific recommendations based on adolescent responses.

Results: Adolescents (n=111) who completed the survey reported a moderate understanding of mindfulness and menstrual pain. Over three-quarters (n=87, 78%) of participants practiced some form of mindfulness and 87% (n=97) of survey participants used nonpharmacological pain management strategies. Teens had a moderate perception that mindfulness could help their menstrual pain (mean 4.51/10, SD 2.45, with higher scores suggesting more interest). Themes were generated related to mindfulness experiences, menstrual pain knowledge and experiences, and app functionality. These themes underscored adolescents’ need for continued support and flexible access to mindfulness activities; their awareness of multiple influences to pain, with potential for further education in this area; and the need for menstrual pain–specific content, along with content relevant to typical day-to-day experiences of adolescents.

Conclusions: Adolescents with menstrual pain have an interest in using a mindfulness app for pain but have unique needs that need to be addressed to ensure app engagement and relevance for this population. Concrete recommendations for future app development are provided.

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KEYWORDS

adolescent health; endometriosis; pain management, biopsychosocial; women’s health; dysmenorrhea; thematic analysis; mHealth; mobile health; app; apps; applications; applications; attitude; attitudes; opinion; opinion; perception; perceptions; perspective; perspectives; interest; intent; intention; survey; surveys; focus group; focus groups; content analysis; mindfulness; meditation; menstrual; menstruation; experience; experiences; pain; youth; adolescent; adolescents; teen; teens; teenager; teenagers

Introduction

Dysmenorrhea, or menstrual pain, is experienced by over 90% of adolescents who menstruate and has been associated with mental health symptoms, nonsuicidal self-injury, and decreased quality of life [1-3]. For a quarter of these youth, the severity of their pain prevents them from engaging in daily activities and contributes to school absenteeism [4]. Increasingly, it is recognized that persistent, unmanaged dysmenorrhea may lead to the development of chronic pain [5,6]. Despite the impacts of dysmenorrhea on adolescent well-being, there are few accessible, evidence-based treatment options available for adolescents. Prevailing interventions are primarily pharmacological, which is not always a good fit given potential side effects and barriers to accessing care [7,8]. There is a need for accessible and effective interventions for adolescents with dysmenorrhea.

Digital health interventions, such as app-based interventions, are increasing in popularity, particularly given their ability to reduce barriers to accessing health-related services [9,10]. Recent estimates show that 95% to 98% of youth and young adults in Canada and the United States have a smartphone [11,12]; the ubiquity of smartphone access suggests that an app-based intervention maybe a viable option for adolescents with menstrual pain in Western populations. Although there is a plethora of apps related to menstruation [13,14], only a fraction of these apps contains pain-related content, and the accuracy and quality of this content are low [15,16]. Importantly, few of the available menstrual pain apps are designed specifically for adolescents [16] who may have different menstrual knowledge [3], menstrual cycle characteristics [17], and app use preferences than adults. Consequently, adolescents may benefit from an app designed specifically for their age group [10,18,19].

User-centered design is a digital intervention design approach that involves collaboration with end users (eg, patients and parents) throughout all stages of app development and implementation. User-centered design in the development of health-based apps has been shown to increase satisfaction, mitigate barriers to engagement, and improve user adoption [20-23]. In the user-centered design, the end user is included in the development process through the use of focus groups and surveys, participatory design sessions, and usability testing [24]. This multistep approach begins with a user needs assessment [21,25], which is integral in identifying and prioritizing the needs of the end user, in this instance, adolescents with menstrual pain.

To our knowledge, there are no apps developed with and for adolescents that incorporate both user-centered design and evidence-based content for the management of dysmenorrhea. Evidence-based nonpharmacological therapies such as cognitive behavioral therapy and mindfulness-based interventions have been applied as treatments for chronic and specific pain-related disorders [26,27]. As a first step in filling the gap in access to nonpharmacological interventions, this study focused on adolescents’ perception of mindfulness as a potential intervention for dysmenorrhea.

Mindfulness-based interventions are rooted in theories of mindfulness and focus on changing one’s relationship with pain and suffering [28]. Research suggests that mindfulness-based interventions may be beneficial in adolescent populations for a range of concerns [29-31] and have demonstrated potential in reducing pain and improving pain acceptance and ability to cope in youth with chronic pain [32]. The aspects of mindfulness in combination with other therapeutic approaches have also been successfully integrated into face-to-face treatments for adults with dysmenorrhea [33]. In this investigation, we focused on determining adolescents’ interest in mindfulness over other interventions for several reasons. First, past research suggests that many youth report positive experiences with mindfulness programs and the impact of mindfulness skills on their day-to-day lives [34-36]. Mindfulness-based interventions also have the potential to lend themselves better to younger teens over approaches that may require adaptation based on cognitive skills [31,37-39]. Additionally, mindfulness strategies (eg, meditations) may be more easily applied by youth in an app-based platform without therapist guidance than other interventions [40,41], which is important given the high prevalence of dysmenorrhea yet limited availability of nonpharmacological treatment options [17,42].

This study reports the first step in the user-centered development of a self-management, mindfulness-based app for teens with dysmenorrhea, that is, a needs assessment. Although digital modalities for the delivery of mindfulness-based interventions, such as smartphone apps, may be a promising means through which pain interventions may be offered, understanding whether teens are interested in mindfulness-based strategies for their pain and what type of content would be valuable to them in an app is essential. The goals of this needs assessment were to identify (1) mindfulness knowledge, experiences, and preferences; (2) menstrual pain management knowledge, experiences, and preferences; and (3) app use experiences and preferences among Canadian adolescents who experience dysmenorrhea. Using a 2-phased approach that relied on both administering a survey (phase 1) and conducting focus groups (phase 2), adolescent views were gained to inform future app development. The findings of this investigation will be used to engage in subsequent steps of the user-centered design process, including usability testing and pilot testing of the resulting app.

Methods

Research Design Overview

An explanatory sequential mixed methods design was selected for this investigation [43]. In this approach, quantitative data are collected first and are followed by the collection of qualitative data to gain a deeper understanding of quantitative findings. In phase 1 of our investigation, descriptive quantitative data and narrative responses were collected via a web-based survey. These findings of this survey are reported in accordance with the CHERRIES checklist (Checklist for Reporting Results of Internet E-Surveys) [44] (Multimedia Appendix 1). Subsequently, phase 2 involved focus groups to gain further insight into the experiences of adolescents described in phase 1. Qualitative findings from the focus group responses are reported in accordance with the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist [45] (Multimedia Appendix 2).

Participants

A convenience sample of participants aged 13 to 17 years was recruited between January and July 2022 to participate in a web-based survey (phase 1) and a focus group (phase 2). To be eligible, adolescents were required to have had their first period, experience pain with their period, and live in Canada. Adolescents who were aged 13 to 15 years were required to have consent from a parent or legal guardian to participate in the survey (note that for simplicity, we refer to “parent” to reflect all guardians who provided consent from hereon). All participants (ie, 13-17 years of age) were required to have parental consent to participate in the focus group.

Ethical Considerations

This study was approved by the University of Saskatchewan Research Ethics Board (BEH 3013). Survey responses from participants aged 16-17 were anonymous. Participants aged 13-15 were known to the research team, but did not report identifying information in the survey and rather entered a participant ID to ensure that survey responses were from participants who had appropriate parental consent. Due to the nature of the focus groups, anonymity was not possible, but the importance of maintaining other participants' confidentiality was discussed prior to beginning each focus group. Survey participants were entered into a draw for 1 of 5 CAD $50 (approximately US $36.89) Amazon gift cards. Focus group participants received the choice of a CAD $50 honorarium or a CAD $50 Amazon gift card (approximately US $36.89) for their participation.

Measures

Needs Assessment Questionnaire

The 27-item needs assessment questionnaire was developed to gather information about adolescents’ (1) phone use patterns and preferences (5 items); (2) mindfulness knowledge and experiences (6 items); (3) pain knowledge and impact of menstruation on daily functioning (5 items); (4) use of existing menstrual and mindfulness apps (1 item); and (5) perceived barriers and facilitators of, interests in, and recommendations for a mindfulness app for adolescents with menstrual pain (6 items). Additionally, the questionnaire queried demographic information (4 items), including age, sex assigned at birth, gender identity, and ethnic or racial background. Question formats throughout the survey included yes or no questions (eg, “have you ever practiced mindfulness or meditated?”), multiple-choice responses (eg, “when do you experience the most pain or physical discomfort with your period [select all that apply]?”), 11-point numeric rating scales (eg, “what would you rate your level of understanding of what mindfulness is?”; 0=no understanding and 10=complete understanding), and open-ended questions (eg, “what would motivate you or help you to use the app to use mindfulness when you are experiencing period pain?”). The measure was developed by the first author (MMG) and reviewed by all coauthors and study research assistants.

Focus Group Interview Guide

A 10-question semistructured interview guide was developed by our multidisciplinary team and comprised questions that built upon the information gathered in the needs assessment survey. Participants were asked about their experiences with pain, including their understanding of contributors to their pain, their experiences with mindfulness, their experience with menstrual apps, their interest in using a mindfulness app for period pain, their perception of challenges and motivators for using health apps, and any suggestions to inform future app development.

Procedure

Phase 1: Web-Based Survey

Adolescents were the primary participants of this study; however, to increase enrollment, the parents of adolescents were also targeted throughout the recruitment and involved in the enrollment phase to provide consent for their adolescent to participate where needed. Participants were recruited using Facebook and Instagram advertisements posted on the research team’s Facebook and Instagram accounts targeting adolescents and parents of adolescents.

Participants aged 16 and 17 years accessed the survey via a link provided in recruitment materials. Prior to gaining access to the survey, participants were required to review the consent form outlining the rationale for the study, the duration of the survey, data storage and security, confidentiality measures, and their right to withdraw. After reviewing the consent form, participants provided their informed consent by proceeding to the next page of the survey. For participants aged 13-15 years, the interested adolescent or their parent completed a web-based form to indicate the adolescent’s interest in the study. A research assistant contacted the parents of each adolescent to confirm the adolescent’s eligibility and obtain parental consent. Adolescent assent was also obtained. Following receipt of consent and assent, the research assistant sent the adolescent a link to the web-based questionnaire.

The survey duration was approximately 10-20 minutes, and the survey was conducted via SurveyMonkey. All survey questions were voluntary and presented across 6 pages with backtracking enabled. Question randomization was not used, and no questions were conditionally displayed. The survey was distributed via 2 survey links: an open survey for adolescents 16-17 years, where IP addresses were used to identify unique survey respondents and prevent multiple, same-person responses, and a closed survey for adolescents 13-15 years, where the link was provided directly to participants by the researchers. Participants had the option of providing their email to be contacted regarding the focus group, entered into the draw for the gift card, or both.

Phase 2: Web-Based Focus Groups

Participants were recruited using Facebook and Instagram advertisements targeting adolescents and parents of adolescents posted on the research team's Facebook account. Additionally, phase-1 adolescents interested in participating in a focus group were able to indicate their interest at the end of the survey. Interested participants were contacted by a research assistant to schedule a consent and assent call via Zoom (Zoom Technologies Inc) with the adolescent and their parents. During the call, the research assistant reviewed the purposes of the study using a shared PowerPoint (Microsoft Corp) presentation. If the family remained interested in participating, the research assistant reviewed the consent and assent information with the family, enrolled the adolescent, and gathered demographic information.

Participants were enrolled in 1 of 3 groups based on their availability. Focus groups were conducted digitally via Zoom and were audio and video recorded to allow for later review. Each group had 4 to 7 participants and lasted up to 90 minutes. All researchers (ie, MMG, ARB, and a research assistant) involved in the focus groups were Canadian female individuals. Focus groups were led by 1 member of the research team and a second team member took field notes. Following the completion of the focus groups, audio from the groups were transcribed verbatim to allow for analysis.

Analytic Plan

Overview

Demographic information from the survey and the focus group were analyzed using descriptive statistics. Across both phases of the sequential explanatory design, we used SPSS (IBM Corp) to calculate quantitative results, and Microsoft Excel was used for the organization of narrative data. Survey responses and focus group responses were analyzed separately, and results were grouped based on findings that addressed each of the study objectives (ie, mindfulness knowledge and experience, dysmenorrhea knowledge and experiences, and app use preferences). Narrative responses from open-ended survey questions and phase-2 focus groups were examined using an experiential realist framework. In an experiential framework, the analyses aim to explore participants' understanding, while a realist framework aims to capture (rather than construct) the reality of participants within the data set [46]. This framework was chosen, given the study goal of understanding adolescents' experiences as a means of proposing concrete recommendations for app development.

Analysis of Survey Responses

Closed-ended survey questions from the needs assessment survey were analyzed using descriptive statistics. Open-ended questions of the needs assessment survey questions were examined question by question. Codes were formulated from responses with no limit placed on how many codes could be developed. Developed codes were then examined for similarities and grouped into themes. Theme frequency was reported to understand how important ideas were to adolescents compared to other ideas [47].

Analysis of Focus Group Responses

Reflexive thematic analysis [46] was used for analysis of the focus group data. Following verbatim transcription of the focus group recordings, an inductive (ie, data-driven) approach to examining the data was taken, with a focus on the semantic level of meaning of responses. Codes were formulated within each question of the focus group interview by 1 member of the research team (MMG), again with no limit placed on the number of codes, and similar codes were grouped to formulate themes. Reflexive thematic analysis involves critically considering the researchers' personal and professional experiences and biases that may impact data interpretation. The research team is interested in improving digital interventions, with backgrounds in nursing and psychology.

Synthesis of Qualitative and Quantitative Findings

To bring a comprehensive understanding of the ideas from each phase and research objective (ie, mindfulness, menstrual pain, and app preferences), the qualitative and quantitative findings were synthesized. The themes generated from focus groups were combined with survey findings related to mindfulness and dysmenorrhea knowledge and experiences and app use preferences to identify resulting needs for adolescents. Specific recommendations for future app development were then generated based on the combined results.

Results

Demographic Information

A total of 143 participants completed some portion of the survey and 108 (76%) completed the final page. Participants who had completed less than 80% of survey questions (n=32, 22%) were considered to have withdrawn and were removed, resulting in a final sample of 111 participants. Demographic characteristics of participants in both phases are summarized in Table 1.

Table 1. Demographic characteristics of survey participants (n=111) and focus group participants (n=16).

Characteristics	Survey participants	Focus group participants
Age (years)		
n	109	16
Mean (SD)	15.97 (1.21)	15.19 (1.52)
Range	13-17	13-17
Gender identity, n (%)		
Girl or woman	103 (93)	15 (94)
Transgender	1 (1)	N/A[a]
Other	7 (6)	1 (6)
Racial or ethnic origin, n (%)[b]		
Arab	3 (3)	1 (6)
Black	2 (2)	N/A
Chinese	2 (2)	N/A
Filipino	1 (1)	N/A
First Nations	10 (9)	N/A
Métis	4 (4)	1 (6)
Inuit	1 (1)	N/A
Latin American	3 (3)	N/A
South Asian	3 (3)	3 (19)
Southeast Asian	1 (1)	N/A
White	93 (84)	13 (81)
Other	1 (1)	1 (6)

[a] N/A: not applicable.

[b] Participants could provide a response in more than 1 category.

Phone and App Use

Among survey participants (n=111), 87% (n=95) had an Apple device and 14% (n=15) had an Android device. Most participants did not have unlimited data (n=70, 63%) or were unsure (n=9, 8%). Most used apps included social networking apps (n=107, 96%), utility apps (n=82, 74%), entertainment apps (n=81, 73%), productivity apps (n=69, 62%), and gaming apps (n=63, 57%).

Mindfulness Knowledge and Experiences

Survey Results

Nearly all survey participants (106/111, 95%) reported having heard of mindfulness. Participants reported a moderate understanding of mindfulness (mean 6.63, SD 2.32 out of 10; 0=no understanding and 10=complete understanding) and how to use mindfulness (mean 5.70, SD 2.59 out of 10; 0=no understanding; 10=complete understanding). Over three-quarters (87/111, 78%) of respondents reported having practiced mindfulness. The most common types of mindfulness activities used by 84 participants who reported any type of activity were meditation (n=57, 68%), yoga (n=53, 63%), breathing (n=32, 38%), music (n=17, 20%), movement (eg, walking; n=10, 12%), and art-based activities (eg, coloring; n=5, 6%). Among survey participants, 53 (48%) reported using meditation apps. YouTube (n=17, 32%), Spotify or other podcast apps (n=10, 19%), Headspace (n=8, 15%), and calm (n=7, 13%) were the most used meditation apps or websites.

Focus Group Results

Overview

Focus group participants were asked to discuss their experiences with mindfulness. Participants' experiences largely occurred in school settings, through their parents, or in mindfulness-based extracurricular, such as yoga classes. Three themes were generated based on participants' described experiences.

Theme 1: Discouraging School Experiences

Exposure to mindfulness at school was common and participants with this experience described challenges with learning mindfulness in this setting. Responses were categorized into 2 subthemes. The first subtheme related to *discontinued support.* Several participants reported that mindfulness was practiced throughout elementary and middle school but that in high school support from teachers in learning and practicing mindfulness stopped, making it difficult to maintain their mindfulness practice. This pattern of reduced support as students age was captured by a participant who described:

> *Before [in elementary school] it'd be every day we'd have something to do with [mindfulness]. Now [in high school] you kind of fend for yourself. You don't get too much support anymore.* [Participant 22, 13 years old]

A second subtheme related to the school setting being an *unconducive environment* for mindfulness was generated. Participants described difficulty practicing mindfulness at school because of distractions in the classroom. They also described feeling self-conscious due to having their peers around or being distracted by noise, which interfered with their perception of how helpful the practice was:

> *When we did it at school...there was a lot of people talking...and it makes it really hard to concentrate. So, I don't think it helps in large groups of people who don't want to take it seriously.* [Participant 42, 17 years old]

Theme 2: Personalization Needed

Participants described a need for mindfulness activities to be interesting or personalized to the individual. The generality of mindfulness was identified as a barrier to its use:

> *I do agree that mindfulness is important and applies to everyone and what can help anyone in many ways. But it doesn't necessarily seem all that inviting when it's super general.* [Participant 61, 16 years old]

Many participants identified yoga as a way through which they practiced mindfulness. Participants noted that not all youth found sitting and meditating to be the most beneficial approach. These ideas were captured by a participant who stated:

> *Some people, especially as teenagers with emotions and energy and whatnot, might find it hard to relax. I know a lot of people who just can't relax or [they] find it really hard to sit still and not talk, but I think mindfulness was a part of finding your way to do that. And if your way is movement or if your way is sitting there with your head down –mindfulness is finding a way that works for you in a way that you find beneficial.* [Participant 124, 14 years old]

Theme 3: Real-Time Use of Mindfulness Is Tricky

Integrating mindfulness into everyday life or sustaining a mindfulness practice was a challenge for youth. The challenges identified by youth included difficulty using mindfulness when it would be most needed, difficulty using strategies when busy, or the tendency to stop using mindfulness when there is no motivation to continue. A participant described the following experience trying to implement mindfulness on their own:

> *I think it did help in terms of lowering my heartrate and making me feel more calm and in the present. But I feel like sometimes when I try to incorporate it into my daily life it just never turns out right, because if I'm stressed, I can't think of a way to calm myself down. It just doesn't work for me that well.* [Participant 1, 16 years old]

The following quotation from a participant captured the challenges with sustaining the practice:

> *...because of COVID I had to stop going [to a yoga class] and now I'm so busy with schoolwork. So now [it's] just pushed aside and [after COVID-19] mindfulness isn't something I do once a week or something like that.* [Participant 21, 14 years old]

Dysmenorrhea Knowledge and Experiences

Survey Results

On average, adolescents who completed the survey rated their knowledge of contributors to period pain and symptoms as moderate (mean 5.39, SD 2.30 out of 10; 0=no knowledge and 10=extremely knowledgeable). They also reported moderate levels of knowledge related to how to manage their menstrual pain (mean 5.78, SD 2.46 out of 10; 0=no knowledge and 10=extremely knowledgeable). Most survey participants (97/111, 87%) reported using nonpharmacological pain management strategies to manage menstrual symptoms, including hot water bottles or heating pads (83/111, 75%), rest or sleep (81/111, 73%), baths or showers (73/111, 66%), exercise (28/111, 25%), relaxation exercises (21/111, 19%), and mindfulness or meditation (16/111, 14%).

Focus Group Results

Overview

Focus group participants were asked to discuss their understanding of factors that contribute to their pain, which resulted in 2 themes.

Theme 1: Wavering Degree of Control Over Menstrual Pain

Participants described their ability to control pain as a variable across their menstrual cycle and impacted by environmental and individual factors. This theme led to 3 subthemes related to the participants' experiences. The first subtheme related to how *context matters*. Participants described that the degree to which they felt comfortable in a situation affected their pain level. Being familiar and comfortable with those around them and being in low stress and calm situations were helpful in managing pain. Similarly, when participants felt in control of the situation, pain was easier to tolerate. This subtheme was captured by the following:

> *If you're somewhere comfortable where you know you have the resources...you feel a lot more comfortable when you get pain. When you're out in public or you have something to do that you need to do you're like a lot more uncomfortable, and it can even be worse because you're not like listening to your body.* [Participant 124, 14 years old]

The second subtheme related to *moments of helplessness* due to menstrual pain. Participants recognized that although pain was generally not constant, there were times in their lives when they felt a loss of control due to pain. This was reflected by 1 participant who stated:

> *I literally woke my parents up at night screaming because my cramps were so bad and I felt bad for screaming. But they hurt that much and that was to the point that one night my mom was like, ok, that's it, you're going on birth control. And I mean, it helps*

> *a bit. But, at the same time, I still get cramps and I'm nauseous, which makes me think maybe I should try a different birth control because in gym, if I go and do something, I get cramps just by doing stuff. And it's really annoying because when I have to go sit off to the side.* [Participant 143, 17 years old]

The final subtheme was *pain management is challenging.* Within this subtheme, there were varying perspectives related to how medication and self-care could be helpful. Several participants acknowledged being aware of activities they could do to help with pain but struggled to be motivated to engage in them. This challenge was well reflected by a participant who stated:

> *...doing exercise helps, but when I'm in pain, to actually start doing it is really, really hard. So, most of the time I just don't end up doing it because I don't feel like getting up and actually starting. But if I were to start, it would probably be better.* [Participant 127, 13 years old]

Within this subtheme, several participants also described medications as either being the only strategy that helped or the only treatment option available to them:

> *I have really bad period pain to the point where I had to get an [intrauterine device], because that was the only thing that would stop it, and then I still had to get prescribed naproxen. So, I know...people say, that exercising helps with period pain, but for me, I find it makes it worse. I cannot really keep doing anything. And, well, nothing will make it really better. Meds would but that's about it.* [Participant 118, 16 years old]

Theme 2: Mind-Pain Interaction

Participants identified a relationship between what went on in their minds and their menstrual pain. Several components of the "mind" influences were discussed by participants. For instance, they described being aware that engaging in another activity could help distract from the pain but that thinking about pain most often led to more pain:

> *I know for me when I have any type of pain, if I'm busy doing something all day or out with friends I don't really notice it as much. And then I come home and I'm lying in bed and it usually hurts more when I'm thinking about it. Then [the pain] usually just doesn't go away until I'm busy again or get myself watching a show or something, and then I just kind of forget about it.* [Participant 42, 17 years old]

Participants also believed that their mood, stress, or the anticipation of pain could increase pain. These ideas were captured in the following quote:

> *My mood definitely affects how it feels. When you're at school and you're getting stressed about something or you're doing physical activity at school or even if it's hanging out with...people who make you feel a certain way, whether that be stressed, annoyed, that sort of thing – it definitely aggravates how you feel. And then it aggravates how you're feeling in regards to your period, your pain.* [Participant 31, 15 years old]

Perceptions of Current and Potential App Use

Survey Results

Nearly two-thirds (70/111, 63%) of survey participants reported using a website or app to track their period, with Flo (34/111, 31%) and Clue (21/111, 19%) being the most common. Participants had a moderate perception that mindfulness could help cope with menstrual periods (mean 4.51, SD 2.45 out of 10; 0=not at all helpful and 10=extremely helpful). Approximately one-third (36/107, 34%) of participants provided a rating of 3 or lower out of 10 that mindfulness could be helpful, 43% (46/107) provided a rating from 4 out of 10 to 6 out of 10, and nearly a quarter (25/107, 23%) of participants provided a rating of 7 out of 10 or higher (Multimedia Appendix 3). Participants (n=111) indicated that if they were to use mindfulness during their period, they would likely use it 1-2 times (n=59, 53%) or 2-4 times (n=42, 38%). From a list of preferred app features provided to participants, adolescents were most interested in period tracking features, receiving feedback after logging pain and symptoms, and seeing insights into their mindfulness use (Table 2).

Table 2. Survey participants' endorsement of each proposed app feature.

App feature[a]	Values (n=110), n (%)
Charts that track your pain from period to period	99 (89)
Receiving feedback after logging your menstrual pain (eg, recommendations to help manage pain)	98 (88)
Seeing how you are doing over time with practicing mindfulness (eg, tracking chart and number of minutes practiced)	75 (68)
Notifications reminding you to track your period	75 (68)
Charts that track other aspects of your period from period to period	67 (60)
Receiving positive feedback after logging your mindfulness practice (eg, way to go! and congratulations!)	66 (60)
Notifications reminding you to practice mindfulness	47 (42)
Sharing how you have been doing on the app with family and friends	10 (9)
Other	13 (12)

[a] Participants could provide a response in more than 1 category.

Survey participants were asked to indicate what would motivate and deter them from using an app for mindfulness when experiencing period pain. The themes from survey participant responses and the frequency of these responses are summarized in Table 3. Reminders to use the app, the app being effective in reducing their pain or increasing knowledge about periods, and the app being engaging were identified as essential motivators. Common barriers included the app not being free, being difficult to use, or having ads.

Table 3. Barriers and facilitators to app use among survey participants.

Barriers and facilitators	Values (n=111), n (%)
Themes related to facilitators to use[a]	
Reminders	32 (30)
Effective	16 (15)
Engaging or rewards	14 (13)
Encouraging or inspiring messaging	11 (10)
Design or aesthetic	8 (8)
Research evidence	8 (8)
Charts or tracking	6 (6)
Feedback	5 (5)
Other	6 (6)
Themes related to barriers to use[a]	
Not free	22 (22)
Difficult to use (eg, complicated, glitches, or lags)	21 (21)
Ads	19 (19)
Too many notifications	15 (15)
Visually unappealing or poor design	14 (14)
Not helpful	9 (9)

[a] Participants' responses were categorized into more than 1 theme, when applicable.

Focus Group Results

Overview

Focus group participants were asked to consider how or when they could see themselves using a mindfulness app to help with their period pain. Two themes were generated.

Theme 1: Manage Painful Parts of Period

Adolescents were most willing to consider using an app during the painful parts of their period. Several indicated they might not be motivated to use the app during parts of their cycle when they did not experience pain.

> *I would probably use it the first three days when I start [my period], because that's when the pain is the*

> *worst. But then after that it’s just fine. So, then I'm good.* [Participant 81, 14 years old]

Participants also noted that an app that helped with the management of severe pain would be beneficial if it provided tools that could be used when not feeling able to move due to pain. This was reflected by the following response:

> *I just think when I see things like “go out and take a hike, breathe some nature,” I'm not feeling very obligated to do that when I'm in my sweatpants and my hair's a mess. I don't really want to do that. But, you know, little things that I can do from the comfort of my bathroom floor would totally help me out in that second and third day during my cycle.* [Participant 119, 17 years old]

Theme 2: Navigate Emotions During Menstrual Cycle

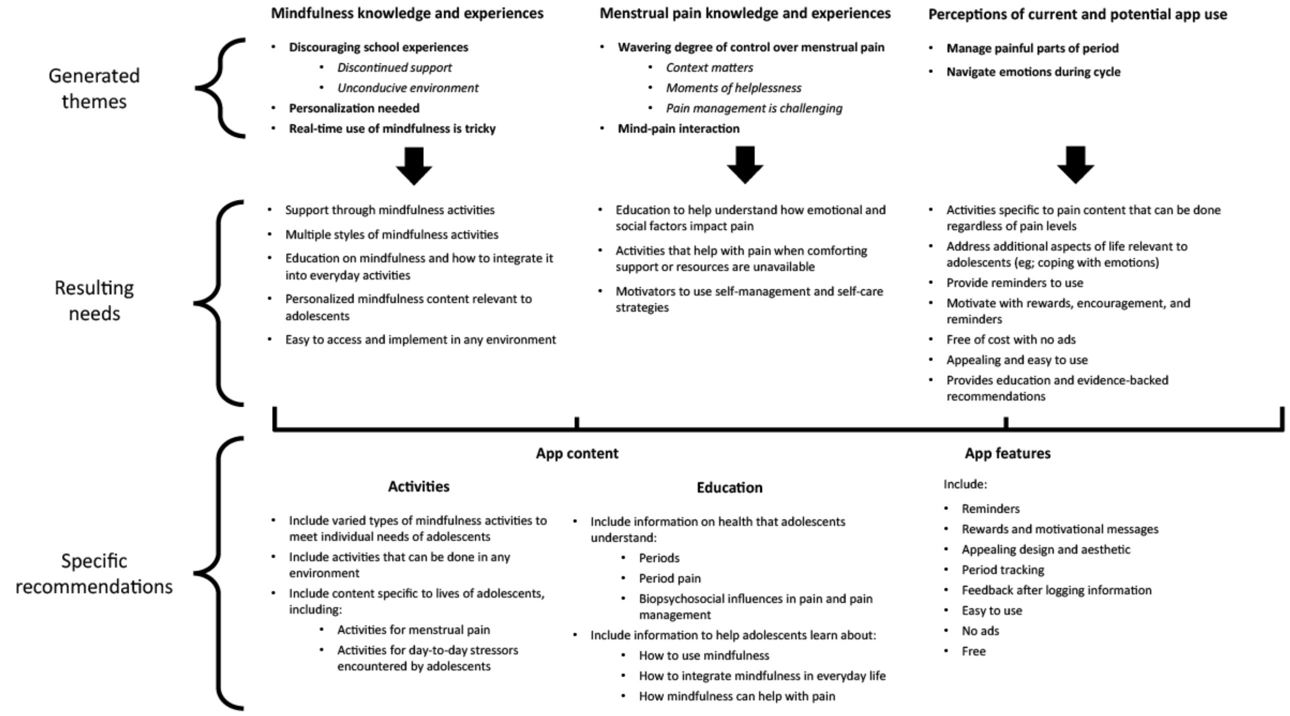
Participants frequently mentioned that emotions that occurred around the time of their period could lead to challenges in their lives. Participants discussed that having tools to manage these emotions would be useful and that they would be motivated to use an app that addressed aspects of their lives beyond pain. For instance, 1 adolescent stated:

> *If it was paired with things I can do to manage those extreme emotions, that would be so incredibly helpful. That would really help me out because paired on top of teenage hormones, mental illness, and then that period pain and that irritability, things get wild. So, it would really be helpful if I had something like that in place.* [Participant 119, 17 years old]

Synthesis of Results: A Summary Model

The findings from the data synthesis process are summarized in Figure 1. The 7 themes and 5 subthemes generated throughout the focus group analysis were merged with survey findings to result in 5 needs related to mindfulness, 3 needs related to menstrual pain, and 7 needs related to app use in menstruation (Figure 1). This process of connecting findings across phases allowed for the development of specific recommendations for future app development. Recommendations were divided into content recommendations and design or app feature recommendations.

Figure 1. Summary model of survey and focus group findings. Generated themes and survey responses were transformed into resulting needs. From the needs, specific recommendations are made for content and features of a future app.



Regarding content recommendations, adolescents wanted information specific to dysmenorrhea, along with activities and information relevant to the experiences and emotions of adolescent life. To counteract inconsistent school support, the app should provide easy access to ongoing support and be usable in any environment. Education content needs to improve understanding of periods, pain, and emotions; evidence-based information is important to youth. Education content needs to outline how mindfulness can help with pain and day-to-day experiences. Recommendations related to features include continuous access, being visually appealing and easy to use, having motivators or rewards built in, having reminders, and that the app be ad-free and of no cost.

Discussion

We examined the specific needs and experiences of adolescents to inform the future development of a mindfulness-based, self-management app for dysmenorrhea. Overall, there was general agreement that mindfulness could be helpful for dysmenorrhea. In line with findings from other researchers [48], many adolescents engaged in some form of nonpharmacological pain management. However, participants reported experiencing pain management challenges and feelings of helplessness around pain, and this was the case even among some participants who used pharmacological options. This is not surprising given that prescribed medications are estimated to only work for a quarter of individuals who use them [8]. Only a small percentage of this survey sample used meditation or mindfulness to manage their menstrual symptoms. Despite low use of mindfulness specifically for menstrual pain, most youth surveyed had used apps or websites to access mindfulness activities, suggesting interest in these approaches for developing mindfulness skills.

Over half of the survey participants had experience with mindfulness, with exposure in school being common, albeit suboptimal. This is consistent with research showing that school-based mindfulness programs may not be effective [49]. Focus group participants provided insight into the reasons for this, including the environment being distracting and the inconsistent support that occurs in school settings. These findings suggest that future app-based interventions need to provide easy and continuous access to guided mindfulness activities. This could be achieved through ongoing access to the app and supportive information in the app, or by the inclusion of some form of app-based mindfulness coaching (eg, access to professional or peer support).

The need for a personalized experience was evident across themes. In school settings, focus group participants were dissatisfied with the generality of mindfulness programs and desired activities tailored to their personal preferences. Difficulty being still and staying engaged with meditations are common for youth [50], and many survey and focus group participants identified active forms of mindfulness, such as yoga, as beneficial. Adolescents also desired a variety of mindfulness activities based on their pain level; mindfulness activities that could be performed lying down when experiencing incapacitating pain were requested by some participants, which contrasted with other youth who preferred movement-based mindfulness activities for when the pain was tolerable. Overall, these diverse needs illustrate that app-based interventions must offer the ability to select from a variety of activities based on personal preference and pain level.

The need for personalization in relation to app content was also identified. Focus group participants voiced the desire for an app that addresses the unique needs of youth, including navigating difficult emotions that may occur throughout adolescence. In line with well-established research across pain conditions [51], adolescents noted increased pain when experiencing strong emotions, as well as pain being exacerbated by social or situational factors. Focus group participants' desire for the inclusion of mindfulness activities that address mental, social, and physical aspects of their day-to-day lives is an important finding of this investigation.

Participant responses also pointed to a need for educational content relevant to early menstruators. Survey participants indicated that evidence-based information explaining how mindfulness may improve pain would motivate them to use the app. Although a general understanding of dysmenorrhea was reported by participants, previous research has found that most youth desire more information about menstrual health [3]. Education programs offered to young women to improve knowledge of dysmenorrhea are effective and increase knowledge and the likelihood of seeking professional help [52].

Across our findings, the importance of a biopsychosocial focus to any future app is evident from the participants' indication that an app needs to address various aspects of their lives and participants' understanding that their pain is affected by more than just their physical experiences. Biopsychosocial considerations are often overlooked in the context of dysmenorrhea [53]; yet, psychoeducation about the biopsychosocial nature of pain is an integral piece to pain management programs [51]. Such educational information may help adolescents engage with psychological approaches and understand how they may apply in the context of period-related pain. Psychoeducation on mindfulness and how it might affect pain would also be relevant in addition to mindfulness activities.

Overall, our findings reflect the relevance of conducting a needs assessment as adolescents provided insightful information into the needs of a future app, which may have been overlooked. In line with a user-centered design, future phases of app development should engage youth to evaluate app content and design to improve the engagement of youth in the app. Nevertheless, this study is not without its limitations. Our sample size is small as the purpose was to understand users' needs rather than to gain an understanding of the prevalence of experiences. Participants were predominantly White and identified as a woman or girl. Adolescents who participated may have had more interest in or knowledge of the topic of menstrual pain than those who did not. As the research was conducted in Canada, menstruation was likely being considered through a Western lens. The generalizability of our findings across diverse populations, including cultural and gender identities, as well as countries with lower access to mobile phones, is limited. Other evidence-based interventions, such as cognitive-behavioral therapy, were not considered in this investigation and may provide valuable alternatives to mindfulness-based approaches.

Dysmenorrhea is common in adolescence, and many adolescents are not receiving adequate treatment for their dysmenorrhea, which is problematic given the established consequences of unmanaged pain. Digital interventions that offer nonpharmacological support for dysmenorrhea may be beneficial. Our findings provide an important framework for future app development. Specific content and app feature recommendations were identified and derived directly from adolescents' preferences and needs. Incorporation of these user recommendations in subsequent app design phases may lead to improved engagement and efficacy of digital intervention, ultimately leading to improvements in the experiences of youth with dysmenorrhea.

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Data Availability

The data sets generated and analyzed during this study are not publicly available due to identifiable information in the data set but are available from the corresponding author on reasonable request.

Conflicts of Interest

None declared.

Multimedia Appendix 1
CHERRIES (Checklist for Reporting Results of Internet E-Surveys) checklist.
[PDF File (Adobe PDF File), 75 KB - pediatrics_v7i1e54658_app1.pdf]

Multimedia Appendix 2
COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist.
[PDF File (Adobe PDF File), 404 KB - pediatrics_v7i1e54658_app2.pdf]

Multimedia Appendix 3
Proportion of participants rating each response option on a 0 to 10 scale for a question inquiring about their perception that mindfulness could be helpful for managing period pain (n=107; 0=not at all helpful and 10=extremely helpful).
[DOCX File , 81 KB - pediatrics_v7i1e54658_app3.docx]

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Abbreviations

CHERRIES: Checklist for Reporting Results of Internet E-Surveys
COREQ: Consolidated Criteria for Reporting Qualitative Research

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Original Paper

Screening and Retaining Adolescents Recruited Through Social Media: Secondary Analysis from a Longitudinal Clinical Trial

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Abstract

Background: Social media has become a popular method to recruit participants, particularly for studies with hard-to-reach populations. These studies still face challenges in data quality and, for longitudinal studies, sample retention. However, in addition to aiding in recruitment, social media platforms can help researchers with participant verification and tracking procedures during the study. There is limited previous research describing how longitudinal studies can use social media to screen and retain participants.

Objective: This paper describes strategies implemented to screen and retain a nationwide sample of sexual minority youth who were recruited through social media platforms for a longitudinal study testing a drug abuse prevention program.

Methods: Our screening strategies for participants included collecting necessary demographic information (name, phone, email, and social media accounts), verifying this information using publicly available web-based records, and sending confirmation emails to ensure working email addresses and correct dates of birth. Retention strategies included communications designed to develop positive participant relationships, incentives for survey completion, regular updating of participant contact information, targeting hard-to-reach participants, and using social media as an alternative means of contacting participants.

Results: During enrollment, although the only demographic data required were a phone number and an email address, 87.58% (1065/1216) of participants provided their Instagram as an alternative means of contact. This form of alternative communication remains the most preferred with 87.40% (1047/1198) of participants continuing to provide an Instagram username as of January 2023, about 3 years after recruitment began. In comparison, other alternative means of contact (eg, Facebook and alternative email) were provided by only 6.43% (77/1198) to 56.18% (673/1198) of participants. Direct messaging on Instagram was used to successfully confirm participant identity, remind participants to take annual follow-up surveys, and update lost participant contact information. Screening and retention strategies used in the study have helped achieve 96.30% (1171/1216) to 96.79% (1177/1216) sample retention across 3 waves of data collection.

Conclusions: Though social media can be a helpful tool to recruit participants, attrition and participant authenticity difficulties may be associated with this method. Screening and retention strategies can be implemented to improve retention. Internet searches are effective for screening youth to ensure they meet eligibility requirements. Additionally, social media—Instagram in this study—can help to track and locate participants who do not respond to traditional contact methods.

Trial Registration: ClinicalTrials.gov NCT03954535; https://clinicaltrials.gov/study/NCT03954535

(JMIR Pediatr Parent 2024;7:e47984) doi:10.2196/47984

KEYWORDS

adolescents; attrition prevention; Instagram; LGBQ; online recruitment; retention; screening; sexual minority; social media; youth

Introduction

With the rise in social media popularity, web-based recruitment methods for clinical trials have become increasingly popular. Social media allows researchers greater access to nationwide samples [1]; adolescents [2-6]; and hard-to-reach populations [7,8], such as sexual minority individuals [9-13] and people who use substances [14-16]. However, some research has associated web-based recruitment with lower retention rates than in-person recruitment methods [17,18]; researchers have theorized that web-based recruitment lacks the connection and commitment from participants that come from in-person recruitment [18]. Further, there is a greater opportunity in longitudinal studies to lose participants over time due to changes in contact information or the desire to no longer participate in the study [19]. Thus, longitudinal studies that recruit through social media are at high risk for participant attrition.

Despite these challenges, researchers have identified methods to increase retention rates of samples recruited on the web, including frequent communication between surveys [20], financial incentives [21], and building positive rapport with participants [21,22]. Previous research has been able to maintain high retention rates after recruiting participants on social media. One study recruited youth aged between 12 and 25 years using advertisements on social media, Google, Craigslist, and a web-based neighborhood forum; they found retention rates of 78.11% at the 3-month follow-up and 72.18% at the 6-month follow-up [23]. Another study recruited using a similar method of advertising on social media, a collaborating website, and a newsletter and found a retention rate of 88.4% at the 2-week follow-up [24]. Our previous research has used social media (eg, Facebook advertisements) to recruit youth for 2 longitudinal web-based drug abuse prevention programs that maintained retention rates of 97% at the 1-year follow-up [25] and 84.75% at 3-month follow-up [13].

Much of what researchers know about using social media recruitment strategies comes from reports using Facebook. Several studies and systematic reviews have confirmed that advertising on Facebook is more cost-effective and time-efficient than in-person recruitment [7,8,14,15,26,27]. Facebook has also been a valuable tool for locating and communicating with participants in longitudinal studies [28,29]. However, trends in social media have shifted in recent years, especially among younger demographics. In 2015, 71% of teenagers reported using Facebook, while only 52% reported using Instagram [30]. This was notably different in 2022 when 32% of teens reported using Facebook, while 62% reported using Instagram [31]. Instagram has already been used as a successful tool in recruiting sexual and gender minority adolescents and young adults [32-38]. Thus, in 2020, we used Facebook and Instagram to recruit for Free2b, a nationwide 5-year web-based drug abuse intervention program for sexual minority youth (ClinicalTrials.gov NCT03954535).

Though recruiting on social media is cost-effective, timely, and grants access to large and diverse samples, it does not guarantee the authenticity of participants that in-person recruitment allows [39,40]. Social media recruitment requires a thorough screening process to confirm and ensure the legitimacy and eligibility of potential participants. However, thorough screening processes may lead to a more committed sample that can withstand attrition typically seen in longitudinal studies recruited on the web. Throughout the Free2b study, we also used Facebook and Instagram to verify youth's identities, maintain contact with participants, and locate hard-to-reach participants. To date, little has been published on the use of social media to screen and retain participants in a longitudinal study. This paper describes how thorough screening processes using internet searches and social media, Instagram in particular for sexual minority youth samples, along with a range of retention strategies, help maintain retention in longitudinal clinical trials for youth recruited through social media.

Methods

Social Media–Based Recruitment

We used Facebook ads and Instagram promoted posts to recruit participants for a longitudinal trial of a drug abuse prevention program called Free2b. By clicking an ad or post, youth were taken to the study recruitment website. This website contained a brief consent video about study procedures, duration, compensation, and eligibility criteria (English speaking; aged 15 years or 16 years; US resident; access to the internet through computer or tablet; and identifying as lesbian, gay, bisexual, queer, or questioning [LGBQ]). At the conclusion of the video, youth who were still interested in participating could connect to a web-based informed assent quiz. The quiz assessed youth's knowledge of study aims, procedures, risks, protections, and compensation. Youth who passed the quiz were then allowed to consent to study participation.

Consented youth were asked to provide demographic information: first name, last name, sexual orientation, date of birth, primary and alternative email, primary and alternative phone number, social media handles (Instagram, Facebook, Twitter, and alternative social media), zip code, and alternate contact information (optional). Youth were expressly told that the alternate contact would only be used if their other forms of contact no longer worked. IP addresses were automatically collected upon form submission.

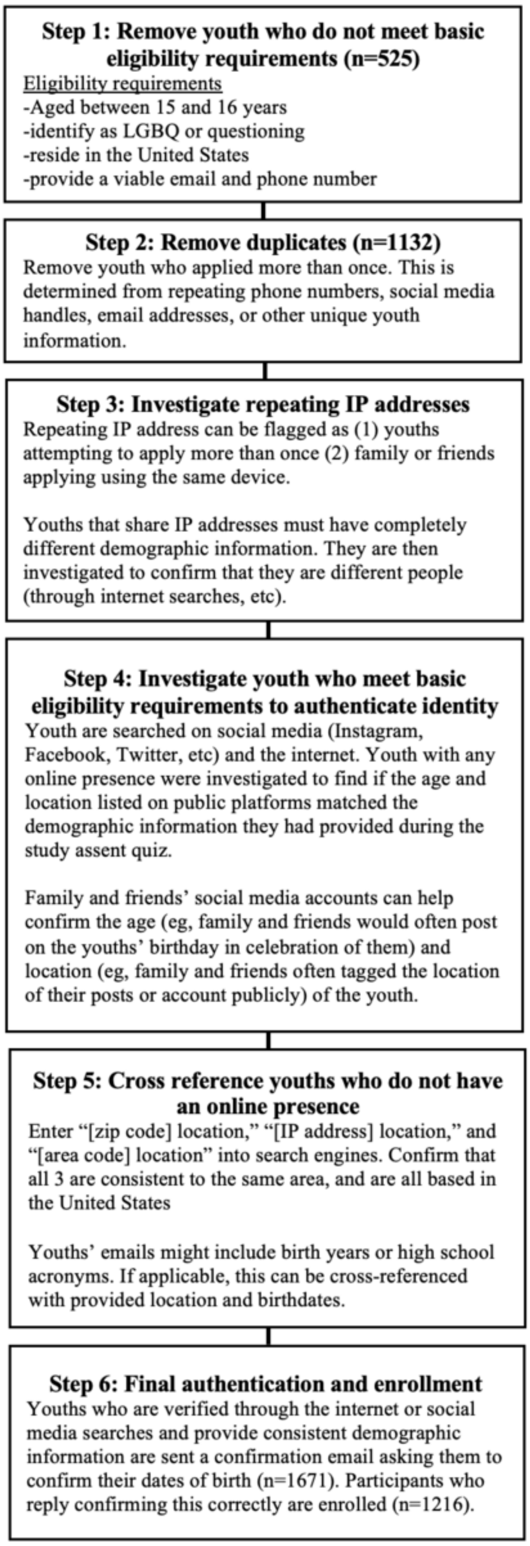
Eligibility Screening and Enrollment

The process to screen consented youth was systemized for research assistants (RAs). RAs were trained to use the steps outlined in Figure 1 to help ensure the authenticity of consenting youth. First, we removed youth who did not meet eligibility requirements: aged between 15 and 16 years, identify as LGBQ or questioning, reside in the United States, and have a phone number and email address. We then removed duplicate names, phone numbers, email addresses, and IP addresses.

To the extent possible, the demographic data from youth who had consented were cross-referenced with information from web-based searches and the social media handles the youth provided. Google searches of names with zip codes often confirmed their existence, location, and age. For example, high school athletes may have profiles showing their names and grades in school. Social media accounts could confirm age and location. Instagram and Twitter bios frequently contained age, high school, and city. Posts and tagged posts were also useful when they referenced birthday celebrations. Confirming sexual orientation was not a required element of screening as many adolescents have not publicly disclosed their sexual orientation and because sexual orientation often changes during adolescence [41]. However, when a lesbian, gay, bisexual, trans, queer, or questioning [LGBTQ] symbol or post was present on youth's social media, it was noted as a point of authenticity; the lack of such content did not exclude youth from the study. For youth with private or limited social media accounts or no web-based presence, we used other methods to help confirm their identities. For instance, an IP address, cell phone area code, and zip code that correlated helped verify a youth's authenticity; sometimes an email address included a birth year that matched their provided age or included a name that matched their provided first and last name.

Once youth cleared the aforementioned steps, we sent them an email asking them to reply back confirming the contact information they provided after consenting and we asked them to provide us with their birthdate. Only youth who replied to this email and who accurately confirmed the birthdate they provided during consent were enrolled in the study and randomly assigned to a study condition.

Figure 1. Flowchart of screening strategies implemented during the recruitment phase. LGBQ: lesbian, gay, bisexual, queer, or questioning.



Step 1: Remove youth who do not meet basic eligibility requirements (n=525)

Eligibility requirements
-Aged between 15 and 16 years
-identify as LGBQ or questioning
-reside in the United States
-provide a viable email and phone number

Step 2: Remove duplicates (n=1132)

Remove youth who applied more than once. This is determined from repeating phone numbers, social media handles, email addresses, or other unique youth information.

Step 3: Investigate repeating IP addresses

Repeating IP address can be flagged as (1) youths attempting to apply more than once (2) family or friends applying using the same device.

Youths that share IP addresses must have completely different demographic information. They are then investigated to confirm that they are different people (through internet searches, etc).

Step 4: Investigate youth who meet basic eligibility requirements to authenticate identity

Youth are searched on social media (Instagram, Facebook, Twitter, etc) and the internet. Youth with any online presence were investigated to find if the age and location listed on public platforms matched the demographic information they had provided during the study assent quiz.

Family and friends' social media accounts can help confirm the age (eg, family and friends would often post on the youths' birthday in celebration of them) and location (eg, family and friends often tagged the location of their posts or account publicly) of the youth.

Step 5: Cross reference youths who do not have an online presence

Enter "[zip code] location," "[IP address] location," and "[area code] location" into search engines. Confirm that all 3 are consistent to the same area, and are all based in the United States

Youths' emails might include birth years or high school acronyms. If applicable, this can be cross-referenced with provided location and birthdates.

Step 6: Final authentication and enrollment

Youths who are verified through the internet or social media searches and provide consistent demographic information are sent a confirmation email asking them to confirm their dates of birth (n=1671). Participants who reply confirming this correctly are enrolled (n=1216).

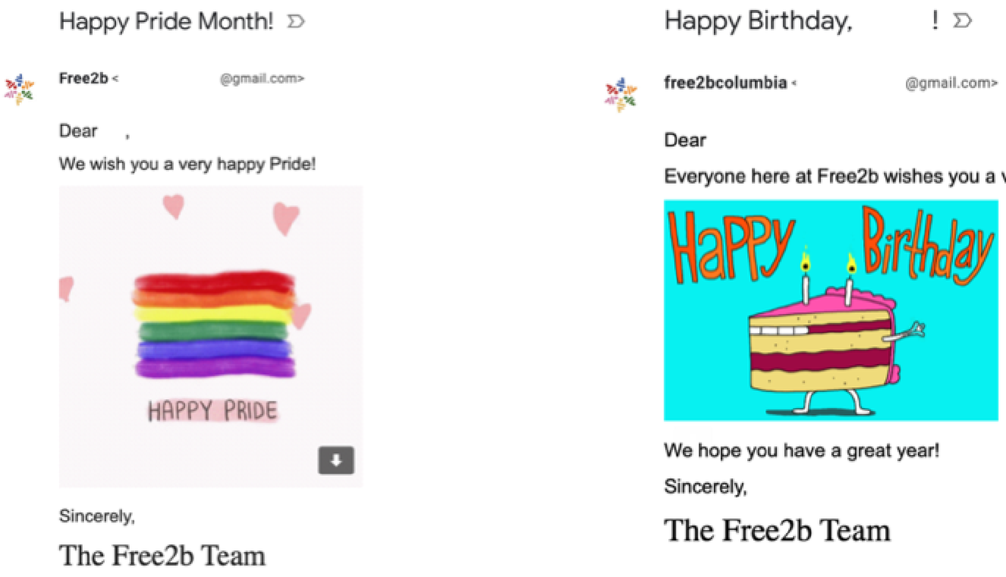
Building Positive Relationships With Participants

Building rapport with participants is important in longitudinal studies to help maintain retention [42,43]. RAs were trained to use a friendly and appreciative communication style to communicate with participants through phone calls, text messages, emails, and direct messages (DMs) on social media. The language used in messages and calls was positive, supportive, understanding, and appreciative of participants' time. For example, RAs frequently started messages with language that acknowledged participants' busy schedules (eg, "I know it's the beginning of the school year and things are probably pretty hectic right now.") to convey an understanding that the study surveys were unlikely to be their priority.

Given our understanding that participants were busy, we maintained the philosophy that no participant is "lost" unless we have no working contact information. However, even when a participant met the standards to be considered "lost," they were not removed from the study. This allowed us to recover participants who may have chosen to skip a survey one year, but then chose to take the next year's survey.

We also built positive relationships by honoring when participants requested needing more time to complete a survey (eg, during finals week). Annual holiday and birthday texts and emails (Figure 2) helped maintain contact but also served to build rapport. Email correspondence encouraged participants to contact us with questions or concerns and included the study phone number and the principal investigator's phone number and email to facilitate this contact.

Figure 2. Examples of holiday and birthday messages sent to participants throughout the study.



Happy Pride Month!

Free2b < @gmail.com>

Dear ,

We wish you a very happy Pride!

Sincerely,

The Free2b Team

Happy Birthday, !

free2bcolumbia < @gmail.com>

Dear

Everyone here at Free2b wishes you a very happy birthday!

We hope you have a great year!

Sincerely,

The Free2b Team

Communication Strategies

Given the importance of sample retention to longitudinal research, timely communication with participants is essential. Project email and social media accounts were checked regularly; RAs were expected to respond immediately to participants' texts, phone calls, emails, or DMs on social media. Each interaction was logged in a shared database to record contact history. This record helped determine the best methods of contact for a participant. Before making contact, RAs read through a participant's contact log for previous successful contacts (eg, a participant might respond to texts more often than calls). RAs were also instructed to vary their contact methods, switching between text, email, voicemail, or social media. These methods increased the chances of participants seeing our communication attempts. We also made an effort to send messages with different wording or images (eg, for holiday cards each year) to participants, rather than repeatedly sending the same template message. This helped our communication come across as individually tailored, rather than as an automated message to all participants.

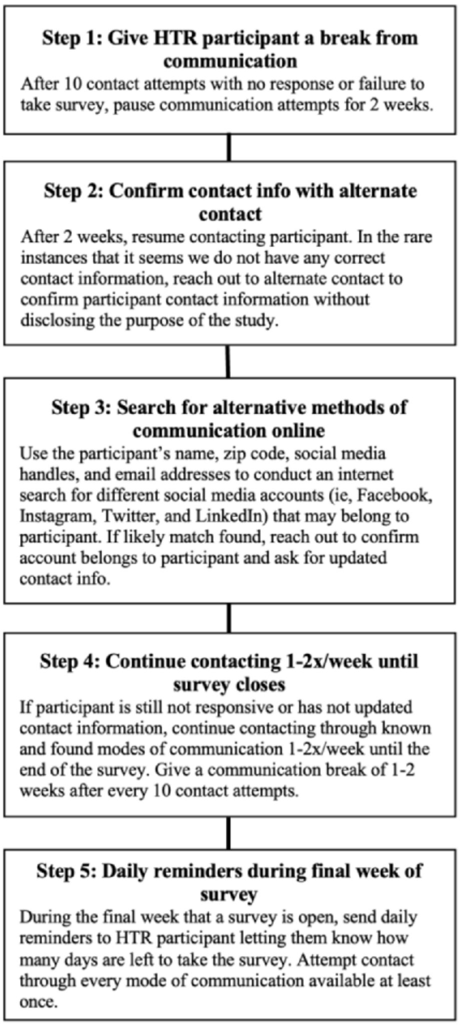
Finally, RAs were instructed to maintain frequent communication and reminders without overwhelming participants. As described earlier, they often started texts and phone calls with understanding language. Additionally, most reminders to take surveys included a link so participants would not have to go through their inbox to find the original survey reminder. When talking to participants on the phone, RAs always offered to send a follow-up text or email with the survey link. Finally, if a participant had not taken a survey after numerous reminders, or they mentioned that they are busy with other activities, we offered to pause communications and asked them when they would like us to check back.

Update Contact Info Surveys

To minimize the likelihood of losing participants between annual surveys due to changes in their contact information, we attempted to update participant contact information quarterly. We provided participants with their phone number or phone numbers; email address or email addresses; social media account handles; zip code; and if they have provided one, their alternate contact's phone number in a brief web-based form. If all of their contact information was up to date, they simply clicked "correct," or they could update their information if necessary. Youth could also continue to provide no alternate contact, add an alternate contact, remove the alternate contact they had provided, or change the one they provided.

Inevitably, some participants are lost over time due to frequent changes in contact information, competing priorities for time, or loss of interest in continuing in the study [44]. If we reached out to a participant more than 10 times with no response, they were considered "hard-to-reach." RAs were trained on standard protocols for contacting hard-to-reach participants (Figure 3). Once a participant became "hard-to-reach," we took a break from contacting them for several weeks. We then conducted an internet search and used social media to try to reconnect. In the rare instance that a cell phone and email was no longer working, and we were confident we were no longer reaching the participant, we discreetly reached out to their alternate contact without disclosing the purpose of the study. Youth who were considered "hard-to-reach" were always asked if they would like to be removed from the study or take a break from participation so that we did not bother them unnecessarily or needlessly spend time trying to collect survey data. Though some youth who did not respond to our survey reminders may no longer have wished to participate, we did not make this decision for them.

Figure 3. Flowchart of steps taken to contact hard-to-reach (HTR) participants and remind them to complete annual surveys.



Step 1: Give HTR participant a break from communication
After 10 contact attempts with no response or failure to take survey, pause communication attempts for 2 weeks.

Step 2: Confirm contact info with alternate contact
After 2 weeks, resume contacting participant. In the rare instances that it seems we do not have any correct contact information, reach out to alternate contact to confirm participant contact information without disclosing the purpose of the study.

Step 3: Search for alternative methods of communication online
Use the participant's name, zip code, social media handles, and email addresses to conduct an internet search for different social media accounts (ie, Facebook, Instagram, Twitter, and LinkedIn) that may belong to participant. If likely match found, reach out to confirm account belongs to participant and ask for updated contact info.

Step 4: Continue contacting 1-2x/week until survey closes
If participant is still not responsive or has not updated contact information, continue contacting through known and found modes of communication 1-2x/week until the end of the survey. Give a communication break of 1-2 weeks after every 10 contact attempts.

Step 5: Daily reminders during final week of survey
During the final week that a survey is open, send daily reminders to HTR participant letting them know how many days are left to take the survey. Attempt contact through every mode of communication available at least once.

Ethical Considerations

Study procedures were approved by the Columbia University Institutional Review Board (IRB-AAAR5072). A waiver of parental permission was granted to reduce risks; such waivers may also increase participation from adolescents who are not out to their parents [45]. Because our sample could be considered a vulnerable population, a detailed data and safety and monitoring plan was also established, and a Data and Safety Monitoring Board met no less than once a year. A primary charge for the Data and Safety Monitoring Board in year 1 was to review Institutional Review Board–approved recruitment and informed consent procedures.

After completing the aforementioned consent processes, participants received US $30, US $35, US $40, US $45, and US $50 for each of the 5 waves of data collection (pretest; posttest; and 1-, 2-, and 3-year follow-up, respectively). Participants were able to choose from several e-gift card options. As soon as a survey was completed, participants were notified that they would receive their e-gift card within 36 hours. Sending e-gift cards in a timely manner showed our appreciation and helped maintain positive relationships with participants. We also reminded participants to redeem their gift cards when they were close to expiring.

Results

Rates of Provided Participant Contact Information

All participants were required to provide a primary email and phone number in order to be enrolled in the study, but 11.76% (143/1216) also provided an alternative phone number and 51.23% (623/1216) provided an alternative email. At the time of recruitment, 87.58% (1065/1216) of enrolled Free2b participants provided an Instagram account as part of their contact information, as compared to 19.98% (243/1216) providing an alternate contact (eg, family or friends), 15.13% (184/1216) providing a Facebook account, and 29.03% (353/1216) providing an alternative social media account (eg, Twitter, Tumblr, or TikTok). Only 10.61% (129/1216) provided no form of alternate contact or social media accounts (Table 1). The percentage of participants with an Instagram account has remained relatively stable in the approximately 3 years since recruitment. Throughout the study, Instagram has remained the most commonly provided alternative method of contact. As of

January 2023, a total of 87.40% (1047/1198) of Free2b participants have provided Instagram handles, while only 22.37% (268/1198) of participants have provided an alternate contact with a cell phone number, 19.37% (232/1198) have provided a Facebook account, 30.47% (365/1198) have provided an alternative social media account, 6.43% (77/1198) have provided an alternative phone number, and 56.18% (673/1198) have provided an alternative email.

Table 1. Number of participants who provided each type of alternative contact information at enrollment and 3 years after recruitment.

Type of contact information	At enrollment (2020; n=1216), n (%)	Currently (January 2023; n=1198), n (%)
Alternate contact	243 (19.98)	268 (22.37)
Alternative email	623 (51.23)	673 (56.18)
Alternative number	143 (11.76)	77 (6.43)
Facebook	184 (15.13)	232 (19.37)
Instagram	1065 (87.58)	1047 (87.40)
No alternate contact number or social media	129 (10.61)	117 (9.77)
Other social media	353 (29.03)	365 (30.47)

Direct Messaging and Locating Hard-to-Reach Participants Through Social Media

If participants have not taken their surveys after multiple automated reminders, they are added to a "call list" to receive personalized communication from RAs. First, RAs attempt to contact them through traditional contact methods (phone calls, text messages, and emails); if this is not effective, they begin adding social media contacts (eg, direct messaging on Instagram) in addition to traditional methods. Of the 17 participants on the call list for Survey 1 who completed the survey, 100% received only traditional contacts, and 0% received a combination of traditional and social media contacts. Of the 102 participants on the call list for Survey 2 who completed the survey, 71.6% (73/102) received only traditional contacts and 28.4% (29/102) received a combination of traditional and social media contacts. Of the 100 participants on the call list for Survey 3 who completed the survey, 77% (77/100) received only traditional contacts and 23% (23/100) received a combination of traditional and social media contacts. Finally, of the 121 participants on the call list during Survey 4 who completed the survey, 81.8% (99/121) received only traditional contacts and 18.2% (22/121) received a combination of traditional and social media contacts (Table 2).

Table 2. The percentage of participants who were on the call list and then took the survey after traditional contact (phone and email) versus a combination of traditional and social media (eg, Instagram direct messages) contacts.

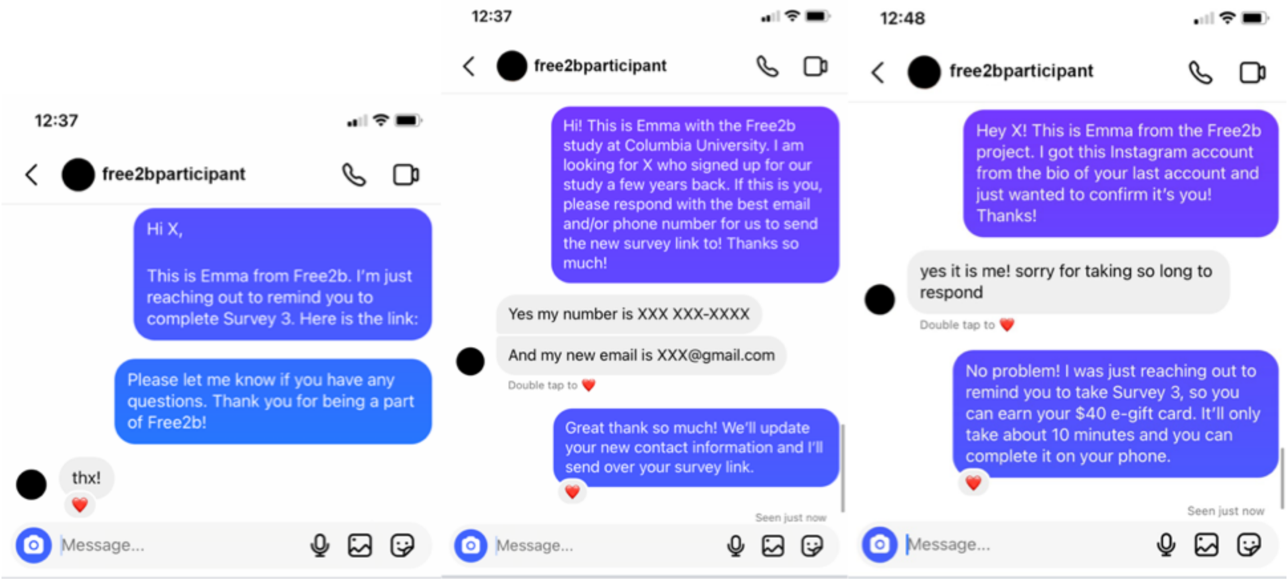
Survey number	Combination of traditional and social media contacts, n (%)	Traditional contacts (phone and email), n (%)
Survey 1 (n=17)	0 (0)	17 (100)
Survey 2 (n=102)	29 (28.4)	73 (71.6)
Survey 3 (n=100)	23 (23)	77 (77)
Survey 4 (n=121)	22 (18.2)	99 (81.8)

Social Media Versus Traditional Contact Methods for Survey Reminders

Both Instagram and Facebook offer a direct messaging feature. However, unlike our attempts to communicate with participants through Facebook DMs, communication through Instagram DMs was frequently successful. As seen in the left screenshot in Figure 4, an anonymized recreation of an interaction with a study participant, Instagram DMs resulted in direct replies or liked messages. Instagram also notified us when the participants read our DMs by displaying "seen" under read messages. Moreover, success of Instagram survey reminders was evidenced by the completion of surveys soon after DM reminders: of the participants who received social media contacts, 41% (12/29) completed Survey 2, 39% (9/23) completed Survey 3, and 27% (6/22) completed Survey 4 within 48 hours of being sent a reminder through DM. In particular, Instagram proved to be a useful method for contacting hard-to-reach participants, who otherwise did not respond to calls, texts, and emails to take follow-up surveys. Attempts to contact participants on Facebook did not yield similar results.

Instagram was also a helpful tool for finding lost participants for whom we had no working contact information. When a participant was "lost," we used Google to search for the participant's new social media accounts. Both Facebook and Instagram were used to DM lost participants, but only Instagram resulted in successful participant discoveries (middle and right screenshots in Figure 4). Despite the success that these examples indicate, there were still instances where our Instagram DMs were ignored, never seen, or we were simply unable to send messages to participant accounts.

Figure 4. Examples of interactions with participants through direct messages on Instagram that have been recreated and anonymized.



Hi X,

This is Emma from Free2b. I'm just reaching out to remind you to complete Survey 3. Here is the link:

Please let me know if you have any questions. Thank you for being a part of Free2b!

thx!

Hi! This is Emma with the Free2b study at Columbia University. I am looking for X who signed up for our study a few years back. If this is you, please respond with the best email and/or phone number for us to send the new survey link to! Thanks so much!

Yes my number is XXX XXX-XXXX

And my new email is XXX@gmail.com

Great thank so much! We'll update your new contact information and I'll send over your survey link.

Hey X! This is Emma from the Free2b project. I got this Instagram account from the bio of your last account and just wanted to confirm it's you! Thanks!

yes it is me! sorry for taking so long to respond

No problem! I was just reaching out to remind you to take Survey 3, so you can earn your $40 e-gift card. It'll only take about 10 minutes and you can complete it on your phone.

Retention Strategies

Our incentives increased in value as the study continued and ranged from US $30-US $50. These incentives are almost always claimed by the participants: 99.59% (1208/1213) claimed their Survey 1 gift card, 99.41% (1170/1177) claimed their Survey 2 gift card, and 99.32% (1168/1176) claimed their Survey 3 gift card. Of the few participants who did not claim their gift cards, only 1 or 2 participants per survey explicitly stated that they did not want their gift card.

Our success in developing and maintaining positive relationships with participants has been demonstrated by the messages we occasionally receive from participants expressing their appreciation for the project:

Example 1:

> *Hi Free2b folks, I just wanted to send a message that the project has seen me through a lot of change (both with time and otherwise)...Thank you for providing this space.*

Example 2:

> *I appreciate you . I am glad to be apart [sic] of this after so many years (it's very exciting).*

Example 3:

> *Thank you! I'm not sure if this is a no-reply kind of thing, but in the case that it's not, I want to show my gratitude! Thank you for the opportunity to be in this study, it really means a lot to me. I am very excited to see the impact this will have! And the money has helped me so much, I was able to pay for my first binder with it! I am eternally grateful.*

Example 4:

> *Good morning to whoever is reading this!!! Hi I'm ______ and I'm a part of the Free2b program and I want to say thank you! Your website has really allowed me to open up with those around me, as a bisexual and proud young female.*

Such messages from participants frequently express gratitude, that the study is helpful for them, interest in the outcome of the research, or that the project has had a positive impact on how they feel about their sexual orientation.

Finally, 3 Update Contact Info Surveys were sent in between each study survey. Participants were not incentivized to complete these surveys, but still, 87.14% (1057/1213) of participants completed at least 1 Update Contact Info Survey between Survey 2 and 3 and 84.17% (1021/1213) completed at least 1 between Survey 3 and Survey 4.

Retention Rates

Our Instagram and Facebook recruitment and screening techniques allowed us to verify and enroll 1216 participants in the Free2b study. Retention at the first survey after enrollment was 99.75% (1213/1216). The second survey, taken about 4 months later, was completed by 96.79% (1177/1216) of participants. We were able to maintain similarly high retention at 96.71% (1176/1216) in the 1-year follow-up survey (Survey 3) and 96.30% (1171/1216) in our 2-year follow-up (Survey 4). Of the participants who did not take Survey 2, a total of 28% (10/36) were recovered in Survey 3. Of the participants who took Survey 2 but not Survey 3, a total of 9% (1/11) were recovered in Survey 4. Additionally, of the participants who did not take Surveys 2 or 3, a total of 17% (5/30) were recovered in Survey 4. Overall, since the end of the recruitment period, we have only lost 6 participants (<1%), as defined by a participant not completing any follow-up surveys to date and having zero working contact information. Despite the difficulty in reaching these participants, they are still invited to participate in each survey, and we contact them each year.

The 3 participants who did not take Survey 1 were exited from the study, and 15 participants asked to exit the study after the first survey. After Survey 2, one additional participant asked to be exited, bringing our total exited participants to 19.

Discussion

Principal Findings

Due to the increased popularity of social media and other messaging platforms, researchers have more opportunities to identify and communicate with participants in longitudinal clinical trials. This paper reports on the use of social media to aid participant screening and retention in a longitudinal study for sexual minority youth. Our findings suggest that a sample recruited through social media platforms can achieve minimal attrition with certain screening and retention strategies. Our results confirm the effectiveness of commonly published retention strategies [42,43,46] and offer new methods, such as using social media to maintain contact with participants. Study findings further suggest that Instagram is an effective method for communicating with and finding potentially lost participants over Facebook for sexual minority youth. This points to the importance of researchers following social media trends to meet their potential or enrolled participants where they are.

Overall, the various retention and screening strategies used in this study have shown promising results, with retention rates ranging from 96.30% (1171/1216) to 96.79% (1177/1216) in follow-up surveys. Our retention rates are somewhat higher than other studies with sexual minority youth. In a study of sexual minority youth whose sample included minors, retention rates at each study wave ranged from 82% to 90% [47]. Another study of sexual minority youth aged between 18 and 19 years found retention rates ranging from 85.9% to 89.5% [48].

Sexual minority youth are a hard-to-reach population, making it difficult to recruit using in-person methods [49]. However, social media has presented an accessible way to reach this demographic [1,2,5,6]. We used Instagram and Facebook to recruit a large nationwide sample of sexual minority youth. But studies that use web-based recruitment can be vulnerable to poor data quality as eligibility is harder to verify compared to in-person methods [40]. A common strategy in web-based recruitment is the use of eligibility screening questions to remove ineligible applicants [39,50]. However, screening questions do not guarantee authentic answers. Moreover, when studies such as ours compensate participants, duplicate or fraudulent enrollees are common [51]. Therefore, the benefits of web-based recruitment can be offset by risks to sample validity and data integrity. There is limited literature outlining the extent of these threats and how to mitigate them [40].

By cross-referencing demographic data provided by the participant with publicly available information and confirming participant birthdates through email, we improved the overall quality of this study data. If we had not validated their email by asking for their birthday confirmation, we may have enrolled people in the study who provided inactive email addresses and who were not 15-16 years old. Without collecting sufficient contact information at the study's onset—primary and alternative phone numbers, primary and alternative emails, social media handles, and an optional alternate contact—sample retention would likely have been lower.

As seen in Table 1, Instagram was consistently the most common alternative contact method youth provided. This is unsurprising given the popularity of Instagram among our age demographic [31]. This may also be due to our recruitment methods through Instagram. Many participants had already interacted with us on Instagram—through DMs, comments, and likes—and thus may have been more comfortable sharing their handle. We have continued to use Instagram to reach participants throughout the duration of the study given its continued popularity among the sample. During survey data collection, reminders through Instagram DM were successful, as seen through the participants who took the survey within 48 hours of receiving a reminder DM. Instagram DMs were also useful to help update participant contact information. Understanding the most popular form of social media among a recruited demographic may help researchers to remain in contact with hard-to-reach participants.

The retention strategies used in this study include those traditionally used in longitudinal clinical trials as well as new methods that reflect the current shifts in social media trends. Traditional methods include survey incentives, building positive relationships with participants, and regularly updating participant contact information [42,43,52]. The incentives for each survey were popular as evidenced by the high number of gift card acceptances after each survey. Training RAs to have consistent communication standards and demonstrate respect for participants' time helped us build rapport. Evidence of our success at building these positive relationships includes when they frequently thanked us for their birthday or holiday messages or upon receipt of their gift card.

Worth noting are the examples of participant messages outlined in our results. Sometimes participants were unsure if they were emailing a "real person" (eg, "not sure if this is a no-reply kind of thing"). This concern likely resulted from the use of templates for mass emails related to surveys or gift cards. Though we personalized these emails with first names, the concerns voiced by some participants is an important reminder that adolescents are savvy and able to detect when correspondence is mass generated versus individually written. Researchers may benefit from ensuring they have a mix of automated and individualized messages, as we did, to maintain positive relationships.

Throughout the study we reached out to participants to update their contact information through a brief survey. This task required minimal effort on behalf of the participant. The ease of use of the survey likely contributed to the high rates of completion. In turn, the correct contact information minimized attrition. These surveys may have also helped us to maintain positive relationships with our participants as we were able to note changes in names, pronouns, and gender identities, thereby minimizing the chance to use a deadname or misgender a participant, which can be detrimental when maintaining rapport with sexual minority youth [53].

Tracking lost participants and finding alternative methods to contact hard-to-reach participants are both crucial to prevent attrition. Throughout the study, we used Instagram to reach out to hard-to-reach participants as an alternative contact method when calls, texts, and emails were ineffective. Social media contacts were successful as seen when participants took their survey within 48 hours of receiving a DM reminder from us. This success is likely attributable to participants' frequent use of the app; those who were active on the platform may have been more likely to see our DMs over calls, texts or emails which can be deemed spam.

When tracking lost participants, we implemented multiple strategies. Researchers have commonly used multiple forms of web-based methods to track participants: search engines (eg, Google) and fee-based directories (eg, White Pages) are 2 common examples [54]. Though search engines are useful to locate participants, they often do not provide new methods of contact. Therefore, we used social media to locate and DM potentially lost participants. Social media platforms, primarily Facebook, have also been used by researchers to search for participants. Despite the reported success shown on tracking through Facebook [28,54,55], we have primarily used Instagram over Facebook due to its higher popularity among our sample (Table 1).

Unless requested to be exited, no participant was considered lost from the study. We used social media to "recover" participants whom we lost contact with due to changes in their contact information. After finding a profile on Instagram that matched their demographic information, we reached out to participants regarding their participation in the study (middle screenshot in Figure 4). In some instances, we were also able to use old accounts to update contact information. After attempting to reach some participants through Instagram, we found that their accounts were no longer active, but they had added a link to their new account in their bio through which we were able to reach them (right screenshot in Figure 4). Overall, Instagram has been useful as an alternative contact method for survey reminders, to track down lost participants, and to build positive relationships with participants.

Limitations

A limitation of using Instagram to screen and maintain contact with participants is that Instagram frequently changes its policies, including how DMs can be sent. In March 2021, Instagram announced it would be banning adults from direct messaging teenagers under the age of 18 years who do not follow the adult's account [56]. This may affect retention efforts when using Instagram as a contact method in a sample of youth. It is unclear how this policy will change in the future. Moreover, people can easily change their profile handle names, preventing us from finding previously provided accounts. An additional limitation of using social media as a method to recover participants is that these methods are more effective with participants who have uncommon names, as it was very difficult to find participants on social media if there were hundreds or thousands of users with the same name. Finally, efforts to communicate or contact participants through social media were likely less effective for participants who were not out or did not want to be publicly associated with our Instagram account.

Conclusion

This paper demonstrates effective screening and retention methods to conduct a longitudinal clinical trial for sexual minority youth. Social media, particularly Instagram, was found to be useful both in the screening process and in maintaining contact with participants throughout the study. Through the use of similar thoughtful screening and retention strategies, others may be able to replicate our high retention rates. Future research is needed to determine the efficacy of individual strategies, as well as to test these strategies in different populations and on new social media platforms as they gain popularity.

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Conflicts of Interest

None declared.

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Abbreviations

DM: direct message
LGBTQ: lesbian, gay, bisexual, trans, queer, or questioning
LGBQ: lesbian, gay, bisexual, queer, or questioning
RA: research assistant

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High-Resolution Eye-Tracking System for Accurate Measurement of Short-Latency Ocular Following Responses: Development and Observational Study

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Abstract

Background: Ocular following responses (OFRs)—small-amplitude, short-latency reflexive eye movements—have been used to study visual motion processing, with potential diagnostic applications. However, they are difficult to record with commercial, video-based eye trackers, especially in children.

Objective: We aimed to design and develop a noninvasive eye tracker specialized for measuring OFRs, trading off lower temporal resolution and a smaller range for higher spatial resolution.

Methods: We developed a high-resolution eye-tracking system based on a high-resolution camera operating in the near-infrared spectral range, coupled with infrared illuminators and a dedicated postprocessing pipeline, optimized to measure OFRs in children. To assess its performance, we: (1) evaluated our algorithm for compensating small head movements in both artificial and real-world settings, (2) compared OFRs measured simultaneously by our system and a reference scleral search coil eye-tracking system, and (3) tested the system's ability to measure OFRs in a clinical setting with children.

Results: The simultaneous measurement by our system and a reference system showed that our system achieved an in vivo resolution of approximately 0.06°, which is sufficient for recording OFRs. Head motion compensation was successfully tested, showing a displacement error of less than 5 µm. Finally, robust OFRs were detected in 16 children during recording sessions lasting less than 5 minutes.

Conclusions: Our high-resolution, noninvasive eye-tracking system successfully detected OFRs with minimal need for subject cooperation. The system effectively addresses the limits of other OFR measurement methods and offers a versatile solution suitable for clinical applications, particularly in children, where eye tracking is more challenging. The system could potentially be suitable for diagnostic applications, particularly in pediatric populations where early detection of visual disorders like stereodeficiencies is critical.

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KEYWORDS

ocular following response; stereopsis; video-oculography; ocular; tracker; vision; pediatric; children; youth; infrared; algorithm; eye tracking

Introduction

Eye movements have long been used to gain insights into the operation of brain structures involved in motor and cognitive processes. Furthermore, they provide opportunities to diagnose nervous system pathologies through their oculomotor signatures [1], including parkinsonian syndromes [2,3], amyotrophic lateral sclerosis [4], Huntington disease [5], Alzheimer disease [6], and minimal hepatic encephalopathy [7].

In our daily lives, we unconsciously engage in various types of eye movements. The involuntary eye movements that are responsible for maintaining the stability of images on the retina include the vestibulo-ocular reflex, smooth pursuit, and optokinetic nystagmus. Abrupt onset of visual motion induces reflexive eye movements with ultra-short latencies, known as ocular following responses (OFRs). These responses constitute the initial component of the optokinetic nystagmus response, supporting the translational vestibulo-ocular reflex in gaze stabilization [8]. Despite their small magnitude, typically compensating for only 4% - 10% of retinal slip, OFRs have proven valuable for investigating the processes underlying visual motion processing in humans and nonhuman primates [9-20]. Furthermore, by using scleral search coils [11] to record eye movements in stereoblind adults, their potential for diagnosing stereoanomalies has been recently revealed [21].

Stereoblindness, the inability to use the disparity between the retinal images from the 2 eyes to sense depth, is an often irreversible central nervous system disorder, with a prevalence of around 7% [22]. It is usually associated with, and often a result of, strabismus (misalignment of the 2 eyes) or anisometropia (a large difference in the refractive power between the 2 eyes). If not treated early, it often leads to amblyopia, a central (and thus not correctable with lenses) visual acuity deficit in 1 eye.

Early diagnosis during the critical childhood period of visual development is crucial to prevent the development of amblyopia, with early intervention (ideally, during the first 12 - 36 months of life) leading to improved outcomes [23-25]. Several clinical tests are currently available to assess binocular depth perception, such as the Titmus, TNO, and Lang tests, but they require patient cooperation, and so are poorly suited to assess stereodeficiencies in infants and young children [26], which remains a challenge.

Measuring OFRs requires minimal subject cooperation. As they are mediated by disparity-sensitive cortical neurons, sensitive to interocular correlations [27], they are affected by stereoblindness [27]. Accordingly, they have the potential to be used to detect stereo deficits in an objective manner, particularly in patient populations not well suited to current methods (such as children, especially preverbal ones, and nonverbal individuals of any age). Despite their potential, due to their small amplitude (usually less than half a degree), OFRs are rarely recorded. Typically, they have been measured using costly eye-tracking equipment, such as scleral search coils and dual-Purkinje eye trackers, which is almost never available in clinical practice. Recently, noninvasive, general-purpose, commercial, video-based eye-tracking systems have also been used to record OFRs, but these require averaging responses over many, often 100 [28-30] or more (up to 400 [30]), repeated presentations of the same stimulus, collected over multiple sessions, a process unsuitable for clinical practice and in pediatric populations.

This need for averaging is due to the limited spatial resolution of commercial eye trackers, which in turn is a consequence of their need to provide high temporal resolution and operate over a large range of eye positions. However, this is the wrong trade-off for the low speed and small size of OFRs, and a video system operating with a different trade-off might achieve the spatial accuracy needed to reliably record OFRs. The aim of our study is to conceptualize, design, and implement a high-resolution eye tracking system, with compensation for small head movements, suitable for noninvasive measurement of OFRs in children. This system is intended to address the challenges associated with traditional eye tracking methods, maximizing subject comfort and minimizing recording duration and required subject cooperation, making it suitable for application in pediatric clinical contexts.

Methods

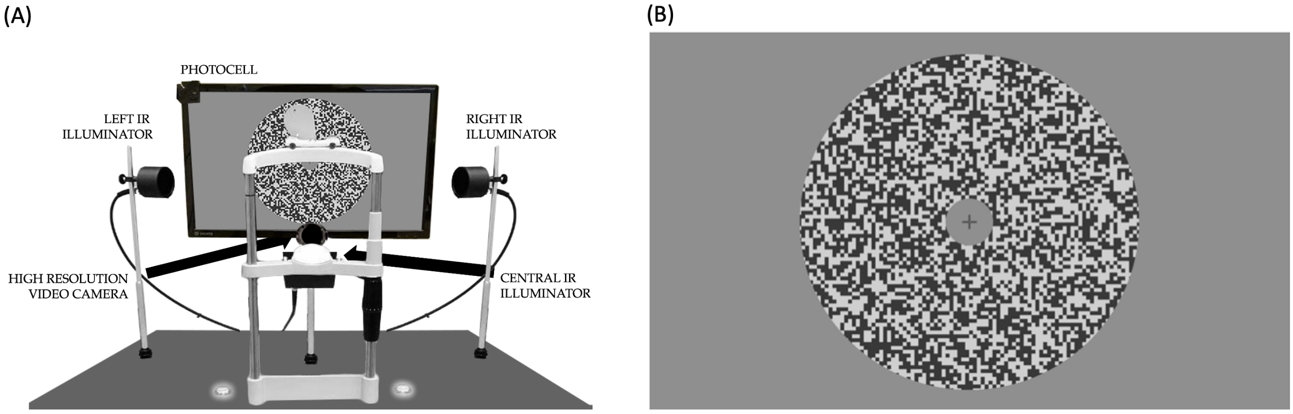
Ethical Considerations

Each participant's parent or legal guardian provided written informed consent prior to their child's involvement in the study. They were informed that the test would not directly benefit their child, that participation was entirely voluntary and unrelated to any clinical care the child was receiving at the eye clinic that day, and that their decision to decline participation would not impact their child's clinical care at the hospital, either currently or in the future. The equipment used in the study was demonstrated to the parent, and a few sample trials were conducted to illustrate the visual stimulation and what was expected of the child. Additionally, the parent was present throughout the testing session. No compensation was provided to participants in this study. To ensure privacy, all data were anonymized prior to analysis to prevent any potential identification of participants. The study (RC 31/24) was conducted in accordance with the Declaration of Helsinki and was approved by the Institutional Scientific Board of the Istituto di Ricovero e Cura a Carattere Scientifico (IRCCS) "Burlo Garofolo."

Requirements

OFRs are reflexive movements, with consistent temporal dynamics and a latency (for high-contrast stimuli) of 70 - 80 milliseconds in humans [28,31]. In a typical experiment, 4 or more different conditions, each corresponding to a different motion stimulus, are presented in succession. Each presentation represents a trial, and each condition is presented once in a block of trials. Multiple such blocks are recorded (possibly over multiple sessions) so that the average response to each condition can then be computed. Typically, a trial lasts between 1.5 and 2 seconds, with a fixation period of approximately 1 second, during which the first frame of the stimulus and a fixation cross are shown on the screen (Figure 1B). This is followed by a short (usually 200-millisecond) period of stimulus motion (during which the fixation cross is not visible), followed by a short period during which a blank screen is presented. Subjects are usually encouraged to limit eye blinking to this blank period.

Figure 1. (**A**) Our custom-designed eye-tracking apparatus. (**B**) Sample random-dot stimulus used to induce ocular following responses in experiments. IR: infrared.



In some cases, the latency is itself a focus of the study; therefore, high temporal resolution is necessary. However, in most cases, the measure of interest is the magnitude of the response (ie, the displacement of the eyes) in the so-called open-loop period [10]. This is the period during which the eye movement itself does not alter the projection of the visual input on the retina, and it goes from the movement latency to twice the latency (after this time, the retinal velocity of the stimulus would become equal to the difference between the actual velocity of the stimulus and the velocity of the eye 1 movement latency earlier). The onset latency varies somewhat from subject to subject and as a function of the contrast and size of the stimulus [10,13,15], but for high-contrast large stimuli, it varies between 70 and 80 milliseconds. Under such conditions, quantifying the OFR as the eye displacement between 80 milliseconds and 160 milliseconds after stimulus onset is appropriate for most subjects.

The most basic system for measuring OFRs must then determine, with the highest resolution possible, the displacement of 1 eye during the open-loop period. The stability of eye fixation during the period that precedes the onset of the OFRs should also be verified, discarding trials in which the subject moved their eyes around stimulus onset (such motion would alter the motion of the stimulus on the retina during the open-loop period). The acquisition of just 3 frames (motion onset, 80 milliseconds later, and 80 milliseconds after that) should suffice for measuring at least OFRs to the simplest stimuli [32]. As we are interested in the motion of the eye in the head, it is important to accurately estimate and subtract off movements of the head over the same time period. More complex visual stimulations, in which the dynamics or the latency of OFRs might be informative, would require higher temporal resolutions. In those cases, the high temporal resolution of an eye coil system (1 millisecond) would certainly be helpful, but it is hard to envision situations in which acquiring more than 10 frames over a 200-millisecond period would be strictly required to answer a scientific or clinical question. Once the images are acquired by the camera, there would then be between 1 and 2 seconds, depending on the exact trial duration, during which the images could be downloaded to disk for offline analysis.

Given the typical size of OFRs, with a maximum displacement during the open-loop period ranging across subjects between 0.05° and 0.5°, a resolution of less than 0.05° would be highly desirable. To put this in perspective, peak-to-peak noise levels with a scleral search coil system, the most sensitive system for recording eye movements, are typically less than 0.03° [33]. In contrast, commercial eye trackers often have difficulties in reliably detecting eye displacements smaller than 0.5° [34,35]. With an average eye diameter of 22 - 24 mm, 0.05° corresponds to a pupil displacement of approximately 10 µm. Head movements of such small amplitudes must therefore also be reliably detected.

We designed and built a video-oculography system, utilizing a combination of off-the-shelf components and custom-designed elements, to fulfill these specifications.

Video Acquisition System

The image acquisition system we designed consists of a high-resolution camera, infrared (IR) illuminators, a photocell to be mounted to the monitor, and an Arduino controller to monitor the output of the photocell and trigger a frame acquisition from the camera. The camera we selected is a monochromatic FLIR Grasshopper 3 GS3-U3-51S5M-C [36]. It contains a Sony IMX250 ⅔” complementary metal-oxide-semiconductor sensor, with a resolution of 2448 × 2048 pixels (approximately 5 megapixels), square pixels with a side of 3.45 µm, and a maximum acquisition rate (at full frame size) of 75 Hz. We paired it with a Computar M5028-MPW2 C-Mount ⅔” 50 mm, f/2.8 lens [37]. Since we are interested in recording in the near-IR spectral range, we blocked the visible spectrum by placing in front of the lens a Hoya R72 IR filter with a cutoff wavelength of 720 nm [38]. To ensure proper lighting, we used 3 IR LED illuminators (1 on each side of the subject and 1 in front of and below the subject). We assembled them using multiple (2 for the front, 12 for the sides) 800-nm LEDs held in custom-designed 3D-printed enclosures. A common problem with commercial eye trackers is that the sustained illumination required by high temporal resolution often results in eye dryness and subject discomfort. To allow for bright IR illumination of the eye during image acquisition while minimizing the amount of IR power delivered to the eye, our illuminators are pulsed for only 2 milliseconds at a time, synchronized with the acquisition of a frame by the camera (the camera exposure duration was set to 1 millisecond to minimize motion blur). When recording 3 frames/trial, in an experiment with 4 stimulus conditions (the bare minimum for OFR experiments), 30 repeated presentations of each condition, and a 2-second trial duration, this results in a 4-minute recording experiment during which the illuminators are lit for only 720 milliseconds. Additional illumination occurs in the setup period required to properly focus the lens on the subject's eye. With an experienced operator, this process typically lasts less than 30 seconds; during this process, frames are acquired at 10 Hz (and the illuminators are lit 2 milliseconds every 100 miliseconds), resulting in an additional 600 milliseconds of IR illumination.

To control the timing of the camera shutter and the illuminators, we designed and programmed an Arduino-based controller and connected a photocell placed in front of the top left corner of the monitor to an Arduino analog-to-digital input. Our stimuli are then designed so that the luminance of the area of the screen under the photocell increases on the frame on which the fixation point is turned off and the experimental stimulus starts drifting. The Arduino-controlled circuit detects this change and sends a 2-millisecond transistor-transistor logic (TTL) pulse to the analog circuit that powers the IR illuminators and the camera shutter. The illuminators are turned on essentially instantly, whereas the camera, which is configured to trigger on the rising edge of the TTL pulse, begins the acquisition of a frame approximately 0.3 milliseconds later. Shutter aperture is set to last 1 millisecond, irrespective of the duration of the TTL pulse. The acquisition of successive frames (with associated illumination pulses) is then triggered automatically by the Arduino controller at the desired delays (with submillisecond resolution). The controller we designed allows for the manual selection (using a rotating knob) of 1 of 9 programs, each associated with different numbers and timings of acquisition frames (relative to the first one, which is always triggered by the photocell). The timing of these sequences can be easily customized by modifying the Arduino code. As mentioned previously, the camera we selected has a pixel size of 3.45 µm, and the minimum focusing distance of the lens we selected is approximately 50 cm (appropriate also for the distance between the subject and the monitor, allowing us to place the camera under the monitor). A camera pixel will therefore cover a square with a side of approximately 40 µm on the subject's eye. Given our desired 10 µm resolution (as detailed previously), our image analysis pipeline will need to detect displacements of one-fourth of a pixel or better. Since even very small translations or vibrations of the head would introduce artifacts of the same order of magnitude as the movements we are attempting to measure, these need to be compensated for.

Head Movement Compensation

The problem of head stabilization is common to all video-based systems (whereas scleral search coil systems are insensitive to small head translations). Gross head stabilization is usually provided by using a chin and forehead rest, often augmented with a headband. This is sufficient for situations in which only a coarse localization of the eye is required, but it is not sufficient when accurate determination of eye position is required.

One solution to the problem is to tightly stabilize the head, which is usually accomplished either through a bite bar (in which the subject's teeth are trapped in a dental mold fixed to the recording apparatus) or through a tight-fitting helmet that is then mechanically or magnetically held firmly in place. However, both of these solutions are impractical, uncomfortable for the subject, and ill-suited to pediatric clinical environments.

A noninvasive solution to this problem, used by most commercial video eye trackers, is to track the reflex on the cornea caused by an IR LED (the corneal reflex or first Purkinje image) [39,40]. When the eye rotates in the head, this reflex does not (to a first-order approximation) move in the image plane (whereas the pupil's center does). In contrast, when the head translates, the reflex translates with it (and so does the pupil's center). To estimate from video images the motion of the eye when the head is not perfectly stabilized, one can then subtract the displacement of the corneal reflex (an estimate of head-in-space motion) from the displacement of the pupil center (an estimate of eye-in-head + head-in-space motion). The resolution of the final measure is limited by the resolution with which the displacement of the corneal reflex can be tracked; in our case, this will also have to be in the order of one-fourth of a pixel or better. We attempted to use this approach but found it unsatisfactory for two reasons: (1) properly placing the illuminators to get an appropriate corneal reflex can be cumbersome and time-consuming, and (2) we could not reliably achieve the desired resolution given the small area covered by the corneal reflex [35].

To more accurately track small movements of the head, we placed an IR-absorbing black circle on a small sticker (which we call a "head marker") just under the bridge of the nose of the subject. We chose this location because it is close to the pupil we image (allowing them to both fit in the same photo frame) and because this area of the face is minimally sensitive to changes in facial expression. Just like the corneal reflex, tracking the head marker allows us to track the motion of the head and infer the movement of the eye in the head, but in a way that is less sensitive to the placement of the illuminators; in addition, due to the size of the marker, it provides high spatial resolution. The only downside is that it requires careful focusing of the camera, as both the pupil and the head marker need to be in focus for optimal resolution.

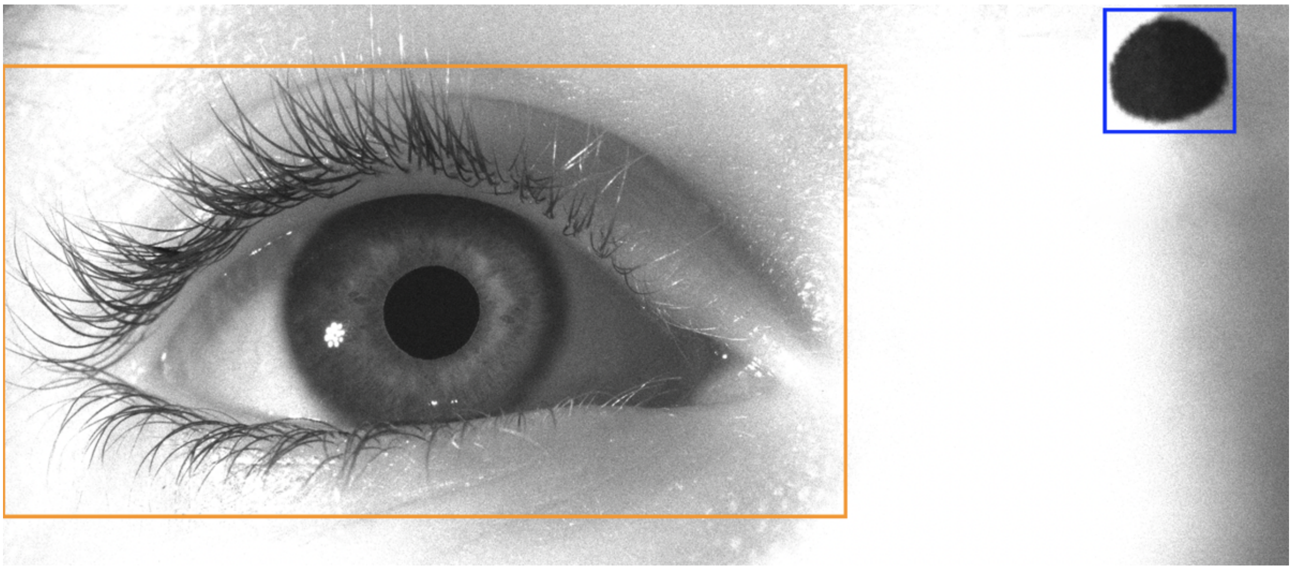
Image Analysis

Region of Interest Detection

During the experiment, all the image frames acquired (3 per trial at a minimum) were stored on disk. All the image processing aimed at extracting the magnitude of OFRs took place offline, after the experiment was over. The first step, as in any image analysis pipeline, was that of identifying regions within the image in which the features of interest are located. Traditionally, the detection of such regions of interest (ROIs) has been handled by feature-based detection algorithms, usually augmented by heuristic rules tailored to the specific problem at hand. For example, the eye region is often isolated using a 3-stage face and eye detection algorithm based on Haar cascade classifiers [41,42]. Alternatively, the high luminance associated with the corneal reflex can be used to locate the eye, specifically targeting the pupil [43]. More recently, the increase in available computational power and the development of deep-learning neural networks have revolutionized image processing, leading to faster and more robust solutions. For object detection tasks, You Only Look Once (YOLO) networks have proven to be very efficient and accurate [44,45]. Furthermore, YOLO networks can detect multiple objects in a single pass through a neural network, making them exceptionally fast [46,47].

For the first stage of our image processing pipeline, we used the YOLO V8 model to identify the image regions that contain the recorded eye and the head marker (Figure 2). A second YOLO network was then used to identify the pupil area within the eye region detected by the first network. We opted against extracting the pupil and the head marker regions directly because they share similar features. Both models were trained using a custom dataset consisting of 1380 images from 84 subjects. For the first model, we created a dataset in which we used classical computer vision algorithms to annotate the ROIs in each image, followed by manual validation. For the second model, we used traditional algorithms to annotate the pupil region within the eye ROIs extracted in the previous step, again followed by manual validation. These datasets were carefully designed to cover a wide range of eye dimensions, shapes, and (to a smaller extent) head tilts, ensuring that the models exhibited robust performance across diverse subject populations. As no deep-learning solution is infallible, we set a threshold on the confidence score generated by the models for the identification of ROIs to discard images in which the regions could not be identified (eg, when a subject blinked and the pupil was not visible or only partially visible). This ensures the accuracy of the subsequent image processing steps.

Figure 2. Sample image captured by our eye-tracking system (eye and marker regions of interest identified by the You Only Look Once model are marked with orange and blue rectangles, respectively). The corneal reflections of our infrared illuminators can also be seen to the left of and below the pupil. As the ocular following responses are conjugate, recording a single eye is sufficient [21].



Head Marker Displacement

As noted above, our goal is to measure the rotation of the eyes within the head over a small time interval (typically 80 milliseconds). To do this, we need to also estimate by how much the head translated in the same period. We do this by measuring the displacement of the head marker across 2 image frames, taken at the beginning and end of the period of interest. Notably, we are not interested in identifying the absolute location of the head marker in each image, only its displacement across images; however, this must be done with subpixel resolution (ideally less than 0.2 pixels).

The solution we have adopted takes the head marker ROIs identified in the 2 images, shrinks them down to a tight rectangle around the marker, then verifies that the rectangles in the 2 images are the same size. This is almost always the case; the exceptions are cases in which there were large movements of the head, and those trials would be discarded anyway. The distance in the image plane of the 2 rectangles gives us the head translation in whole pixels. To find the subpixel fraction of the displacement, we then performed a 2D cross-correlation between the area within the rectangle in one image and the 9 regions with the same area that are within 1 pixel of the rectangle in the other image. This yields a 3 × 3 matrix of cross-correlation values, which we subjected to Fisher r-to-Z transformation, then bilinearly interpolated to find the subpixel location of the peak. We also used a quadratic interpolation but saw no significant improvement in accuracy. The pixel and subpixel displacements were then added to provide our estimate of head displacement.

Pupil Displacement

The solution we adopted for the head marker cannot be used for the pupil because the pupil's size (and to some extent its shape) changes continuously, even within 80 milliseconds [48,49]. Accordingly, we used an algorithm that extracts the pupil's center in each image. First, we took the pupil region identified by the YOLO network and shrank it down to a tight rectangle around the pupil. Next, we used a series of filters (ellipses of various sizes and aspect ratios) to locate the pupil center with pixel-level resolution. As the previous step already provided a fairly accurate bounding box for the pupil, only a few filters were needed. If no filter resulted in a good enough match (a very rare occurrence), the trial was discarded. We then fit an anti-aliased annulus to the pupil, restricting our search space to ± 1 pixel around the pixel size identified with the first step. The limiting factor of the accuracy in vivo is the shape of the pupil (which is not always perfectly elliptical). More importantly, its location is not rigidly tied to the direction of the visual axis, introducing a hard limit on the spatial resolution of any pupil-based eye position determination [50-52], making estimates of accuracy based on an artificial eye, found on commercial system specifications, hard to translate in practice. The displacement of the eye (in the plane of the image) was then computed by simply subtracting the coordinates of the center of the ellipses fitted to the pupil in the 2 images. Finally, the displacement of the eye in the head was estimated by subtracting from this pupil displacement the displacement of the head marker computed previously.

Results

Overview

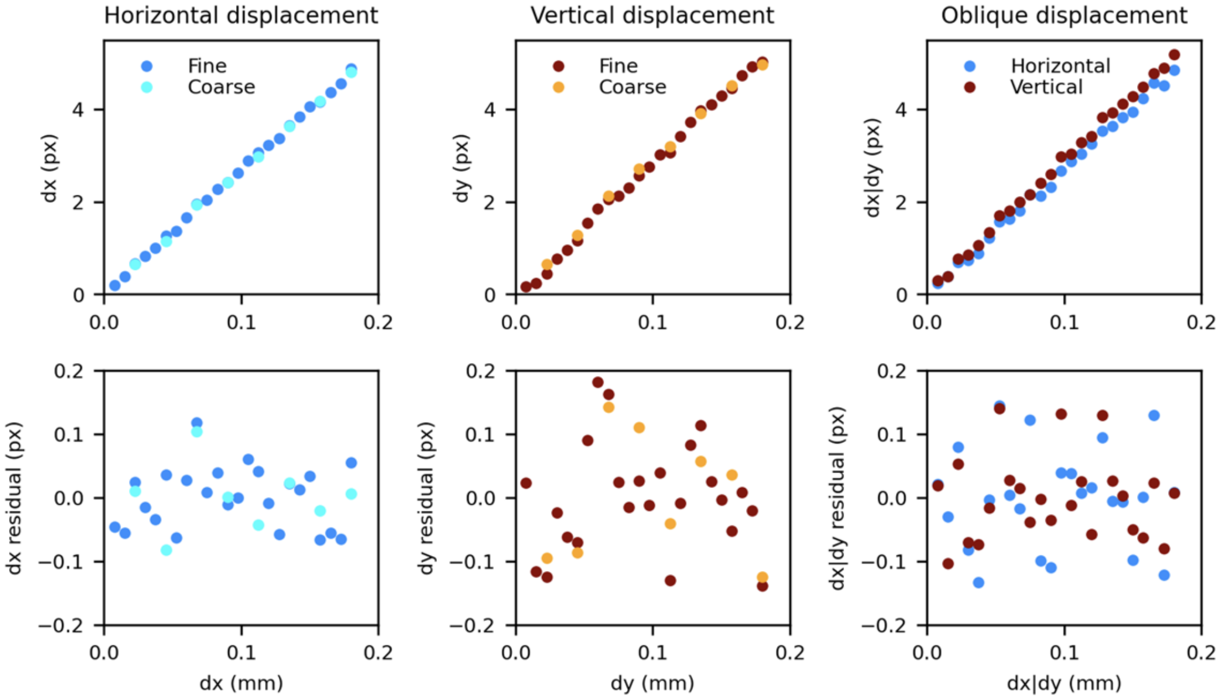
To assess our system's performance, we: (1) evaluated the resolution of our head marker displacement algorithm in artificial and real-use settings, (2) compared the OFRs measured simultaneously with our system and with a scleral search coil in an experienced adult subject, and (3) evaluated the ability of the system to measure OFRs in a clinical setting. As mentioned previously, we consider calibration results obtained with an artificial eye, common in the literature, to be of limited value in practice, and did not pursue that approach.

Artificial Marker Calibration

We mounted a head marker on a plastic block attached to a manual X-Y micro manipulator rigidly mounted to the end of a table. On the same table, we rigidly mounted our camera approximately 50 cm from the head marker. We then displaced the marker in small increments (by a total distance of up to 180 µm) either horizontally, vertically, or diagonally, and manually triggered the camera to acquire images of the marker at various displacements. Horizontal and vertical series were repeated with either a fine (7.5 µm) or coarse (22.5 µm) increment; only the fine increment was used for the oblique displacements. The displacement of the marker between each of the images and the initial reference image was then extracted with the algorithm described.

In Figure 3, we plotted the estimated (in pixels) and actual (in mm) displacement of the marker for all experiments, as well as the residuals obtained by regressing out from the estimated displacements a linear prediction based on the data.

Figure 3. Artificial marker calibration results. Top row: estimated displacement (y-axis, in pixels) and actual displacement (x-axis, in mm) of the marker across all experiments. Bottom row: residuals after linear regression. Px: pixels.



The slope of the regression matches what we expected from the geometry of the setup, with a slight difference in slope between horizontal and vertical displacements, likely due to an imperfect alignment of the camera. The standard deviation of the residuals varied between 0.05 pixels in the horizontal direction and 0.08 pixels in the vertical direction (corresponding to 2 - 3 µm of displacement). This is better than our desired 10 µm accuracy, although the conditions of this test (ideal lighting, minimal vibrations, accurate focus) are not those of everyday practice.

Reliability Estimation of Head-Tracking Method in an Adult Population

To estimate the reliability of our head-tracking method under actual recording conditions, we recruited 7 subjects (6 males, 1 female, aged 21 - 51 years). All subjects had healthy vision (normal or with slight myopia), did not wear eyeglasses or contact lenses during the experiment, and had no difficulties seeing or fixating their gaze on the fixation target. Note that the goal of this experiment was to evaluate our ability to detect small head movements; therefore, small uncorrected optical deficits were inconsequential. We presented to our subjects moving stimuli known from previous studies to induce strong OFRs: a patch of high-contrast random dots (Figure 1B) that drifted either up or down at 50°/s within a 28° diameter circular aperture. During each trial, we captured 4 frames at specific time points: t0=0 milliseconds, t1=80 milliseconds, t2=100 milliseconds, and t3=180 milliseconds. Given that our system extracts the displacement of the head marker's position across pairs of frames, if it were perfectly accurate, the sum of the displacements between frames t0 and t1 and between frames t1 and t3 should exactly match the sum of the displacements between frames t0 and t2 and between frames t2 and t3 (in both cases representing the displacement between frames t0 and t3). Differences between these 2 sums represent a measurement error.

We found that, across subjects, the mean (SD) of the head displacement measurement error (computed as described previously) was 0.09 pixels in the horizontal direction and 0.11 pixels in the vertical direction (corresponding to <5 µm of displacement). As expected, this is worse than in the artificial setting described before, but still better than our requirements.

Comparative Evaluation of the Designed System and Scleral Coils for Measuring OFRs

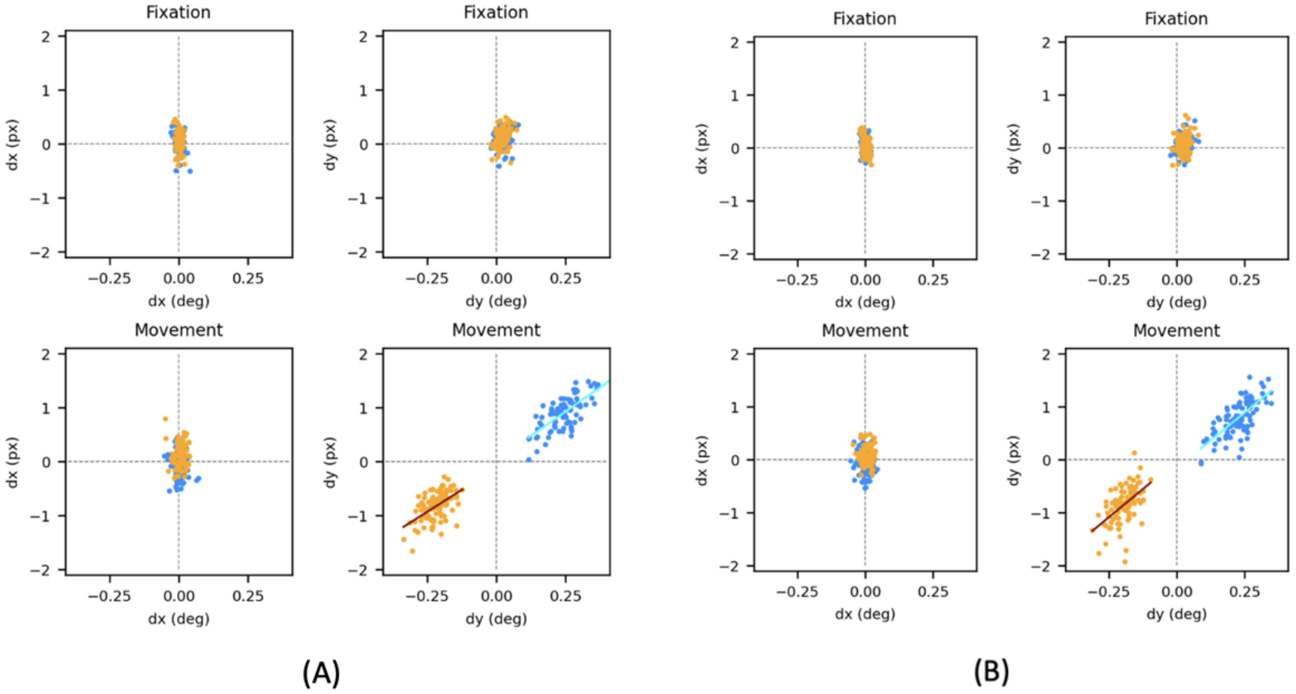
To evaluate the overall ability of our system to measure OFRs, we then fitted a subject with a scleral search coil and performed an experiment in which we presented a high-contrast random dot stimulus that drifted either up or down at 50°/s within a 28° diameter circular aperture. The subject (male, 51 years old) was highly experienced, having participated in hundreds of OFR recording sessions with scleral eye coils, and was used to the discomfort associated with wearing coils and to suppressing saccades and blinks. We recorded the induced OFRs using both the search coil and our video-based recording system. This was repeated twice; in the first session, we placed the camera on the side of the monitor (ie, a little farther from the subject), while in the second session, we placed it under the monitor (ie, closer to the subject; this was the location of choice for all our subsequent uses of the system).

In Figures 4A and B, we plotted the results of these experiments, showing separately horizontal and vertical deviations measured with the 2 systems (coils on the abscissa in degrees, eye tracker on the ordinate in pixels) during the fixation and movement windows. Using a highly practiced subject with steady fixation has the advantage of evaluating the system under close to ideal conditions. We separately analyzed responses to upward (blue) and downward (orange) drifting stimuli. Converting the pixel displacements extracted by our software into equivalent degrees of visual angle, we found consistent results across the 2 sessions. During the fixation epoch, the variability (SD) of the coil signal ranged between 0.01° and 0.02°, whereas that of the eye-tracking system ranged between 0.03° and 0.05°. During the movement period, along the horizontal direction, the variability of the coil signal was 0.02°, while that of the eye tracker ranged from 0.04° to 0.06°.

During the movement period, the scatter in the vertical direction was considerably larger (SD between 0.04° and 0.06° for the coil, and 0.08° for the eye tracker), but part of that scatter was due to variability in the underlying movement that is being measured (ie, the OFRs).

If we assume that all the shared variability is due to the underlying signal and that the noise of the 2 eye-tracking systems is uncorrelated, we can then assign all the covariance to the OFRs and use the correlation coefficient between the 2 measures to infer the actual variability of each measurement system. This yields a vanishingly small estimate of noise for the coil system and an estimate of the noise introduced by the eye tracker of between 0.06° and 0.07°. Since the coil system cannot have infinite resolution, this indicates that there is some shared variability (possibly due to head movements that were not perfectly compensated for), so these values represent an upper limit estimate of the noise introduced by our video recording system. Its resolution is very close to our desired goal, and it is likely at the limit of what can be obtained with a pupil-tracking system. However, note how much farther away the distributions of values measured for upward versus downward movements along the x-axis are compared to the y-axis, resulting in a d' measure that is almost twice as large with coils. This highlights the superiority of the coil system in ways that accuracy numbers do not convey.

Figure 4. Simultaneous ocular following response recordings with search coils and our eye tracker in a single adult subject. (A) Setup with the camera on the right of the monitor (1 pixel corresponds to approximately 0.29°). (B) Setup with camera under the monitor (1 pixel corresponds to approximately 0.24°). Each dot represents a different trial, color-coded based on the stimulus direction of motion (orange=downward, blue=upward); we plotted the eye-in-head displacement based on coil measurements (in degrees) on the x-axis, while the displacement based on our eye tracker measurements (in pixels) was plotted on the y-axis. Horizontal and vertical eye displacements in the head were plotted separately for the fixation (0 - 80 milliseconds, top row) and movement (80 - 160 milliseconds, bottom row) epochs. The rationale for selecting these epochs is outlined in the Methods section (Requirements). Deg: degrees; px: pixels.



Evaluation of System Performance in a Clinical Pediatric Population

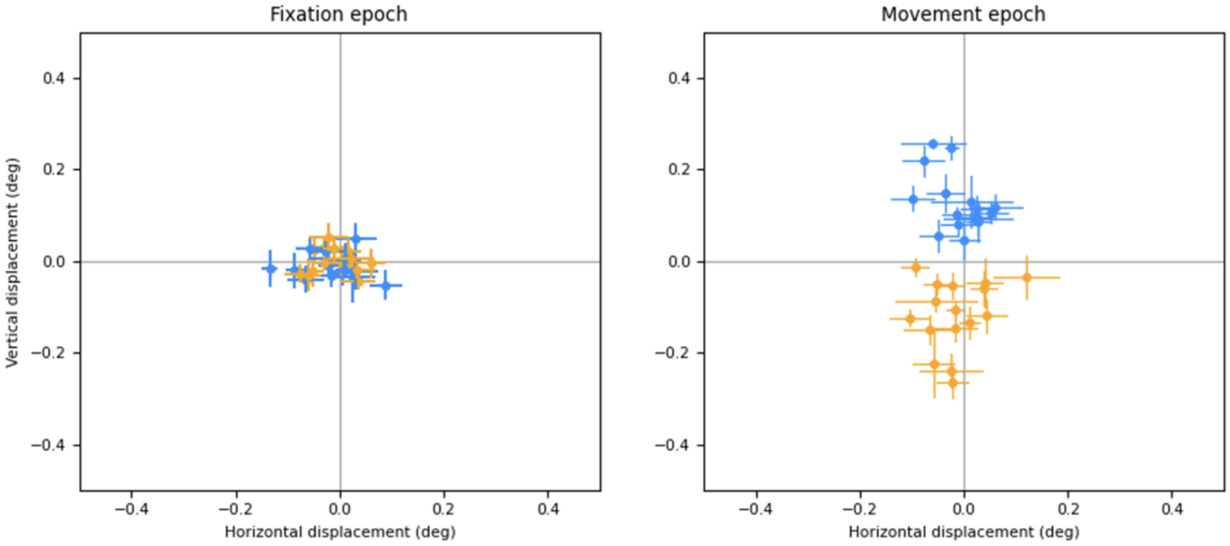
As the steady fixation and cooperation typical of a highly experienced subject cannot be expected in a clinical setting, it is also important to evaluate the ability of the system to detect OFRs in a varied clinical population. As one of the goals behind the development of this recording system is to be able to record OFRs in children, we measured OFRs in a cohort of 16 cooperating children (7 males, 9 females, aged 5 - 12 years) at the Ophthalmology Department at the Institute for Maternal and Child Health-IRCCS “Burlo Garofolo” (Trieste, Italy). All children underwent a complete ophthalmological and orthoptic examination, with indication of the best corrected visual acuity, the cycloplegic refraction, and the presence of any horizontal and/or vertical manifest strabismus angle with prisms. The inclusion criteria for normal subjects were at least best corrected visual acuity of 20/20 without correction, a cycloplegic refraction between 0.50 and 2.00 diopters, without astigmatism, without anisometropia, and absence of any type of strabismus.

We separately analyzed responses to upward (blue) and downward (orange) drifting stimuli. The displacements of the eye (eye-in-head) during the fixation epoch (frames t1=80 milliseconds versus t0=0 milliseconds) and the movement epoch (frames t2=160 milliseconds versus t1=80 milliseconds) were then computed by subtracting the head marker displacements (head-in-space) from the pupil displacements (eye-in-space). The rationale for selecting these epochs is outlined in the Methods section (Requirements). These measures were all computed in pixels and were then converted to degrees of visual angle based on the geometry of our recording systems, assuming an eye diameter of 22 mm (average for children in this age group) and resulting in a conversion factor of 0.168°/pixel.

In Figure 5, scatter plots of the average eye displacements for all 16 subjects during the fixation (left) and movement (right) epochs are shown. In the fixation period, there was no significant displacement (unpaired 2-tailed *t* test, $P>.05$) in any of the subjects. In the movement epoch, all subjects showed significant differences (unpaired 2-tailed *t* test, $P<.05$) between vertical displacements induced by vertically drifting stimuli (upward versus downward).

This demonstrates that, with this system, it is possible to measure OFRs in children in a clinical environment, with minimally instructed subjects, during a single, brief recording session lasting less than 3 minutes.

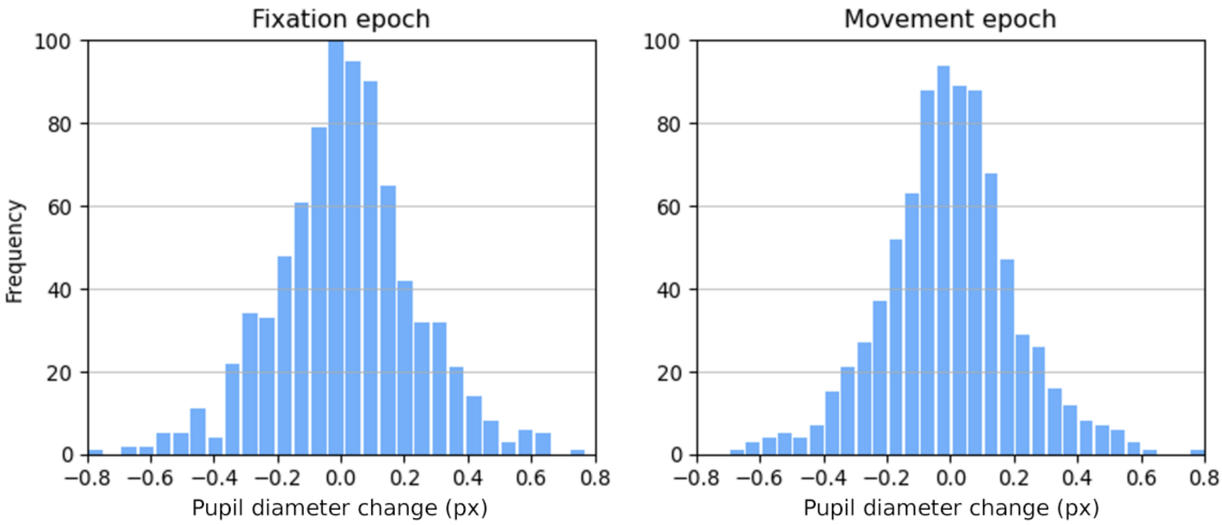
Figure 5. Eye-tracker ocular following response recordings for 16 children in response to stimuli drifting upward (blue) or downward (orange). Average (and ±1 SEM bars) eye displacements recorded in 16 subjects are plotted separately for the fixation (left panel) and movement (right panel) windows. Deg: degrees.



Pupil Diameter Changes as a Possible Cause of Error in the Measurement

The data from the previous experiment allowed us to quantify the variation in pupil size that can be expected in OFR experiments. In Figure 6, we report the distribution of pupil diameter changes (expressed in camera pixels) that we observed in the 16 pediatric subjects during the fixation (mean 0.01, SD 0.22) and movement epochs (mean 0.00, SD 0.21). Since the SD of the pupil diameter change is equal to our desired accuracy, changes in pupil diameter cannot simply be assumed to be negligible and ignored.

Figure 6. Distribution of pupil diameter changes (expressed in camera pixels) during the fixation (left panel) and movement (right panel) epochs, pooled across 16 subjects.



Discussion

Eye movements can provide a window through which we can gain insight into brain function and dysfunction [53-55]. This has long been recognized; over the years, several methods for recording eye movements have been developed, leading to numerous scientific and clinical discoveries. Unfortunately, because of the challenges in recording them, the potential diagnostic value of OFRs has only been recognized recently.

Here, we described a system that, thanks to a spatial resolution that approaches that of a magnetic search coil system, allows for the recording of OFRs noninvasively in a pediatric clinical setting. The system could potentially be useful for the identification of stereodeficiencies in young children and nonverbal adults. Due to the sensitivity of OFRs to motion and disparity signals, more widespread recordings in clinical populations will likely lead to additional clinical applications of the proposed solution.

Traditional eye movement recordings methods such as scleral search coils and dual-Purkinje eye trackers offer high precision but are expensive and complex to use. In addition, the former is invasive, while the latter requires strict head stabilization, both undesirable in pediatric populations. Commercial, video-based eye-tracking systems are now in widespread use, despite their often-high cost. However, they lack the desired spatial accuracy [35], thus requiring extensive averaging over long recording sessions, making them impractical for routine clinical use. Our system addresses these problems.

Further improvements in spatial resolution are possible but would not be easy to achieve. As the pupil changes shape and size constantly (Figure 6) and wobbles in the eye as it moves [48-52], significantly higher resolutions based on pupil tracking are probably unachievable. Tracking the motion of the iris would be a natural next step, but partial occlusion from the eyelids introduces hurdles, especially for vertical movements. In any case, increases in the spatial resolution of eye tracking would have to be matched by improved spatial resolution in the detection of head movements, an equally daunting task.

The proposed system, thanks to its demonstrated ability to noninvasively record OFRs in short recording sessions, offers a versatile solution suitable for clinical applications, particularly in a pediatric population, where eye tracking is more challenging. The system could potentially be suitable for diagnostic applications, particularly in pediatric populations, where early detection of visual disorders like stereodeficiencies is critical.

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Conflicts of Interest

None declared.

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Abbreviations

IR: infrared
IRCCS: Istituto di Ricovero e Cura a Carattere Scientifico
OFR: ocular following response
ROI: region of interest
TTL: transistor-transistor logic
YOLO: You Only Look Once

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Fact or Fiction—Accelerometry Versus Self-Report in Adherence to Pediatric Concussion Protocols: Prospective Longitudinal Cohort Study

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Abstract

Background: Concussion, or mild traumatic brain injury, is a growing public health concern, affecting approximately 1.2% of the population annually. Among children aged 1 - 17 years, concussion had the highest weighted prevalence compared to other injury types, highlighting the importance of addressing this issue among the youth population.

Objective: This study aimed to assess adherence to Return to Activity (RTA) protocols among youth with concussion and to determine if better adherence affected time to recovery and the rate of reinjury.

Methods: Children and youth (N=139) aged 5 - 18 years with concussion were recruited. Self-reported symptoms and protocol stage of recovery were monitored every 48 hours until symptom resolution was achieved. Daily accelerometry was assessed with the ActiGraph. Data were collected to evaluate adherence to the RTA protocol based on physical activity cutoff points corresponding to RTA stages. Participants were evaluated using a battery of physical, cognitive, and behavioral measures at recruitment, upon symptom resolution, and 3 months post symptom resolution.

Results: For RTA stage 1, a total of 13% of participants were adherent based on accelerometry, whereas 11% and 34% of participants were adherent for stage 2 and 3, respectively. The median time to symptom resolution was 13 days for participants who were subjectively reported adherent to the RTA protocol and 20 days for those who were subjectively reported as nonadherent (*P*=.03). No significant agreement was found between self-report of adherence and objective actigraphy adherence to the RTA protocol as well as to other clinical outcomes, such as depression, quality of life, and balance. The rate of reinjury among the entire cohort was 2% (n=3).

Conclusions: Overall, adherence to staged protocols post concussion was minimal when assessed with accelerometers, but adherence was higher by self-report. More physical activity restrictions, as specified in the RTA protocol, resulted in lower adherence. Although objective adherence was low, reinjury rate was lower than expected, suggesting a protective effect of being monitored and increased youth awareness of protocols. The results of this study support the move to less restrictive protocols and earlier resumption of daily activities that have since been implemented in more recent protocols.

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KEYWORDS

pediatric concussion; guidelines; adherence; return to school; return to sport; actigraphy

Introduction

Concussion, or mild traumatic brain injury, is a public health epidemic with an annual incidence of approximately 1.2% of the population [1]. According to the 2019 Canadian Health Survey on Children and Youth, head injuries or concussions had the highest weighted prevalence at 4.4% among children aged 1 to 17 years in Ontario, compared to other injury types [2].

In 2015, our research team developed evidence-based Return to Activity (RTA) and Return to School (RTS) protocols for children and youth with concussion [3,4]. These protocols (now updated) [5], and similar protocols based on the Sports Concussion Consensus statements [6,7], are the main management strategy for concussion recovery. It is important to determine whether youth adhere to these protocols before they can be evaluated in randomized control trials. At present, the most common method to assess adherence to the RTA/RTS protocols in youth is through self-report [6,8]. Literature suggests, however, that self-reported adherence estimates in youth are impacted by time since injury, age, mechanism of injury, receptivity to recommendations, and gender differences in activity [9-11]. To assess adherence, device-based measures of physical activity should be used, as they are reliable and minimize the bias associated with self-report [12-18]. As such, the primary aim of this study was to evaluate adherence to the RTA protocol using accelerometry and compare accelerometry-based adherence to self-report. The secondary objective was to evaluate postconcussion symptoms, recovery times, and rate of repeat head injury as well as to determine an association between adherence to RTA protocols and outcomes related to symptoms, repeat head injury, cognition, balance, quality of life, and depression. It was hypothesized that youth who were more adherent would have a lower incidence of repeat injury; shorter times to RTA; and better outcomes in quality of life, mental health, and cognition. Henceforth, youth will be used to refer to participants aged 5 - 18 years in this study.

Methods

Ethical Considerations

This study was approved by the Hamilton Integrated Research Ethics Board (REB #14 - 376). Informed assent/consent was obtained from participants and parents.

Study Design

Participants were recruited from the local Hospital Emergency Department, community referrals from their primary physician, and rehabilitation or sports medicine clinics. Eligibility criteria included the following: a physician-diagnosed concussion within the past 12 months, being 5 - 18 years of age, active symptomatology, and English-speaking ability. Youth were deemed ineligible if they had a confirmed brain injury requiring resuscitation, admission to the pediatric critical care unit, or surgical intervention, and if they refused to wear the ActiGraph. This prospective longitudinal cohort study had 3 measurement time points: recruitment/first visit; symptom resolution; and final visit, which occurred 3 months post symptom resolution or 6 months post enrollment if symptoms did not resolve within the study time frame. This investigation consisted of various outcomes, including electroencephalogram, [19,20] magnetic resonance imaging (MRI) [21], cognition [22,23], and sleep [24], which were published previously. Data on self-reported adherence, and adherence to RTS protocols specifically, were published by DeMatteo et al [8].

Assessment of RTA and RTS Protocol Stages and Symptoms

The CanChild protocols [3,4] consist of 6 stages of RTA and 5 stages of RTS, made with reference to the Zurich guidelines [25]. Youth were advised that no high intensity physical activity or contact sports was permitted while they were symptomatic. They were also informed that “rest” does not equate to social isolation or sensory deprivation. Once recruited, youth received the ActiGraph and the 2015 CanChild protocols [3,4] immediately. Participants completed surveys every 48 hours using REDCap (Research Electronic Data Capture; version 14.5.10, 2024; Vanderbilt University)—a browser-based data management application [26]. The surveys included the Post-Concussion Symptom Scale (PCSS) [27], RTA/RTS stages, and an assessment of cognitive activity [3]. The PCSS [27] is common across concussion evaluations [7] and consists of a 22-symptom checklist scored on a 0 - 6 Likert scale. This was adapted for younger children using a dichotomous yes/no scale [28]. The cognitive scale assessed cognitive activity on a scale of 1 - 5 and was adapted from Brown et al [29]. The second in-person visit occurred at symptom resolution. The label of symptomatic or nonsymptomatic was based on the return of participants’ self-identified current reporting of symptoms to their preinjury symptom status.

Measurement of Adherence to Protocols

To assess physical activity in the RTA protocols, youths were outfitted with an ActiGraph Gt3X waist-worn monitor accelerometer (ActiGraph LLc). The ActiGraph accelerometer provides a high-resolution measure of the duration, intensity, and frequency of movement and is validated for use in youth [12-17]. Participants were provided standardized instructions on how to wear the accelerometer and to record times of nonwear in a log diary. Accelerometry data were downloaded into 30-second epochs and visually inspected by trained personnel to ensure wear times matched those reported by participants. The data were cleaned to remove any nonwear periods or spurious data using ActiLife (version 6.13.4; ActiGraph LLc). The 30-second epoch was selected for analyses, as shorter epochs are more accurate to measure exercise intensity during intermittent physical activity [30]. Only valid days, defined as at least 6 hours and no more than 19 hours of wear time, were included in the analysis. Activity count data were then scored for analysis of adherence. To do this, daily time spent being sedentary or engaging in light physical activity (LPA), moderate activity, vigorous physial activity, and moderate-to-vigorous physical activity (MVPA) were calculated using the Evenson et al [14] cut points. Youth were considered adherent if there was 80% adherence to the physical activity requirements for the corresponding stage of the RTA protocol. Only participants who had complete actigraphy data were included in analyses (n=84). For stage 1, unlimited LPA was permitted, MVPA was limited to ≤2.5% of wear time and no consecutive bouts of ≥5 minutes at any intensity were recommended. In stage 2, baseline activity observed in stage 1 was permitted, as well as an extra 30 minutes of LPA, but no consecutive bouts ≥5 minutes of MVPA were recommended. In stage 3, baseline activity observed in stage 2 was permitted, as well as an extra 60 minutes of MVPA and upto two 15-minute bouts of MVPA. Only adherence to RTA stages 1 - 3 were assessed with accelerometry because these stages had quantifiable activity amounts defined in the RTA protocol [4], and RTS did not have objective adherence data.

Subjective reported adherence to the RTA/RTS protocols was based on the following criterion: if participants received a label of "yes" to the questions asked by the research personnel: "Has the child been following the RTA/RTS guidelines correctly?" based on a self-reported progression through the RTA/RTS stages being associated with a decreasing self-report PCSS score. [8] Participants were categorized separately for RTA and RTS. Participants labeled as "Did not adhere" to both RTS and RTA, as well as participants labeled as "Adhered" to one but not both RTA and RTS protocols, were deemed "Did not adhere."

Standardized Neurocognitive, Depression, Quality of Life, Coordination, and Balance Tests

Participants completed the short form of the Children's Depression Inventory (CDI) [31]; the KIDSCREEN-52 [32]; Immediate Post-Concussion and Cognitive Test (ImPACT) [33]; and subsets of balance, bilateral coordination, running speed, agility, and strength from the Bruininks-Oseretsky Test of Motor Proficiency Second Edition (BOT-2) [34] at each in-person visit.

Statistical Analyses

Demographic and injury data are presented as mean (SD), recruitment details are reported in percentages, and the PCSS score is reported as median, which better reflects the data due to a few outliers. Adherence for each participant was calculated for stages 1 - 3 of RTA as described above. Adherence was determined a priori to be considered the primary predictor of outcomes, but as the adherence rate was very low, alternative analyses were performed (as explained in the *Results* section). The ActiGraph calculated adherence for RTA was then compared to the self-reported rating of adherence for RTA, and agreement was assessed using Cohen κ.

The rate of repeat head injury was calculated as a percentage of total injuries. A Mann-Whitney *U* Test was performed to assess time to RTA stage 3 and 6 and time to symptom resolution for those who adhered or did not adhere [15,35]. Only participants who reported continued symptoms up until 3 months post symptom resolution, self-reported adherence to RTA/RTS, and reported the final stage of RTA/RTS were analyzed. Participants who responded "no" to the question "On more than one occasion, have you had any symptoms of concussion in the last two weeks?" were given a PCSS score of 0. Significance was set at *P*=.05. Scores for the BOT-2, CDI, ImPACT, and KIDSCREEN-52 were reported as mean (SD) and median. All the data were tested for normality using the Shapiro-Wilk test. Time to symptom resolution, time to stages, and PCSS scores were not normally distributed. Data were analyzed using SAS (version 9.4; SAS Institute) and SPSS (version 23.0; IBM Corp), with significance set at *P*<.05.

Results

Overview

Of the 139 participants who consented to the study, 107 (76.9%) participants completed follow-up assessments, 12 (8.6%) participants were lost to follow-up, and 20 (14.3%) participants withdrew from the study. Of the 20 participants who withdrew, 7 (35%) participants did so immediately after consent, 12 (60%) participants withdrew after the first in-person visit, and 1 (5%) participant withdrew before the final visit.

The cohort included 64 (46%) boys and 75 (54%) girls with a median age of 13.4 years. A total of 103 (74.1%) participants sustained their concussion via a sports-related injury, with most injuries obtained during recreational play (n=29, 28%) and ice hockey (n=26, 25%). This was the first concussion for 58.3% (n=81) of participants (Table 1). The median time from injury to the first visit was 7.8 days (mean 34.8 days, minimum 2.9 hours, and maximum 320.9 days). The mean time from injury to symptom resolution visit was 95.4 (SD 43.4) days for first in-person visits and 162.6 (SD 75.7) days for final visits.

Of the participants who remained in active enrollment (n=114), 16 (14%) participants did not achieve symptom resolution in the 6-month follow-up period (Table 1). Median time to symptom resolution was 16 days (Q1-Q3: 8-28; mean time 27, SD 33 days).

The rate of participants having another concussion during the follow-up period was 2% (n=3).

Table . Participant demographics, symptom resolution, and rate of reinjury (N=139).

Demographics	Values
Age (N=139)	
Mean (SD)	13 (2.85)
Median (Q1-Q3)	13.4 (10.9-15.2)
Sex (N=139), n (%)	
Male	64 (46)
Female	75 (54)
Number of previous concussions (N=139), n (%)	
0	81 (58.3)
1 - 2	45 (32.3)
3 - 5	8 (5.8)
>6	4 (2.9)
Mechanism of injury (N=139), n (%)	
Sports/recreational play	103 (74.1)
Non–sports-related injury/fall	22 (15.8)
Assault	5 (3.6)
Motor vehicle collision	4 (2.9)
Other	3 (2.1)
Post-Concussion Symptom Scale baseline score (n=131), median (Q1-Q3)	36 (17-56)
Achieved symptom resolution (n=114), n (%)	
Symptom-free within 7 days	2 (1.7)
Symptom-free in 8 - 14 days	16 (14)
Symptom-free in 15 - 28 days	31 (27.2)
Symptom-free in 29 - 89 days	35 (30.7)
Symptom-free in >90 days	14 (12.3)
Never achieved symptom resolution	16 (14)
Withdrew/lost to follow-up prior to symptom resolution (n=25), n (%)	
Unknown	11 (44)
Past 30 days	3 (12)
Past 60 days	2 (8)
Past 90 days	9 (36)
Rate of reinjury (N=139), n (%)	3 (2.1)

ActiGraph Adherence Evaluation

Based on the participant analysis, 13% (4/30) of participants adhered to stage 1; 11% (8/74) adhered to stage 2; and 34% (17/50) adhered to stage 3 (Table 2). Of note, only 1 participant from this cohort (N=139) adhered to all 3 stages.

Table . Days of participant adherence per stage to the Return to Activity (RTA) protocols based on actigraphy (N=139).

Participant ActiGraph adherence data (N=139)	Stage 1	Stage 2	Stage 3
Wear time criteria met, n (%)	30 (21.6)	74 (53.2)	50 (36.0)
Adhered	4 (13.3)	8 (10.8)	17 (34)
Did not adhere	26 (86.7)	66 (89.2)	33 (66.0)
Wear time criteria not met or PCSS[a] and stage data not available, n (%)	109 (78.4)	65 (46.8)	89 (64.0)

[a]PCSS: Post-Concussion Symptom Scale.

ActiGraph data with sufficient wear time and the corresponding PCSS score and RTA stage were considered complete and then analyzed in 30-second epochs for 80% adherence to stages 1, 2, and 3. Participants were labeled as “Adhered” to each stage if they had at least 1 day in adherence to ActiGraph cut points for stage 1, 2, or 3. Participants were given a final label of “Did not adhere” if they did not meet the cut points corresponding to stage 1, 2, or 3.

Subjective Reported Adherence

Of the 105 participants with self-reported data, 59 (56.1%) participants adhered to the RTA protocol [11], 56 (53.3%) adhered to the RTS protocol, and 50.4% (n=53) were adherent to both protocols (Table 3).

Table . Subjective adherence reported for the Return to School (RTS) and Return to Activity (RTA) protocols (n=105).

Adherence	RTS	RTA	RTS and RTA
Adhered, n (%)	56 (53.3)	59 (56.1)	53 (50.4)
Did not adhere, n (%)	49 (46.6)	46 (43.8)	52 (49.5)

Objective ActiGraph Versus Subjective Self-Report

Cohen κ was performed to determine if there was agreement between actigraphy and self-reported adherence to the RTA protocol. There was no statistically significant agreement between the two measures (κ=0.49, 95% CI 0.32 - 0.66; *P*=.57; Table 4). Among the 84 participants with both ActiGraph and self-reported data, there was 48% (n=40) agreement between the two. A total of 36 (43%) participants self-reported adherence to the RTA protocol but failed to meet the ActiGraph adherence cut points.

Table . Agreement of adherence between ActiGraph versus subjective report (n=84). There was no statistically significant agreement between the two measures (κ=0.49, 95% CI 0.32 - 0.66; *P*=.57).

Subjective report	Actigraphy		
	Adhered, n (%)	Did not adhere, n (%)	Total, n (%)
Adhered	16 (19)	36 (43)	52 (62)
Did not adhere	8 (9)	24 (29)	32 (38)
Total	24 (29)	60 (71)	84 (100)

Time to Symptom Resolution and RTA/RTS Completion

Those with subjective reported adherence to the RTA protocol had a significantly shorter time in days (median=13) to symptom resolution than those who did not subjectively adhere (median=20; *U*=724.50; *P*=.03; Table 5).

The difference in time to symptom resolution was assessed, using a Mann-Whitney *U* test, for participants who self-reported adherence and nonadherence to RTA and RTS protocols (n=90). Time to symptom resolution was calculated as the time from initial injury to symptom resolution. Only participants who had a date of symptom resolution verified by research personnel were included in the analyses.

There was no statistically significant difference in time from injury to RTA stage 3 (*P*=.61) or stage 6 (*P*=.24) for participants who self-reported adherence or nonadherence (Tables 6 and 7).

Table . Time to symptom resolution and Post-Concussion Symptom Scale (PCSS) score for youth with concussion based on subjective adherence or nonadherence to Return to Activity (RTA) and Return to School (RTS) protocols (n=90).

Variable		RTA			RTS		
		Adhered	Did not adhere	*P* value	Adhered	Did not adhere	*P* value
Time to symptom resolution (days)							
	Total, n	49	41	—[a]	47	43	—
	Mean (SD)	23.0 (30.7)	32.9 (36.6)	—	21.6 (26.1)	34.0 (39.7)	—
	Median	13.0	20.0	—	13.0	17.0	—
	Minimum	2.0	2.0	—	2.0	2.0	—
	Maximum	157.0	174.0	—	157.0	174.0	—
	Mean rank	40.15	51.89	.03[b]	41.38	50.0	.12
PCSS score at symptom resolution							
	Total, n	40	37	—	44	42	—
	Mean (SD)	2.4 (10.6)	7.4 (15.1)	—	4.5 (11.7)	7.4 (14.6)	—
	Median	0.0	0.0	—	0.0	0.0	—
	Mean rank	37.06	41.09	.29	42.90	44.13	.78

[a] Not applicable.

[b] Statistically significant.

Table . Time in days to return to activity (RTA) for youth with concussion based on subjective adherence or nonadherence to the RTA protocol (n=105).

Time to RTA (days)	RTA stage 3			RTA stage 6		
	Adhered (n=34)	Did not adhere (n=19)	*P* value	Adhered (n=41)	Did not adhere (n=36)	*P* value
Mean (SD)	56.4 (60.1)	38.8 (54.9)	.61	59.9 (41.5)	63.1 (65.3)	.24
Median	29.8	15.2	—[a]	47.3	31.6	—
Minimum	7	6	—	12	11	—
Maximum	247	221	—	156	276	—

[a] Not applicable.

Table . Time in days to return to school (RTS) for youth with concussion based on subjective adherence or nonadherence to the RTS protocol (n=105).

Time to RTS (days)	RTS stage 3			RTS stage 5		
	Adhered (n=36)	Did not adhere (n=22)	*P* value	Adhered (n=47)	Did not adhere (n=41)	*P* value
Mean (SD)	28.3 (39.9)	13.2 (8.7)	.06	65.2 (57.9)	58.9 (64.2)	.05
Median	13.8	10.7	—[a]	45.7	27.5	—
Minimum	5	5	—	11	7	—
Maximum	199	44	—	252	253	—

[a] Not applicable.

PCSS Score at Symptom Resolution

The difference in the average number of symptoms as reported on the PCSS or postconcussion system inventory at stage 5 of RTS and stage 6 of RTA was assessed, using a Mann-Whitney *U* test, for participants who self-reported adherence and nonadherence to RTS/RTA protocols (n=86). There was no statistically significant difference in the PCSS score at stage 5 or stage 6 of RTS (*P*=.78) and RTA (*P*=.29), respectively, for participants who adhered or did not adhere to the protocols (Table 5).

Adherence and Nonadherence: Depression, Quality of Life, Neurocognitive, and Balance Tests

The KIDSCREEN-52 physical and psychological well-being subsections scores improved from the first to final visit across most participants. The scores were considered "high," demonstrating that participants felt they were physically fit and healthy and viewed life positively [29]. Participants' CDI total T-score decreased for symptoms of depression from the first to the final visit (*P*=.33), where scores were in the average/low range (<60). Across all 3 visits, most participants scored in the "average" category. From the first to the final visit, the ImPACT subsection scores increased, suggesting an improvement in cognitive performance (*P*=.13).

There was no significant difference in the BOT-2, CDI, and KIDSCREEN-52 total or subsection scores between those who reported they subjectively adhered or those who did not adhere to the RTA and RTS protocols. There was a significant difference in the ImPACT Impulse Control Composite Score at the final visit for those who adhered to the RTA protocol (mean score 7.3, SD 5.1) versus those who did not adhere (mean 11.9, SD 11.7; *P*=.04).

Discussion

This prospective cohort study examined adherence to the RTA protocol, the rate of reinjury and time to symptom resolution among youths with concussion. It is one of the few investigations that has assessed physical activity in youth with concussion using accelerometry [36]. Our findings indicate that youth have lower adherence to RTA stages, as measured by accelerometry, when physical activity is more restricted, with adherence improving as more activity is allowed. Actigraphy analysis showed that 13% of participants were adherent to the RTA stage 1; 11% were adherent to stage 2; and 34% were adherent to stage 3. Huber et al [37] examined collegiate and high school football players post concussion using the Fitbit Charge HR. The authors found that athletes with concussion had a great deal of variability in activity levels the first few days post injury, suggesting differences in how the athletes interpreted "rest." Although in Huber et al [37] the activity monitors were worn for only 2 weeks, their findings are similar to ours in that there is lower adherence in the early stages. In our study, the generally low adherence rate was not conducive to any statistical prediction analyses or modeling, as the study had set an a priori standard of 80% compliance to qualify as "adherent" to predict whether these adherent youth would have better outcomes. This required examining the data in other ways, resulting in compelling findings. First, we observed that the PCSS score decreased as youth progressed through the RTS/RTA protocols [8] and remain low at the final stage of RTS/RTA, despite low adherence according to activity monitoring. We also observed a rate of reinjury of merely 2%, which is lower than the rates presented in the literature [38,39]. In addition, the same referral-based sample of patients at the McMaster Acquired Brain Injury Concussion Clinic in the 2013 - 2014 period (before the RTA/RTS protocols were first introduced) documented a reinjury rate of 37% among the 464 youths followed clinically. Notably, 36 (43%) participants self-reported adherence to the RTA protocol but failed to meet the actigraphy cut points. This suggests that they believed they were following the activity recommendations outlined in the protocols. It is speculated that they had modified their typical activities to some degree, which then felt like adherence to them. Presumably, their activity choices were guided by symptom relief and moderated by the conservative approach used in the CanChild protocols [3,4]. It also suggests that our arbitrary choice of 80% for a label of adherence was unrealistic, too high, and maybe even unnecessary. It was observed that participants who self-reported adherence to the RTA protocols achieved symptom resolution in a median of 13 days, and those who self-reported nonadherence achieved symptom resolution in 20 days. These data suggest that the mere presence of the protocols may alter behaviors, facilitating symptom resolution and reducing rates of reinjury as noted above.

The lack of adherence meant the youth were doing more than what the protocols recommended, which may seem contradictory to the low reinjury rate and symptom recovery patterns. However, existing evidence has shown that some cognitive and physical exertion early in recovery leads to shorter recovery times and syptom improvement [31,32,38-42]. In addition, Grool et al [43] examined 2413 youths with concussion and observed that physical activity within 7 days of acute injury was associated with reduced risk of persistent postconcussion symptoms [43]. Therefore, the nonadhering youth in our study were, in fact, getting some physical and cognitive activity early on. Yet the fact that they were not fully participating in activity may have contributed to the positive outcomes. The patterns demonstrated by the youth in this study provide valuable information for clinicians. They help define what activities and treatments are tolerable and acceptable for youth post concussion, meaning these are the levels of activity and treatment that youth can manage without exacerbating symptoms or causing further harm. Additionally, the study may indicate what is helpful, meaning the interventions or practices that contribute to positive outcomes and aid in the recovery process.

In light of these findings [8], along with data from our systematic review [44], the RTA/RTS protocols have been updated [5]. Some major revisions include a shortened rest period in stage 1 and the recommendation that youth progress through the stages before they are symptom free [5]. With these latest revisions, adherence of youth to the 2019 RTA/RTS protocols is expected to be greatly improved, although this requires further investigation.

This study is not without limitations. First, data on race and socioeconomic status were not collected. Second, adherence to RTA stages 1 - 3, but not stages 4 - 6, were assessed because only these stages had quantifiable physical activity cut points. Therefore, we were unable to objectively assess adherence to the later stages of the RTA protocol. Third, we accepted youth with concussion experiencing both acute and prolonged symptoms due to the nature of the research question. As such, the variability in time to symptom resolution and stage may be due to the prolonged symptoms of some participants. Finally, although we were able to retain the majority of participants, some were lost to follow-up or never achieved symptom resolution within the study period.

Overall, adherence to staged protocols post concussion was minimal according to the accelerometric data, but it was higher by self-report. More physical activity restrictions as specified in the RTA protocol, resulted in lower adherence. Although adherence was low, reinjury rate was lower than expected, suggesting a protective effect of being monitored and increased youth awareness of protocols. The results of this study support the move to less restrictive protocols and earlier resumption of daily activities that have since been implemented in more recent protocols.

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Conflicts of Interest

None declared.

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Abbreviations

BOT-2: Bruininks-Oseretsky Test of Motor Proficiency Second Edition
CDI: Children’s Depression Inventory
ImPACT: Immediate Post-Concussion and Cognitive Test
LPA: light physical activity
MRI: magnetic resonance imaging
MVPA: moderate-to-vigorous physical activity
PCSS: Post-Concussion Symptom Scale
REDCap: Research Electronic Data Capture
RTA: Return to Activity
RTS: Return to School

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Original Paper

Exploring the Use of a Length AI Algorithm to Estimate Children's Length from Smartphone Images in a Real-World Setting: Algorithm Development and Usability Study

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Abstract

Background: Length measurement in young children younger than 18 months is important for monitoring growth and development. Accurate length measurement requires proper equipment, standardized methods, and trained personnel. In addition, length measurement requires young children's cooperation, making it particularly challenging during infancy and toddlerhood.

Objective: This study aimed to develop a length artificial intelligence (LAI) algorithm to aid users in determining recumbent length conveniently from smartphone images and explore its performance and suitability for personal and clinical use.

Methods: This proof-of-concept study in healthy children (aged 0-18 months) was performed at KK Women's and Children's Hospital, Singapore, from November 2021 to March 2022. Smartphone images were taken by parents and investigators. Standardized length-board measurements were taken by trained investigators. Performance was evaluated by comparing the tool's image-based length estimations with length-board measurements (bias [mean error, mean difference between measured and predicted length]; absolute error [magnitude of error]). Prediction performance was evaluated on an individual-image basis and participant-averaged basis. User experience was collected through questionnaires.

Results: A total of 215 participants (median age 4.4, IQR 1.9-9.7 months) were included. The tool produced a length prediction for 99.4% (2211/2224) of photos analyzed. The mean absolute error was 2.47 cm for individual image predictions and 1.77 cm for participant-averaged predictions. Investigators and parents reported no difficulties in capturing the required photos for most participants (182/215, 84.7% participants and 144/200, 72% participants, respectively).

Conclusions: The LAI algorithm is an accessible and novel way of estimating children's length from smartphone images without the need for specialized equipment or trained personnel. The LAI algorithm's current performance and ease of use suggest its potential for use by parents or caregivers with an accuracy approaching what is typically achieved in general clinics or community health settings. The results show that the algorithm is acceptable for use in a personal setting, serving as a proof of concept for use in clinical settings.

Trial Registration: ClinicalTrials.gov NCT05079776; https://clinicaltrials.gov/ct2/show/NCT05079776

(JMIR Pediatr Parent 2024;7:e59564) doi:10.2196/59564

KEYWORDS

computer vision; length estimation; artificial intelligence; smartphone images; children; AI; algorithm; imaging; height; length; measure; pediatric; infant; neonatal; newborn; smartphone; mHealth; mobile health; mobile phone

Introduction

Regular and accurate measurement of anthropometric parameters in young children is important for monitoring growth and development, and for facilitating timely interventions to ensure appropriate growth [1,2]. Body length measurements are required for two key World Health Organization (WHO) growth standards: (1) length for age and (2) weight for length [3]. Accurate length measurement requires specialized equipment (a properly calibrated length board), skilled personnel, and a cooperative child [4-7]. Studies have reported inaccuracy and variability of length measurements, even in clinical settings [5,6,8,9]. In practice, achieving the "gold-standard" level of accuracy with the standard method is very challenging for untrained or inexperienced personnel. Although parents and caregivers want to track their children's growth closely, many find measuring their child's length at home technically challenging. Thus, there is an unmet need to develop a tool that is easy to use and addresses the key obstacles in taking accurate length measurements. This can potentially be upscaled and deployed in both personal or home and clinical environments.

Mobile devices are increasingly used for fast and efficient collection of real-world data, especially through smartphone images. Advances in artificial intelligence and computer vision technology, particularly deep learning, have enabled complex image recognition and prediction tasks to be performed on such image data [10-14]. These include challenging tasks such as predicting the physical size of a 3D object from one or more 2D images, which could translate to clinical use in determining a person's anthropometric measurements. Most of the existing image-based approaches focus on predicting the standing height of adults [15,16], although a couple of approaches for predicting the recumbent length of young children have been proposed [17,18]. Unlike manual measurements, these automated image-based approaches do not rely on standardized positioning of the child's body but must overcome certain challenges to produce accurate predictions. The relevant body parts must be automatically identified within the image by locating key landmarks such as the head and limb joints. The length prediction method must also account for body parts having variable orientation and distance from the camera, which affects their apparent lengths in the image. Image artifacts, such as blurring due to the child's movement, must also be detected and accounted for. One group proposed a stereoscopic vision system that uses 2 cameras to photograph the child simultaneously from different angles and estimates the child's body length based on the 2 images using the parallax principle [17]. Another group proposed a method involving the detection of customized round markers placed on the child's body before image capture. The markers allow both the detection of body landmarks in the image and the estimation of their 3D position relative to the camera; these are used to predict overall body length [18]. However, neither approach fully overcomes all current challenges with child length measurement since they still require specialized equipment or additional manual setup.

We developed a length artificial intelligence (LAI) algorithm to automatically predict children's length from smartphone images. To our knowledge, the LAI algorithm is the first approach that does not require specialized equipment or precise placement of body segment markers for length prediction. This innovative approach could make it much more practical and convenient for parents or caregivers to take regular length measurements for their children. In this proof-of-concept study, we examined the LAI algorithm's performance for automated length prediction and compared its performance with international standards such as those from the WHO [19-21] and measurements taken in general or community health clinic settings [8,22]. These comparisons allowed us to assess the feasibility of using the LAI algorithm in scenarios where specialized equipment and skilled personnel are unavailable. In addition, we explored users' experience and expectations for a digital measurement tool that could be used in home or clinic environments.

Methods

Study Design and Participants

An exploratory, observational, cross-sectional pilot study was conducted between November 2021 and March 2022 at KK Women's and Children's Hospital, Singapore. The study was prospectively registered at ClinicalTrials.gov (NCT05079776).

Eligible participants were children aged between 0 and 18 months whose parents (1) had a smartphone or tablet with access to the internet, (2) were able to complete the study questionnaires, and (3) took and uploaded images onto an online form. Children who were unable to undergo length measurement by the standardized technique recommended by the WHO [23] (eg, children with structural abnormalities of the lower limbs or orthopedic conditions such as club foot and hip dysplasia) were excluded from the study.

The study duration was a maximum of 2 days. On day 1 (clinic setting), investigators measured the participant's body length using the standardized WHO length measurement technique [23]. They then used a smartphone to take 6 top-view photos of the participant in a supine position. Each photo included a standard-size reference card. On day 1 or 2 (home setting), parents took and uploaded 6 smartphone photos of the participant in a supine position with the reference card. Investigators and parents were given a list of image quality requirements and guidelines for capturing good-quality images. Parents and investigators completed their respective user experience questionnaires after the image upload process.

Ethical Considerations

KK Women’s and Children’s Hospital’s independent ethics committee approved the study before its initiation (approval no.: 2021/2540). The study was conducted in accordance with good clinical practice, the Declaration of Helsinki, and the local laws and regulations of Singapore. Written informed consent was obtained from the parent(s) of each participant before any study-related activities were undertaken. The participants’ parent(s) received vouchers (equivalent to 30 Singapore dollars, or US $22.32) as a token of appreciation for participating in the study. Participant data were pseudonymized for analysis.

Study Assessments

Standardized Length Measurements

The body length of the participant was measured twice by investigators to the nearest 0.1 cm using the standardized WHO technique [23]. As the participants were younger than 2 years old, measurements were taken supine by 2 investigators using an infant length board. The average of the 2 measurements was recorded as the participant’s body length and used as input to the LAI algorithm. If the 2 measurements differed by more than 0.5 cm, a third measurement was taken and the average of the three measurements was used.

User Experience Questionnaires

Customized questionnaires were used to capture user feedback from investigators and parents on their experience with taking suitable photos according to the study requirements and on other items relating to using a digital measurement tool, including expected accuracy and desirable features.

LAI Algorithm Overview

The LAI algorithm uses state-of-the-art imaging and machine learning techniques to estimate a participant’s length from a single image, such as a smartphone photo. The current algorithm was designed to predict the length of children up to 18 months. The input to the algorithm is a digital image of the participant in a supine position and a reference object (standard size card, 85.6 mm by 54.0 mm). The first step involves extracting image features for both the participant and the reference card (Figure 1). Landmark extraction models are used to detect landmarks on the participant’s face and body (shoulders, hips, knees, ankles, heels, etc) within the image. These estimate the length of individual body segments in pixels. The card detection and card segmentation models are used to locate the reference card in the image and compare its pixel dimensions against its known physical dimensions to generate a pixel per metric value. The feature extraction step thus generates a set of quantitative features used in the length prediction step (Figure 1). A model incorporating these features predicts the total body length in millimeters. The algorithm returns a predicted length value as output only if the key feature extraction steps (body and card features) are successful.

Figure 1. LAI algorithm overview. From an input image of a child in a supine position and a standard reference object, anthropomorphic landmarks of the body and face are extracted, along with the detection and segmentation of the reference object (a standard size card, 85.6 mm by 54.0 mm). These are used by the LAI algorithm to predict the length of the child. LAI: length artificial intelligence.

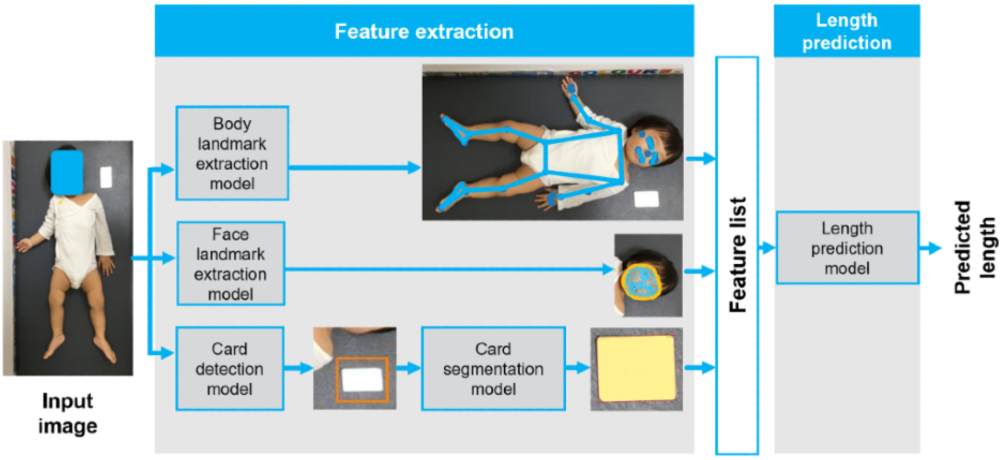


Image Datasets

The investigator and parent datasets consisted of all images taken by the investigators and the parents, respectively.

Image Requirements

To maximize the number of images usable for length prediction, photo-taking guidelines were given to investigators and parents. This included no clothing on the head or feet (eg, cap, socks, etc); no loose or baggy clothing to ensure that the body contour was visible; high contrast between the background, participant, and reference card; participant and reference card placed on the same flat and stable surface; participant positioned not more than 10 cm from the reference card; taking the image at an angle of 90 degrees from the surface on which the participant and card were placed; and participant’s legs not bent with the entire body visible to the camera. Images that fail to meet these requirements, such as those shown in Figure 2A-F, may fail to generate length predictions.

Following further testing and optimization, automated flags (warnings) were incorporated into the LAI (Figure 3). This allows the tool to detect uploaded images that do not meet the specified requirements and warn users that length prediction may be unsuccessful. In total, 4 different types of warnings were implemented.

Figure 2. Challenges with image-based length prediction. Images that pose challenges for length prediction by the LAI algorithm include those where (A) the camera is not positioned perpendicularly (90-degree angle) above the participant during image capture, (B) the participant and reference card are not placed on a flat horizontal surface, (C) there is blurring or glare, (D) there are baggy clothes on participant affecting the visibility of body contour, (E) there is low contrast of the participant with background, and (F) the face or body is not fully visible. LAI: length artificial intelligence.

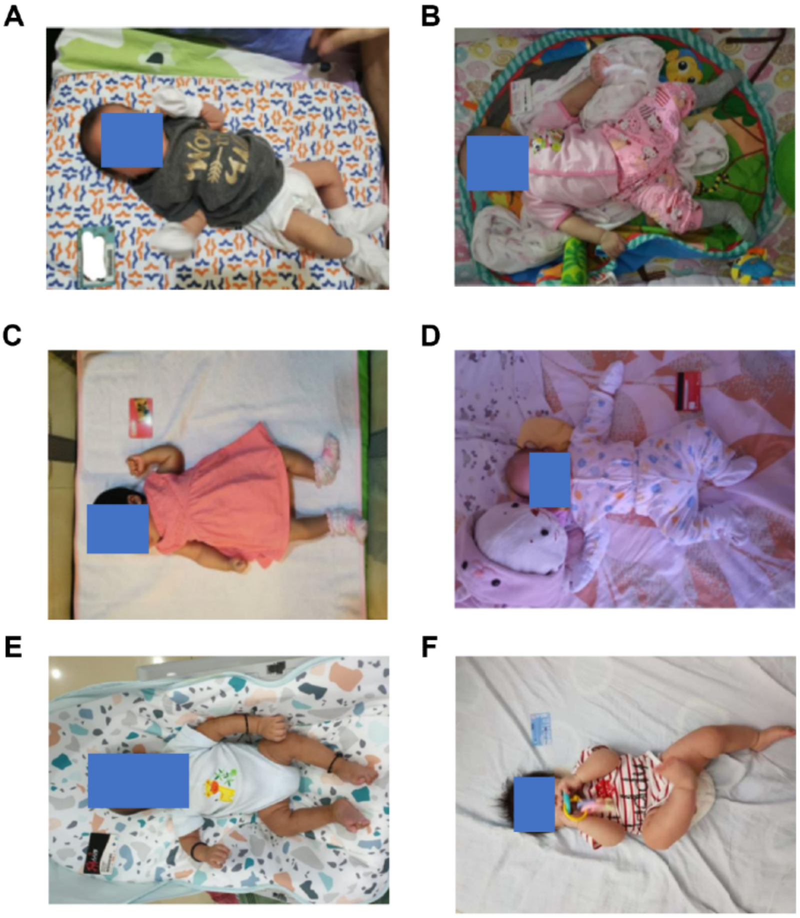
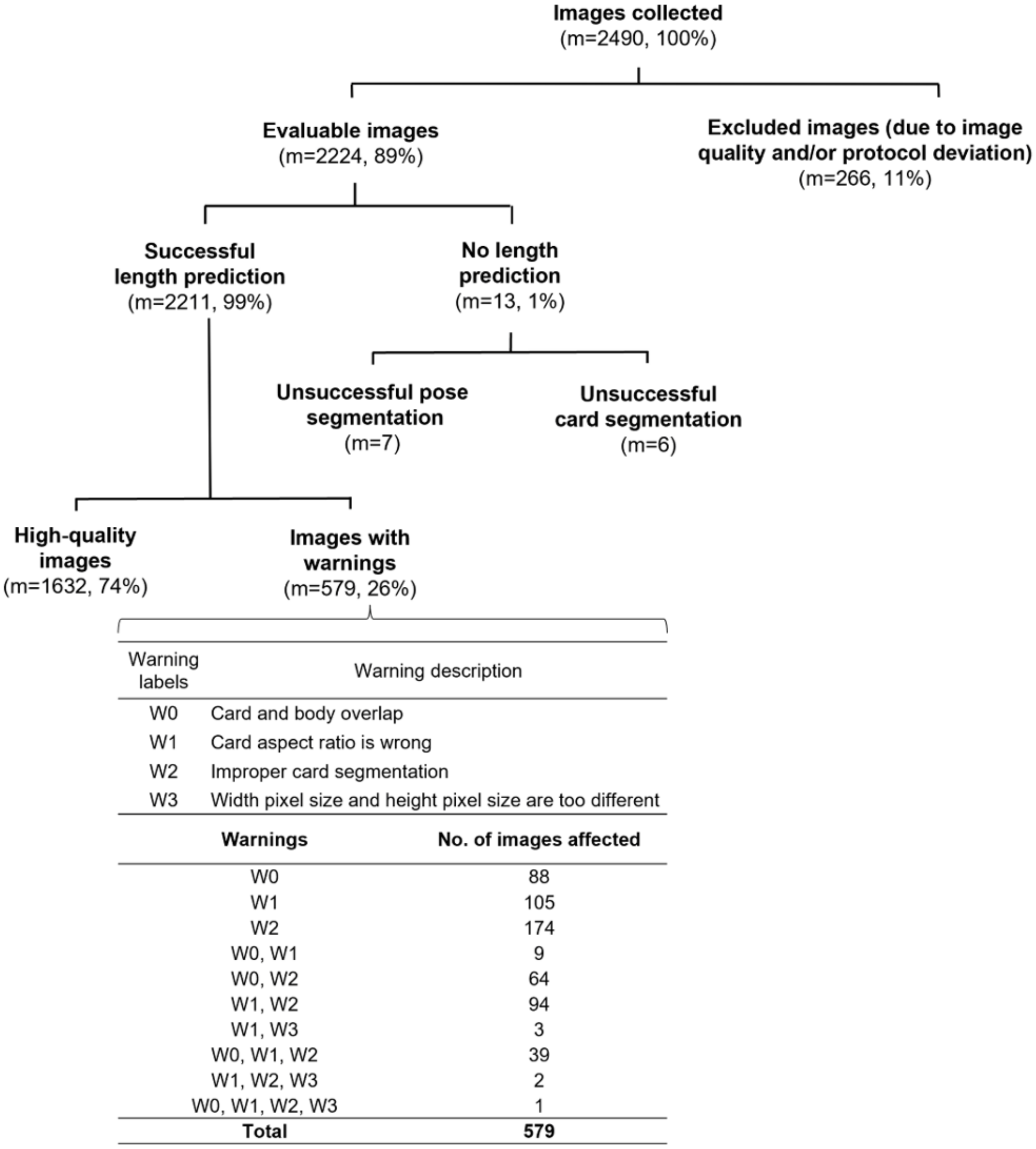


Figure 3. Schematic diagram of image flow. A total of 2490 images were collected in this study and 2224 images were analyzed. A total of 266 images were not analyzed due to protocol deviations (resubmission of images, submission of images outside the stipulated visit window, or images that did not meet the requirements). Of 2224 images analyzed, 2211 images produced a length prediction. The algorithm did not produce a prediction for 13 images due to unsuccessful pose segmentation (m=7) or unsuccessful card segmentation (m=6). High-quality images refer to images that did not generate any warnings. m (%): number and percentage of images in the specified category.



Warning labels	Warning description
W0	Card and body overlap
W1	Card aspect ratio is wrong
W2	Improper card segmentation
W3	Width pixel size and height pixel size are too different

Warnings	No. of images affected
W0	88
W1	105
W2	174
W0, W1	9
W0, W2	64
W1, W2	94
W1, W3	3
W0, W1, W2	39
W1, W2, W3	2
W0, W1, W2, W3	1
Total	**579**

Model Training and Performance Metrics

The LAI model was trained on the set of images collected by investigators (investigator dataset) and the investigator-generated length measurements. As described above, a set of features was generated, along with warnings. Only images that did not produce warnings were used to train the model. A 5-fold cross-validation was performed. Cross-validation is a statistical resampling method commonly used in applied machine learning to evaluate model performance with limited datasets [24,25]. The dataset was divided into 5 folds (subsets of data used for model training and testing) using 3 criteria: each participant's images should appear in only 1-fold; similar numbers of participants and images per fold; and similar distribution of measured body lengths across folds. In addition, details are provided in the *Cross-Validation Procedure* section in Multimedia Appendix 1. A bagged model was used for prediction. Hyperparameter optimization (HPO) incorporated a random feature selection step and was implemented using a state-of-the-art HPO framework [26]. The training was performed using a 2-step process. In the first step, a model was trained on all images from the investigators in the current training fold. A subset of these images within the 90th percentile of the training error was then selected, and the model was retrained on these images to ensure that outliers did not affect the training. Finally, all test images (from the investigators and parents) without warnings within the current fold were used to predict and calculate validation errors. The average validation error from all folds was used to drive the HPO framework to find the best model.

Performance metrics were calculated on a per-image and per-participant basis. For a given image i, the body length (p_i) predicted by the trained model was compared with the corresponding participant's WHO-standardized length measurement (m_i) to derive the following performance metrics: error (E_i, cm: difference between measured and predicted length $E_i = [m_i - p_i]$); absolute error (AE_i, cm: absolute value of the error $AE_i = E_i$); and absolute percentage error (APE_i, %: AE as a percentage of the length measurement,). Bias (average of *E*, cm;), mean AE (MAE; average of AE, cm), mean APE (average of APE, %), percentages at each AE cutoff (≤1 cm, ≤2 cm, ≤5 cm, and ≤10 cm), and percentages at each APE cutoff (≤2%, ≤5%, ≤10%, and ≤20%) were also calculated. Missing values due to errors, where the model did not return a predicted length value, were counted and reported separately. For participants with successful length predictions based on at least 9 images, the predictions for each image were averaged to generate a single predicted length for that participant.

The performance of the LAI model was evaluated using 5-fold cross-validation performed on the combined investigator + parent datasets and investigator-generated length measurements. To assess the LAI algorithm's performance relative to measurements in general clinic settings [8,22], the appropriate performance metrics were compared with published values for the technical error of measurement (TEM), an index commonly used in anthropometry to assess the accuracy and reliability of measurements [19-21].

Statistical Analysis

Due to the exploratory nature of this study, there was no formal sample size calculation. It was estimated that a complete dataset from 200 participants (standardized length measurements, images taken by investigators, images taken by parents, and completed questionnaires from investigators and parents) would allow model performance to be adequately assessed. Assuming a 20% dropout rate, 250 participants were planned for enrolment.

Descriptive statistics were used to summarize participant characteristics and user experience questionnaire responses. Continuous variables were summarized using mean, median, and minimum and maximum values. Discrete variables were summarized using percentages and frequencies by category, including missing values. No statistical testing of formal hypotheses was conducted.

Results

Characteristics of Participants and Image Data

In total, 215 participants were enrolled in the study, of whom 50.7% (n=109) were female. The mean age was 6.1 (SD 5; range: 0.0-17.7) months and the median age was 4.4 months. All participants completed the clinic-based data collection procedures, and 200 participants completed both clinic-based and home-based data collection procedures to provide a complete dataset of length measurements, images, and questionnaires.

A total of 2490 images were taken and uploaded (1290 images by 8 investigators at the clinic and 1200 images by 200 parents at home; Figure 3). Of these, 89.3% (2224/2490) of images were analyzed, and 10.7% (266/2490) were excluded due to image quality or protocol deviations.

Length Prediction Performance of the LAI Algorithm

The LAI produced a length prediction for 2211 (99.4%) out of 2224 images (Figure 3). In total, 0.6% (13/2224) of images did not produce a prediction due to either unsuccessful pose segmentation (7 images) or unsuccessful card segmentation (6 images). For the set of 1632 high-quality images (those that did not generate any warnings; Figure 3), the bias (mean error) for individual image predictions was minimal (0.03 cm; Table S1 in Multimedia Appendix 1). Most of the length predictions for these individual images (1557/1632, 95.4%) were within 10% of the measured length (Figure 4 and Table S1 in Multimedia Appendix 1). We found that length prediction was improved by averaging over multiple images for a participant. For 88 participants who had predictions for ≥9 images, the majority of these averaged length predictions (71/88, 81%) were within 5% of the measured length (Figure 4 and Table S1 in Multimedia Appendix 1).

The overall distributions of errors for individual image predictions and participant-averaged predictions are illustrated in Figure 5 [8,19,20,22]. Published interobserver TEM ranges for length measurements from the WHO Multicenter Growth Reference Study (0.48 cm [19], 0.70 cm [20]) and general clinics or community health settings (1.41 cm [22], 1.25-1.59 cm [8]) are indicated on the figure for comparison. The MAE for individual image predictions was 2.47 cm, and the MAE for participant-averaged predictions was 1.77 cm, which approaches the TEM range reported in general clinics or community health settings [8,22].

A quarter of the images with successful length predictions (579/2211, 26.2%) generated at least 1 warning (Figure 3). For this study dataset, the most common warning was improper card segmentation. The numbers of images affected by each type of warning are shown in Figure 3. Figure 6 illustrates the percentages of images available for length prediction under scenarios where different warning types are ignored, and the corresponding MAE values. The length prediction workflow can be adjusted to use more or less stringent settings, which affects the number of images retained for prediction and prediction error. Retaining fewer but higher quality images (fewer warnings) for prediction resulted in smaller MAE values (2.47 cm on images without any warnings); conversely, ignoring more warning types allowed more images to be used, but led to an increased MAE (3.39 cm using all images regardless of warnings). Similarly, the MAE for participant-averaged predictions decreased from 2.48 cm (n=155) to 1.77 cm (n=88) when only high-quality images without warnings were used for prediction (Table S1 in Multimedia Appendix 1).

Figure 4. Scatter plot depicting length predictions made by the model versus gold-standard length measurements made by the investigators. For length predictions on individual images, the majority fell within 10% of the participant's measured length. For averaged length predictions (per participant, for participants who had predictions from ≥9 images), the majority fell within 5% of the measured length. Blue circles represent predictions from all individual images. Red squares represent averaged predictions for children who had predictions from at least 10 images. The thick black line indicates the ideal prediction (ie, length prediction equal to the measured length). Dashed lines represent 5% and 10% deviations from the ideal prediction.

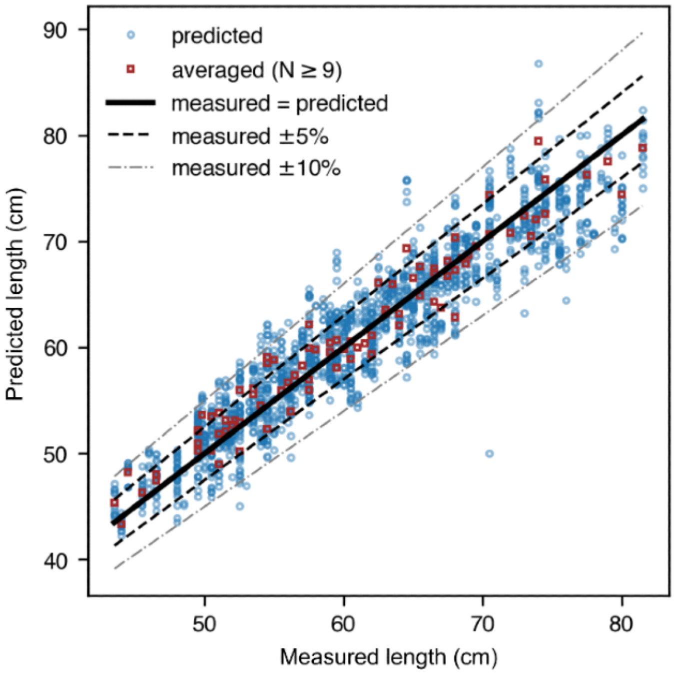


Figure 5. The overall distribution of errors (residuals) for individual image predictions (blue dots) and participant-averaged predictions made by the model. These were presented alongside published interobserver TEMs of "gold standard" length measurements from WHO (0.48 cm and 0.70 cm) and general clinics or community health settings (1.41 cm and 1.25-1.59 cm). The MAE of individual image predictions was 2.47 cm. When averaged, the predictions had an MAE of 1.77 cm, which approaches the TEM range reported in general clinics. MAE: mean absolute error; TEM: technical error of measurement; WHO: World Health Organization.

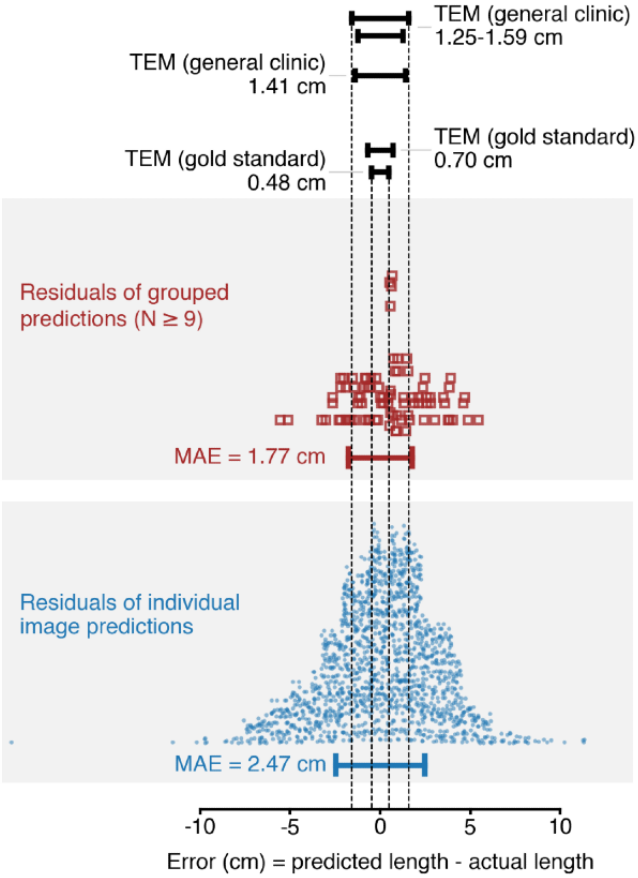
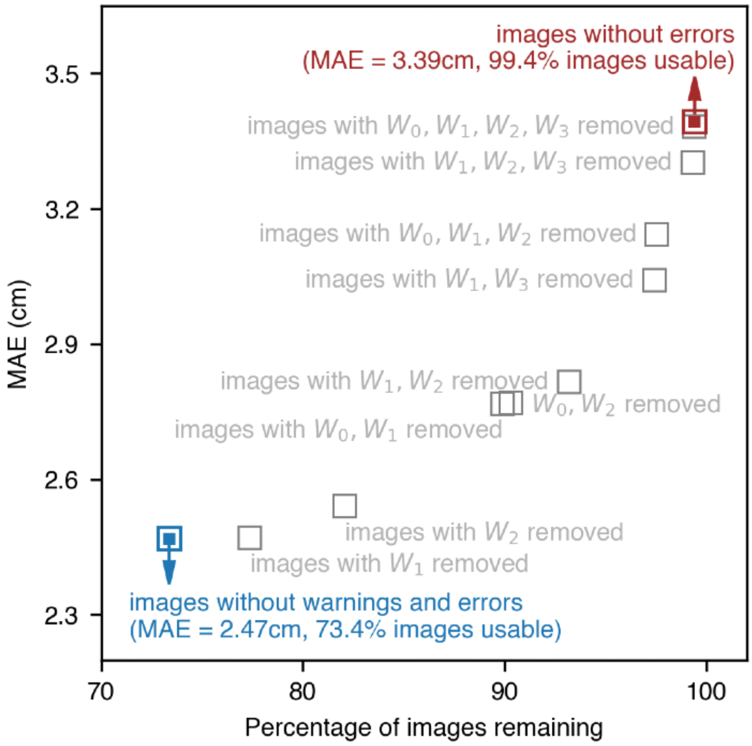


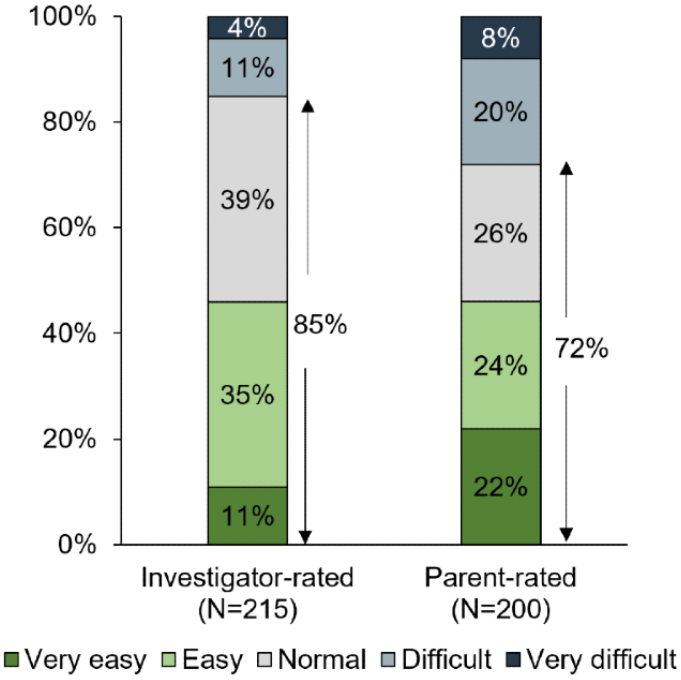
Figure 6. A plot illustrating the percentage of images available for length prediction and the corresponding MAE under varying scenarios where combinations of different warnings were ignored. Ignoring more warning types allowed more images to be used but yielded less accurate length predictions. Warnings: W0, card and body overlapping; W1, incorrect card aspect ratio; W2, improper card segmentation; W3, width, and height pixel size are too different. MAE: mean absolute error.



User Experience

In most cases, investigators and parents reported that they did not find it difficult to capture the required images (Figure 7). Investigators and parents rated the photo-taking process as very easy, easy, or normal for most participants (182/215, 84.7% participants, and 144/200, 72% participants, respectively).

Figure 7. Ease of collecting images as rated by investigators and by parents. N represents the number of participants for which the investigator or parent provided a rating.



User Feedback on the Use of a Digital Tool for Length Measurement

In total, 7 (88%) of 8 investigators indicated that they would be likely or very likely to use a digital tool that could automatically measure a child's length from an image, if available for clinical use (Multimedia Appendix 2). A similar proportion (7/8, 88% investigators) reported that they would be likely or very likely to recommend a digital length measurement tool to parents for home use, if available.

As for parents, most (143/196, 73% responses) were not currently taking length measurements regularly (at least once a month or more frequently) at home, whereas 57.1% (112/196) never measured length at home and 16.3% (32/196) measured less frequently than once a month (Multimedia Appendix 3). However, 91.5% (183/200) felt that a digital tool that could automatically predict length from an image would be useful or very useful for them to measure their child's length at home (Multimedia Appendix 3), and 88.5% (177/200) indicated that they would use such a tool at least once a month or more frequently (Multimedia Appendix 3).

Investigators and parents were asked about the magnitude of difference between standard clinic measurements and the length predicted by a digital tool that they would find acceptable in their typical use settings. For all investigators, only differences of ≤1 cm (4/8, 50% investigators) or ≤2 cm (4/8, 50% investigators) with respect to clinic measurements were considered acceptable (Multimedia Appendix 4). For most parents, differences of ≤1 cm (63/200, 31.5%) or ≤2 cm (93/200, 46.5%) were deemed acceptable, although a small proportion of parents considered differences of up to 5 cm acceptable.

Additional Desirable Features for an Automated Growth Measurement Tool

Apart from automated length measurement, investigators and parents highlighted several additional features that would be desirable in an image-based tool. Key desired features included estimating other anthropometric measurements, such as weight, head circumference, and growth-tracking functionality. Half of the investigators (4/8, 50%) suggested it would be useful to estimate other anthropometric parameters. A quarter (2/8, 25%) of investigators indicated that having a growth-tracking function would help detect growth abnormalities. In addition, 16% (32/200) of parents wanted the tool to be able to estimate weight or other anthropometric measurements. In total, 40% (80/200) of the parents wanted to be able to track their child's height, length, or both over time and have these measurements presented alongside the corresponding WHO height-for age and length-for-age charts.

Discussion

Principal Findings

Length measurement is challenging in clinical practice, especially among children younger than 2 years of age, where inaccuracy and interobserver variability in length measurements have been documented in primary care and community health settings [5,8,27]. Without proper equipment and training, it is impractical to expect parents and caregivers to take accurate and reliable length measurements at home regularly. Approaches for computer-assisted body length estimation from digital images have been proposed but involve elaborate requirements for data capture or procedures that may cause disturbances to the child [17,18] and limit their real-world feasibility and applicability. In contrast, the LAI algorithm was designed to have minimal requirements in terms of equipment and user training: only a smartphone and a readily available reference object (standard-size credit card) are required for data collection.

In our study, both parents and investigators found it easy to take the required photos for automated length estimation. Results from this proof-of-concept study suggest that the LAI algorithm, when trained on high-quality length measurements and image data, can predict children's body length with minimal systematic error and accuracy approaching that achieved in general clinics or community health settings. This indicates the potential for future implementations of the LAI algorithm to make growth monitoring more accessible to nonexpert users. The MAE for individual image predictions was 2.47 cm, and our results suggested that length prediction could be improved by averaging across multiple images of a child: participant-averaged predictions had a smaller MAE of 1.77 cm, which approaches the published interobserver TEM range (1.25-1.59 cm) reported in general clinics and community health settings [8,22]. Thus, the LAI algorithm would enable parents to estimate their child's length using images captured using their smartphones, with accuracy comparable to length measurements in general clinics or community health settings. Published reports indicate that the level of accuracy considered acceptable ranges from 0.5 cm to 2.0 cm, depending on the clinical indication for which length measurements are required [5,6,9,19-22,27]. For clinical growth monitoring, the WHO Multicenter Growth Reference Study protocols recommend interobserver differences of <0.7 cm for length [20], and the Standardized Monitoring and Assessment of Relief and Transitions (SMART) manual indicates an acceptable limit of <0.5 cm for height [28]. Growth measurement studies commonly report differences of ≤0.5 cm for expert anthropometrists [19-21,29]. This is consistent with the views of the study investigators, who indicated that they considered an accuracy of within 1 cm acceptable in an expert clinical setting.

Although smartphones greatly facilitate data collection for LAI algorithm, it is not always possible to consistently capture high-quality images of a child, which affects the accuracy of predictions. Commonly encountered image quality issues include the visibility of body landmarks obscured by clothing or limb position (Figure 2). Within the current LAI algorithm, we implemented a system that detects issues with uploaded images and generates warnings that these could affect length prediction (Table S1 in Multimedia Appendix 1). The settings can be tuned to ignore warnings and allow more images to be used for length prediction but at the cost of generating less accurate predictions. We envision that future versions of the tool will be integrated into a smartphone application that offers real-time feedback to guide parents or caregivers in positioning the baby and the standard-size reference object. Such feedback, including alerts about potential image quality issues and guidance on how to avoid or reduce key sources of error, would help users to take photos that are more likely to result in accurate predictions.

Other technologies, such as depth-of-field sensors available on some consumer devices, could potentially be integrated to further improve performance. Time-of-flight or light detection and ranging sensors can provide depth-of-field information that could be used with the current image-based algorithm to increase length prediction accuracy. Relevant practical considerations include the availability and accuracy of these technologies, especially for smaller participants like infants.

This proof-of-concept study collected images and corresponding length measurements and used these to explore the feasibility of a digital tool that can be used in home environments and in clinics to monitor growth over time. Due to the limited data available, a cross-validation approach was adopted to maximize the information that we could obtain about the tool's performance. This lack of an external validation sample may introduce limitations such as underestimation of error when the model is applied to new datasets, and systematic errors if the model's assumptions do not hold on to other datasets. Although care was taken to ensure that the reference measurements were as accurate as possible by using a standardized protocol (WHO method) and trained personnel, we have not formally accounted for the possibility of human error in the length measurements used for training.

Findings from our study have been used to refine the tool further, and projects to evaluate the feasibility and acceptability of the improved version are ongoing. At present, the proof-of-concept results suggest that the LAI algorithm's current performance may be compatible with personal use, such as general growth tracking at home, as its performance approaches that of manual length measurement in general clinics or community health settings [8,22]. Using the LAI algorithm, parents could record length measurements more frequently and conveniently at home. This idea is consistent with feedback from parents of the children in our study. Most parents reported that they did not measure their child's length at home; on the other hand, they indicated that an automated measurement tool was desirable and would be used at least monthly or more frequently. Besides automated length measurement, parents wanted a tool capable of estimating other anthropometric parameters and allowing them to track their child's growth with reference to WHO growth charts [3]. This user feedback provides valuable insights that can guide future development of the tool.

Conclusion

One of the main strengths of the current LAI approach is its simplicity and practicality for nonexpert end users. Data collection requires no specialized equipment or training; physical discomfort and disturbance to the child are minimized. This innovative approach explored the feasibility of image-based automated body length estimation that can be conveniently performed in a wide range of environments by any user. The potential value of such tools to nonexpert users is underscored by the range of studies that explore the possibilities of digital technology-assisted anthropometry [30,31]. The feedback collected from parents and clinicians in this study will inform future versions of the tool to better cater to the unique requirements of different users. It should be noted that the LAI algorithm's performance was evaluated only using data from healthy children (those without known growth-related conditions). Further studies with different populations will be needed to guide the design and optimization of the LAI algorithm for use in more specialized clinically oriented tasks such as monitoring for abnormal growth.

It should be noted that this was a proof-of-concept study to demonstrate the feasibility and acceptability of the LAI tool for estimating body length in young children (aged <18 months) in the home and similar environments. The performance achieved to date suggests that the current version of the LAI algorithm would not replace the standard clinical method used by health care professionals, but there is potential for future development to enhance its accuracy and applicability. Although the tool does not currently meet the requirements for highly accurate measurement in specialist clinical applications, our findings suggest that improving image quality is one way to increase length prediction accuracy. Integration of other technologies, such as depth-of-field sensors available on some consumer devices, could be explored to further improve performance. The current performance of the LAI algorithm, coupled with its ease of use, suggests it has the potential to be a feasible method of measuring a child's length for use by parents with accuracy approaching that of general clinic or community health settings.

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Conflicts of Interest

MH, JW, SSM, UN, and AF are employees of Danone Nutricia. CMC, DC, and FY are investigators of this study.

Multimedia Appendix 1
Cross-validation procedure, important limitations of the current LAI method and potential solutions, and performance of LAI for length prediction.
[DOCX File , 38 KB - pediatrics_v7i1e59564_app1.docx]

Multimedia Appendix 2

Investigator ratings (N=8) on how likely they were to use and recommend a digital tool to measure a child’s length in a clinical setting. N represents the number of respondents.

[PNG File , 54 KB - pediatrics_v7i1e59564_app2.png]

Multimedia Appendix 3

Parents’ (N=200) assessment of the (A) frequency of length measurement in the home in terms of how often they currently measure their child’s length manually at home and how often they would measure their child’s length if they had a digital tool that could automatically measure length from an image, and (B) usefulness of such a digital tool. N represents the number of respondents.

[PNG File , 179 KB - pediatrics_v7i1e59564_app3.png]

Multimedia Appendix 4

Acceptable magnitude of difference between LAI-predicted length and standardized length measurement for investigators n=8) and parents (n=200). N represents the number of respondents. LAI: length artificial intelligence.

[PNG File , 38 KB - pediatrics_v7i1e59564_app4.png]

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Abbreviations

AE: absolute error
APE: absolute percentage error
HPO: hyperparameter optimization
LAI: length artificial intelligence
MAE: mean absolute error
SMART: Standardized Monitoring and Assessment of Relief and Transitions
TEM: technical error of measurement
WHO: World Health Organization

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Impact of COVID-19 on the Pediatric Primary Care Model in Catalonia: Analysis of Changes in the Number and Type of Face-to-Face and Remote Visits

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Abstract

Background: The outbreak of COVID-19 has turned the care model of health systems around the world upside down. The health care crisis has led to opportunities for digital health to deliver quality care, and the system has been redirected toward telemedicine. In Catalonia, Spain, as of March 2020, the pattern of visits in primary care pediatric consultations changed, such that face-to-face visits decreased in favor of non–face-to-face visits.

Objective: This study aimed to analyze variations in the types of pediatric visits in primary care centers in Catalonia before and after the onset of COVID-19.

Methods: This was a descriptive observational study based on administrative data. The number and type of visits to primary care pediatric services in Catalonia between January 2019 and December 2022 were studied.

Results: A drop of more than 80% in face-to-face visits and an increase of up to 15 times in remote visits were observed as of March 2020 compared to the previous year. Subsequently, the face-to-face attendance rate began to recover, although it did not reach the same rate as before COVID-19. Non–face-to-face visits were maintained, representing more than 20% of the total after more than 2 years of the pandemic.

Conclusions: COVID-19 has been the trigger for a transition in the types of visits to primary care pediatric services. The COVID-19 pandemic was a clear catalyst for the integration of telemedicine in Catalan pediatric health care. In this context, although face-to-face consultations have recovered in absolute numbers, after the pandemic period, the weight of telemedicine has increased.

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KEYWORDS

COVID-19; remote consultation; primary health care; digital health; pediatric; face-to-face; telemedicine

Introduction

The COVID-19 pandemic has turned the care model of health systems around the world upside down, causing a significant and often unexpected transformation or disruption in the way health care services are delivered and organized worldwide [1]. In Catalonia, Spain, the health care crisis has led to opportunities for digital health to deliver quality care, and the system has been redirected toward telemedicine [2,3].

Both primary care (PC) centers and hospitals in Catalonia and in many other countries had to adapt to the new situation, where in the face of uncertainty, people (including children) were recommended to not go to health centers in person unless strictly necessary [4,5]. Therefore, as of March 2020, the pattern of visits changed in PC pediatric consultations [6,7]. As with all other services, face-to-face consultations decreased considerably while non–face-to-face consultations increased significantly worldwide [8,9]. In Spain, the reduction in visits during the first months of the declaration of the state of alarm mainly affected child health program check-ups and acute demand due to infectious diseases [10]. In general terms, the acute infections that decreased the most once the strictest confinement started were respiratory and digestive infections [11]. At the same time, telephone consultations multiplied considerably. Later, in June 2020, despite the expected difficulties due to the fear of users and health care workers and the barrier of accessibility to PC, face-to-face attendance was not as low, as health care was managed more appropriately [12].

A multicenter study coordinated by the Spanish Association of Primary Care Paediatrics in June 2020 explains how PC pediatric services were organized during the first wave of COVID-19 and indicates that, in general, pediatricians followed the center's own contingency plan and that total consultations reduced by approximately 40% to 50% compared to the same period of the previous year [13]. There was a very significant increase in the rate of teleconsultations, such that more than 90% of pediatricians made teleconsultations as opposed to 38% who did so before the pandemic. In contrast, a decrease in on-site visits was noted, and these were mostly (88% of the cases) visits for the child health program.

In Catalonia, an autonomous community of the Spanish state with full competence in health matters, public health care coverage is guaranteed to all citizens through almost 400 PC centers. In pediatrics, in addition to visits for acute and chronic diseases and follow-up, the child health program called *Infància amb Salut* [14] is applied. It is a protocol developed by the Public Health Agency of Catalonia and includes actions that are carried out individually by the PC pediatric team for preventive visits and check-ups, scheduled between 0 and 14 years of age. It includes screenings, vaccines, and health education. It is implemented throughout the public health network of Catalonia. In this way, access to a high-quality child health service is guaranteed universally, that is, for all children and adolescents residing in Catalonia regardless of their socioeconomic situation or place of residence. These visits are called child health check-ups and have specific characteristics, which are different from the visits carried out for acute or chronic diseases or follow-ups.

A previous analysis conducted in Catalonia suggests that non–face-to-face visits (telephone and teleconsultation) increased threefold during the pandemic, while face-to-face visits fell by almost half. Despite this, there are no specific data on the evolution of the pattern of PC pediatric visits throughout the COVID-19 pandemic [15]. In this context, the objective of this study is to describe the quantitative evolution of different types of visits, both remote or electronic and on-site, from 2019 to 2022 in PC pediatric services in Catalonia.

Methods

Study Type

This was a retrospective, descriptive, and observational study in the Autonomous Community of Catalonia, Spain.

Population, Place, and Study Period

The study population comprised a sample of all the children who resided in Catalonia and accessed services between January 1, 2019, and December 31, 2022. This extended study period allowed for the collection of comprehensive data on the demand of child health care services over a period of 4 years.

Data were collected from the Information System of Information Technologies of the Primary Care Services of Catalonia database belonging to the Catalan Health Institute. Data regarding the number and type of visits between January 2020 and December 2022 were analyzed and compared to the corresponding period in the previous year (2019; ie, before the pandemic).

Variables

Three variables were considered: date of visit, number of visits in a given day, and type of visit; the latter is a categorical variable with 7 types of visits that are established in pediatric PC in Catalonia (9C, 9R, 9D, 9T, 9Ev, 9E, and 9Ec), which were reworked into 3 groups: face-to-face (9C, 9R, and 9D), synchronous non–face-to-face (9T and 9Ev), and asynchronous non–face-to-face (9E and 9Ec) visits. Table 1 summarizes the particularities of each visit type in relation to face-to-face attendance, duration, and synchronicity.

Table . Characteristics of the types of visits to pediatric primary care in Catalonia.

Designation	Types of visits	Face-to-face attendance	Average duration (min)	Synchronicity
9C	Spontaneous medical appointments	Yes	12	Yes
9R	Child health program check-up	Yes	20	Yes
9D	Home visit	Yes	30	Yes
9T	Telephone consultation	No	6	Yes
9Ev	Video call consultation	No	12	Yes
9Ec	Consultation through the eConsultation digital platform	No	6	No
9E	Non–face-to-face consultation (report, prescription, etc)	No	6	No

There are 3 types of face-to-face visits: short visits dedicated practically to acute demand (9C), child health program check-ups (9R), and home visits (9D). Synchronous non–face-to-face visits include telephone consultations (9T) and video call consultations (9Ev). Asynchronous non–face-to-face consultations comprise eConsultations (9Ec) through La Meva Salut, a personal digital health space, and non–face-to-face consultations (9E), which include consultations where the health care professional does not have direct contact with the user—often because it has been managed through administrative staff, involving procedures such as medication plan preparation, report writing, test evaluation, data management, interconsultation between professionals, and coordination with other services.

Statistical Analysis

To describe variables, we expressed continuous variables as means and SDs, and we summarized categorical variables as percentages. As for the *t* tests, a Welch unequal variances (2-tailed) *t* test was carried out to compare the mean of total pediatric visits made each month for 2019, 2020, 2021, and 2022, to check if there had been a recovery of total visits. Then, the same Welch test was performed for each group (face-to-face, remote synchronous, and remote asynchronous). Bonferroni correction has been applied to all *P* values. All statistical analyses were conducted using R software (version 4.1.0; R Foundation for Statistical Computing), and the significance level was set at 5%. To smooth the plots, a 14-day rolling average was performed.

Ethical Considerations

No ethical approval was required, as analyses were conducted only on aggregated data.

Results

General Evolution of Visits to PC Pediatric Services

Figure 1 [16,17] shows the evolution of the average number of daily visits made during the study period, between January 2019 and December 2022, to PC pediatric services in Catalonia, grouped according to the type of visit. The vertical stripes indicate the 8 waves of COVID-19 that can be defined in Catalonia with data from the Statistical Institute of Catalonia and the Information System for the Surveillance of Infections in Catalonia (*Sistema d'Informació per a la Vigilància d'Infeccions a Catalunya*; SIVIC) [16,17]. It is evident how during 2019, the volume of activity in PC pediatric services was predominantly through face-to-face visits and that this pattern changed completely after COVID-19.

Figure 1. Average number of daily visits by type (face-to-face, synchronous non–face-to-face, and asynchronous non–face-to-face) to pediatric primary care in Catalonia between January 2019 and December 2022. The vertical stripes indicate the 8 waves of COVID-19 in Catalonia.

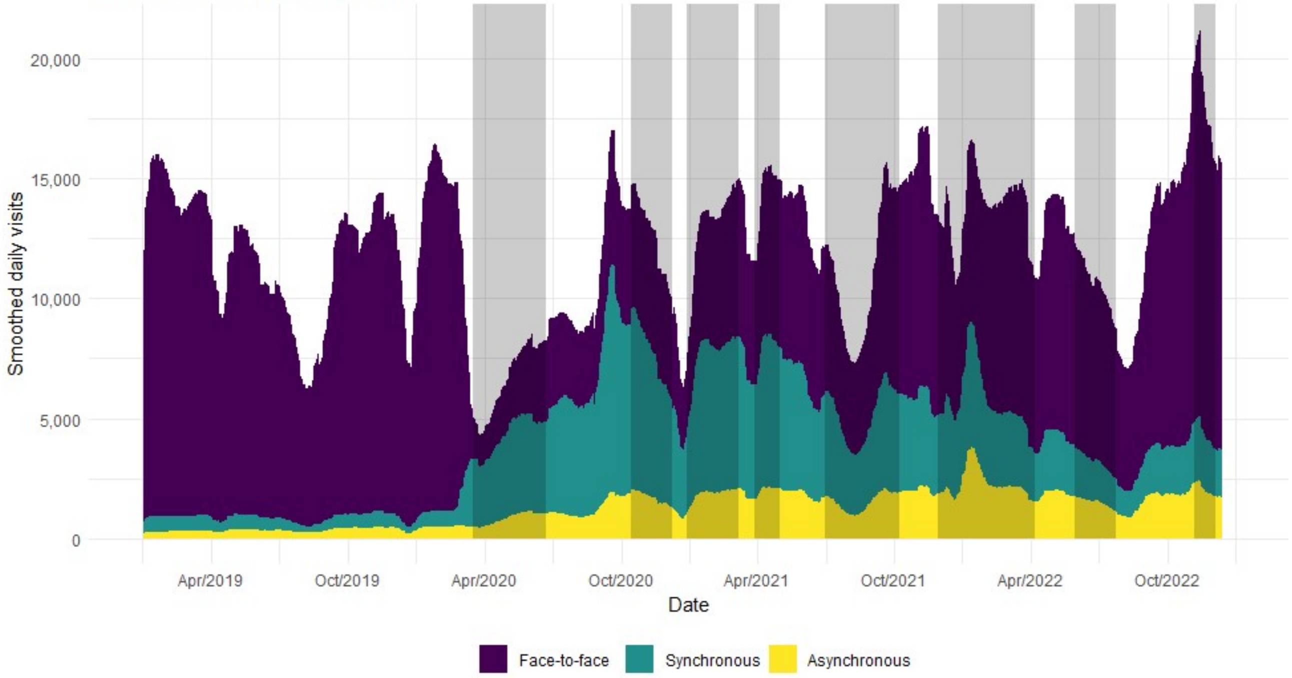
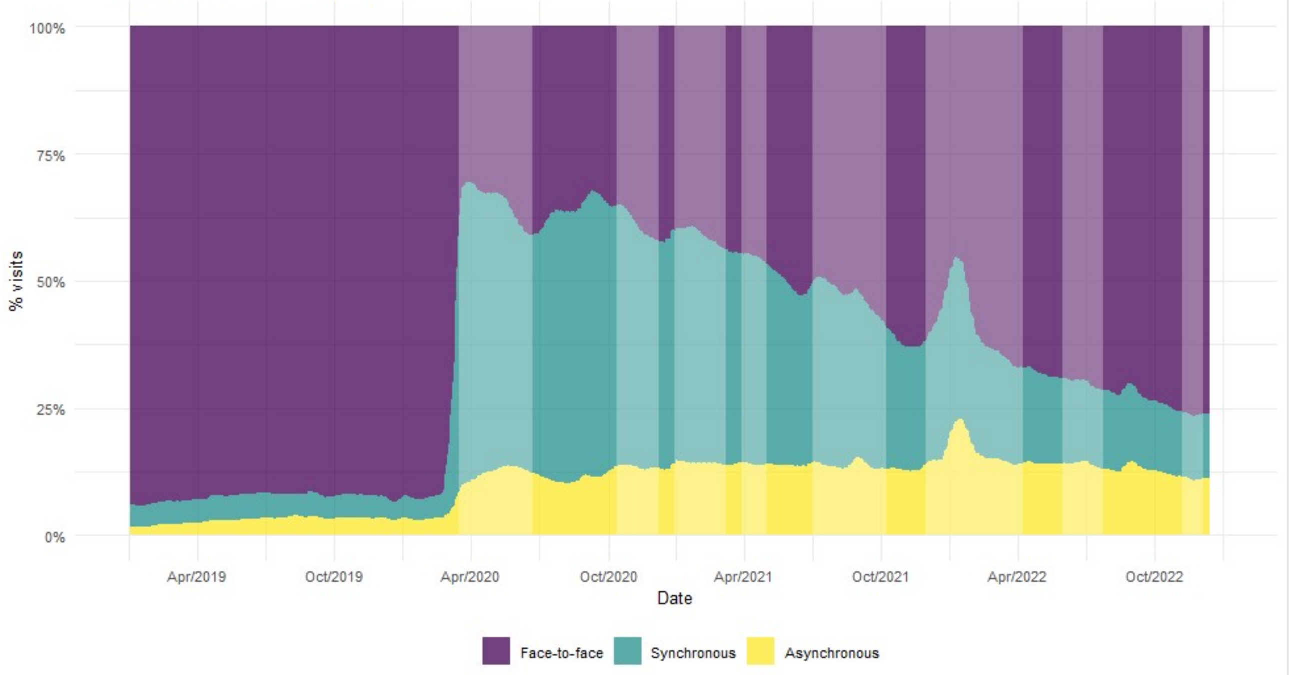


Figure 2 [16,17] shows the distribution of the 3 types of visits to PC pediatric services in Catalonia over the last 3 years. The drop in the relative weight of face-to-face visits with the outbreak of the COVID-19 pandemic is noteworthy. Later, they slowly picked up again but did not reach the 2019 proportion at the end of the study. Figure 2 shows that face-to-face visits had recovered in absolute numbers but not in proportion because telemedicine consultation had increased its weight. In parallel, synchronous and asynchronous remote visits grew and changed the pattern of consultation types during the months of the pandemic. At the end of the study period, non–face-to-face visits gained ground, clearly changing the distribution of the types of visits.

Figure 2. Distribution of daily visits by type (face-to-face, synchronous non–face-to-face, and asynchronous non–face-to-face) to pediatric primary care in Catalonia between January 2019 and December 2022. The vertical stripes indicate the 8 waves of COVID-19 in Catalonia.



Evolution of Visits According to the Type of PC Pediatric Services

Overview

The data corresponding to the results discussed below are shown in Multimedia Appendix 1, which shows the average daily number of visits in total and by types of visits, separated by month, to PC pediatric services in Catalonia between 2019 and 2022. The change, expressed as a percentage, was calculated with reference to the same period in 2019 and analyzed to see if it was statistically significant.

Total Visits

With the emergence of COVID-19 in March 2020, visits decreased significantly from the previous year. It can be observed that the number of daily visits decreased from 15,389 in the month of February 2020 (*P*=.32; vs February 2019) to 9515 in the month of March 2020 (*P*=.001; vs March 2019). The sharpest decrease relative to 2019 was in the month of April 2020 with 5102 visits per day on average (*P*<.001; vs April 2019). This represents a drop of more than 30% of total visits in March and more than 50% in April compared to the same months of the previous year.

In August 2020, compared to August 2019, the number of visits bounced back and the volume of daily visits did not show significant decreases again. In some months it was even significantly higher. The figure for November 2022 stands out, a month in which a maximum of 18,976 visits per day on average was reached (*P*=.002; vs November 2019), which is 40% more visits than the same period of the reference year (Multimedia Appendix 1).

Face-to-Face Visits

Regarding face-to-face visits, it can be observed that as of March 2020, there was a significant reduction that persisted until July 2022, the month from which a change in trend was observed and the levels of 2019 were recovered. In April 2020, this decrease was at its maximum and reached 85%, with 1604 visits on average per day compared to 10,987 in April 2019 (*P*<.001). Further on, the reduction was between 48% and 79% throughout 2020, between 17% and 67% in 2021, and between 13% and 47% in 2022, all with respect to 2019 (Multimedia Appendix 1).

Synchronous Non–Face-to-Face Visits

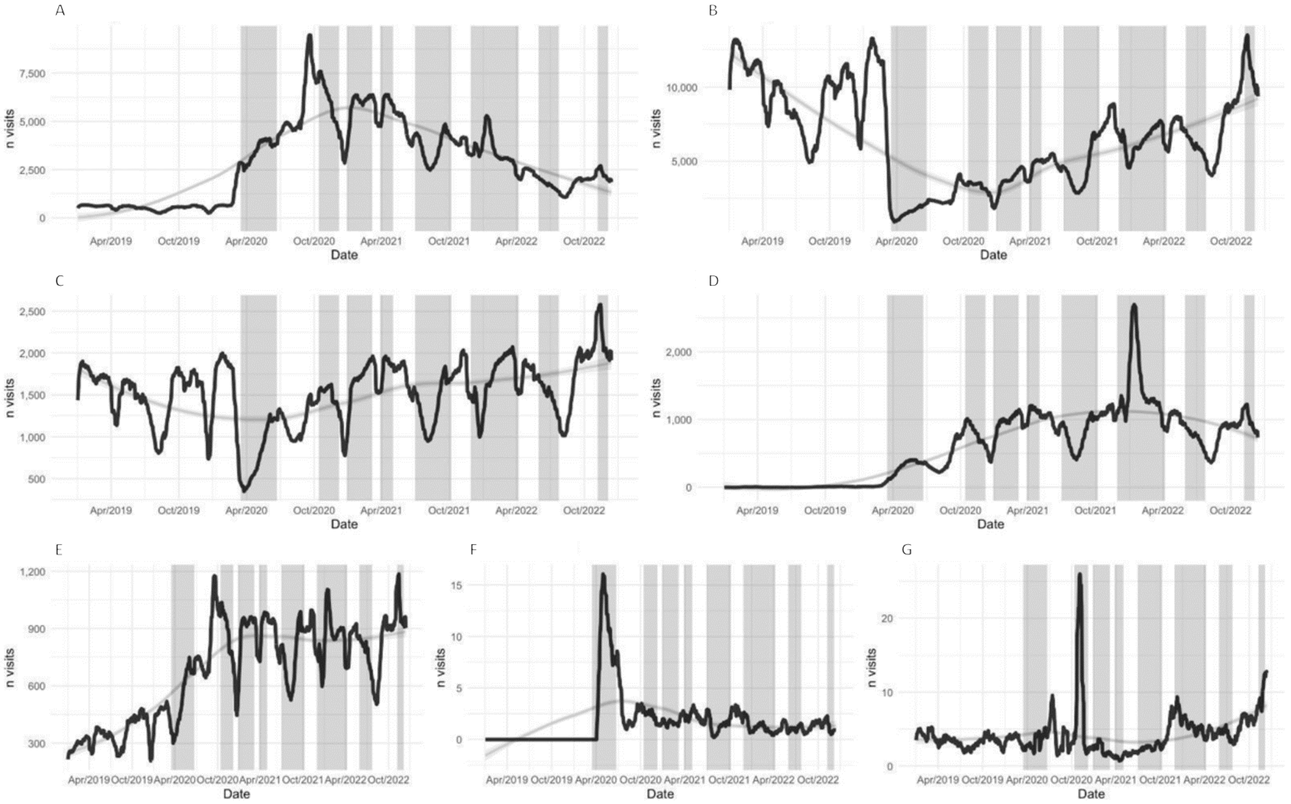
As for synchronous non–face-to-face visits, a statistically significant increase was noted starting in March 2020 that was maintained until the end of the study period. March 2020 saw a 200% increase in average daily visits and an increase from 620 daily remote visits in March 2019 to 2073 in March 2020 (*P*<.001). The increase was maintained, and synchronous remote visits went from representing 4.5% of total visits in 2019 to occupying 20% of total visits in 2022 (Multimedia Appendix 1).

Asynchronous Non–Face-to-Face Visits

Asynchronous non–face-to-face visits also experienced a statistically significant rise that had already been observed since January 2020 compared to the previous year. While in the first 3 months they had risen by around 60%, from April onward they rose by more than 90%, in May they rose by 154%, and they continued to increase during the following months. Growth continued and asynchronous remote visits increased from 2.8% of total visits in 2019 to 16% of total visits in 2022 (Multimedia Appendix 1).

Finally, Figure 3 [16,17] shows the evolution of the average number of daily visits according to the different subtypes (9C, 9D, 9R, 9T, 9Ev, 9E, and 9Ec).

Figure 3. Average daily visits by subtypes to pediatric primary care in Catalonia between January 2019 and December 2022: (A) 9T, (B) 9C, (C) 9R, (D) 9Ec, (E) 9E, (F) 9Ev, and (G) 9D. The vertical stripes indicate the 8 waves of COVID-19 in Catalonia.



Looking at face-to-face visits by subtypes, we can observe a marked reduction in face-to-face visits for acute diseases (9C) starting in March 2020, with a subsequent slow and progressive recovery that did not reach the previous values until November 2022. With respect to the check-ups of the *Infància amb Salut* (9R) program, a significant reduction was also detected as of March 2020, which recovered rapidly and practically completely during the second half of 2020. Pediatric home visits (9D) represented a very small volume with respect to total visits and did not undergo major changes during the years analyzed. However, a spike in these visits was noted during November 2020.

Regarding synchronous remote visits by subtypes, telephone consultations (9T) tripled from February to March 2020 and increased more than tenfold, peaking in September of the same year. Thereafter, a progressive decrease in the number of calls was observed, which at the end of the study period remained above the reference year. As for video call consultations (9Ev), although the values were also very low, we saw the emergence of this type of visit, with a sporadic peak between April and May 2020. Subsequently, they returned to a practically imperceptible level.

Regarding asynchronous remote visits, non–face-to-face visits (9E) already had a progressive growth before the pandemic, but it was between March and September 2020 when the sharpest increase was seen, which was maintained until the end of the period studied. Pediatric eConsultations (9Ec) rose slowly from March 2020 and stabilized at a higher position than before March 2020. A sporadic peak was detected in January 2022.

Discussion

Principal Findings

The aim of the study was to analyze the change in the types of pediatric visits to PC centers in Catalonia between 2019 and 2022, following the COVID-19 pandemic. In this context, we have been able to describe the evolution and coexistence between the different types of visits, both face-to-face and non–face-to-face visits, as well as the change in the pattern of pediatric consultations during this period. In summary, the results showed that non–face-to-face visits increased from around 10% of the total in January 2020 (before the pandemic) to almost 25% in December 2022 (after the pandemic). Half of these were telephone consultations and the other half were eConsultations.

Total visits to PC pediatric services fell from March 2020 and did not recover in overall number until September of the same year. From there, the overall volume resumed, with some subsequent fluctuations more or less in line with subsequent waves of COVID-19. In the first wave, there was a marked decrease in face-to-face visits and an increase in teleconsultations, in accordance with the literature. In a study conducted in a PC center in Madrid during the month of June 2020, it was observed that 51% of the visits were remote [18]. Other studies, both nationally and internationally, have also stated that between March and May 2020, the pattern of visits to PC centers changed [19,20]. There was a significant predominance of remote visits, especially by telephone, over face-to-face visits [21].

In the second, third, and fourth waves, face-to-face visits continued to decrease, while remote consultations continued to increase. During the fifth wave, defined by the Delta strain inmid-2021, there was a decline in both face-to-face and remote consultations, possibly because it was not a strain that affected the pediatric age group very much [22]. Nevertheless, remote visits continued to represent a significant part of the total number of visits. This fact changed with the sixth wave, starring the Omicron strain, between December 2021 and February 2022, which particularly affected children [23,24]. The corresponding peak of visits shows that more than half of the consultations at that time were non–face-to-face. During the seventh wave, in mid-2022, no change in the pattern of visits was detected. The eighth wave coincided with the marked increase in total visits, especially face-to-face visits, detected in pediatric services as of November 2022. The considerable increase in visits from November 2022 onward, which exceed prepandemic levels, could be due to the increase in infections reactive to ceasing use of protective measures against COVID-19. This phenomenon has been called immunity debt and may pose a risk for serious epidemics in the near future [25].

A breakdown of visits between face-to-face and non–face-to-face visits clearly shows a drop in the proportion of face-to-face visits and a rise in remote visits as of March 2020. Attendance recovered to prepandemic levels during November 2022 in absolute numbers but not in proportion. Although the number of total visits increased at the end of 2022 compared with 2019, the percentage of face-to-face visits decreased and the percentage of remote visits increased; thus, the results highlight that, during the pandemic, the pattern of the type of pediatric PC visits has changed, as seen in other studies [15,26].

In relation to acute demand (9C), the drop was very sharp, and the recovery was very slow, such that it was not until November 2022, two years later, that levels prior to March 2020 were reached again. This result is similar to the findings of other studies that detected a lower number of visits during the months following the onset of the pandemic, especially in acute infections [27-29]. This may be due to a lower circulation of pathogens other than the SARS-CoV-2 coronavirus. In general, it appears that the reduction in face-to-face attendance did not have much negative impact on urgent pediatric pathology care [30]. However, some studies have reported problems of diagnostic delays, such as an increase in complicated appendicitis cases [31]. On the other hand, an increase in overweight and obesity, technology use, sleep disorders, anxiety and distress, domestic violence, social isolation, and behavioral disturbances were also detected, especially in adolescents [32]. Likewise, due to the reduction in face-to-face attendance, an alteration in the circulation pattern of some respiratory viruses was observed during the subsequent season (2020-2021), especially for respiratory syncytial virus, which had an unusual peak of incidence in midsummer, as reported by the SIVIC [17].

As for the child health check-ups (9R) of the *Infància amb Salut* program, they recovered earlier than visits for acute diseases (9C). Although a drop was detected during March 2020, coinciding with the first wave of COVID-19 and stricter confinement, these visits recovered more quickly and were at the prepandemic level by the end of 2020. Quantification of the delay and losses of check-ups and vaccines showed that vaccination coverage decreased in all the autonomous communities of Spain by between 5% and 60%, depending on age and the type of vaccine [33]. The Spanish Society of Immunology, the Spanish Society of Paediatric Infectious Diseases, and the Spanish Association of Paediatrics published a document in April 2020 with complete information on the decreased uptake of vaccines, along with the criteria for the prioritization of childhood vaccination during the state of alarm carried out by the Ministry of Health [34]. Following the publication of similar figures, European pediatric societies called for the immediate recovery of vaccination programs, since compliance with the established vaccination schedule is one of the prerequisites for dealing with the resulting problems, such as immunity debt and the decreased uptake of vaccines [35].

Telephone consultations (9T), prior to March 2020, represented a minimal volume of total pediatric consultations. The onset of COVID-19 led to an exponential increase in the number of such consultations. They peaked during September 2020, probably coinciding with the start of that year's school year. Later, an oscillation in the number of calls was observed, although they remained at a higher value than in the period prior to the study. Therefore, the results suggest that telephone consultations have been one of the most widely used tools, both by users and professionals, to replace face-to-face visits during the pandemic [36]. This growth could be due to the ease of use of the telephone as well as to the organization of visits in PC centers, where it was established that the first patient assessment should always be made by telephone [37].

Regarding video call consultations (9Ev), the results have shown that they were used very little during the first wave of home confinement, and this is in agreement with the literature [38]. This low use could be explained by the limited technological resources for video visits, the technical difficulty it could pose for patients with lower digital literacy, and the fact that there was an impression that they did not add value to telephone consultations or eConsultations. Although they are currently practically not used in PC, the literature shows that they have a potential yet to be explored [39,40]. A systematic review conducted in 2021 on telemedicine in pediatrics, which includes 11 studies, concluded that care through call and video-call type visits in various pathologies (obesity, asthma, mental disorders, otitis media, and skin disease) can be comparable to, and in some cases even better than, face-to-face care; for these cases, it is necessary to improve user access and the effectiveness of services [41].

As for telemedicine consultations (9E), which are conducted without the patient being present, they were already on the rise before the pandemic but skyrocketed as of March 2020. One possible explanation is that since most of the COVID-19 cases in pediatrics were mild, many visits were probably made remotely, to indicate the result of the rapid viral detection test to administrative personnel, without ever having contact with health care personnel.

The pandemic was a clear catalyst for the use of eConsultation (9Ec). High use figures were reached and maintained at the end of the study period. In pediatrics, a peak of such visits was detected during January 2022, coinciding with the Omicron wave, which affected children in large numbers but had with low morbidity. Thus, the results of this paper and the literature suggest that eConsultation is here to stay [42].

It is also worth noting that although COVID-19 was a catalyst for the use of telemedicine in clinical practice, the Catalan health system has been promoting digital transformation through various "health plans" and different initiatives since 2011 [43-45]. In this context, the use of teleconsultation during the lockdown was essential to manage the health emergency at that moment. However, the Catalan health system had the digital infrastructure to cope with the situation and provide assistance. The population's experience of teleconsultation during the lockdown may have an impact on them, and the results also showed that currently, almost 25% of people used teleconsultation after the pandemic period.

During the COVID-19 pandemic, other modalities of pediatric telemedicine care for parents of patients were tested with good resolution and acceptance results, such as the creation of a Twitter (subsequently rebranded as X) profile called Equipo Pediatría HCSC (@EquipoHCSC) by a trained team of pediatricians in Madrid that resolved questions through private messages [46]. Another example is that of a health center in Zaragoza that had already developed an email consultation process, and they observed that during the strictest confinement, its use increased to the detriment of face-to-face consultations, although the most used modality was the telephone [47].

In relation to the use of information and communication technologies in pediatrics, there is the advantage, in general, that there is less of a digital divide on the part of users than in other areas. Several studies indicate that this is due to the age and education that parents usually have [48,49].

It was not only in pediatrics that a sharp reduction in face-to-face visits and a parallel growth in remote visits were detected. Equivalent results have been obtained from family and community medicine [50,51]. Telemedicine, however, has limitations in the human, technological, and economic spheres, and these must be understood by all parties involved. In addition, it is subject to current legislation based on the Organic Law on Data Protection and the doctor-patient confidentiality relationship. Thus, telehealth programs depend largely on the health care setting in which they are implemented. Conditions may change after the pandemic, and further studies will be needed [52].

In short, although the absolute number of face-to-face visits has recovered throughout the pandemic, telemedicine consultations established themselves as an important type of visit and made up almost a quarter of daily visits by the end of 2022. This indicates that some consultations that were previously carried out in person are now likely to be done remotely.

This analysis may contribute to a reorganization of the current model of PC pediatric services, which has been affected for years by the deficit and heterogeneous territorial distribution of professionals [53]. It can also help develop evidence-based guidelines for pediatric remote care focused on accessibility, quality, equity, and efficiency, as has been done in other territories [54,55]. It remains to be seen how, from now on, the application of digital health tools is managed in the field of PC pediatric services in Catalonia, as well as at a more global level, and whether it contributes to improving the current organization.

Limitations

This study has certain limitations that should be taken into consideration. First, the study did not examine the quality of care or patient outcomes that may have been associated with the changes in PC visits. Therefore, it is not possible to make conclusions about the overall impact of the changes on patient health. Second, the study did not take into account non–COVID-19–related factors that may have influenced PC visits during the pandemic. These factors include changes in patient behavior, such as reluctance to seek medical care due to the fear of contracting COVID-19, or changes in health care provider availability due to workforce shortages or redeployment to COVID-19 care. These factors may have contributed to the observed changes in PC visits and should be considered in future studies.

Conclusions

The COVID-19 pandemic has been a period of transition for the types of visits to PC pediatric services in Catalonia. It has undeniably accelerated the adoption of telemedicine in various health care systems, including pediatric care in Catalonia. In this context, although face-to-face consultations have recovered in absolute numbers, after the pandemic period, it is evident that telemedicine has gained prominence and plays a significant role in health care delivery. Thus, digital health tools are becoming a real possibility within current pediatric care, and it is difficult to imagine care without the technological integration acquired during the pandemic.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Average daily visits in total and for each type of visit (face-to-face, synchronous non–face-to-face, and asynchronous non–face-to-face), separated by month, to primary care pediatric services in Catalonia between January 2019 and December 2022. Percentage change with respect to the same period in 2019, SD, and *P* value are also shown.
[XLSX File, 42 KB - pediatrics_v7i1e49943_app1.xlsx]

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Abbreviations

PC: primary care
SIVIC: Sistema d’Informació per a la Vigilància d’Infeccions a Catalunya (Information System for the Surveillance of Infections in Catalonia)

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Touching Technology—Parents’ Experiences of Remote Consultations for Children With Severe Congenital Cardiac Conditions: Quasi-Experimental Cohort Study

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Abstract

Background: Remote consultations (RCs) using videoconferencing was recommended by the General Medical Council as the method for clinicians to provide patient consultations during the COVID-19 pandemic. Facilitating this while providing high-quality care depends on the usability and acceptability of the technology.

Objective: This project aimed to investigate parents’ experiences of using videoconferencing technology for real-time RCs with children who had congenital heart defects during the COVID-19 pandemic lockdown.

Methods: This study’s design was quasi-experimental and was underpinned by the Unified Theory of Acceptance and Use of Technology model that seeks to explain and predict an individual’s intention to use a technology. Parents were informed of this study by the medical team, posters were made available in the wards and clinics, and leaflets were left for browsing. Clinician screening of potential participants led to the identification of 33 children and parents who were enrolled on this study. The intervention was a web-based RC by medical staff using a secure, interactive videoconferencing platform (Pexip). Each child and their mother or father received 8 RCs with the same specialist doctor or nurse. Measurements were taken using web-based questionnaires pre and post consultation at the first, middle, and last events; questions were focused on the acceptability, usability, and clinical applicability of RCs. Parents’ experiences were explored using recorded interviews and analyzed thematically.

Results: In total, 29 children aged 4 - 1052 (mean 95, SD 191.14) days completed the project, receiving a total of 189 RCs as part of their routine care. Parents’ prior experience of consultation via videoconference was low; however, as time progressed, their use and acceptance of the technology increased. The intervention was warmly received by all parents who found the face-to-face component particularly useful for discussion with their child’s medical team. Furthermore, parents noted the savings on time, money, and childcare.

Conclusions: While in-person consultations are considered the gold standard of patient care, increasing pressures on health services and staff reduce availability. Given the ease of access and additional benefits experienced by parents and their children, it is proposed that hybrid models of consultation and care provision are equal, if not superior, to in-person consultations in the management of children with severe congenital heart defects while reducing costs and pressure on the health service and parents.

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KEYWORDS

congenital heart disease; pediatric cardiology; pediatric cardiologist; pediatric; parent; digital health; digital technology; digital intervention; telemedicine; telehealth; virtual care; virtual health; virtual medicine; remote consultation; telephone consultation; video consultation; remote patient monitoring; technology acceptance; videoconferencing consultations

Introduction

The Royal Belfast Hospital for Sick Children (RBHSC) is the only dedicated center for pediatric congenital heart disease (CHD) in Northern Ireland (NI) and provides a specialized service for the whole population. Since 2003, the RBHSC pediatric cardiology team has provided a sustainable home monitoring service for children with CHD post discharge from the pediatric cardiology unit [1-11]. This service has provided valuable ongoing contact and follow-up consultations between children and their parents and pediatric cardiology consultants and nurses, and it has reduced the need to travel to the hospital as frequently as would previously have been required. Considerable evaluation of the RBHSC pediatric cardiology remote consultations (RCs) using a videoconference service has already been conducted, and the data demonstrated an effective system providing reliable follow-up for babies or children assessed and monitored using audio and visual technologies [3,10]. This approach has been verified as effective and safe in a systematic review of telemedicine for pediatric cardiology [12]. RCs for pediatric care can offer a more timely response and enhanced quality of care when compared to in-person consultations [13-17]. Parents have reported a reduction in anxiety and an increase in satisfaction with services when receiving RCs compared to hospital consultations [6,10,13,18,19]. The evidence to support the use of telemedicine in general has been increasing over the last 2 decades, and there is now consensus on the benefits to children, their parents, health care staff, and the health service [7,13,20-23].

The COVID-19 pandemic presented major concerns for families regarding bringing children with CHD out of the safety of their home to the hospital, and the risk of exposing them to possible infection during travel or at their hospital appointment. Due to the COVID-19 pandemic, the use of telemedicine has been encouraged [24,25], and RC is ideal for patients, as it reduces the risk of exposure to infection [9]. Therefore, in order to meet the clinical needs of children and protect them and their families, the RBHSC service was expanded to offer remote pediatric cardiology RCs to children aged up to 16 years.

Initially, the RBHSC home monitoring service was facilitated by videoconferencing using Tandberg (Overland Tandberg) and Cisco (Cisco Systems, Inc) devices and software set up in the hospital videoconferencing suite and in the patient's own home. The device and, if required, broadband were installed in the patient's home by the Belfast Health and Social Care Trust. However, during the pandemic, engineers could not enter homes due to the risk of infection, and the Tandberg and Cisco infrastructure could no longer be installed in patients' homes. Therefore, as of April 2020, when in-person consultations were considered high risk, to maintain RCs and provide greater access, the RBHSC and parents of children with CHD started using a secure, videoconferencing platform (Pexip) with the aim of providing optimal RCs to assess, monitor, and manage condition progression during the pandemic.

The videoconferencing platform is accessed via the Pexip software application; can be downloaded to any internet-enabled device, including a smartphone, tablet, or computer; and provides a broad cloud-based, virtual meeting space that can only be accessed using a personal identification number code. The platform has a high level of interoperability, which allows access to users via a broad range of existing platforms. While increased accessibility may result in issues in terms of security, the developers state that the platform uses "formalized internal information security best practices," complies with ISO/IEC 27001:2103 and ISO /IEC 27701:2019 standards for information security and privacy and is General Data Protection Regulation compliant. It allows efficient bandwidth use regardless of where the meeting participants are located, ensuring high-quality video and audio. However, some people may experience technical challenges with, for example, the software and hardware, resulting in barriers to the adoption and acceptance of RCs [26]. New technologies in the clinical setting must be assessed and monitored to ensure they meet the ongoing needs of children, their parents or carers, and clinical staff. Therefore, the aim of this project was to evaluate parents' experience, perceived usefulness, usability, and acceptability of using a videoconferencing platform for remote pediatric cardiology consultations during COVID-19.

Methods

Study Design

This quasi-experimental cohort study ran from October 6, 2020, until April 27, 2022, and explored qualitative and quantitative outcomes of using a videoconferencing application for the delivery of 8 pediatric cardiology consultations to each patient to augment patient care during the challenges posed by the COVID-19 pandemic. Web-based questionnaires were developed using Qualtrics software. Based on the Unified Theory of Acceptance and Use of Technology (UTAUT) model [27], adapted for testing the videoconferencing application, the usefulness, usability, and acceptability of videoconferencing RCs were investigated. Parents provided feedback on their experiences of using videoconferencing and taking part in the project during interviews facilitated using WhatsApp (Meta Platforms) video calls.

Findings from this study relating to the number of attendances to the hospital, including both initiated and avoided attendances, as a result of RCs using videoconferencing have been presented elsewhere (Gillender et al, in press, December 2024).

Recruitment

Parents of children diagnosed with CHD were identified in the hospital ward, outpatient departments, or other pediatric cardiology satellite units within NI. Parents were approached by a pediatric cardiology clinician who informed them about the project and provided the participant information packs (PIPs). Parents provided written informed consent via email, WhatsApp, or post to 1 researcher (JEMM).

In order to minimize any risk of cross-contamination with coronavirus, the PIPs were printed and prepared while adhering to a strict protocol whereby a single masked operative, wearing gloves, prepared and packaged the PIPs. PIPs were delivered directly to the hospital where they remained in locked storage until required.

Parent or carers who had a child aged 0 - 16 years attending pediatric cardiology at the RBHSC were invited to participate and receive 8 RCs as part of their child's routine home monitoring care provision. The inclusion criteria included access to a device on which to download the videoconferencing application and ability to understand spoken and written English. The State Trait Anxiety Inventory (STAI) [28] was used as a screening tool, and parents with a score greater than 65 who chose to opt out of the project were excluded.

Parental anxiety levels were measured prior to the first RC and at the end of the project, using a web-based version of the validated self-completion STAI questionnaire [28], which indicates anxiety levels for a single point in time. The average STAI score for working adult females is 35.2 (SD 10.61), and for males, it is 35.72 (SD 10.40); the score is also age dependent [28]. However, given the nature of the medical condition under consideration, anxiety scores above the average for this population were expected. Based on previous research involving parents with children with CHD in NI [29] and a South American validation study of the STAI and the Beck Depression Inventory [30], the mean STAI scores for participants with anxiety was 52.8 (SD 11.42), giving a cutoff score of 65.

Videoconferencing Application

The videoconferencing platform can be easily accessed via the application, downloaded to any device, and used straight away. In most cases (21/32, 66%), participants were assisted with downloading and testing the application during an in-person discussion with the research doctor (JG). However, if children had already been discharged parents received an instruction sheet via email (Multimedia Appendix 1). RCs were carried out by JG and RB together or separately. Upon completion of the project children who continued to require home monitoring had further RCs.

Data Collection

Parents completed a baseline questionnaire at enrollment (T0) to collect demographic details and information about their use and experience of technology. Approximately 24 hours before and after the first (T1), fourth (T2), and eighth (T3) RC, parents were asked to complete the UTAUT questionnaire and details about their child's most recent RC. The UTAUT model is a theoretical framework that seeks to explain and predict an individual's intention to use a technology, as well as their actual use of that technology [27]. This questionnaire has been validated across a wide range of countries and for assessing different types of technologies [31,32]. Questions related to the quality of the technology interface based on work by Zhang et al [33] were also included. The UTAUT is designed to be adjusted to fit the technology under investigation, and therefore a certain amount of rewording was expected [27].

The UTAUT model is based on several key constructs:

1. Performance expectancy: An individual's belief that using a technology will lead to improved performance in a specific activity.
2. Effort expectancy: An individual's belief that using a technology will be easy and require minimal effort.
3. Social influence: The influence of others (eg, family, friends) on an individual's decision to use a technology.
4. Facilitating conditions: The availability and accessibility of necessary resources (such as training and support) that enable an individual to use a technology.

Table 1 shows the questions used in the project in relation to each construct. As part of the project, if required, parents were supplied with weighing scales and an oxygen saturation monitor to report their child's weight and oxygen saturation at each RC and for use as required.

Table . Project-specific questions used in relation to each construct of the Unified Theory of Acceptance and Use of Technology questionnaire.

Construct	Measure item
Performance expectance	• Using Pexip speeds up my child's care • Using Pexip makes it easier to manage my child's care • Pexip will increase the quality of my child's care • I find Pexip useful for my child's care
Effort expectancy	• Learning to operate Pexip has been easy for me • I find Pexip flexible • I find Pexip easy to use • Using Pexip takes too much time • Using Pexip is complicated • Learning to use Pexip has been easy for me • Overall, I believe that Pexip is easy to use
Social influence	• People who are important to me think that I should use Pexip • The hospital has helped me to use Pexip • The hospital has supported me to use Pexip
Facilitating conditions	• I have control over using Pexip • There is someone available to help me with any difficulties I have with Pexip • Using Pexip fits well with my and my child's routine

Parent Interviews

Parents were invited to discuss their experience of using the videoconferencing application for their children's routine RCs. Interviews were conducted via WhatsApp by 2 members of the research team (MS and JEMM) using open and closed questions. WhatsApp was used to ensure parents skills and experience relating to the use of the videoconferencing application was strictly confined to the RCs. All interviews were audio recorded and carried out within 1 week following T1, T2, and T3 and at parents' discretion. Training in the use of video calls was not required, as all parents were experienced users.

Interviews were analyzed using Braun and Clarke's Reflexive Thematic Analysis method [34]. This approach was considered the most suitable to explore the lived experiences of using videoconferencing and add meaning to the findings from the UTAUT questionnaire.

Statistical Analysis

Descriptives statistics were generated. Frequencies, means, and SDs were generated according to variable type. Cronbach α's were generated for constructs (Table 1). Using repeated measures analysis of variance, the pre- and postintervention UTAUT questionnaire data points were analyzed.

Ethical Considerations

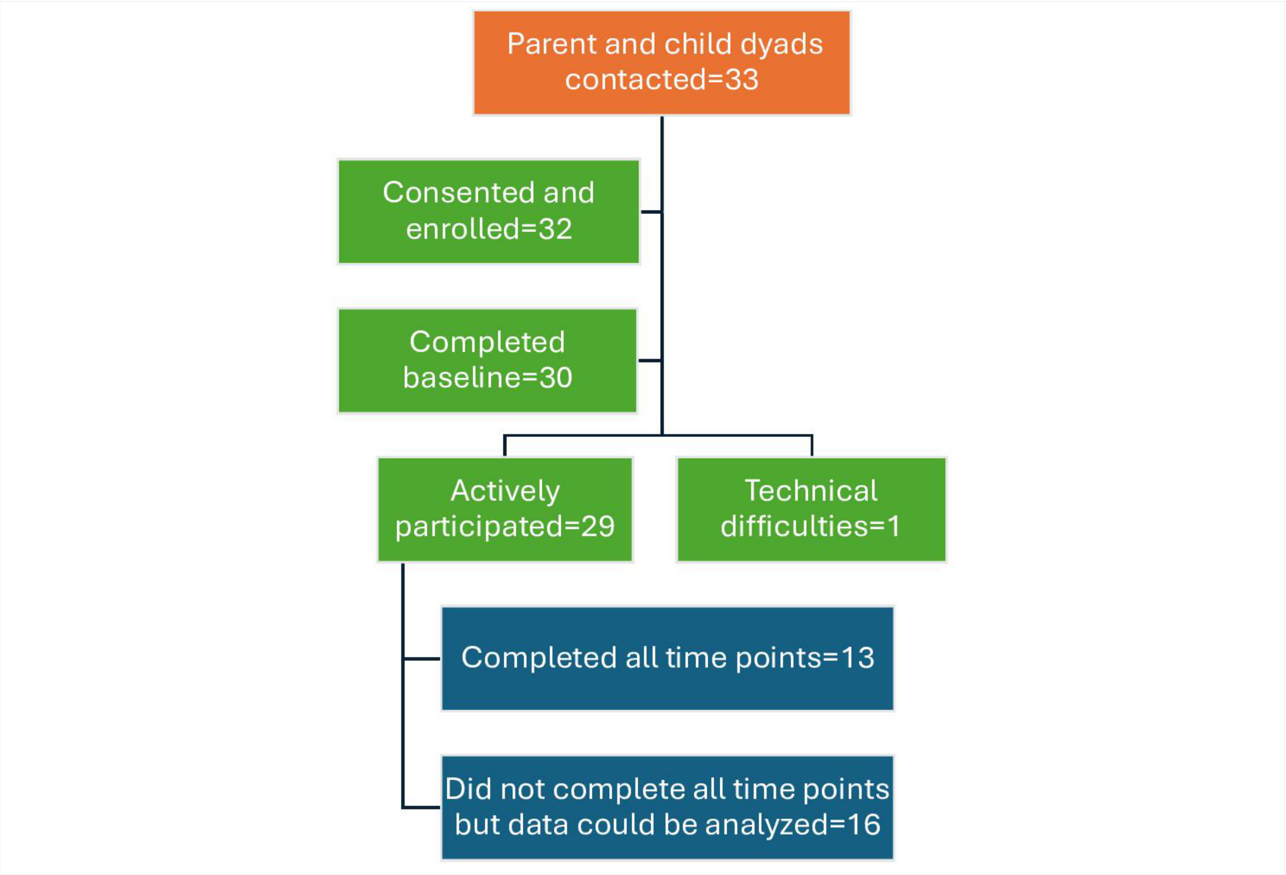
Ethical approval was granted by East of England—Cambridge South Research Ethics Committee on September 23, 2020 (20/EE/0190) and Confirmation and Capability at Belfast Health and Social Care Trust was granted on October 6, 2020 (HSC Trust reference: 20028MS-SW). All parents and children had the choice to opt out of the study or leave the study at any time after providing informed consent, without the need to provide a reason and without otherwise affecting the medical care children received. All quantitative data collected were anonymized, and all qualitative data were deidentified before analysis. In this study, no compensation was provided to parents or children for their participation.

Results

Recruitment

The parents of 33 children were approached while their child was an inpatient at the RBHSC or a regional general hospital (n=21) or was attending an outpatient clinic (n=12), and 32 child and parent dyads provided written consent and were enrolled in the project. For 1 child, both parents actively participated in the project (participants 1004a and 1004b). In total, 30 dyads (31 parents) completed the baseline questionnaire, and 1 dropped out due to technical issues. Therefore, 29 child and parent dyads completed the project, with 13 completing all time points. Figure 1 demonstrates the flow of participants throughout the project.

Figure 1. Recruitment and retention flowchart for the pediatric cardiology remote consultation project.



Participant Characteristics

Of the parents who completed the project, 93% (n=28) were mothers, 11 of whom were first-time mothers, and 6 (54.5%) of these received their child's diagnosis post birth. None of the parents had an STAI score above 65. Of the 29 children participating, 38% (n=11) were female. In total, 23 children were aged younger than 3 months at enrollment (mean 37.62, SD 32.5 d), 5 were aged between 3 months and 1 year, and 1 child was over 34 months (1052 d). Families resided across all 5 Health and Social Care Trusts in NI at a maximum distance of 133.1 km from the RBHSC, equating to a 3- to 4-hour round trip (Multimedia Appendix 2). Table 2 shows the demographic characteristics of the participating parents and children. The participating children had a range of complex conditions requiring surgery within the first 6 months of life (Table 3). In total, 17 children had a surgery or procedure during their participation. Half of the children had a coexisting congenital anomaly, with Down syndrome being the most common (n=7, 24%).

Table . Demographics of the parents (n=30) and children (n=29) who completed the pediatric cardiology remote consultation project.

Characteristics		Participants
Gender (parents), n		
	Female	28
	Male	2
Age of parents (years), mean (range; SD)		32.9 (20 - 47; 5.5)
Education level of parents, n		
	No qualifications	0
	High school	6
	College	8
	Apprenticeship	2
	Undergraduate	6
	Postgraduate	8
Distance from home to Royal Belfast Hospital for Sick Children (km), mean (range; SD)		49.3 (2.3 - 133.1; 39.61)
Timing of child’s diagnosis, n		
	Antenatal	13
	Postnatal	16
Sex (children), n		
	Female	11
	Male	18
Age of children at enrollment (days), mean (range; SD)		98 (4 - 1052; 191.14)

Table . Conditions of children included in the pediatric cardiology remote consultation project.

Primary cardiac diagnosis	Cases (n=29), n (%)
Tetralogy of Fallot	7 (24)
Atrioventricular septal defect	5 (17)
Ventricular septal defect	4 (14)
Shone complex (days)	2 (7)
Dysplastic tricuspid valve	2 (7)
Coarctation of aorta	2 (7)
Complex single ventricle pathology	2 (7)
Transposition of the great arteries	1 (3)
Patent ductus arteriosus	1 (3)
Total anomalous pulmonary venous drainage	1 (3)
Cardiomyopathy with severe outflow obstruction	1 (3)
Restrictive and hypertrophic cardiomyopathy	1 (3)

Videoconferencing Enabled Remote Consultations

In total, 201 (range 1 - 8) RCs were completed as part of the project, with the first RC (T1) taking place at a mean duration of 25.07 (SD 17.74; range 0 - 57) days following discharge.

Data gathered at baseline demonstrated that 23% (7/30) of parents were somewhat or not very experienced in the use of technology (Table 4). However, following their first experience using videoconferencing for RCs (T1) 83% (20/24) agreed that it was easy to use. At T3, 100% (n=17) agreed it was easy to use.

Table . Participating parents' (n=30) self-reported level of experience of using technology at baseline (T0).

What is your level of experience in using the following	Not very experienced or somewhat experienced, n (%)	Neither experienced or inexperienced, n (%)	Quite experienced or very experienced, n (%)
Electronic devices such as smart phones and tablets	6 (20)	3 (10)	21 (70)
Computers	9 (30)	3 (10)	18 (60)
Talking to others on video calls	8 (26.7)	3 (10)	19 (63.3)
Technology overall	7 (23.3)	4 (13.3)	19 (63.3)

A total of 63 post-RC questionnaires out of a possible 90 were completed, giving a 70% completion rate. On these occasions, 100% (n=29) of parents agreed or strongly agreed with the question "The problems and or questions I had were answered to my satisfaction during the videoconference."

During 97% (61/63) of the RCs, parents used smartphones, including iPhone (n=24, 38%) or Android (n=37, 59%) smartphones. For 2 calls, an iPod was used. For 21% (13/63) of the calls, an audio problem was reported; these were resolved on most occasions by hanging up and reconnecting or performing a forced stop of the videoconferencing application and reconnecting. No parents reported an issue with the video quality of the RCs.

Technology Acceptance

The Cronbach α coefficients for the constructs in the UTAUT adapted for this study were 0.94 for performance expectancy, 0.91 for effort expectancy, 0.76 for social influence, and 0.77 for facilitating conditions, suggesting that the questions presented in the questionnaire were correlated and measured the same concepts.

Across the 4 constructs of the UTAUT, results showed a nonstatistically significant trend upward (n=14). Therefore, this suggests that as parents became more experienced at using videoconferencing for RCs their beliefs in its ease of use and their acceptance of it were enhanced.

Parents' Experiences

A total of 41 interviews were conducted via video call with 26/30 parents (Table 5) to assess parents' experiences. The total duration of interviews analyzed was 19 hours and 56 minutes. Further, 1 parent declined to take part in any interview, and 4 could not take any calls due to their baby being admitted to hospital, work commitments, and scheduling issues. In total, 5 participants enrolled in the project completed all 3 interviews. Parents did the interviews most often with their child; alone; or with other family members present, including their child's other parent, sibling, or grandparent. On average, interviews lasted 20 minutes. Data saturation was achieved.

Table . Number of parents (n=30) completing video call interviews on the pediatric cardiology remote consultation project.

Video call interviews	Parents completing interviews (n)
No interview	5
1 interview	14
2 interviews	6
3 interviews	5

Parents reported their main concerns discussed at each RC were feeding, including breast feeding; weight; medications; surgery timing; surgical wounds; and details about their child's condition. Further, 1 parent reported that they asked about childhood vaccinations and about taking their baby swimming. At T1 (n=23) and T2 (n=20), 100% of parents agreed their problems or questions were answered to their satisfaction during the RC, and 94% (15/16) of parents agreed at T3. Following the RCs, parents agreed it had been beneficial at T1 (19/23, 83%), T2 (20/21, 95%), and T3 (13/17, 76.5%).

An experienced member of the pediatric cardiology team assessed key clinical parameters during each RC. These included the child's feeding, weight, medications, color, breathing, oxygen saturation, and overall well-being. The clinical outcomes from this study are reported separately (Gillender et al, in press, December 2024).

Of the 26 parents who were interviewed 100% felt using videoconferencing for RCs was helpful, were pleased to have the opportunity to use it, and would recommend it to others. Benefits included reduced time and cost for the family in terms of travel, fuel, and childcare costs, having a planned call with a pediatric cardiology specialist at a time that worked for them and their family, and the flexibility of the RC.

Thematic analysis of the post-RC video call interviews using Braun and Clarke's approach [34] identified 5 key themes:

- The ease of using videoconferencing for RCs
- The reassurance of having regular RCs
- The value of the visual component of the RCs
- The opportunity to ask questions during RCs
- The non–health-related benefits of RCs

Discussion

Principal Findings

Parents caring for sick children are vulnerable to “social, psychological, physical, relational, individual, and financial” risks [35], which can lead to detrimental effects on the well-being of their children and other family members [36]. However, caring for children at home can have positive effects for the child, parents, and wider family, and strong, trusting relationships between parents and the clinical care team may reduce parental stress levels and contribute to resilience [37,38].

Remote patient monitoring has become more prevalent and relevant as the pressures on health care providers and service delivery increase. However, RC can only provide sustainable and optimal health care when considered within the reality of the patient lived experience; clinical expertise; and available finances, services, and resources.

In this project, over half of the parents had a baby whose CHD diagnosis was made postnatally. Navigating the complexities of new parenthood, an unexpected diagnosis, and new methods of interacting with health professionals using technology, all during the uncertainty of the COVID-19 pandemic, led to parents feeling frightened with deep concerns about all aspects of their child’s health.

> *I was frightened, it’s the only reason I said I would go home, if I had something like that [videoconferencing for RC], if they give me contact with somebody* [Mother 1027]

Parents’ Experiences of Videoconferencing Enabled Remote Consultations to Manage Their Child’s CHD

The Ease of Using Videoconferencing for Remote Consultations

Findings from the UTAUT questionnaire showed that using videoconferencing for RCs got easier over time and became more acceptable. Parents found the informal coaching in downloading and using the application to be very beneficial and the written instructions easy to follow. Although 27% (8/30) of parents reported limited experience of talking to others on video calls, they reported that they found the videoconferencing application easy to use, suggesting they would be more likely to connect.

> *You literally just click on the app, it’s…really straightforward, I called him [doctor] and it worked…it’s very simple* [Mother 1010]

Parents quickly became experienced using videoconferencing for RCs and meeting with the clinical team. They were better prepared for the calls, actively made decisions to improve the interactions, and set up in a way that worked best for them. For example, having their baby undressed for visual assessment, weighing their baby in advance, and having the oxygen saturation monitor nearby or attached to the baby. In addition, if there was an issue with the audio or video quality during a RC they reconnected to resolve the issues or used a forced stop of the videoconferencing application. As their skill and knowledge increased, their confidence increased, and they found it easier to ask questions.

> *Before I went on the calls I was a wee bit anxious…I didn't know what I was expecting, but it actually made me feel quite at ease because I know now that…every two weeks we do it* [Mother 1023]

The Reassurance of Having Regular Remote Consultations

Becoming a parent can have major physical, social, and psychological implications [39], and new parents require help and support from family and friends to successfully navigate their new role and responsibilities [40]. However, when their baby has a complex medical condition, support and guidance are also required from specialist medical teams, as well as building strong relationships to optimize the child’s care using the most appropriate techniques and technologies [35,41]. Remote monitoring, while essentially about the patient, also supports parents’ emotional well-being and empowers them which is essential for the continued and sustained welfare of their children.

> *I think it’s great to get the confidence to be able to take the lead in the child’s care and obviously have that support in the background. I think sometime parents can be overwhelmed by medical staff and they might think they’re not doing things right, but a parent’s intuition is always the best intuition I think* [Mother 1004]

The Value of the Visual Component of the Remote Consultations

This project aimed to provide the highest quality of interactions via synchronous RCs. Parents were impressed by the quality of the video and felt that the visual aspect was key for them. Theoretically, “ocularcentrism,” where people need to see each other to enable them to communicate more effectively, is likely an important determinant in their preference to use videoconferencing for RC [42].

> *Describing symptoms over the phone isn't that useful because they ask you what colour he is and it’s hard to describe a colour over the phone, it’s hard to describe his breathing over the phone, it’s so much better if they can just actually see him and look at him…the seeing bit is key* [Mother 1001]

RCs allow parents to care for their child at home while ensuring very sick children are rapidly admitted to a hospital when required [16]. The RBHSC team was experienced in carrying out RCs and in using the video and audio to assess babies and children, and parents trusted the doctor and the continuity of care.

> *I thought she [baby] just had reflux but it was [doctor] on the call made the call, calm as you like, “I'll see you in the Royal [RBHSC] in an hour”. And I was like, why is he dramatizing this?… Of course then when we arrived…that was that, she was going for a stent. But I didn't realise she was sick, because you know, to me she’s not blue, although she is blue*

> *to other people…. So I think, because I'm constantly looking at her, I didn't realise she was sick and I was blaming the machine [oxygen saturation monitor] and he was like "I think maybe you should just come on up," and I was thinking why's he taking me up that road?… and she was admitted…so without this [RC] I would never have ever in a million years ever phoned and said she's off form because for me it was reflux and I just thought she'll be fine…. When I got up there, I realised the extent of it, I totally owe her life to him…he was so calm, I just thought he was being dramatic, you know really checking her out…he saved her that day, he definitely did* [Mother 1003]

Opportunity to Ask Questions During Remote Consultations

In a web-based survey, 90% (n=10) of parents of children with CHD reported that the question *How many children have heart surgery and how many survive?* was important or really important to them [29]. Parents have many questions regarding their child's condition but often find it difficult to have the confidence or be "brave" enough to ask.

> *it gives me massive confidence, massive…as I say I wouldn't be panicky anyway but I've never had a cardiac baby before…. I do tend to have a lot of questions* [Mother 1024]

Non–Health-Related Benefits of Remote Consultations

Many parents simply cannot stay at the hospital with their sick child for long periods of time. They feel they neglect their other children, do not have time to travel long distances to the hospital, or do not have the finances or support infrastructure to do so, exacerbating their feelings of stress and anxiety. RC is convenient, as it reduces costs, time, childcare, travel, preparation, and waiting for children and their parents, especially for those in remote areas [15,19,43-46]. Parents in this project agreed with this.

> *it's just so convenient especially with home schooling at the minute because the three of them [other children] are at home…it saves me round trips so it therefore saves you on your pocket, it saves you time because it's not just an hour up the road and down the road, you have to consider your parking…then your appointment takes maybe three hours it's a whole day, a whole day, its mad!* [Mother 1003]

Flexibility of the timing of the RCs was important to parents to enable them to have some time to prepare for the call, and the overall convenience improved parents', and therefore their child's, experience. It also facilitated streamlined RCs and improved use of time for the clinicians.

> *It's so flexible which is brilliant it's not like having to be at the hospital for a certain time with parking and everything that goes with it…it would be half a day if we had to go to the hospital because getting packed up and all his stuff and medications, getting to the hospital, getting parked, getting in, and the phone call was 15, 20 minutes* [Mother 1019]

COVID-19

In response to the COVID-19 pandemic, the General Medical Council (GMC) [47] recommended that "doctors should...triage and treat patients by remote consultations where possible," and the Royal College of Physicians [48] stated "there has never been a time when effective remote consultations have been needed more." The number of visits and in-person consultations at the RBHSC were reduced during this project, therefore reducing the risk of infection for vulnerable children. Interestingly, however, COVID was only mentioned on 4 occasions by 4 parents. Further, 3 were not that concerned about COVID.

Additionally, 1 parent was concerned that their child could "catch something" while at the hospital. Nevertheless, they still wanted their child to have in-person consultations at the hospital.

> *if you're going up there [RBHSC] every week then obviously there's a chance…that something could happen or she could catch something…but I still like going up every so often just for that wee bit extra reassurance* [Mother 1013]

Comparison to Tandberg

The necessary move away from the Tandberg and Cisco remote monitoring system to the Pexip application RCs meant no installation of hardware was required. The application could be downloaded to any device, and RCs could begin immediately once children left the hospital allowing them to be discharged sooner. Compared to static Tandberg, the videoconferencing application was superior in terms of the cost of hardware installation and convenience, bed availability, carbon footprint, and potentially workforce sustainability. By using mobile phones, parents could zoom in on their baby, enabling the clinicians to visually assess the baby. The health care providers could also see the surroundings of the babies, which may be an important tool if there were concerns about the home environment. In 2018, the GMC [49] published a report commissioned to inform the regulatory requirements relating to telemedicine in the United Kingdom, with the key focus being to ensure that patients' safety was not compromised. The GMC [47] provided a flowchart to assist clinicians to "weigh up the factors" regarding whether to provide treatment remotely or in person. However, this guidance does not mention the technological tools and skills required of the patient or carer. The reported usefulness, usability, and acceptance of the videoconferencing application for RCs by parents suggest it would be rapidly adopted by parents who quickly and easily learn to use the application, set up to optimize the call, and troubleshoot, making it as easy as possible for them to connect and engage with clinicians.

Managing and monitoring the care of sick children are the main focus for clinical teams during RCs. However, they also have the potential to provide reassurance and support to parents by reducing their anxiety and giving them a vital role in the care and decisions regarding their own baby at a time when many may be overwhelmed by a CHD diagnosis. In a project in China, Zhang et al [50] used the WeChat platform for remote monitoring of infants with CHD. It included a clinician led live daily interactive question and answer session for parents and led to a reduction in parents' depression and anxiety [50].

Limitations

It is important to remember that while NI has the highest rates on fiber broadband availability in the United Kingdom, a proportion of the population have poor internet access, mainly homes in rural areas [51] both in NI and worldwide. However, no child should be disadvantaged by a lack of internet, and continued support, as required, from the RBHSC and in other jurisdictions in terms of hardware and software is warranted. Such provision should be viewed as an investment, not a cost. Worldwide, key to the success of RC provision is parent and carer involvement, including training, guidance, and support to enhance digital literacy and confidence in using technology.

Throughout the project, parents and the RBHSC pediatric cardiology team were clear that RCs should not and would not replace in-person consultations. Although they reported RCs were as good, parents still valued the hands-on, in-person consultations above RCs. Therefore, and as shown in this current project, a hybrid model of RCs and in-person consultations based on patient needs would provide the best possible care. However, the duration between in-person appointments may be lengthened if parents find this acceptable and children are well.

Caution is needed when using RCs for remote monitoring of children. Not all parents were regularly available for RCs, and it was suggested by 1 parent that some could use remote monitoring in negative ways by not disclosing details about the child's health if they faced financial or emotional difficulties.

> *In-person I know they'll not let me go home if she's not right whereas, if you were a wee bit careless you could mask what's going on…because you can't be bothered doing the [trip to the hospital] or the other thing is, probably if you struggled financially…maybe it's just not possible to do the trip so maybe you're going to tell lies* [Mother 1003]

As clinicians continue to use RCs more for remote monitoring, they are at risk of experiencing digital fatigue, "a state of mental exhaustion and disengagement caused due to prolonged exposure to digital tools, apps, and screens" [52]. Therefore, it is important to protect clinicians who are already under unprecedented levels of pressure as patient numbers continue to increase. It is also important that for clinicians who are new to RCs or are using a new software for RC, extra support and time are provided to develop their skills in identifying issues and using the technology.

Future Opportunities

As remote monitoring becomes more prevalent, future opportunities for additional functionality may include artificial intelligence (AI) and machine learning to enhance engagement and reduce workload. AI could be incorporated to schedule appointments, and natural language processing could be used to automatically parse and interpret RC dialog to provide personalized reminders and follow-up tasks. Machine learning algorithms could be embedded for continuous monitoring of and real-time feedback on data from oxygen saturation monitors, to identify high-risk patients and target interventions.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Pexip application download instruction sheet provided to participating parents.
[DOCX File, 1094 KB - pediatrics_v7i1e54598_app1.docx]

Multimedia Appendix 2
Map of Northern Ireland showing the home locations (blue) of participating child and parent dyads in relation to the Royal Belfast Hospital for Sick Children (red).
[DOCX File, 312 KB - pediatrics_v7i1e54598_app2.docx]

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Abbreviations

AI: artificial intelligence
CHD: congenital heart disease
GMC: General Medical Council
NI: Northern Ireland
PIP: participant information pack
RBHSC: Royal Belfast Hospital for Sick Children
RC: remote consultation
STAI: State Trait Anxiety Inventory
UTAUT: Unified Theory of Acceptance and Use of Technology

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Opportunities for Telemedicine to Improve Parents' Well-Being During the Neonatal Care Journey: Scoping Review

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Abstract

Background: Neonatal intensive care unit admissions of newborns are emotional and stressful for parents, influencing their mental and physical well-being and resulting in high rates of psychological morbidities. Significant research has been undertaken to understand and quantify the burden of a newborn's medical journey on parents' well-being. Simultaneously, an increase has been observed in the development and implementation of telemedicine interventions, defined as the remote delivery of health care. Telemedicine is used as an overarching term for different technological interventions grouped as real-time audio-visual communication, remote patient monitoring, and asynchronous communication. Various telemedicine interventions have been proposed and developed but scarcely with the primary goal of improving parental well-being during their newborn's medical journey.

Objective: This study aims to identify telemedicine interventions with the potential to improve parents' well-being and to present the methods used to measure their experience.

Methods: A scoping review was conducted, including empirical studies evaluating telemedicine in neonatal care that either measured parental well-being or included parents in the evaluation. Abstract and title screening, full-text screening, and data extraction were performed by three researchers. Two researchers were needed to reach decisions on both the inclusion and extraction of articles.

Results: The review included 50 out of 737 screened articles. Telemedicine interventions focused mainly on daily visits at the neonatal intensive care unit and discharge preparedness for parents. Surveys were the primary tool used for outcome measurement (36/50, 72%). Aspects of parents' well-being were evaluated in 62% (31/50) of studies. Telemedicine interventions developed to provide education and support showed a potential to improve self-efficacy and discharge preparedness and decrease anxiety and stress when they included a real-time telemedicine component.

Conclusions: This scoping review identified specific telemedicine interventions, such as real-time audio-visual communication and eHealth apps, that have the potential to improve parental well-being by enhancing self-efficacy and discharge preparedness, and reducing anxiety and stress. However, more insights are needed to understand how these interventions affect well-being. Parents should be included in future research in both the development and evaluation stages. It is important to not only measure parents' perceptions but also focus on the impact of a telemedicine intervention on their well-being.

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KEYWORDS

telemedicine; telehealth; neonatal care; parental well-being; family-centered care; pediatrics; neonates; newborns; parents; neonatal intensive care unit; NICU

Introduction

Admission of a newborn to a neonatal intensive care unit (NICU) places a high emotional burden on parents [1]. This often unexpected neonatal admission exposes the parents to a high risk of developing psychological morbidities, including posttraumatic stress disorder [2]. Parental well-being, referring to the overall mental, emotional, and physical health of parents during and directly after the medical journey of their newborn, influences child development [3,4] and the risk of developing long-term psychological morbidities for the parents [5]. Their well-being is influenced by the stress or anxiety they experience due to the severity of the child's medical condition [6,7]. Additionally, their mechanisms for coping with the medical situation and traumatic moments, as well as their self-efficacy and confidence in their parenting skills, can further influence their well-being [7-9].

Despite the increasing awareness of the relevance of parents' well-being during the neonatal care journey, insights into parents' needs and effective interventions to enhance their well-being are lacking [10]. Steps have been taken to identify needs and factors that influence parental well-being [10-13]. Identified parental needs during the care journey include informational needs, emotional needs, involvement in decision-making, financial needs, practical needs, and ways to cope with transfers and discharge [10,11,14]. Furthermore, parent-infant bonding and social support are important factors associated with depressive symptoms within the first 12 months after discharge from the NICU [12,15]. Discharge from the hospital is affected by communication, unmet informational needs, and the management of expectations and perceptions, exposing an important role for peer support and improved communication by health care providers [13]. Consequently, suggested opportunities to improve parental well-being often focus on communication and informational provisions [16].

Telemedicine interventions are emerging, including within neonatal care [17]. Telemedicine is defined as the remote delivery of health care [18] and is often grouped in (1) remote patient monitoring, (2) real-time health care provider–to–health care provider or health care provider–to–patient consultations, and (3) asynchronous (non–real-time) telecommunication [19]. With telemedicine interventions focusing on the transfer of information, communication, and participation by family members, it has the potential to fulfill the exposed parental needs described above [20]. The importance of parental involvement when developing, evaluating, and implementing telemedicine interventions is underscored by the noticeable increase in the use of patient/parent-reported experience measures (PREMs) and patient/parent-reported outcome measures (PROMs) for evaluating telemedicine interventions [21]. Despite the potential and growing use of PREMs and PROMs, telemedicine interventions are rarely implemented with the primary aim of enhancing parental well-being [22,23]. Therefore, this study aimed to identify telemedicine interventions that potentially enhance parental well-being during the neonatal care journey by performing a scoping review.

Methods

The scoping review was conducted following the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) guidelines for scoping reviews [24].

Eligibility Criteria

Using the PICO (Population, Intervention, Comparator, Outcome) framework, the following inclusion criteria were defined:

- The population/setting of the study must be during the neonatal care journey.
- The intervention must be a telemedicine intervention.
- There was no restriction on the comparator group.
- The outcome measures should include aspects of parental well-being or parents' perception of the intervention.
- The included studies must be published and use an empirical study design.

The neonatal care journey was demarcated from the neonate's admission to a neonatal ward in the first week of life and ranged from immediately after birth to 12 months of follow-up. Therefore, studies were excluded when they included only healthy neonates, neonates admitted to a nursery directly after birth, or neonates with congenital abnormalities admitted to a hospital ward later than the first week of life. Telemedicine was defined as the remote delivery of health care, without any restrictions on the technologies used [18]. Long existing technologies, such as telephonic consultations or SMS updates, were purposefully included in this review to include the whole variety of interventions. However, digital health applications that did not provide health care were excluded, such as electronic patient record systems, medical decision support tools, organization tools, or interventions used for training medical professionals. Eligible outcome measures including parental well-being or parents' perception of the intervention were (1) PREMs, for instance focusing on the usability or satisfaction of the intervention; (2) measures on how the intervention influences the parent's journey, for instance, travel time saved; and (3) PROMs regarding their well-being, such as depression, anxiety, self-efficacy, or posttraumatic stress disorder. These outcome measures were not confined to quantitative outcomes or validated questionnaires, as qualitative studies can provide a more nuanced description of experiences.

Articles published before the year 2000, not available in English or Dutch, without full-text availability, or with a nonempirical study design (protocols, reviews, editorials, etc) were excluded.

Search Strategy

Medline, Embase, Web of Science, Cochrane, and Google Scholar databases were searched using the following search terms: telemedicine, neonatal care, parents or caregivers, and experience or perspective (complete search is presented in Multimedia Appendix 1). The search was performed on February 23, 2024.

Screening

Title and abstracts were screened by three independent researchers (JW, CM, FB) using the Covidence (Veritas Health Innovation) program for systematic reviews. Two discussion sessions were organized to align the interpretation of the eligibility criteria. Two reviews were needed to reach a decision, and conflicts were resolved by discussion. Full-text screening was performed by JW, CM, and FB.

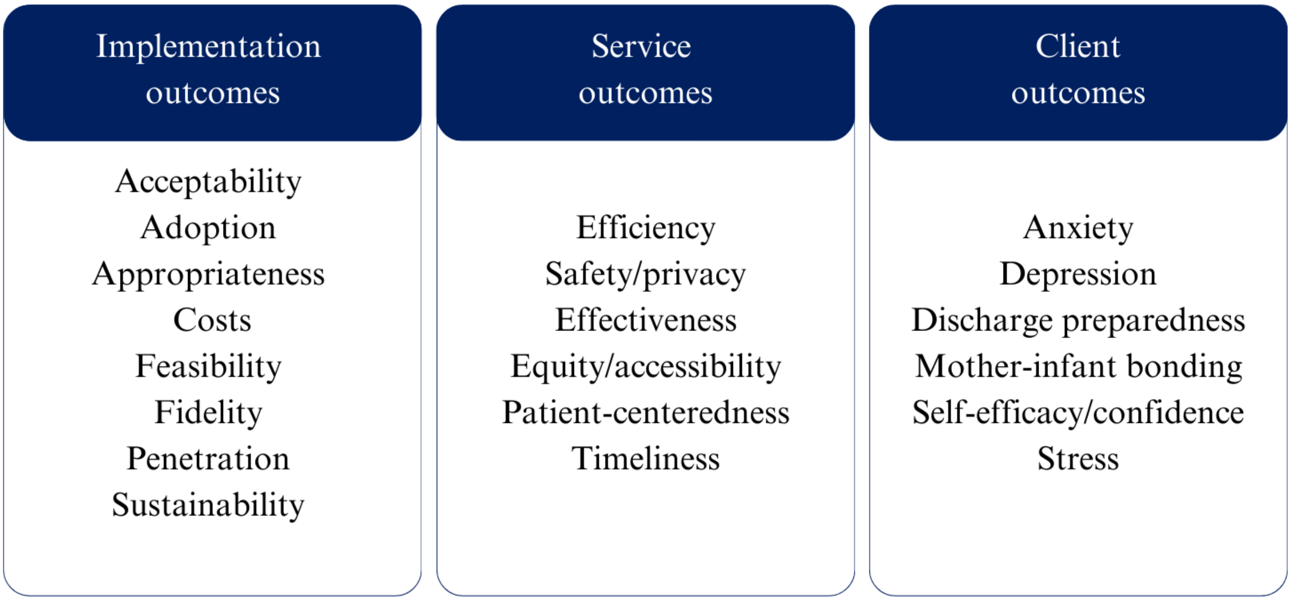
Data Extraction

The data extraction form was reviewed and tested by three reviewers (CM, FB, JW). Data were extracted by CW, and JW verified all extraction data. The following data items were extracted per included study:

- Background information on the study: title, author, year of publication, country of origin, study design, and aim of the study
- Information on the telemedicine intervention: name of the intervention, purpose, type of telemedicine; users, and the moment of use within the neonatal care journey
- Methods of evaluation and the participants
- Outcomes of the study

Outcomes were extracted following the implementation science framework by Proctor et al [25] suggesting the categorization of outcomes into implementation outcomes (how is the implementation used and appreciated in clinical practice?), service outcomes (how does the implementation influence the way clinical care is delivered?), and health outcomes (how does the implementation affect patient/parent outcomes?). Relevant outcomes for this specific scoping review are visualized in Figure 1. For health outcomes, this review focused on components of parental well-being, for instance, stress levels, confidence in their parenting role, and self-efficacy. This outcome framework categorizes PREMs into implementation or service outcomes and PROMs into health outcomes [21].

Figure 1. Outcome categorization used for this scoping review adapted from the framework of Proctor et al [25].



Data Synthesis

Baseline characteristics of the included studies were presented for the study design, type of telemedicine, methods, and results categories. Extracted data were presented in an overview table and synthesized qualitatively for each step in the neonatal care journey. We defined the following steps in the journey: daily visits at the NICU, ongoing support at the NICU, transfers between NICUs, discharge from the hospital to home, and the first 12 months of follow-up.

Ethics and Involvement

Due to the literature review nature of this study, ethical approval was deemed unnecessary. Parents and patients were involved in the design of the study, the interpretation of the results, and writing of the manuscript via experts from the neonatal parent and patient advocacy organization Care4Neo (author SOB).

Results

Characteristics of Included Studies

After removing duplicates, 737 studies were selected for title and abstract screening. Interrater agreements were 78.9%, 82%, and 82.6% with a Cohen κ of 0.42, 0.59, and 0.48, respectively. Full texts were screened for 158 articles, resulting in the selection of 50 included studies (see flowchart in Figure 2). Complete data extraction of the included studies is presented in Multimedia Appendix 2. Included articles were predominantly published recently, with 76% (n=38) published in the last 5 years, and 50% (n=25) originated in the United States, with Scandinavian countries as the runner-up (n=10, 20%). Parents were included when designing the intervention in 12% (6/50) of studies. Frequently mentioned purposes of the telemedicine intervention were to remotely follow up on the neonate after discharge and save the family travel time (n=14, 28%) and to allow parents to see their infant at the NICU (n=11, 22%). All purposes are presented in Table 1.

Within the 50 articles, surveys (n=36, 72%) and interviews (n=10, 20%) were the most used evaluation methods, and they included 6 to 298 caregivers per study. Most of the interventions included real-time telemedicine technology (n=32, 64%) with 58% (29/50) including videoconferencing. Mobile apps facilitated the intervention in 21 studies, mainly used for educational or supporting content (8/21, 38%) and the transition to home and remote follow-up (15/21, 71%). Interventions were often part of a comprehensive health care program, using multiple technologies to facilitate different moments of contact between parents and health care providers (Multimedia Appendix 2).

Figure 2. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) inclusion flowchart.

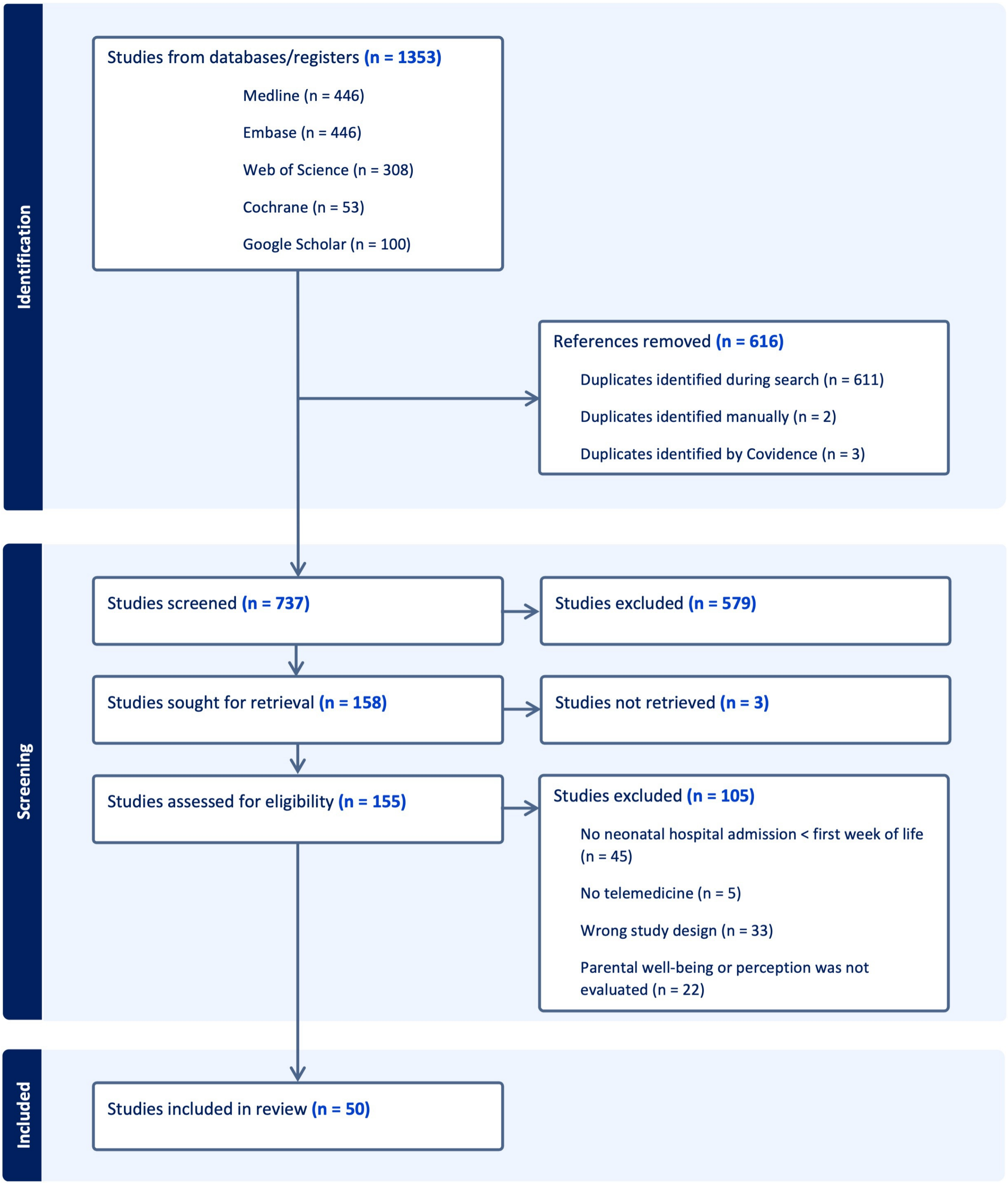


Table . Purpose of the telemedicine interventions.

Purpose of telemedicine intervention	Frequency (n=50), n (%)
Remote follow-up and save the family travel time	14 (28)
Allow parents to see their infant in the NICU[a]	11 (22)
Improve transition from NICU to home	8 (16)
Provide psychosocial and emotional support	6 (12)
Provide education to enhance confidence and self-efficacy	5 (10)
Facilitate telerounds with a remote expert to prevent transfers	3 (6)
Provide regular medical updates to families	3 (6)

[a] NICU: neonatal intensive care unit.

Outcome Measurements

The assessed outcome categories and methods of outcome measurement are presented in Table 2. Three out of 50 studies were in the design phase and were only able to hypothesize the outcomes, and therefore they were not included in the analysis of the outcome measures. The majority of studies used surveys (36/47, 77%) to assess the parents' satisfaction and the effect on their well-being. Qualitative research methods such as interviews, focus groups, and workshops were applied in 23% (11/47) of studies and in all (3/3) studies designing an intervention. Of the 4 studies that used health records or usage logs, 2 studies presented usage logs in addition to qualitative data, whereas 2 studies only used data from the medical records system for establishing outcomes (Multimedia Appendix 2).

The surveys used to evaluate implementation outcomes varied. Some were validated questionnaires like the telemedicine usability questionnaire. Almost all used a 5-point Likert scale format. Service outcomes were either qualitative themes (eg, privacy concerns, accessibility of health care) or the potentially avoided travel distance or time. The Parental Stressor Scale (PSS-NICU) was the most frequently used standardized questionnaire (8/25, 32%) evaluating parental stress. The Parenting Sense of Competence Scale was used in 16% (4/25) of studies to evaluate self-efficacy. Nine of the 25 studies that evaluated client outcomes using surveys used a nonvalidated questionnaire, developed by the research team, to evaluate parental discharge preparedness, self-efficacy, or satisfaction with the delivered health care. An overview of the used questionnaires is shown in Multimedia Appendix 3. Client outcomes assessing the impact on the parents' well-being were focused on depression, anxiety, stress, bonding, and self-efficacy.

Table . The number of studies assessing different outcome categories and the methods used.

Methods used	Implementation outcomes (n=33)[a], n (%)	Service outcomes (n=11)[a], n (%)	Client outcomes (n=31)[a], n (%)
Surveys	26 (79)	8 (73)	25 (81)
Qualitative methods	9 (27)	3 (27)	7 (23)
Health records/usage logs	2 (6)	1 (9)	1 (3)

[a] Only 47 of the 50 articles were examined because the remaining 3 studies were in the design phase and were therefore only able to hypothesize the outcomes.

Parental-Neonatal Care Journey

Overview of the Journey

An overview of telemedicine interventions for each moment in the parental-neonatal care journey is presented in Figure 3. Their impact on implementation outcomes, service outcomes, and health outcomes is presented in Table 3. Most telemedicine interventions focused on the follow-up after hospital discharge (22/50, 44%), the discharge from the NICU to home (18/50, 36%), or daily visits to the NICU (18/50, 36%). None of the interventions focused on transfers between hospital wards or hospitals.

Figure 3. Overview of included telemedicine interventions for each step in the neonatal care journey. NICU: neonatal intensive care unit.

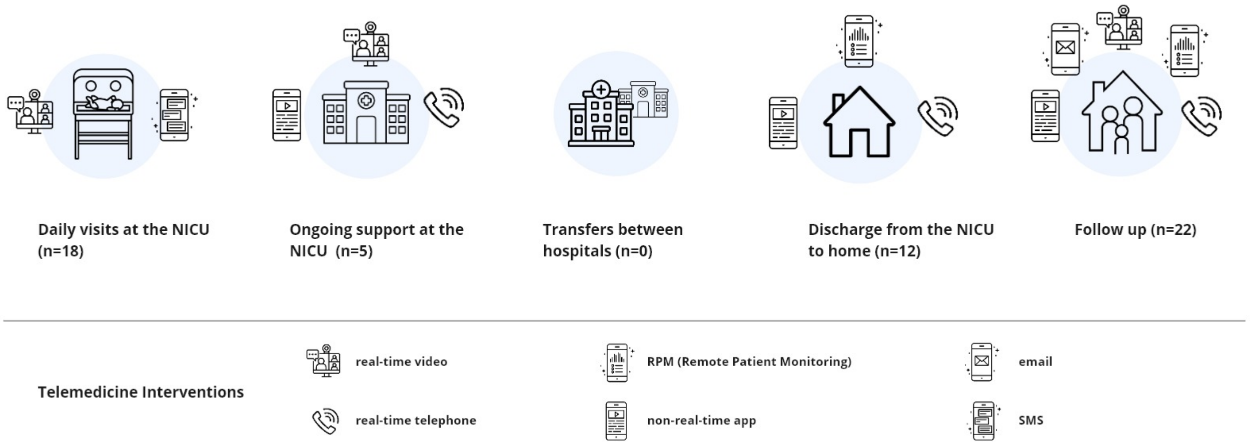


Table . Telemedicine interventions per moment in the parental-neonatal care journey.

Moment in the journey, purpose, and technology	Implementation outcomes	Service outcomes	Client outcomes
Daily visits at the NICU[a] (n=18)			
Allow parents to see their infant remotely [26-36]			
Real-time video	• *Acceptability*: high satisfaction • *Adoption*: high usage rates • *Appropriateness*: easy to use • *Feasibility*: training of staff is necessary, technical issues • *Sustainability*: how to schedule maintenance of the tool	• Privacy concerns	• Decreased stress (2 survey studies; PSS-NICU[b]) • No difference in stress, anxiety, depression (2 survey studies; STAI-S[c]. PSS-NICU, MIB[d], DASS-21[e]) • Reduction of stress, anxiety and increase in confidence (3 interview studies) • Increased stress due to video unavailability or traumatic images without explanation. • Hypervigilance due to 24-7 video availability (interview study)
Telerounds with remote expert [37-39]			
Real-time video	• *Acceptability*: high satisfaction. Comfortable talking to remote neonatologist • *Feasibility*: high video/audio quality	• Higher attendance of parents to daily rounds	• Not evaluated[f]
Virtual family-centered rounds [36,40]			
Real-time video	• *Acceptability*: high satisfaction • *Adoption*: 50% used intervention • *Appropriateness*: easy to use	• Higher attendance of parents to daily rounds	• NICU staff felt they had a positive impact on caregivers
Provide medical updates [41,42]			
Real-time video, SMS	• Videoconferencing was *feasible*, *acceptable* and *reliable*	• No impact on satisfaction with treatment and staff	• No reduction in parental concerns (interview study)
Provide lactation support [43]			
Real-time video	• Not evaluated	• Not evaluated	• Increased percentage exclusively breastfeeding
Ongoing support at the NICU (n=5)			
Educational, empower and reduce anxiety [44-48]			

Moment in the journey, purpose, and technology	Implementation outcomes	Service outcomes	Client outcomes
Non–real-time app	• *Acceptability*: satisfied with social support and interaction • *Appropriateness*: perceived as useful	• Not evaluated	• Increased readiness for discharge • Higher self-efficacy (survey study; PSOC[g]) • No impact on stress and anxiety (survey study; PSS-NICU, GAD-7[h]). • Hypothesized to serve as a source of emotional encouragement (one interview study)
Real-time telephone, video	• *Acceptability*: high satisfaction • *Fidelity*: 44% completed intervention	• Not evaluated	• Decreased anxiety and stress (survey study; BAI[i], IDAS-GD[j], EPDS[k])
Transfers between hospitals (n=0)	• Not evaluated	• Not evaluated	• Not evaluated
Discharge from the hospital to home (n=12)			
Educate and empower parents [48-54]			
Non–real-time app, RPM[l], real-time telephone	• *Acceptability*: high satisfaction • *Appropriateness*: easy to use	• Increases care accessibility	• Increased discharge preparedness (survey study) • Higher self-efficacy (survey study; PSOC) • Increased mother-infant bonding (survey study; MPAS[m]) • Decreased stress (survey study; PSS-NICU) No difference in parenting confidence (survey study; KPCS[n], MABISC[o])
Follow-up (n=22)			
Improve transition to home [51,52,54-58]			
Non–real-time app, RPM, real-time video	• *Acceptability*: high satisfaction • *Appropriateness*: easy to use • *Feasibility*: high video/audio quality • *Fidelity*: high rates of usage	• Satisfied with discharge handoff. • Replaced hospital visits thus saved travel time.	• Earlier adjusting to home, establishing normalcy (interview study) • Increased self-efficacy (survey study) • Helped parents in their role (two studies)
Remote follow-up [50,59-72]			

Moment in the journey, purpose, and technology	Implementation outcomes	Service outcomes	Client outcomes
Non–real-time app, RPM, emails, telephone	• *Acceptability*: fun • *Appropriateness*: easy to use • *Feasibility*: remote scoring had equal quality as in-person • *Fidelity*: high return rates of surveys	• Not evaluated	• Increased confidence (two interview studies) • No increase in parenting confidence (survey study; KPCS, MABISC)
RPM app with real-time video	• *Acceptability*: high satisfaction • *Adoption*: 50% attendance to appointments • *Appropriateness*: easy to use • *Feasibility*: technical issues reported	• Replaced hospital visits • Improved approachability, affordability, and availability	• Increased self-efficacy/confidence (3 survey studies; PSOC, one interview study)

[a] NICU: neonatal intensive care unit.

[b] PSS-NICU: Parental Stressor Scale–NICU.

[c] STAI-S: State-Trait Anxiety Inventory.

[d] MIB: Mother Infant Bonding Questionnaire.

[e] DASS-21: Depression Anxiety Stress Scale.

[f] Not evaluated was stated when none of the included studies were evaluated for the specific outcome measure.

[g] PSOC: Parenting Sense of Competence Scale.

[h] GAD-7: 7-item Generalized Anxiety Disorder.

[i] BAI: Beck Anxiety Inventory.

[j] IDAS-GD: Inventory of Depression and Anxiety Symptoms.

[k] EPDS: Edinburgh Postnatal Depression Scale.

[l] RPM: remote patient monitoring.

[m] MPAS: Maternal Postnatal Attachment Scale.

[n] KPCS: Karitane Parenting Confidence Scale.

[o] MABISC: Mother and Baby Interaction Scale.

Daily Visits to the NICU

All telemedicine interventions at the NICU used real-time audiovisual communication, either to allow parents to see their infants or for daily rounds with remote parents or experts. Facilitating a bedside camera accessible for parents resulted in high usage rates. It also resulted in a decrease in stress and anxiety, and an increase in confidence in multiple survey studies with randomized controlled designs [26,27] and interview studies [28-30]. Other studies found nonsignificant differences for stress, anxiety, and bonding with evident positive trends in open-ended questions [31,32].

Three important negative outcomes were found: technical aspects, privacy, and hypervigilance. Incidence of technical issues ranged widely (from 5% to 60%) and staff reported doubts about training and maintenance protocols [27,28,31,41]. Furthermore, unexpected unavailability of the video connection triggered stress and fear in parents, not knowing what was happening to their infant [28,33]. Privacy concerns for both the infant and the NICU staff were mentioned [28,33]. Extensive security evaluation of the data connection prior to implementation was included in most study protocols to ensure privacy for the infant. Privacy of the NICU staff, on the other hand, was an unexpected negative outcome in two studies [27,33]. Their main concerns were the fear of behaving differently when being watched by parents while taking care of the infant and the liability risk for neonatologists when medical emergencies are being recorded. Lastly, the possibility of watching your infant 24-7 resulted in hypervigilance for some parents [28]. Parents explained that being able to constantly watch their infant made their home feel less restful. Virtual family-centered rounds, some with remote experts present, all had high satisfaction rates. Rosenthal et al [40] showed a relatively low adoption rate, with only 48.6% of parents attending the virtual rounds at least once. However, there was an evident increase in parental participation during rounds in this group, with the attendance rate being 3.4 times higher compared to the control group without virtual rounds, suggesting a positive effect in a selected group of parents. Makkar et al [37] also found higher participation rates in the telerounds with remote experts. Impact on parental health outcomes was not evaluated for virtual rounds.

Ongoing Support and Education

Although interventions for educational and supportive purposes targeted different moments in the neonatal care journey, they shared the same telemedicine aspects. These interventions were designed as comprehensive programs including a smartphone- or tablet-based application with interactive functions and planned moments of contact with health care professionals.

An example is the “My Bridgham Baby” app [44], including (1) practical information regarding the NICU; (2) information on the role as a parent for their admitted infant; (3) support services for parents and their families; (4) discharge education, checklists and milestones before discharge; (5) mental health services for parents; (6) advice on financial and insurance resources; and (7) information regarding the follow-up. This app also includes a chat function to ask questions to the medical team. Self-efficacy [48,59] and discharge preparedness increased [44,49], and one controlled trial showed nonsignificant trends in parenting confidence [50]. Two studies included parental perspectives in the design phase by hosting focus groups, both recommending the integration of social support facilitation into the app [45,54]. Interventions that included real-time telemedicine (telephone or video) showed a decrease in anxiety and stress [46,47,53].

Discharge Preparedness and Follow-Up

Almost half of the included studies focused on the transition to home and follow-up (24/50, 48%). The majority of these interventions (16/24, 67%) used a combination of telemedicine modalities: apps and videoconferences. Only a few of them (3/24, 13%) used the app as a means to actively gather information on the patient [57,61,66], the definition of remote patient monitoring. As expected, studies concluded that telemedicine results in accessible health care, saving travel time and money for parents [51,55,56,58,68,72]. Furthermore, the parental sense of competence at home increased, probably due to the easily accessible option of asking questions to professionals [52,55,58,61,63,65,66,71,72].

Discussion

Principal Findings

In this scoping review, we aimed to identify the potential of telemedicine interventions to improve parental well-being during the neonatal care journey of their infant. Telemedicine interventions included in our review had two main purposes: (1) to overcome physical distance through remote follow-ups and virtual family-centered rounds with remote experts, allowing parents to see their infant remotely, and (2) to prepare parents for discharge by providing information and social support. The majority of the interventions were part of a comprehensive program, entailing a telemedicine intervention with, for instance, a structured set-up over time, multiple functionalities, and moments of contact with health care providers. Of the included studies, 70% (33/47) evaluated parental opinions on the intervention, like usability and technical quality, and 66% (31/47) assessed the actual impact of the intervention on the parents’ well-being, like stress, self-efficacy, depression symptoms, and unmet needs. This review draws attention to three main gaps in the literature:

- None of the telemedicine interventions focused on the transfers between hospitals, despite this being an urgent unmet need for parents [11].
- There is a need for assessing not only implementation satisfaction but also the actual impact on the parents’ well-being, ideally in both the short- and long-term.
- The variety of methods and questionnaires used to evaluate parents’ well-being and experiences creates a great challenge to compare the outcomes of different studies, which is a commonly mentioned issue when integrating results of parents’ well-being evaluations at the NICU [9]. Also, the variety of methods for evaluating telemedicine interventions aligns with a recent systematic review examining the evaluation of patient and staff experience with remote patient monitoring, which similarly noted a lack of consensus and standardization in evaluation methods [73].

Categorization of telemedicine interventions was challenging. Included interventions were often part of a comprehensive program including multiple technologies. Unfortunately, a significant number of included studies failed to fully describe the program and, perhaps more importantly, to present the results behind parents’ satisfaction with the intervention. Moreover, the majority of the underlying studies provided limited information on the characteristics of the included parents. Factors such as age, socioeconomic status, family situation, and ethnicity influence parental needs [74,75] and are relevant when interpreting the observed impact of telemedicine, individualizing interventions, and ensuring availability of technology to all patients. Integrating findings from the included studies on both intervention satisfaction and its impact on parents’ well-being was therefore challenging. To enhance generalizability and implementation, it is recommended to provide comprehensive descriptions of the entire program and the included participants, and to particularly highlight intervention components that are vital for parents.

Furthermore, the impact on parental well-being is mainly established in studies using technology as a means to provide emotional or educational support. This suggests using the technology should not be the primary goal, but that the potential impact derived from the actual content of the delivered care, education, or support should be the goal. In other words, the telemedicine intervention should be the means and not the end. On the other hand, usage and uptake of the telemedicine intervention are essential in order to reach the intended impact. It remains important to reflect on the parental needs that are being targeted by the intervention and if telemedicine is the best intervention to improve the experience. More comprehensive, probably qualitative, research into the parental journey and the unmet needs is advised before designing new interventions. Subsequently, it is essential to invite parents to participate when designing and implementing a telemedicine intervention, using a participatory study design with, for instance, co-creation sessions.

Strengths and Limitations

By purposefully including the whole range of technological interventions, including mature technologies like telephone consultations, SMS, or email services which have been part of health care for decades [76], we aimed to create a comprehensive overview. Furthermore, by including studies that evaluate not only the impact on parental well-being but also parental perceptions of telemedicine interventions, we were able to demonstrate the current level of parental involvement in the different phases of telemedicine research, including designing, implementing, and evaluating interventions. Also, we did not limit our inclusion to specific study designs. These three considerations resulted in a complete overview of all technological interventions that have been studied. Despite the scoping nature of the review, and therefore missing the quality appraisal, the three reviewers facilitated a robust and transparent inclusion process by predefining eligibility criteria, performing validation sessions, and extracting data with two independent researchers.

Despite efforts to be comprehensive, this review likely missed some studies. More specifically, by excluding protocols and trial registrations, we overlooked ongoing studies, such as a cluster randomized controlled trial for virtual family-centered hospital rounds [77] and the neoPARTNER study [78]. Considering the majority of included studies were published within the last 5 years, we expect the number of studies currently being performed to be relevant. Another challenge in this review was to capture the entire scope of the parental journey, as a lack of universal terminology and definitions posed significant obstacles. To minimize the risk of missing important parental aspects, we chose very broad terms for the search string (experience, perspective, perception, depression, anxiety, stress, satisfaction, etc). With this extensive search string, we screened and included articles focusing also on parents’ views of the technology instead of solely reviewing the impact on their care journey.

Practical Implications

Based on the included studies, several practical recommendations can be provided. This review clearly found educational and supportive telemedicine interventions, often delivered through a mobile or tablet application with multiple functionalities, have a positive impact on discharge preparedness. Furthermore, bedside cameras can be useful to improve infant bonding and reduce stress when caregivers are unable to be present at the NICU. However, an important remark is that privacy concerns of medical personnel, hypervigilance, and increased stress are pitfalls of the continuous availability of a bedside camera. Remote follow-up was often provided by a telemedicine program that includes an app and scheduled contact moments with health care providers (video or telephone). While remote follow-up improves the accessibility of health care by saving parents travel time and making parental confidence increase, it has not been proven to reduce stress, depression, or anxiety. The opportunities of telemedicine interventions, as described above, prove to be effective when used in the context of a comprehensive telemedicine program including informational provisions, moments of communication, and social support.

Conclusion

Telemedicine interventions have the opportunity to improve parents’ well-being during their neonatal care journey, especially when enhancing discharge preparedness and when aiming to overcome physical distance using bedside webcams, virtual family-centered rounds, or remote follow-ups. We advise future researchers to (1) properly describe their telemedicine intervention to enhance generalizability and (2) assess the impact on parents’ well-being when evaluating the intervention, ideally using a combination of validated questionnaires (PROMs; eg, the Parental Stressor Scale) and in-depth interviews. Furthermore, when designing and piloting new interventions, a critical reflection on the targeted parental needs, by involving parents in the study and using co-creation sessions, is essential to improve their journey.

Acknowledgments

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Authors' Contributions

JW and FB, together with MK, SOB, and HRT designed the study. JW, FB, and CM were responsible for article screening and data extraction. FB and CM made visualizations. HRT, SOB, IR, and MK contributed to interpreting the results. JW wrote the manuscript, with FB and HRT as co-writers. All authors reviewed the manuscript and agreed with the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy.
[DOCX File, 20 KB - pediatrics_v7i1e60610_app1.docx]

Multimedia Appendix 2
Data extraction overview.
[XLSX File, 31 KB - pediatrics_v7i1e60610_app2.xlsx]

Multimedia Appendix 3
Used questionnaires for measuring parent-reported outcome measures and parent-reported experience measures.
[DOCX File, 20 KB - pediatrics_v7i1e60610_app3.docx]

Checklist 1
PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) checklist.
[PDF File, 186 KB - pediatrics_v7i1e60610_app4.pdf]

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Abbreviations

NICU: neonatal intensive care unit
PICO: Population, Intervention, Comparator, Outcome
PREM: patient/parent-reported experiences measure
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews
PROM: patient/parent-reported outcome measure

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Original Paper

Access to Primary Care Telemedicine and Visit Characterization in a Pediatric, Low-Income, Primarily Latino Population: Retrospective Study

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Abstract

Background: Since the COVID-19 pandemic, telemedicine has been widely integrated into primary care pediatrics. While initial studies showed some concern for disparities in telemedicine use, telemedicine uptake for pediatric patients in a low-income, primarily Latino community over a sustained period has yet to be described.

Objective: We aimed to assess the relationship between demographics, patient portal activation, and telemedicine visits, as well as characterize diagnoses addressed in telemedicine, in a low-income, primarily Latino population over time.

Methods: A multidisciplinary team conducted outreach for telemedicine and patient portal activation with the adoption of a new electronic health record. Data were collected on all in-person and telemedicine visits from February 2020 through April 2021 for 4 community-based pediatric practices. The outcomes included patient portal activation, telemedicine use, and reason for telemedicine visits. Bivariate tests and multivariate regression analyses were conducted to assess the independent effects of demographics on the likelihood of portal activation and having a telemedicine visit. Telemedicine diagnoses were categorized, and subanalyses were conducted to explore variations by age and month.

Results: There were 12,377 unique patients and 7127 telemedicine visits. Latino patients made up 83.4% (n=8959) of the population. Nearly all patients (n=10,830, 87.5%) had an activated portal, and 33.8% (n=4169) had at least 1 telemedicine visit. Portal activation decreased with age >2 years (2-4 years: adjusted odds ratio [aOR] 0.62, 95% CI 0.51-0.76; 5-11 years: aOR 0.28, 95% CI 0.23-0.32; 12-14 years: aOR 0.29, 95% CI 0.23-0.35; and 15-17 years: aOR 0.46, 95% CI 0.36-0.58). Spanish-speaking (aOR 0.52, 95% CI 0.45-0.59) and non-Latino patients (aOR 0.64, 95% CI 0.54-0.76) had decreased odds of activation and having a telemedicine visit (aOR 0.81, 95% CI 0.74-0.89 and aOR 0.71, 95% CI 0.62-0.81, respectively). The top 5 diagnostic categories for telemedicine were infectious disease (n=1749, 26.1%), dermatology (n=1287, 19.5%), gastrointestinal (n=771, 11.7%), well and follow-up care (n=459, 7%), and other specialty-related care (n=415, 6.3%). Infectious disease showed the most variation over time. Age-based patterns included a decrease in the proportion of infectious disease diagnoses by increasing age group and a higher proportion of well and follow-up care in older ages. Additional telemedicine diagnoses included common infant concerns for patients younger than 2 years of age; pulmonary, asthma, and allergy concerns for toddler or school-age children; behavioral health concerns for younger adolescents; and genitourinary and gynecologic concerns for older adolescents.

Conclusions: The high engagement across demographics suggests feasibility and interest in telemedicine in this low-income, primarily Latino population, which may be attributable to the strength of outreach. Language-based disparities were still present. Telemedicine was used for a wide range of diagnoses. As telemedicine remains a vital component of pediatric health care, targeted interventions may enhance engagement to serve diverse pediatric patient populations.

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KEYWORDS

telemedicine; telehealth; pediatric primary care; COVID-19 pandemic; disparities; primary care; pediatrics; portals; access; accessibility; accessible; use; demographics; low income; Latino; Hispanic; Spanish; mobile phone

Introduction

Before the COVID-19 pandemic, telemedicine was described as having the capacity to revolutionize pediatric care provision [1]. Despite this promise, only 15% of pediatricians reported using telemedicine in 2016 [2]. The most cited barriers then included insufficient payment, a lack of confidence in diagnoses that were made through telemedicine, patient reluctance and perceived lack of usefulness, and insufficient infrastructure [2,3]. The COVID-19 public health emergency triggered a rapid national shift to telemedicine, and decreased regulations and better payment parity allowed its adoption. As telemedicine has expanded, concerns about its potential to exacerbate health disparities have been raised [4-6]. The limited data that exist show that low digital health literacy, cultural preferences, and limited access to the internet and technological devices may limit engagement in telemedicine visits for certain populations [7]. Given the wide adoption of telemedicine, it is important to understand patterns of telemedicine uptake and use in diverse communities. In this study, we aim to characterize telemedicine visits for over a year during the pandemic in a low-income, primarily Latino population.

Methods

Study Environment

This study evaluated the patterns of outpatient telemedicine use among families of patients younger than 18 years of age from 4 community-based pediatric practices affiliated with NewYork-Presbyterian Hospital/Columbia University Irving Medical Center (NYP/CUIMC), New York. These practices are part of an ambulatory care network staffed by a single pediatric group practice using a common electronic health record (EHR) and have around 19,000 patients. The practices serve a primarily Latino and publicly insured population and provide primary care and refer out for subspecialty care. Demographic and visit data were collected for all patients with in-person or telemedicine visits during the study period. The study period spanned from February 2020 when a new EHR system was launched (described in the Telemedicine Implementation section), and data collection extended through April 2021.

Telemedicine Implementation

In February 2020, a new EHR, Epic Systems, was launched across NYP/CUIMC. When the COVID-19 pandemic began in March 2020, NYP/CUIMC rapidly expanded telemedicine capacity across the network. Pediatric telemedicine was still in the pilot phase before the pandemic, orchestrated by 1 clinical champion. Early in the pandemic, there was an expansion of staff outreach. Extensive bilingual phone outreach for patient portal activation began in March 2020. Teams prioritized rapid patient enrollment due to the ongoing pandemic. Telemedicine capabilities were quickly expanded to accommodate acute care concerns and follow-up needs. Telemedicine visits were conducted through an Epic Systems video app. Patients were required to have access to a smartphone, tablet, or computer with internet capacity. If using a mobile device, they needed to download and install the Epic MyChart app, and then register for an account, which can be done in English or Spanish.

Although patients had the option to self-enroll digitally there was significant outreach to assist patients with the enrollment process. In March 2020, teams were created for the express purpose of patient enrollment. The bilingual team (Spanish or English) consisted of 17 staff and was interpreter supported for other languages. Administrators pulled data from the prior EHR and created detailed spreadsheets of all patients for enrollment. Staff was trained in enrollment, including health care proxy setup, as well as data management to track enrollment. There were rapid cycle performance improvement meetings to optimize protocols. Staff called patients and parents and assisted them in enrolling portal accounts. In some cases, families were assisted to create email accounts, as this was required for account access. A subset of patients with high risk was additionally prioritized by the primary care sites for outreach. Patients were deemed high risk by the criteria of the federal Maternal and Child Health Bureau’s children with special health care needs designation [8]. Many high-risk patients had a community health worker or care manager on their care team, and these staff also assisted in setting up the portal account. In some cases, community health workers used video calls to aid in setting up portal access. Additionally, if patients did not already have a portal account at the time of an in-person visit, providers or staff at the clinic could assist with portal access in person. When outreach was completed over the phone to set up portal access, the staff member confirmed portal setup by asking if the patients received an automated welcome message or if they could see their appointments or other portal components after setup. In our EHR, each patient chart clearly indicates whether they have activated their portal, and this is also confirmed by staff and providers at patient appointments.

Most telemedicine appointments were initiated when parents requested an appointment for an acute concern. The nursing staff triaged the concern and determined whether to schedule an in-person or telemedicine visit. Triaging protocols were agreed upon in advance by nursing and physician representatives and evolved throughout the COVID-19 pandemic. For patients with a primary language other than English, team members used a third - party interpreter service.

Study Variables and Outcomes

Patient demographics including age, sex, race, ethnicity, preferred language, and insurance status were extracted from the EHR for all individual patients who were seen in person or on telemedicine. All ages reported refer to the patient's age. Race and ethnicity data were collected by self-report.

Our institution has been part of a multi-institutional framework to more accurately collect race and ethnicity data in service of identifying and addressing health disparities, which has now been adapted by many other large health systems across the country since 2020 [9,10]. We collect information from patients using the standard US Office of Management and Budget 2-question format for race and ethnicity as well as 2 follow-up questions specified by the New York State Department of Health regarding granular ethnicity and granular race. Race and ethnicity values are typically captured during registration, either by front desk staff or on a tablet used by patients to electronically register at appointments. Patients were informed that it is optional to self-report and that patient information is confidential.

Data were collected for all patient visits within the study period, including both in-person and telemedicine visits. The primary study outcomes were patient portal activation (needed for telemedicine visits) and the presence of a video visit, referred to herein as a telemedicine visit. Another variable characterized was the primary diagnosis from telemedicine visits.

For diagnosis data, categories were created by the research team (MSS, PRP, and EB-S) after a review of the primary diagnosis of visits in our initial data in a qualitative manner. Two team members (MSS and EB-S) reviewed and classified all diagnoses manually into categories. A third team member (PRP) then reviewed all of the diagnosis classifications, grouped categories together with iterative feedback from authors, and clarified any ambiguous diagnoses. Each visit diagnosis as coded in the EHR was only assigned to 1 particular category. When there was ambiguity regarding categorization, the full-visit documentation was reviewed to most accurately categorize the diagnosis, and each of these decisions was reviewed by 2 authors (PRP and EB-S). The categorization was iterative with continuous refinement and validation until a consensus was reached.

Statistical Analysis

Analyses on demographic data and the presence of portal activation reflect the dataset of individual patients (n=12,377). Descriptive outcomes of diagnoses seen on telemedicine reflect unique telemedicine visits (n=7127), in which patients who have had multiple telemedicine visits are represented more than once. Chi-square analyses were conducted to examine associations between patient demographics and portal activation and having a telemedicine visit (separately). Multivariable logistical regression analyses were then conducted. Any variable that had a significant univariate 2-tailed *t* test at $P \leq .10$ was used as a variable for the multivariable analysis, based on the literature on purposeful selection [11,12]. For portal activation, covariates included were age (categorical: <2, 2-4, 4-11, and 12-18 years), language (categorical: Spanish, English, and other), and ethnicity (Latino and non-Latino). For the presence of a telemedicine visit, covariates included were age (categorical: <2, 2-4, 4-11, and 12-18 years), language (categorical: Spanish, English, and other), ethnicity (Latino and non-Latino), and race (White, Black, and other). There were no additional covariates in the model.

On the telemedicine visit data (n=7127), diagnoses from telemedicine visits were categorized and described overall. Subanalyses were conducted to explore variations in diagnoses by age and month. Statistical analyses were performed using SPSS software (version 28; IBM Corp). The significance level was set at $\alpha=.05$.

Ethical Considerations

The study protocol was reviewed and approved by the Columbia University Irving Medical Center Institutional Review Board (#AAAS8260). This institutional review board approval covered secondary analysis without additional consent. Data collection, storage, analysis, and reporting adhered to institutional guidelines. There was no compensation of participants, as only secondary data were used.

Results

Overall, there were 12,377 unique patients with visits during the time period. Half (n=6183, 50%) of the patients were female, 52.6% (n=6509) were younger than 5 years of age, 44.6% (n=5497) were Spanish speaking, 83.4% (n=8959) were Latino, and 21% (n=2160) were Black (Table 1). Insurance data from televisits showed that 95% (n=6360/6695) of patients were publicly insured. Of all patients (N=12,377), 10,830 (87.5%) had activated the patient portal. Of all patients, 33.8% (n=4169) had at least 1 telemedicine visit. Of those who activated their portal account and subsequently had an in-person or video visit, 38.5% (n=4169/10830) had a video visit. Of those with a telemedicine visit, 37.7% (n=1572/4169) had more than 1 telemedicine visit, the median number of visits was 1 (IQR 1-2; range 1-15).

The highest proportion of patient portal activation was for patients at the 2 extremes of age ranges. Of all patients younger than 2 years of age (n=4390), 94.1% (n=4129) had activated the portal, and of those between 15 and 17 years of age (n=1090), 87.2% (n=950) had portal activation. School-age children (5-11 years; n=3503) had the lowest rate at 80.1% (n=2807). On multivariable logistic regression analysis, decreased odds of portal activation were seen with age >2 years (2-4 years: adjusted odds ratio [aOR] 0.62, 95% CI 0.51-0.76; 5-11 years: aOR 0.28, 95% CI 0.23-0.32; 12-14 years: aOR 0.29, 95% CI 0.23-0.35; and 15-17 years: aOR 0.46, 95% CI 0.36-0.58). Decreased odds of portal access were seen for those speaking Spanish (aOR 0.28, 95% CI 0.23-0.32) or another non-English non-Spanish language (aOR 0.62, 95% CI 0.47-0.81) and being non-Latino (aOR 0.64, 95% CI 0.54-0.76; Table 1). Demographic characteristics associated with having had at least 1 telemedicine visit were similar but not the same as those for portal activation. School-age children were again least likely to have had at least 1 visit compared to those younger than 2 years of age (aOR 0.80, 95% CI 0.72-0.90), but adolescents had slightly greater odds of having a visit (aOR 1.17, 95% CI 1.00-1.36). Decreased odds of a visit were seen for those who spoke Spanish (aOR 0.81, 95% CI 0.74-0.89) or other non-English and non-Spanish language (aOR 0.65, 95% CI 0.52-0.81) or were non-Latino (aOR 0.71, 95% CI 0.62-0.81). Those who did not identify as Black or White also had decreased odds of having a telemedicine visit (aOR 0.89, 95% CI 0.81-0.98; Table 1).

Table 1. Patient portal activation and the presence of telemedicine visits for unique patients by demographics.

	All participants (N=12,377), n (%)	Portal activation, n (%)[a]	Portal nonactivation, n (%)[a]	*P* value	aOR[b] (95% CI)[c]	Telemedicine visit, n (%)[a]	No telemedicine visit, n (%)[a]	*P* value	aOR (95% CI)[d]
Age range (years)				*<.001*[e]				*<.001*	
<2	4390 (35.5)	4129 (94.1)	261 (5.9)		Reference	1556 (35.4)	2834 (64.6)		Reference
2-4	2119 (17.1)	1908 (90)	211 (10)		*0.62 (0.51-0.76)*	711 (33.6)	1408 (9.4)		0.94 (0.83-1.06)
5-11	3503 (28.3)	2807 (80.1)	696 (19.9)		*0.28 (0.23-0.32)*	1060 (30.3)	2443 (69.7)		*0.80 (0.72-0.90)*
12-14	1275 (10.3)	1034 (81.1)	241 (18.9)		*0.29 (0.23-0.35)*	426 (33.4)	849 (66.6)		0.94 (0.81-1.09)
15-17	1090 (8.8)	950 (87.2)	140 (12.8)		*0.46 (0.36-0.58)*	434 (39.8)	656 (60.2)		*1.17 (1.00-1.36)*
Language				*<.001*				*<.001*	
English	6212 (50.3)	5607 (90.3)	605 (9.7)		Reference	2221 (35.8)	3991 (64.2)		Reference
Spanish	5497 (44.6)	4655 (84.7)	842 (15.3)		*0.52 (0.45-0.59)*	1781 (32.4)	3716 (67.6)		*0.81 (0.74-0.89)*
Other	629 (5.1)	534 (84.9)	95 (15.1)		*0.62 (0.47-0.81)*	175 (27.8)	454 (72.2)		*0.65 (0.52-0.81)*
Sex				.33				.62	
Male	6192 (50)	5399 (87.2)	733 (12.8)		—[f]	2107 (34)	4085 (66)		—
Female	6183 (50)	5427 (87.8)	756 (12.2)		—	2078 (33.6)	4105 (66.4)		—
Ethnicity				*.04*				*<.001*	
Latino	8959 (83.4)	7889 (88.1)	1070 (11.9)		Reference	3188 (35.6)	5771 (64.4)		Reference
Non-Latino	1787 (16.4)	1543 (86.3)	244 (13.7)		*0.64 (0.54-0.76)*	529 (29.6)	1258 (70.4)		*0.71 (0.62-0.81)*
Race				.37				*.04*	
Black	2160 (21)	1904 (88.1)	256 (11.9)		—	710 (32.9)	1450 (67.2)		0.95 (0.82-1.08)
White	3164 (30.8)	2778 (87.8)	386 (12.2)		—	1146 (36.2)	2018 (63.8)		Reference
Other	4949 (48.2)	4308 (87)	641 (13)		—	1709 (34.5)	3240 (65.5)		*0.89 (0.81-0.98)*

[a] Percentages use the n value in the “All participants” column as the denominator.

[b] aOR: adjusted odds ratio.

[c] Covariates for portal activation are age, language, and ethnicity.

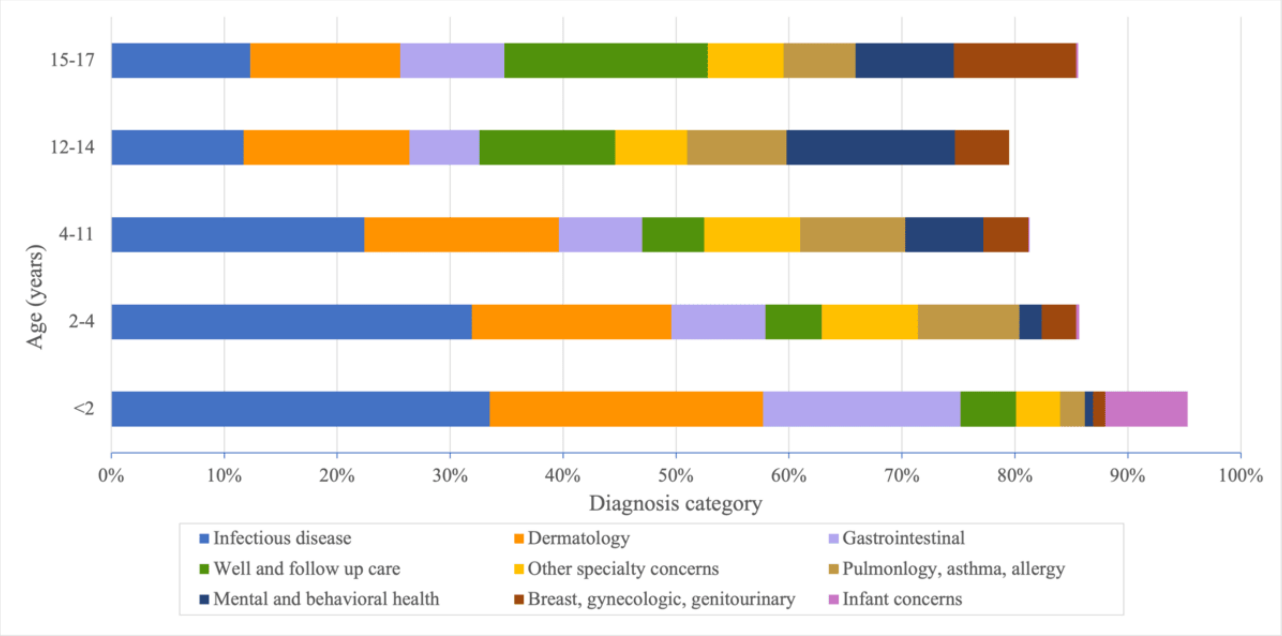
[d] Covariates for telemedicine visits are race, age, language, and ethnicity.

[e] Values in italics format indicate statistically significant findings.

[f] Not applicable.

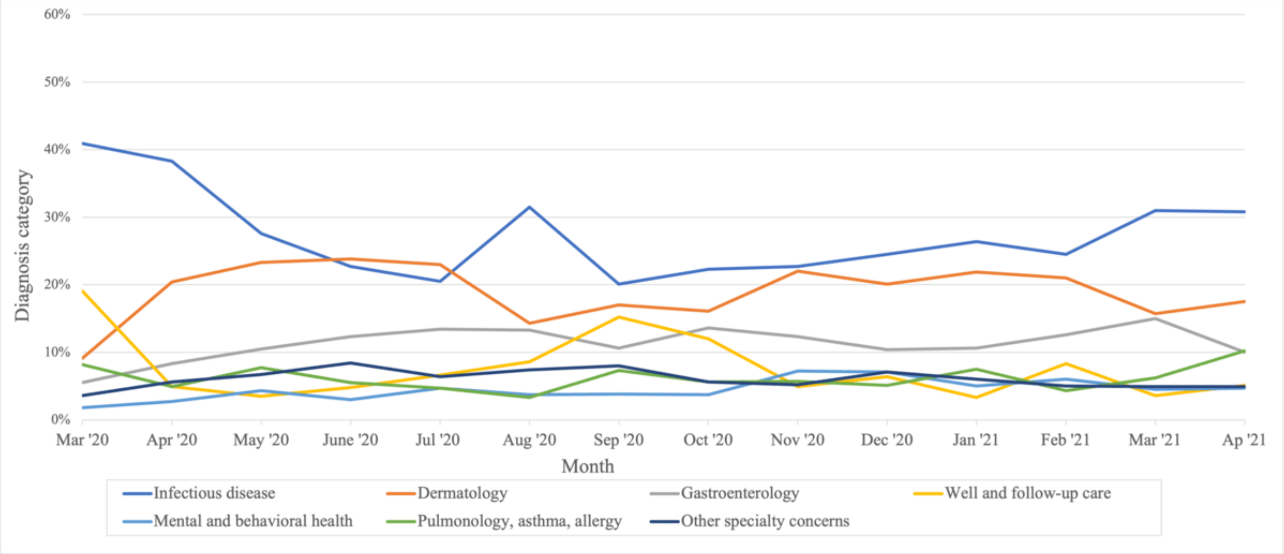
During the study period, there were 7127 telemedicine visits. The top 5 diagnoses categories were infectious (n=1860, 26.1%), dermatology (n=1389, 19.5%), gastrointestinal (n=771, 11.7%), well and follow-up care (n=499, 7%), and other specialty-related care (n=449, 6.3%). Patterns in telemedicine diagnoses differed by age (Figure 1). Infectious disease, the most common overall diagnosis category, was high in all age groups. However, there was a steady decrease in the proportion of the infectious disease category by increasing age group. For example, in visits for children of 0-2 years of age (n=2663), infectious disease made up 33.5% (n=892) of all visits versus only 12.3% (75/610) of visits for adolescents of 15-17 years of age. Dermatologic concerns were the second-most predominant diagnosis category for all age groups. There were also age-based patterns in well and follow-up care, as well care was more predominant for older age groups. For the 0- to 2-year age group (n=4390), there was a high proportion of gastrointestinal concerns (n=467, 17.5%) as well as other infant concerns (n=195, 7.3%), which included breastfeeding problems, colic, nasolacrimal duct stenosis, and teething. In the 2- to 4-year age group (and 5- to 11-year age group), pulmonary, asthma, and allergy-related diagnoses were the third-most prevalent concern. In the 12- to 14-year age group, the most predominant category was behavioral and mental health concerns (n=93). For the 15- to 17-year age group, genitourinary, gynecologic, and breast concerns were within the top 5 categories (n=66), which was not seen for any other age group.

Figure 1. Age-based variation in telemedicine diagnosis categories.



Patterns in diagnoses also changed by month (Figure 2). The number of video visits overall rose in spring 2020, peaking in May 2020 (n=629) and then decreasing in June (n=609), July (n=536), and August (n=520). After a small bump in September (n=558), telemedicine visits made up between 400 and 530 visits per month. At the onset of telemedicine visits in March 2020, the infectious disease made up the highest proportion of visits (45/110, 40.9%), and well and follow-up care accounted for an additional 19.1% (21/110). The proportion of infectious disease cases declined in the spring, then rose again to peak by August 2020, and after this, consistently made up the highest proportion of telemedicine diagnoses. In our clinic system, as in-person visits became more available later in the pandemic, infectious disease diagnoses continued to make up the highest proportion of telemedicine visits. After the initial high proportion of well and follow-up care visits, these visits declined rapidly in April 2020, then rose again to a peak in August and September 2020. In the spring of 2020, the proportion of dermatology diagnoses as a fraction of all diagnoses rose steadily until June 2020 when dermatology diagnoses made up of 23.8% (145/608 visits in June) of televisits. After this, dermatologic diagnoses made up between one-tenth and one-quarter of all cases. Other diagnosis categories showed less variation over time. After a slow increase over the spring of 2020, gastrointestinal diagnoses made up the third-most common category for most months. Mental and behavioral health made up a very small proportion of cases initially (2/110, 1.8%) but slowly rose up to 7.2% (33/461) by December 2020, after which it made up between 4.7% and 7.1% (from 23/491 to 32/453) of cases.

Figure 2. Temporal variation in telemedicine diagnosis categories.



Discussion

Principal Findings

In this study, which assessed telemedicine use immediately after rollout in the early pandemic period, we found that widespread access to telemedicine, as measured by portal activation, is possible in a low-income, primarily Latino community. In this population, telemedicine appointments were used for a wide array of diagnoses across the age spectrum. Our findings have implications for the use of telemedicine to support and augment pediatric primary care provision for diverse patient populations.

Comparison to Prior Work

In our study population, which was largely publicly insured, we found that of all patients seen, 87.5% (10,830/12,377) had an active portal account, and a third had at least 1 telemedicine visit with the use of multipronged bilingual outreach for portal activation. Schenker et al [13] studied a pediatric primary care practice during the first 5 months of the pandemic and found that public insurance was a significant negative predictor of having had a video visit. We did identify some demographic disparities, particularly in language. Non-English speakers had decreased odds of portal activation and of having a video visit, with the lowest visits among those who spoke neither English nor Spanish. Similar to our findings, Blundell et al [14] found that in a pediatric dermatology practice, patients speaking Spanish had lower rates of having an email address in the EHR and lower rates of having an activated patient portal account. Conversely, Schenker et al [13] did not find language to be a significant predictor of telemedicine use. Rodriguez et al [15] found that patients with limited English proficiency had less access to telemedicine and also reported worse experiences with video visits as compared to in-person visits. The authors posit that this may be related to difficulty with interpreter use, providers or patients perceiving video visits to be less effective, or digital barriers. It is likely that these barriers are also present in our patient population [15]. While our clinical sites are fully bilingual and have a strict interpreter policy with access to all languages, outreach in different languages to let families know about multilingual telehealth could be helpful both in person at visits by front desk staff and providers and by nurses when providing triage. Paper sheets that have portal access codes and set-up instructions could be made available in multiple languages (not only English or Spanish) for staff to distribute. Other interventions in the literature include the use of patient navigators for telemedicine [16]. The use of telemedicine navigators was found to benefit physicians and patients along with being cost-effective. Some authors have also described digital rooming [17]. This involves the use of medical assistants to call patients prior to telemedicine appointments for help with connecting to the visit digitally and found some success with increasing the likelihood of patients appropriately connecting to the visit. This is not specifically targeted at non-English and non-Spanish speakers; however, if adapted to serve these populations, for example, with the routine use of interpreters, it could also function to increase accessibility. In our literature review, we find that both interventions have been used to a greater extent for adult populations [16,17].

Interestingly, in our study population, being Latino was associated with higher odds of both portal activation and having at least 1 visit. It is important to note that we consider our race and ethnicity data to reflect social constructs, and differences in outcomes by race and ethnicity provide an understanding of structural health care disparities that may further drive inequities [18]. Understanding differences in telemedicine use by race and ethnicity provides evidence for targeted interventions to decrease institutional or systemic bias and racism. Looking across the pediatric and adult literature, the relationship of telemedicine use by race and ethnicity has been mixed. Several studies have described that White patients are more likely to use telemedicine [13,19]. Some studies early in the pandemic show decreased telemedicine use in Latino or Hispanic populations compared to White patients [20,21]. However, others such as Samson et al [22] found that Hispanic and Asian patients had higher use of telemedicine than White or Black patients. Some authors have hypothesized that there are modifying factors, such as geographical differences, or community preferences that affect use within ethnic groups [23].

Strengths and Limitations

It is not entirely clear why our Latino patient use was higher than non-Latino use. We believe that the differences seen in our study are at least partially attributable to our outreach. Our team aimed to increase access for all patients and also focused on decreasing barriers for Latino and Spanish-speaking patients. A multidisciplinary approach to enrollment was critical—for example, staff, patient financial advisors, care managers, community health workers, and care providers could all assist with enrollment and interact with patients in different contexts. Our enrollment occurred with major tenets of cultural competency in place, described as the "tailoring of health care delivery to meet patients' social, cultural and linguistic needs" [24]. Many staff on the enrollment team, particularly staff, patient financial advisors, and community health workers, come from the same community and regional background as our patients. Many of them identify as Latino and spoke Spanish. Anecdotally, staff reported that when they were able to identify with families, they could provide more trust and reassurance for families who had reservations about the process of enrollment or telemedicine participation. Further, as part of the drive for patient enrollment, staff were supported to iterate enrollment protocols, particularly to target barriers for families with respect to language, culture, and health literacy such as using language for enrollment that was patient-responsive and reflective of the local Spanish dialect. We believe that devoting time and resources to patient enrollment and engaging patient-facing staff to increase our cultural competency are reflected in our results of Latino enrollment.

In regard to the use of video visits, there may be other systematic differences between non-Latino and Latino populations that make telemedicine visits more convenient or accessible for Latino patients in our study population as compared to in-person visits. These could be social determinants of health, such as job or transportation-related factors, or even demographic factors such as parent age or parental comfort with technology used for video visits. Our high level of engagement across demographics, including in Latino patients, suggests feasibility and interest in telemedicine in this low-income, diverse population and underscores the importance of outreach.

Telemedicine engagement, as indicated both by portal activation and telemedicine visits, also showed age-related variation. Patients younger than 2 years of age and those between 15 and 17 years showed the most engagement. Other authors have reported similar patterns. Walters et al [19] reported families of patients younger the 1 year of age as more likely to use telemedicine, whereas Schenker et al [13] found that older patients were more likely to have had video visits. The frequency of well-child visits for infants and a higher rate of contact with the health care system may have influenced higher portal activation rates for children younger than 2 years of age. In our health care system, adolescents are given individual portals with enhanced confidentiality at 12 years of age. Older teens in the 15- to 17-year age group likely have the skills to independently access their portal and obtain telemedicine and may find televisits a convenient way to access care. Research on adolescents and caregivers has shown that telemedicine is widely acceptable for this age group [25,26]. Of all age groups, school age children (5-11 years) had the lowest proportion of telemedicine use. Possible barriers may be that parents of elementary school children have a stronger preference for in-person visits or the times telehealth visits are offered are not amenable to parent or child schedules as compared to younger and older age groups.

We found that video visits were used for a wide range of diagnoses including acute care, well care, and mental health concerns. Video visit diagnosis patterns can be assumed to be guided by the needs of patients and families, as well as the triage protocols used by nursing staff who directed patients to in-person or video visits. Temporal variation in diagnoses illustrates the evolving nature of the COVID-19 pandemic, with a high prevalence of infectious disease case concerns in March 2020 and subsequent intermittent peaks. Well and follow-up care also peaked in the spring of 2020 when in-person care was reserved for more acute concerns but subsequently did not remain as common a reason for telemedicine. Overall, the categories of infectious disease, gastroenterology, and dermatology stayed high throughout the study period, showing that telemedicine may be a useful modality to address these common pediatric complaints. The persistence of the infectious disease category highlights the relevance of telemedicine to manage routine infectious conditions beyond COVID-19. In a qualitative study on telemedicine for acute respiratory concerns, parents reported that they prefer telemedicine because it is easier and it decreases wait time, disruptions in schedules, and exposure to other ill children in a waiting room [27]. Telemedicine may also help with use patterns elsewhere in a health care system. For example, Walters et al [19] asked caregivers who used telemedicine for acute concerns about potential alternatives and found that a substantial portion would have gone to the emergency department or urgent care center (16.5%) or opted not to seek care (11.3%) if telemedicine was not an option. Indeed, our most common categories—infectious disease, dermatologic, and gastrointestinal concerns—make a large component of pediatric urgent care and emergency department visits [28]. Our findings have potential implications for strengthening telemedicine policies, for example, improving triage algorithms for common diagnostic categories, so that telehealth visits provided by the medical home can serve as an effective alternative to using emergency services or meet the needs of patients who have barriers to in-person visits.

There were also notable patterns in diagnosis categories by age group. Though common in all age groups, infectious disease visits were less common for older individuals. Infectious disease was the most common diagnosis category for infants through school-aged children, but for younger adolescents, mental health was most predominant, and for older adolescents, it was well and follow-up care. Dermatologic concerns consistently ranked as the second-most predominant category for all groups. Additional associations by age included common infant concerns for patients younger than 2 years of age; pulmonary, asthma, and allergy-related concerns for school-age children; and genitourinary and gynecologic concerns for older adolescents. These age-dependent shifts in diagnoses emphasize the evolving health care needs of pediatric patients and the acceptability by both parents and providers to address a variety of concerns through telemedicine. Other studies have found age differences in telemedicine use [13,29] but have not examined age-related variation in diagnoses to the extent of this study. In the postpandemic era, both primary care pediatricians and caregivers expect to use telemedicine as a routine part of care provision for acute as well as chronic concerns [19,30-32]. As telemedicine further integrates into primary care practices, understanding age-based variation in use can help strengthen practice-level policies to appropriately and optimally meet the evolving needs of patients and caregivers.

This study has several limitations. First, our findings have geographical and temporal limitations for generalizability. Given that we studied telemedicine use with the onset of the pandemic from February 2020 to April 2021, we do not have a prepandemic comparison group. Our data here also reflect the unique time period in the first year of the pandemic when there was a relative lack of familiarity with web-based medicine. We know telehealth use has evolved during and beyond the pandemic. For example, Solo-Josephson et al [33] found that later in the pandemic, patients using telemedicine had a larger range of preferred languages spoken. The unique manner in which the COVID-19 pandemic progressed in New York City and the local health care and public policy responses are not necessarily representative of other geographical locations. Furthermore, given our community, our findings may be more generalizable to other populations with a predominant proportion of Latino patients or another similar ethnic majority. Other studies have described a similar pivot to telemedicine in pediatric care with the onset of the pandemic [13,14,27,30-32,34,35]. As compared to other institutions, the deployment of the Epic Systems EHR was a unique circumstance at the beginning of our project. Though portal activation was not required of all patients, there was a great deal of outreach to promote activation during the initial few months. The fact that we were able to capture activation in real time was significant, and our results indicate the importance of outreach with such new interventions. However, it is possible that telemedicine use would be different if there had not been a temporal overlap with the deployment of a new EHR. In addition, in our study, the outcomes measured were patient portal activation and the presence of a telemedicine visit. While these are important metrics, we do not describe other factors related to use, such as the reasons for choosing telemedicine over in-person visits, barriers to telemedicine, and patient satisfaction with telemedicine. Further, there were some limitations related to data categorization. Regarding demographic data, we recognize that EHRs have historically had inaccuracies in race and ethnicity data, particularly for Latino, Asian, Native American, and Pacific Islander patients [36]. As it relates to pediatric patients, EHRs and databases may also show discordance for children versus adults, given the additional challenges of gathering data for pediatric patients [10]. Our institution has been part of a multi-institutional framework, starting in 2020, to address some of these challenges. This campaign, We Ask Because We Care, is an exemplar of improvement in data collection. This methodology has now been adapted by other large health systems in the United States since 2020 [9,10]. The framework includes continuous measurement and monitoring with real-time dashboards. Finally, there were also some challenges related to the classification of the diagnosis data. In the diagnosis data, there were some diagnoses that could arguably fit into multiple categories (eg, chest pain as “cardiac” or “musculoskeletal”). We aimed to enhance validity and limit misclassification through detailed chart review where there was ambiguity, as well as iterative categorization and verification by multiple authors.

Future Directions

Avenues for future research include longer-term analysis and qualitative exploration of barriers and facilitators of telemedicine in specific populations, including Latino and Spanish-speaking families, such as factors related to demographic or socioeconomic conditions. Another avenue of further study would be to investigate variations in preferences or satisfaction with telemedicine in different age groups, particularly in the postpandemic period.

Conclusions

Our study provides valuable insights into the implementation of telemedicine in pediatric primary care, particularly for Latino patients, as well as use for common pediatric diagnoses across age groups and over time. As telemedicine has emerged as a vital component of pediatric health care, these findings can inform targeted interventions to enhance accessibility, improve engagement, and tailor telemedicine services to the diverse needs of pediatric patients and families.

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Conflicts of Interest

None declared.

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Abbreviations

aOR: adjusted odds ratio
EHR: electronic health record
NYP/CUIMC: NewYork-Presbyterian Hospital/Columbia University Irving Medical Center

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Web-Based Parent Training With Telephone Coaching Aimed at Treating Child Disruptive Behaviors in a Clinical Setting During the COVID-19 Pandemic: Single-Group Study With 2-Year Follow-Up

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Abstract

Background: There is a lack of studies examining the long-term outcomes of web-based parent training programs implemented in clinical settings during the COVID-19 pandemic.

Objective: The aim is to study 2-year outcomes of families with 3- to 8-year-old children referred from family counseling centers to the Finnish Strongest Families Smart Website (SFSW), which provides digital parent training with telephone coaching aimed at treating child disruptive behaviors.

Methods: Counseling centers in Helsinki identified fifty 3- to 8-year-old children with high levels of disruptive behavioral problems. Child psychopathology and functioning as well as parenting styles and parental mental health were collected from parents at baseline; posttreatment; and at 6-, 12-, and 24-month follow-ups.

Results: The SFSW program had positive long-term changes in child psychopathology and parenting skills. Improvements in child psychopathology, including Strengths and Difficulties Questionnaire total score (Cohen *d*=0.47; *P*<.001), Strengths and Difficulties Questionnaire conduct scores (Cohen *d*=0.65; *P*<.001), and Affective Reactivity Index irritability scores (Cohen *d*=0.52; *P*<.001), were maintained until the 24-month follow-up. Similarly, changes in parenting skills measured with the Parenting Scale, including overreactivity (Cohen *d*=0.41; *P*=.001) and laxness (Cohen *d*=0.26; *P*=.02), were maintained until the 24-month follow-up. However, parental hostility changes were not maintained at long-term follow-up (Cohen *d*=−0.04; *P*=.70).

Conclusions: The study shows that the SFSW parent training program can yield significant long-term benefits. Findings indicate that the benefits of the treatment may vary between different parenting styles, which is important to consider when developing more personalized parenting interventions.

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KEYWORDS

parent training; disruptive behavior; child psychopathology; child functioning; behaviors; behavioral; coaching; web-based; family counseling; child; disruptive; counseling; training; parents; parenting; telephone; telehealth; telemedicine; pediatrics; COVID-19

Introduction

There is growing evidence from randomized controlled trials (RCTs) that parents can be trained to intervene and reduce child disruptive behaviors and improve their parenting skills [1-3]. Parent training has been found to be the most effective way to prevent and treat disruptive behaviors (patterns of, eg, defiant, disobedient, hostile, and externalizing behavior) among children [4-6] and is considered one of the most-validated therapeutic techniques in child mental health [7]. In the face of the unmet need for accessible evidence-based treatment programs to tackle early-onset childhood disruptive behaviors, digitally administered remote treatments provide solutions that require fewer personnel, that may be less stigmatizing, and that can reach geographically remote areas [8,9]. Examining the long-term outcomes of an intervention is an essential step in ensuring the sustainability of its effects. A recent meta-analysis on RCTs showed that parenting interventions based on social learning theory are effective in reducing physical and emotional violence at immediate posttest, but effects decrease over time [10]. However, to our knowledge, there are no long-term follow-ups (ie, more than 12 months) of digital parent training interventions in clinical settings. The Finnish Strongest Families Smart Website (SFSW) intervention is an 11-week program that includes parent training delivered through a digital platform and assisted by weekly telephone coaching. Previously, we conducted an RCT, screening families at regular health checkups for 4-year-old children. Children who had parent-reported high levels of disruptive behavior were screened for targeted SFSW intervention. The sample included 232 children in each study group, an intervention group, and an educational control group. At a 24-month follow-up after randomization, the results maintained efficacy in reducing a wide range of child psychopathology and improving parenting skills [11].

Child behavior problems are associated with psychological distress and financial costs and with a poor long-term outlook if they are not addressed [1]. Early intervention is crucial to help mitigate these impacts and support healthier development trajectories. This study targets an important gap in the current literature on long-term follow-ups of digital parent training interventions in clinical settings. We assessed the long-term outcomes of families participating in the SFSW parent training program in a clinical setting at baseline and at 12 and 24 months after baseline. A unique contribution of this study is that the SFSW parent training program was administered to the study cohort during the worst phase of the COVID-19 pandemic when the Helsinki capital region was partially isolated from other parts of Finland. Other services were severely limited, albeit the need for services was great. The SFSW program was an already existing, empirically tested, and, importantly, digitalized intervention targeting children's disruptive behavior problems. Due to the crisis, it was considered ethically inappropriate to conduct a randomized controlled study design in this study. The program completion rate was high. The 6-month follow-up findings of this program were very promising and have been reported previously [12]. There were significant changes in most of the child psychopathology measures, including the Child Behavior Checklist (CBCL) externalizing score (mean 7.0, 95% CI 4.9 - 9.0; *P*<.001), and when parenting skills were measured with the Parenting Scale (PS), the results showed significant changes in the total score (mean 0.5, 95% CI 0.4 - 0.7; *P*<.001) [12].

Our aim with this paper is to report long-term changes in children's functioning, psychopathology levels, parenting skills, and well-being from baseline until the 24-month follow-up. We hypothesized that the previously reported positive effects of the SFSW at the 6-month follow-up [12] would be at least partly maintained at the 24-month follow-up.

Methods

Study Population

The study included families with children between the ages of 3 and 8 years who exhibited elevated levels of disruptive behavior when screened by professionals from 8 different family counseling centers in Helsinki. Family counseling centers operate under social services and provide low-threshold services. The centers contribute to child development by reinforcing parenting skills and family relationships. They provide direct support, offer advice to assisting services, and facilitate referrals to specialized services. At family counseling centers, parent training that addresses child-rearing challenges is offered through individual or group sessions. The recruitment was based on identified needs. Health care and social welfare professionals from the counseling centers identified families that were in need of support for child disruptive behavior and selected families who were suitable for the remotely administered SFSW parent training program. During the pandemic lockdowns, face-to-face sessions were not possible, underscoring the importance of remote support methods.

Ethical Considerations

Ethics approval for the study was received from the ethics committee of the University of Turku (statement 25/2018), and the study also received a research permit from the city of Helsinki (HEL 2020-006651). Parents provided written informed consent and were advised that participation in the study was voluntary and they had the right to withdraw at any time. This is a single-group study design with repeated measurements. Parents completed questionnaires at baseline; posttreatment; and at 6, 12, and 24 months after starting the program. The study encompassed 50 families and took place from May 2020 to November 2022. Earlier findings comparing baseline, posttreatment, and 6-month follow-up results have been reported previously [12].

Recruitment, Eligibility, and Procedure

The professionals identified children with high levels of disruptive behavior problems. In addition, parents completed the Strengths and Difficulties Questionnaire (SDQ) [13,14] and were included if their child had a high level of conduct problems (≥5 points in the SDQ conduct scale) and if the parents perceived their child to have difficulties concerning emotions, behavior, or social interactions based on one item inquiring parents about these aspects. Additionally, inclusion in the study required at least 1 parent to be a native Finnish or Swedish speaker with access to both a telephone and a device with internet connectivity. Exclusion criteria were if a child had been diagnosed with autism, Down syndrome, fetal alcohol syndrome, an intellectual disability, or severe mental disorders, which would indicate a need for services beyond the scope of the digital SFSW program. Eligible families were invited to participate and directed to the SFSW website to provide their formal consent and fill in the baseline questionnaires. Commencing with the completion of baseline questionnaires, participants progressed through SFSW. A flowchart on the study procedures is provided in inMultimedia Appendix 1.

Intervention

The SFSW parent training program used digital materials (eg, psychoeducational material, video clips, and home exercises) and telephone coaching. The program focused on enhancing skills to improve parent-child relationships, complemented by weekly telephone sessions conducted by trained family coaches—licensed health care professionals, including nurses and public health nurses. The content of each web-based session included an introduction, session content, video exercises, troubleshooting, review, and practical application of the new skills. Each session featured multimedia components and digital exercises, and parents were encouraged to complete the session before the next phone call. All coaching calls were systematically recorded and subjected to random audits by the coach supervisor to ensure fidelity. The telephone sessions were scheduled at the end of the previous weekly call for a duration of 1 hour each. The family coach followed up in case the family missed an appointment, and possible rescheduling of coaching sessions was done per SMS text message or email contact by the parent.

The SFSW program has previously been shown to be effective [11,15] and can successfully make the transition to implementation settings [12,16,17]. Table 1 includes an outline of the weekly themes covered in SFSW. The program was sequential, that is, the parents completed 1-week theme before moving to the next. The primary goal was for parents to recognize positive behaviors in their children and respond positively. The second aim was to apply learned skills in everyday situations, using positive methods to reinforce the child's positive behavior. The end of the program focused on solidifying the application of newfound positive parenting skills in daily life to support the child's positive behavior. Parents practiced these skills with their children and discussed their progress during weekly telephone calls with their family coach, which were scheduled aiming to ensure sustainability beyond the program's completion. As previously reported [12], the average time spent on the program website for each of the 11 themes was 48.0 (SD 25.6) minutes, and the mean duration of telephone coaching was 35.3 (SD 8.8) minutes per call. The total mean duration per theme, including both digital materials and telephone coaching, was 83.3 (SD 28.0) minutes.

Table . Themes of the SFSW[a] web-based parent training program for children with behavioral problems.

Session	Goals
1. Notice the good	Boost the child's self-esteem, boost the parent's self-esteem, and change the parent's view of their child
2. Spread attention around	Strengthen the child's empathy skills
3. Ignore whining and complaining	Teach parents self-regulation
4. Prepare for changes	Reinforce good daily routines
5. Plan ahead at home	Boost the self-esteem of the child and parent and involve the child in planning
6. Chart and stickers	Involve the child in planning and reinforce good daily routines
7. Plan ahead outside the home	Boost the self-esteem of the child and parent and involve the child in planning
8. Working with daycare	Help the child to manage and succeed
9. Time-out	Teach self-regulation and consistency
10 and 11. Problem-solving revision and future application of skills	Teach parents skills to support child development and prepare for future challenges
12. Booster	Remind parents of positive proactive parenting skills

[a] SFSW: Strongest Families Smart Website.

Measurements

The parents completed questionnaires at baseline, after the program, and at 6, 12, and 24 months after they had started the program. In addition, demographic details of the family, children, and parents were collected during the screening phase. All of the measurements used in this study have demonstrated adequate reliability and criterion validity metrics and were described more extensively in our previous paper [12]. For brevity, we mention them briefly below, while a comprehensive description is provided in Multimedia Appendix 2.

Child Psychopathology and Functioning

Child psychopathology was assessed using the Finnish version of the 25-item SDQ [13,14], which measures challenges the child experiences in emotions, behavior, or social interactions [18]. Perceived difficulties were gauged through a single question regarding challenges in emotions, behavior, or social interactions, with response options ranging from no difficulties to severe difficulties. Disruptive behavior was gauged by the externalizing subscale of the CBCL for ages 1.5 - 5 years (99 items) [19], focusing on an externalizing subscale with 24 items related to attention issues and aggressive behavior (our primary outcome) along with the CBCL's total score. Child irritability was measured by the Affective Reactivity Index (ARI), which includes 6 irritability symptom items and 1 impairment item [20]. A 17-item questionnaire, derived from Barkley's Home Situations Questionnaire [21], measured the parents' experiences of their child's functioning and behavior in daily situations. We used the 24-item Inventory of Callous-Unemotional Traits (ICU) [22] to assess 3 precursors of child psychopathy: callousness, uncaring, and unemotional traits [23,24].

Parenting, Parental Mental Health, and Satisfaction

The PS, a 30-item tool, was used to evaluate 3 dysfunctional parenting discipline styles: laxness, overreactivity, and hostility, reflecting rule enforcement, responses to mistakes, and using verbal or physical force, respectively [25,26]. We used the 21-item Depression, Anxiety, and Stress Scale (DASS-21) to assess parental stress, anxiety, and depression symptoms in the past week [27].

Statistical Analysis

Descriptive statistics include numbers and percentages for categorical variables and means and SDs for continuous variables. The categorical variables were analyzed with Pearson chi-square or Fisher exact tests and the continuous variables with 2-sample 2-tailed *t* test. We analyzed the outcome variables using linear mixed-effect models for repeated measurements with time as a within-factor. The modeling framework enables to use restricted maximum estimation method, which handles data with missing observations. Therefore, there was no need to apply any separate imputation method. We used linear contrasts to estimate changes from baseline to 12 and 24 months as well as changes from 12 to 24 months. We included the sex, age, and maternal education of the children as covariates in all models. The McNemar test was applied to test the change in the number of children with a total SDQ score above the 90th percentile (ie, abnormal range) at baseline and at the 24-month follow-up. The effect sizes of all outcome variables were calculated as 2-tailed *t* test effect sizes using Cohen *d*. The statistical analyses were performed using SAS statistical software (version 9.4; SAS Institute Inc).

Results

Participant Characteristics

The study comprised 50 families who were referred to the program, of which 44 (88%) completed the whole 11-week SFSW program. In total, 24-month follow-up assessments were obtained from 37 (74%) families. As shown in Table 2, 37 (74%) of the 50 children were boys. A total of 48 (96%) children had definitive or severe behavioral problems at baseline, and only 2 (4%) had minor behavioral problems based on a single item in the parent report, “Overall, do you think that your child has difficulties in 1 or more of the following areas: emotions, behavior, or being able to get on with other people?” Table 2 also presents a comparison between the families who completed the 24-month follow-up and those who did not. The table shows the difference in maternal education—in the noncompleter group, mothers were less educated. The completers and noncompleters did not differ on parenting style measures or psychopathology symptoms.

Table . Baseline characteristics of enrolled families, and comparison between families completing and those not completing the 24-month follow-up measurements.

Baseline characteristics			All families (n=50)	Families completing the 24-month follow-up (n=37)	Families not completing 24-month follow-up (n=13)	*P* value[a]
Family and parent characteristics						
	Family structure, n (%)					.21
		Biological parents	38 (76)	30 (81)	8 (62)	
		One biological parent	11 (22)	6 (16)	5 (38)	
		Other	1 (2)	1 (3)	0 (0)	
	Age (years), mean (SD)					
		Maternal	31.9 (4.3)	31.9 (3.5)	31.6 (6.2)	.86
		Paternal	32.8 (3.7)	32.3 (3.6)	34.5 (3.7)	.10
	Maternal educational level[b], n (%)					.047
		College or university degree	38 (78)	31 (86)	7 (54)	
		Lower	11 (22)	5 (14)	6 (46)	
	Paternal educational level[c], n (%)					.46
		College or university degree	32 (70)	23 (66)	9 (82)	
		Lower	14 (30)	12 (34)	2 (18)	
	Mother's native language, n (%)					.55
		Finnish	45 (90)	34 (92)	11 (85)	
		Swedish	3 (6)	2 (5)	1 (8)	
		Other	2 (4)	1 (3)	1 (8)	
	Father's native language[c], n (%)					.21
		Finnish	37 (80)	29 (83)	8 (73)	
		Swedish	3 (7)	1 (3)	2 (18)	
		Other	6 (13)	5 (14)	1 (9)	
	Parenting Scale, mean (SD)					
		Total	3.5 (0.5)	3.5 (0.5)	3.5 (0.3)	.81
		Laxness	2.8 (0.8)	2.8 (0.8)	2.8 (0.7)	.95
		Overreactivity	4.3 (1.2)	4.1 (1.2)	4.6 (1.2)	.25
		Hostility	1.9 (0.8)	1.8 (0.8)	1.9 (0.8)	.71
	DASS-21[d], mean (SD)					
		Total	22.6 (14.9)	20.8 (14.2)	28.0 (16.3)	.13
		Depression	6.6 (7.1)	5.3 (5.8)	10.5 (9.1)	.07
		Anxiety	2.8 (4.3)	2.9 (4.3)	2.6 (4.6)	.86
		Stress	13.2 (6.6)	12.6 (6.9)	14.9 (5.6)	.28
Child characteristics						
	Sex, n (%)					.14
		Female	13 (26)	12 (32)	1 (8)	
		Male	37 (74)	25 (68)	12 (92)	
	Age (years), n (%)					.33

Baseline characteristics		All families (n=50)	Families completing the 24-month follow-up (n=37)	Families not completing 24-month follow-up (n=13)	*P* value[a]
	3-5	30 (60)	24 (65)	6 (46)	
	6-8	20 (40)	13 (35)	7 (54)	
Behavioral problems, n (%)					.43
	Minor	2 (4)	2 (5)	0 (0)	
	Definite	30 (60)	20 (54)	10 (77)	
	Severe	18 (36)	15 (41)	3 (23)	
CBCL/1.5-5[e], mean (SD)					
	Total	62.1 (22)	63.6 (21.9)	57.7 (22.6)	.41
	Externalizing	25.7 (7)	26.0 (6.9)	24.9 (7.6)	.63
SDQ[f], mean (SD)					
	Total	19.8 (4.8)	20.2 (4.6)	18.5 (5.1)	.26
	Emotional	3.5 (2.3)	3.7 (2.2)	3.0 (2.5)	.34
	Conduct	7.5 (1.4)	7.5 (1.4)	7.2 (1.5)	.50
	Hyperactivity	6.0 (2.4)	6.1 (2.3)	5.5 (2.5)	.46
	Peer	2.8 (1.9)	2.9 (1.9)	2.7 (2.0)	.78
	Prosocial	5.2 (2.0)	5.1 (2.1)	5.2 (1.7)	.88
	Impact	3.0 (1.7)	3.0 (1.6)	2.9 (2.1)	.93
ARI[g], mean (SD)					
	Irritability	8.6 (3.2)	8.7 (3.0)	8.4 (3.7)	.74
ICU[h], mean (SD)					
	Total	27.4 (7.7)	26.5 (7.3)	30.1 (8.6)	.16
	Callousness	8.9 (3.6)	8.5 (3.5)	10.0 (3.8)	.19
	Uncaring	14.5 (3.5)	14.2 (3.6)	15.2 (3.3)	.37
	Unemotional	4.1 (3.0)	3.8 (2.7)	4.8 (3.8)	.30
Everyday situations (child behavior), mean (SD)					
	Total	42.9 (11.3)	43.8 (11.2)	40.3 (11.7)	.34
	Transition situations	14.7 (4.4)	14.9 (4.4)	14.2 (4.7)	.65
	Dining situations	7.8 (3.0)	8.1 (3.0)	7.0 (2.9)	.27
	Situations outside home	10.4 (3.3)	10.8 (3.3)	9.5 (3.3)	.23
	Home situations	10.0 (3.1)	10.1 (3.1)	9.6 (3.5)	.63

[a] Refers to statistical test comparing families completing the 24-month follow-up to those who did not.

[b] One missing observation.

[c] Four missing observations.

[d] DASS-21: 21-item Depression, Anxiety, and Stress Scale.

[e] CBCL/1.5-5: Child Behavior Checklist for preschool children.

[f] SDQ: Strengths and Difficulties Questionnaire.

[g] ARI: Affective Reactivity Index.

[h] ICU: Inventory of Callous-Unemotional Traits.

Long-Term Changes in Child and Parenting Measures

Descriptive statistics of child psychopathology, child function level, parental skills, and parental mental health at baseline and at 12 and 24 months after baseline are presented in Table 3. A statistical comparison of the different time points is presented in Table 4. In terms of child psychopathology, significant improvements between baseline and the 12-month follow-up as well as between baseline and the 24-month follow-up were found in CBCL total scores and externalizing scores, SDQ total scores and most subscales (emotional, conduct, hyperactivity, and peer problems), and irritability measured with the ARI scale. At the same time, there was a significant deterioration in CBCL total and externalizing scores and SDQ prosocial behavior scores between the 12-month and 24-month follow-ups.

Table . Child psychopathology, child functioning level, parental skills, and parental mental health at baseline and 12 months and 24 months after the baseline (n=50).

Variable			Baseline[a], mean[b] (SE)	12 months[c], mean (SE)	24 months[d], mean (SE)
Child psychopathology					
	CBCL/1.5-5 [e]				
		Total	61.8 (5.5)	43.8 (5.8)	50.2 (5.9)
		Externalizing	25.5 (1.9)	18.0 (2.2)	20.2 (2.2)
	SDQ [f]				
		Total	19.8 (1.1)	14.4 (1.3)	15.3 (1.3)
		Emotional symptoms	3.5 (0.5)	2.1 (0.5)	2.7 (0.5)
		Conduct problems	7.3 (0.4)	5.1 (0.4)	5.2 (0.5)
		Hyperactivity	6.8 (0.6)	5.5 (0.7)	5.7 (0.7)
		Peer problems	2.1 (0.4)	1.5 (0.4)	1.5 (0.5)
		Prosocial behavior	5.6 (0.5)	6.4 (0.5)	5.8 (0.5)
		Impact	3.2 (0.4)	2.0 (0.4)	2.7 (0.4)
	ARI [g]				
		Irritability	9.3 (0.8)	6.2 (0.8)	6.4 (0.8)
	ICU [h]				
		Total	25.9 (1.8)	22.5 (2.0)	24.1 (2.0)
		Callousness	8.1 (0.8)	6.2 (0.9)	6.1 (1.0)
		Uncaring	14.0 (0.8)	12.0 (0.9)	13.3 (0.9)
		Unemotional	4.2 (0.7)	4.6 (0.7)	5.1 (0.8)
Child functioning level					
	Everyday situations				
		Child behavior—total	42.4 (2.7)	33.4 (3.0)	33.6 (3.0)
		Transition situations	13.9 (1.1)	10.5 (1.1)	11.1 (1.1)
		Dining situations	7.8 (0.7)	6.7 (0.7)	6.4 (0.7)
		Situations outside home	10.3 (0.8)	8.0 (0.8)	7.8 (0.8)
		Home situations	10.3 (0.8)	8.0 (0.9)	8.2 (0.9)
Parental skills					
	Parenting Scale				
		Total	3.5 (0.1)	3.1 (0.1)	3.2 (0.1)
		Laxness	2.8 (0.2)	2.4 (0.2)	2.5 (0.2)
		Overreactivity	4.4 (0.3)	3.6 (0.3)	3.8 (0.3)
		Hostility	2.2 (0.2)	1.9 (0.2)	2.2 (0.2)
Parental mental health					
	DASS-21 [i]				
		Total	24.4 (3.8)	20.3 (3.9)	23.5 (4.0)
		Depression	8.2 (1.5)	6.7 (1.5)	7.7 (1.5)
		Anxiety	2.7 (1.0)	2.9 (1.1)	3.4 (1.2)
		Stress	13.5 (1.7)	10.6 (1.8)	12.5 (1.9)

[a] Measurements before the program started.

[b] Least-squares means.

[c] Measurements at 12 months after starting the program.

[d] Measurements at 24 months after starting the program.

[e] CBCL/1.5 - 5: Child Behavior Checklist for preschool children.

[f] SDQ: Strengths and Difficulties Questionnaire.

[g] ARI: Affective Reactivity Index.

[h] ICU: Inventory of Callous-Unemotional Traits.

[i] DASS-21: 21-item Depression, Anxiety, and Stress Scale.

Table . Changes from baseline to 12 months and 24 months after in child psychopathology, child function level, parental skills, and parental mental health.

Variable			Baseline[a] to 12 months[b]			Baseline to 24 months[c]			12 months to 24 months	
			Mean (95% CI)	*P* value	Cohen *d*	Mean (95% CI)	*P* value	Cohen *d*	Mean (95% CI)	*P* value
Child psychopathology										
	CBCL/1.5-5 [d]									
		Total	17.4 (9.8 to 25.0)	<.001	0.49	11.0 (3.5 to 18.5)	.005	0.32	−6.4 (10.2 to −2.7)	.001
		Externalizing	7.5 (4.7 to 9.9)	<.001	0.66	5.2 (2.4 to 8.1)	.001	0.39	−2.3 (−4.1 to −0.4)	.02
	SDQ [e]									
		Total	5.4 (3.5 to 7.3)	<.001	0.62	4.5 (2.4 to 6.5)	<.001	0.47	−0.9 (−2.1 to 0.3)	.34
		Emotional	1.4 (0.7 to 2.1)	<.001	0.43	0.8 (−0.0 to 1.7)	.053	0.21	−0.6 (−1.1 to −0.1)	.03
		Conduct	2.2 (1.6 to 2.8)	<.001	0.78	2.1 (1.4 to 2.8)	<.001	0.65	−0.1 (−0.7 to 0.5)	.68
		Hyperactivity	1.2 (0.5 to 2.0)	.002	0.34	1.0 (0.3 to 1.8)	.008	0.29	−0.2 (−0.8 to 0.3)	.44
		Peer	0.6 (0.1 to 1.0)	.02	0.25	0.6 (0.1 to 1.2)	.03	0.24	0.1 (−0.4 to 0.6)	.77
		Prosocial[f]	−0.8 (−1.4 to −0.2)	.009	−0.27	−0.2 (−0.8 to 0.4)	.45	−0.08	0.6 (0.1 to 1.1)	.02
		Impact	1.2 (0.6 to 1.8)	<.001	0.45	0.5 (−0.2 to 1.1)	.15	0.16	−0.7 (−1.3 to −0.2)	.01
	ARI [g]									
		Irritability	3.1 (1.9 to 4.3)	<.001	0.57	2.9 (1.7 to 4.1)	<.001	0.52	−0.2 (−1.4 to 1.0)	.71
	ICU [h]									
		Total	3.4 (0.9 to 5.9)	.008	0.30	1.7 (−0.8 to 4.2)	.17	0.15	−1.7 (−3.7 to 0.4)	.11
		Callousness	1.9 (0.6 to 3.2)	.004	0.31	1.9 (0.5 to 3.4)	.008	0.29	0.0 (−1.2 to 1.3)	.94
		Uncaring	2.0 (0.7 to 3.2)	.003	0.33	0.8 (−0.3 to 1.8)	.17	0.15	−1.2 (−2.3 to −0.2)	.03
		Unemotional	−0.4 (−1.0 to 0.1)	.14	−0.16	−0.9 (−1.8 to 0.0)	.04	−0.22	−0.5 (−1.2 to 0.2)	.14
Child's ability to function										
	Everyday situations (child behavior)									
		Child behavior total	9.1 (5.3 to 12.9)	<.001	0.52	8.9 (4.9 to 12.8)	<.001	0.49	−0.2 (−3.3 to 3.0)	.91
		Transition situations	3.4 (2.0 to 4.9)	<.001	0.52	2.8 (1.2 to 4.4)	.001	0.38	−0.6 (−1.7 to 0.5)	.27
		Dining situations	1.0 (0.2 to 1.9)	.01	0.28	1.4 (0.6 to 2.3)	.001	0.37	0.4 (−0.4 to 1.2)	.36
		Situations outside home	2.3 (1.1 to 3.4)	<.001	0.43	2.6 (1.4 to 3.7)	<.001	0.49	0.3 (−0.7 to 1.2)	.54
		Home situations	2.2 (1.1 to 3.3)	<.001	0.45	2.0 (0.9 to 3.2)	.001	0.40	−0.2 (−1.2 to 0.9)	.73

Variable			Baseline[a] to 12 months[b]			Baseline to 24 months[c]			12 months to 24 months	
			Mean (95% CI)	*P* value	Cohen *d*	Mean (95% CI)	*P* value	Cohen *d*	Mean (95% CI)	*P* value
Parental skills										
	Parenting Scale									
		Total	0.5 (0.3 to 0.6)	<.001	0.68	0.4 (0.2 to 0.5)	<.001	0.49	−0.1 (−0.2 to 0.0)	.15
		Laxness	0.4 (0.1 to 0.6)	.002	0.35	0.3 (0.1 to 0.5)	.02	0.26	−0.1 (−0.4 to 0.1)	.39
		Overreactivity	0.8 (0.5 to 1.1)	<.001	0.59	0.6 (0.3 to 0.9)	.001	0.41	−0.2 (−0.4 to 0.1)	.09
		Hostility	0.2 (0.0 to 0.3)	.01	0.28	−0.0 (−0.3 to 0.2)	.70	−0.04	−0.2 (−0.5 to −0.0)	.03
Parental mental health										
	DASS-21 [i]									
		Total	4.0 (−0.8 to 8.9)	.10	0.18	0.9 (−4.2 to 5.9)	.73	0.04	−3.2 (−8.3 to 1.9)	.22
		Depression	1.5 (−0.7 to 3.8)	.17	0.15	0.6 (−1.4 to 2.6)	.57	0.06	−1.0 (−2.8 to 0.8)	.29
		Anxiety	−0.2 (−1.7 to 1.2)	.74	0.04	−0.7 (−2.7 to 1.2)	.45	0.08	−0.5 (−2.0 to 1.0)	.51
		Stress	2.9 (0.7 to 5.0)	.009	0.29	1.0 (−1.1 to 3.2)	.34	0.10	−1.9 (−4.3 to 0.6)	.14

[a] Measurement before the program started.

[b] Measurement at 12 months after the program started.

[c] Measurement at 24 months after the program started.

[d] CBCL/1.5‐5: Child Behavior Checklist for preschool children.

[e] SDQ: Strengths and Difficulties Questionnaire.

[f] Increase in prosocial SDQ subscore indicates improvement.

[g] ARI: Affective Reactivity Index.

[h] ICU: Inventory of Callous-Unemotional Traits.

[i] DASS-21: 21-item Depression, Anxiety, and Stress Scale.

We conducted an additional analysis of 37 (74%) of the 50 parents who completed the SDQ questionnaire both at baseline and at the 24-month follow-up as well as the parent training program. This analysis showed that 30 (81%) of the 37 children had a total SDQ score above the 90th percentile (ie, abnormal range) at baseline, while only 14 (38%) remained in the abnormal range at the 24-month follow-up (*P*<.001, McNemar test), based on the population sample of 4‐ to 16-year-old children [12]. To examine the children in the proximity of cutoff thresholds, we also used the 80th percentile cutoff point (ie, abnormal or border range), which showed that 36 (97%) children were above the cutoff point at baseline, while the respective figure at the 24-month follow-up was 23 (62%), indicating a highly significant change (*P*<.001, McNemar test).

When parents were asked about perceived difficulties regarding their child’s behavior problems with a single question—“Overall, do you think that your child has difficulties in 1 or more of the following areas: emotions, behavior, or being able to get on with other people?”—at baseline, 2 (5%) of 37 had no or minor problems, 20 (54%) had definite problems, and 15 (41%) had severe problems. The respective figures at the 24-month follow-up were 14 (38%), 14 (38%), and 9 (24%; *P*=.001, McNemar-Bowker test).

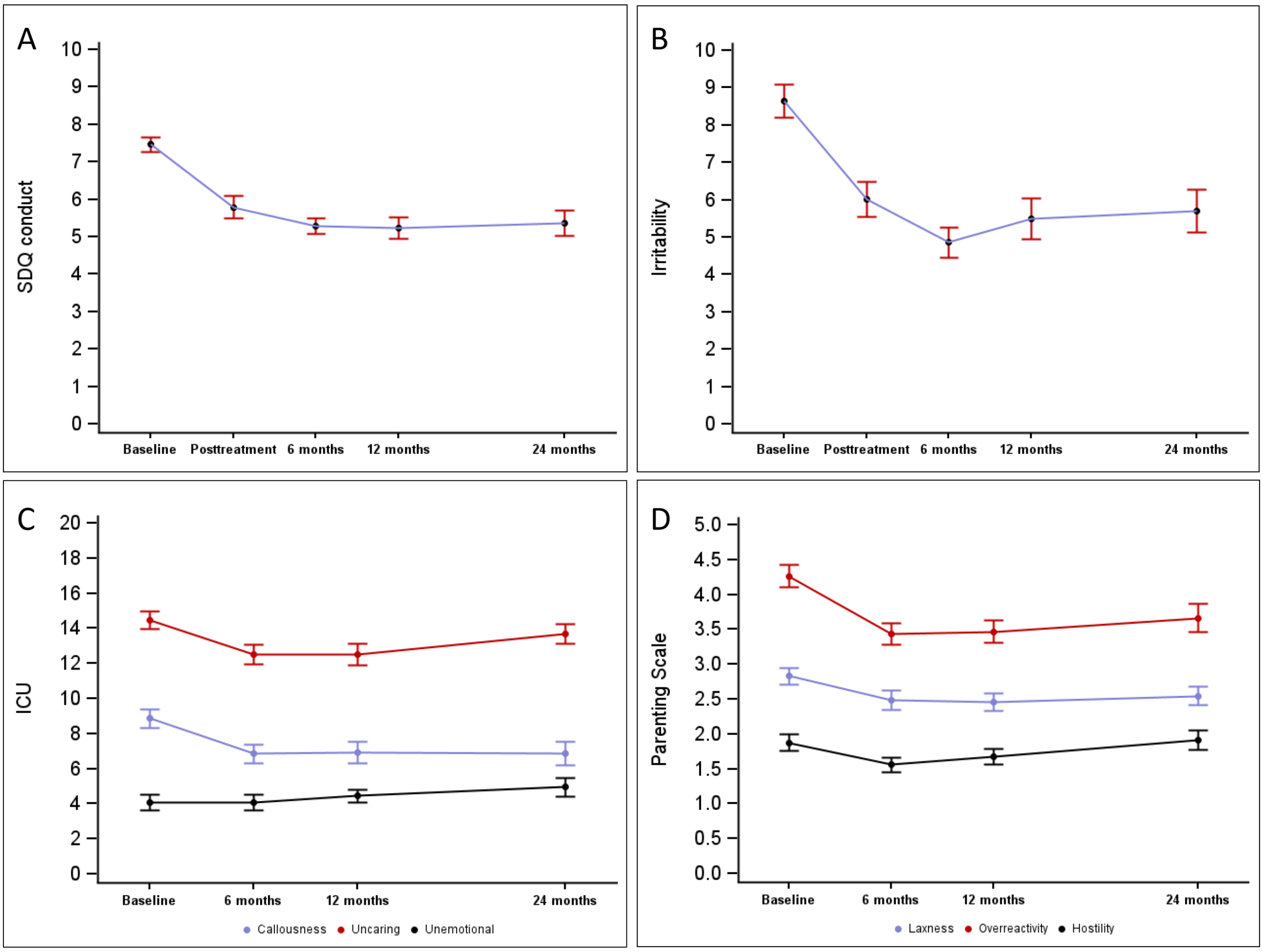
Among the child psychometric measures, callousness and uncaring improved between baseline and the 12-month follow-up. However, uncaring deteriorated between the 12- and 24-month follow-up, and no significant improvement was found between baseline and 24 months. The SFSW parent training program did not have any significant positive association with unemotional traits at the 12- or 24-month follow-up.

Child functioning in everyday situations (eg, transitions, dining, and home and outside home activities) improved significantly between baseline and both follow-up points. No significant change was observed between the 12- and 24-month follow-up comparisons.

Interestingly, there were differences between parenting styles regarding the long-term changes. Parental overreactivity and laxness improved between baseline and the 12-month follow-up and between baseline and the 24-month follow-up. Parental hostility showed improvement between baseline and the 12-month follow-up but not between baseline and the 24-month comparison. In fact, hostility showed significant deterioration between the 12- and 24-month follow-up. We observed no significant association in parental mental health problems, measured with a 21-item Depression, Anxiety, and Stress Scale, between baseline and either of the follow-ups.

Finally, to graphically illustrate the key findings, Figure 1A-D describes the changes of main outcome measures across time points including posttreatment and at the 6-month follow-up, which has previously been reported in detail [12]. Of note, the PS and ICU were not measured at posttreatment. The figures illustrate that SDQ conduct and ARI irritability scores exhibited the largest improvement between baseline and posttreatment and further improvement between posttreatment and the 6-month follow-up; the findings at the 12- and 24-month follow-ups were rather stable. Among the ICU measures, callousness and uncaring showed improvement between baseline and the 6-month follow-up. After that, callousness stayed quite stable, while uncaring and unemotional showed deterioration. As for the parenting measures, all parenting styles showed improvement between baseline and the 6-month follow-up. After that, overreactivity and laxness were quite stable, while hostility showed deterioration.

Figure 1. (A-D) Mean curves of SDQ conduct scores, irritability scores, ICU scores, and Parenting Scale subscores. (A) SDQ conduct scores over time (model-based least-squares means, SE). (B) Irritability scores over time (model-based least-squares means, SE). (C) ICU subscales over time (model-based least-squares means, SE). (D) Parenting Scale subscores over time (model-based least-squares means, SE). ICU: Inventory of Callous-Unemotional Traits; SDQ: Strengths and Difficulties Questionnaire.



Discussion

Principal Findings

To the best of our knowledge, this is the first study on long-term follow-up of digital-guided parent training intervention among children referred to treatment from specialized care. The findings mostly complement the previously conducted 6-month follow-up study [12] by showing that the SFSW program was associated with significant improvements in children's externalizing symptoms (our primary outcome) at 12 and 24 months after baseline. Of note, most of the improvement took place between baseline and posttreatment assessment, and the level of externalizing problems showed stability from the 12- to the 24-month follow-up. This study's importance is in demonstrating that digital parent training with weekly remote phone coaching seems to lead to enduring improvements in disruptive behavior problems in children with severe disruptive behavior problems. The findings align with a 24-month follow-up study of the SFSW program [11,15-17], which was used as a preventive and early intervention among 4-year-old children, identified through national medical checkups [28]. However, since the target group was different, the level of disruptive behavior problems among the children in this study was much more severe [12], which suggests the promise of such interventions in supporting populations with different levels of symptom severity.

Most comorbidities such as hyperactivity, emotional and peer problems, and child functioning in everyday situations maintained their improvement from baseline to the 12- and 24-month follow-ups as well. Interestingly, the program seemed to have a very clear association with decreased irritability. This novel finding implies that some of the major effects of parent training may be associated with decreasing irritability in parent-child interactions; this requires further research.

For some problems, such as callous-unemotional traits, improvement was reported at the 12-month follow-up but not at the 24-month follow-up. Callous-unemotional traits characterize a specific subgroup of children exhibiting early starting, stable, and severe conduct problems. It has been argued that conventional parenting interventions frequently prove ineffective within this subgroup [29,30].

Another important finding was that the responses to the parent training program seemed to differ according to parenting styles. Improvements in parent overreactivity and laxness were shown both in the comparison between baseline and the 12- and 24-month follow-ups, while parental hostility improved until the 12-month follow-up, then deteriorated to the same level as at baseline. It could be interpreted that parental hostility is, in the long run, resistant to parent training programs. It is also possible that accumulated stressors during the COVID-19–related public health restrictions may have posed an additional strain on some parents' psychological resources [31-33] and on their ability to maintain positive approaches to their child.

There is limited research on the effects of parenting interventions on reducing parental hostility. Parental hostility can have broad impacts within the family, potentially disrupting the ability of one parent to maintain a positive relationship with their child [34]. There is a significant positive correlation between parent hostility and child aggression, indicating that the more hostile parents are toward others, the more aggressive their children tend to be [35]. Similar findings regarding conduct problems, callous-unemotional traits, and parenting were made in a previous study [36], where higher levels of parental harshness were related to higher levels of child conduct problems and callous-unemotional traits. Children subjected to abuse resulting from their parents' aggressive behavior may experience adverse effects on their self-control and exhibit challenges in impulse control by acting impulsively, speaking before thinking, and demonstrating a reduced capacity to tolerate frustration or cope with failure [37]. There are also findings showing that parental attitudes play a substantial role in the gradual enhancement of a child's self-control, exerting a significant impact on the individual [35]. In cases where parent training proves to be ineffective in the long term in reducing parental hostility, the parent could benefit from receiving personal support or therapy to address this issue. It is likely that more tailor-made and targeted interventions and treatment plans would benefit this subgroup of families, which are at risk of falling into this kind of negative cycle.

When the study started in May 2020, Helsinki was grappling with the peak of the COVID-19 pandemic, marked by a state of emergency declared nationwide in Finland. Stringent social distancing measures were enforced in the region to curb the virus's transmission, significantly affecting families residing in the area. The COVID-19 pandemic has highlighted the importance of exploring remote, digital, or digitally assisted solutions for ensuring that young children, and their families, are provided with prompt support for mental health problems. This study demonstrated that technology can provide effective alternatives to traditional face-to-face interventions and can overcome a number of barriers during crises. Technology can be used to provide the right treatment at the right time, with high levels of support and fidelity, providing greater access and convenience and requiring fewer costs and less time.

Limitations

It is important to acknowledge certain limitations. The present results from our clinical sample do not necessarily generalize across community samples. Since no a priori power analysis was performed, we cannot exclude the possibility that the study was underpowered. We note that with a sample size of 50 participants, we had 80% power to detect an effect size of 0.35 (1-tailed, α=.05). The study design did not allow for direct conclusions regarding the program's efficacy, as it lacked an intervention-control group design. However, the COVID-19 pandemic meant that treatment and family counseling services could not be provided in the usual way, and conducting a randomized controlled study design would have been considered ethically inappropriate. Due to the lack of a control group, it is not possible to exclude the possibility of some age-related spontaneous improvement reflected in the results. Nevertheless, an earlier RCT using population-based screening in Finland showed that the SFSW intervention was effective at 2-year follow-up [11]. Furthermore, the constraints of social distancing, which included school closures, also prevented us from conducting direct observations of parenting, clinical assessments, and teacher ratings. It is possible that some consequences of those restraints are also reflected in some of our measures, such as the SDQ prosocial and peer subscales.

Conclusions

This study provides support for the utility of remotely delivered parent training interventions. Incorporating remote interventions into child mental health services also serves as a safeguard during crisis situations such as COVID-19.

The study shows that remote digital child mental health services bring substantial benefits to families that can last for up to 2 years. Overall, the study emphasizes that guided digital parent training programs can be a crucial component in developing evidence-based treatment practices for children and families.

The study also emphasizes the importance of conducting long-term follow-ups to understand long-term intervention gains. The study results indicate that different parenting profiles and child psychopathology may have varying effects on the long-term outcome of the program. This finding is important when developing personalized parenting interventions for increased impact.

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Conflicts of Interest

AS is the founder and director of Digifamilies, a provider of evidence-based treatments to Finnish public health services. AB received grant funding from The Israel National Institute for Health Policy Research, the National Institutes of Health, and the Israeli Scientific Foundation. He also provides consultancy services to ifeel. The remaining authors have no conflicts of interest to disclose.

Multimedia Appendix 1
Flowchart of study procedures.
[DOCX File, 36 KB - pediatrics_v7i1e63416_app1.docx]

Multimedia Appendix 2
Comprehensive description of measurements.
[DOCX File, 21 KB - pediatrics_v7i1e63416_app2.docx]

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Abbreviations

ARI: Affective Reactivity Index
CBCL: Child Behavior Checklist
ICU: Inventory of Callous-Unemotional Traits
PS: Parenting Scale
RCT: randomized controlled trial
SDQ: Strengths and Difficulties Questionnaire
SFSW: Strongest Families Smart Website

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Parent-Led Applied Behavior Analysis to Impact Clinical Outcomes for Individuals on the Autism Spectrum: Retrospective Chart Review

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Abstract

Background: Autism spectrum disorder (ASD) can have traits that impact multiple domains of functioning and quality of life, which can persevere throughout life. To mitigate the impact of ASD on the long-term trajectory of an individual's life, it is imperative to seek early and adequate treatment via scientifically validated approaches, of which applied behavior analysis (ABA) is the gold standard. ABA treatment must be delivered via a behavior technician with oversight from a board-certified behavior analyst. However, shortages in certified ABA therapists create treatment access barriers for individuals on the autism spectrum. Increased ASD prevalence demands innovations for treatment delivery. Parent-led treatment models for neurodevelopmental conditions are effective yet underutilized and may be used to fill this care gap.

Objective: This study reports findings from a retrospective chart review of clinical outcomes for children that received parent-led ABA treatment and intends to examine the sustained impact that modifications to ABA delivery have had on a subset of patients of Montera, Inc. dba Forta ("Forta"), as measured by progress toward skill acquisition within multiple focus areas (FAs).

Methods: Parents received ≥40 hours of training in ABA prior to initiating treatment, and patients were prescribed focused (<25 hours/week) or comprehensive (>25 - 40 hours/week) treatment plans. Retrospective data were evaluated over ≥90 days for 30 patients. The clinical outcomes of patients were additionally assessed by age (2-5 years, 6-12 years, 13 - 22 years) and utilization of prescribed treatment. Treatment encompassed skill acquisition goals; to facilitate data collection consistency, successful attempts were logged within a software application built in-house.

Results: Improved goal achievement success between weeks 1 - 20 was observed for older age, all utilization, and both treatment plan type cohorts. Success rates increased over time for most FAs, with the exception of executive functioning in the youngest cohort and comprehensive plan cohort. Goal achievement experienced peaks and declines from week to week, as expected for ABA treatment; however, overall trends indicated increased skill acquisition success rates. Of 40 unique combinations of analysis cohorts and FAs, 20 showed statistically significant positive linear relationships ($P<.05$). Statistically significant positive linear relationships were observed in the high utilization cohort (communication with $P=.04$, social skills with $P=.02$); in the fair and full utilization cohorts (overall success with $P=.03$ for the fair utilization cohort and $P=.001$ for the full utilization cohort, and success in emotional regulation with $P<.001$ for the fair utilization cohort and $P<.001$ for the full utilization cohort); and in the comprehensive treatment cohort (communication with $P=.001$, emotional regulation with $P=.045$).

Conclusions: Parent-led ABA can lead to goal achievement and improved clinical outcomes and may be a viable solution to overcome treatment access barriers that delay initiation or continuation of care.

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KEYWORDS

applied behavior analysis; autism spectrum disorder; parent training; patient outcomes; skill acquisition; pediatrics

Introduction

Autism spectrum disorder (ASD) impacts multiple domains of functioning and quality of life, which can persevere through an individual's lifetime [1,2]. These impacts span an individual's interpersonal relationships; intrapersonal experience and well-being; family finances; and parental stress [3-5]. Mitigating the impact of ASD on the long-term trajectory of an individual's life and the immediate familial well-being requires early and adequate treatment. Applied behavior analysis (ABA), a gold-standard treatment for ASD, employs scientifically validated and evidence-based approaches to foster skill acquisition across varying domains [6-8]. ABA is typically prescribed within the patient's treatment plan as comprehensive (treatment intensity ~25 - 40 hours/week) or focused (treatment intensity ~10 - 25 hours/week) treatment [9,10], as determined by a board-certified behavior analyst (BCBA). ABA treatment can be delivered via a behavior technician (BT) meeting age, education, and training requirements (>40 training hours) with BCBA oversight [9].

Although treatment success for ABA has extensive documentation in literature, this treatment approach suffers from several challenges that impede access and implementation [6-8]. Shortages in the BT and BCBA workforce result in difficulties with access and wait lists, particularly for individuals residing in remote geographical areas, leading to treatment delays [11-13]. Although the Behavior Analyst Certification Board (BACB) provides general guidelines, the traditional ABA model lacks a standard approach, as treatment plans need to be individualized. With the prevalence of ASD growing continually over the past several decades, expanding ABA access is necessary to ensure that individuals on the autism spectrum can develop and master social, emotional, and daily living skills [13].

The proximity of parents and/or caregivers (hereinafter referred to as “parents”) to individuals on the autism spectrum within daily living environments presents an opportunity to supplement or deliver naturalistic ABA treatment. In fact, many health insurance companies require a parent component (eg, participation in treatment) in order to ensure that treatment progress can be generalized in different settings [14]. Parent-led therapies have the added benefit of eliminating barriers such as wait lists and scheduling difficulties that occur with ABA treatment in clinical settings. Research has validated the effectiveness of parent-led therapies/interventions for ASD and other neurodevelopmental disorders [11,15-21]. Heitzman-Powell et al used a virtual platform to train parents in geographically remote areas to deliver ABA, after which parents gained an average of >39% increase in ABA knowledge; their successful ABA implementation also increased by >40% [11]. Molnár et al examined a parent-delivered early intensive behavioral intervention (EIBI), a form of ABA, and observed improvements in outcomes across different metrics [22]. Oono et al conducted a systematic review of trials examining parent-led interventions for children on the autism spectrum, and they found statistically significant improvements in language/communication and a reduction in ASD severity [23].

Our study contributes to the body of research on patient outcomes resulting from parent-led ABA. However, our work stands out from most prior work on parent- or caregiver-delivered ABA, as we present the outcomes of sustained real-world treatment outside of a research setting, which has the downside of a defined and relatively short study period. Our previous pilot study [18], which is related to this work, examined how nontraditional ABA modalities benefitted patient outcomes compared to traditional ABA. In this work, we report upon the sustained impact that modifications to ABA delivery have had on a subset of patients of Montera, Inc. dba Forta (hereinafter, “Forta”). Particularly, we describe how individuals receiving parent-led ABA treatment progressed toward goal achievement in terms of skill acquisition within multiple focus areas (FAs). Notably, this study is not a research trial study, but rather a retrospective chart review reporting on clinical outcomes of patients in parent-led ABA treatment.

Methods

Overview

Active patients of Forta between October 2022-May 2023 with a diagnosis of ASD per the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) diagnostic criteria [24] were considered for the study. Patients with incomplete documentation of goal progress and without a minimum of 90 days of data were excluded. The 90-day threshold ensured patients would be at least halfway through a typical 6-month ABA treatment plan. This resulted in 30 patients with sufficient data for analysis, as shown in the attrition chart (Figure 1). Patients included in the data analysis had available longitudinal data ranging from 15 - 20 weeks. Variation in available data resulted from patients initiating treatment with the company at different time points. Prior to treatment delivery, parents of patients completed ≥40 hours of ABA training using a virtual, web-based program adhering to BACB standards [25]. After training, the parents were required to pass an Initial Competency Assessment to demonstrate the skills and knowledge required to deliver ABA treatment. Upon successfully passing the Initial Competency Assessment, the parents became BTs and were assigned to a BCBA for supervision of the treatment process in accordance with the BACB guidelines [25]. Unlike typical BTs that deliver ABA treatment to more than one patient during a given week, the parents that became BTs focused on leading treatment delivery solely for their own children.

Demographics for the 30 patients whose data were processed and analyzed are displayed in Table S1 in Multimedia Appendix 1. Demographic data were obtained from ABA treatment patient intake forms completed by parents. The average patient age was 8.39 years (aged 2.81 - 22.60 years at the start of their data collection), and 77% (23/30) of the patients were males. Within the total patient cohort, 2 patients had syndromic ASD (both with DiGeorge syndrome, mild ASD, took no medication) and 28 patients had nonsyndromic ASD, where syndromic versus nonsyndromic ASD was defined according to Genovese and Butler [26]. At the beginning of the study, 14 patients took no medication, 3 were administered nonprescription medication or supplements (eg, antihistamines, multivitamins, probiotics, melatonin), 5 were administered antipsychotics, and 8 were administered prescription medication other than antipsychotics (eg, stimulants for attention-deficit/hyperactivity disorder, replacement hormones, anticonvulsants). We are not aware of any medication changes during the course of the study.

Patients were grouped by utilization of the number of ABA treatment hours that were prescribed by the BCBA who conducted the intake assessment and provided treatment oversight (Figure 1). To determine each utilization cohort, utilization data for each patient were averaged over their individual studied time period (≥15 weeks) and that average was used to classify each patient as having fair, full, or high utilization. The high utilization patient cohort completed ≥95% of the prescribed ABA treatment hours; the full utilization patient cohort completed 80% to <95%; and the fair utilization patient cohort completed <80%. Patients were assessed within three age cohorts (2.00 - 5.99 years, 6.00 - 12.99 years, and 13.00 - 22.99 years) and by their assignment to a focused (<25 hours/week) or comprehensive (>25 to 40 hours/week) ABA plan (Figure 1). The age cohorts align with existing research examining effects of ABA treatment across various ages [27].

The patient age distribution in each utilization cohort is shown in Figure 2A. There were 11 patients in the high utilization cohort (received ≥95% of prescribed treatment), 11 patients in the full utilization cohort (received 80% to <95% of prescribed treatment), and 8 patients in the fair utilization cohort (received <80% of prescribed treatment). Figure 2B displays overall utilization rate trends for all patients within each utilization cohort. Weekly utilization was averaged on a weekly basis for each patient and represents the percentage of prescribed weekly ABA treatment hours that patients utilized during the study. Previous studies indicated that utilization of >80% of prescribed ABA hours can be regarded as a “full dose” of ABA treatment (ie, full utilization) [28,29].

Following the intake assessment, the BCBA provided each patient with a highly individualized treatment plan establishing specific goals for skill acquisition based on that individual patient’s strengths and weaknesses across multiple FAs. For complex skill acquisition goals, goals were broken down into multiple treatment targets for the patient to master the entire goal. For example, within the communication domain, if a patient was prescribed the skill acquisition goal of “identifying common objects,” the patient could be further assigned the targets of “identifying a chair” and “identifying a cup” to work on. The process of mastering each goal involved the patient working on one or more targets associated with that specific skill acquisition goal. On average, patients in the analysis cohort worked on 21.1 skill acquisition goals and associated targets during the study period.

To measure clinical outcomes for each patient, the study solely evaluated skill acquisition goals. Patient progress toward mastering a particular skill was assessed with quantifiable parameters (ie, number of successful attempts to complete a task). This evaluation served as an indicator of the patient’s level of achievement toward a specific goal, a measurement technique that may be better suited to indicate clinical progress and outcomes than standard of care assessments [30]. The goal achievement data are reported as the percentage of successful attempts to complete a task out of all attempts, reported as percent of trial data. The goal achievement data were averaged weekly for each patient for each skill acquisition goal they worked on during that week. Goal achievement data are expressed as a percentage value ranging from 0% (0 successful attempts) to 100% (all attempts were successful). This is a method similar to that used by Choi et al, in which patient progress in ABA treatment was measured by the desired percent of goals versus actual goals achieved [31].

Baseline data for each skill acquisition goal for each patient were collected either by BCBA or parent assessment. This provided the opportunity for the BCBA to personalize the treatment plan and progress measurement. Longitudinal goal achievement data for each patient were logged for each skill (subsequent to baseline data measurement for that particular skill) by the parent BT during the course of ABA treatment sessions on a software application built in-house. This application facilitated streamlined data collection and analysis. Following the creation and implementation of a treatment plan, specific goals were tracked on the application, which provided a user-friendly interface for parent BTs to log session data, while having the additional benefit of ensuring a robust and streamlined data collection and analysis process. During a treatment session, parent BTs could select a specific skill acquisition goal or target thereof from the assigned treatment plan and report the total number of attempts and how many were successful. As data were easily accessible, parent BTs could review data after the treatment session to complete notes and progress reports. The application also provided a user-friendly mechanism for the BCBAs to track progress over time and ensure the most pertinent skill acquisition goals were being implemented and evaluated. Data for the analysis in this study were collected through the application, encompassing the data for all skill acquisition goals across all treatment sessions for the 30 patients with ≥90 days of data. With direct clinical data, there is a limitation on interrater reliability, as each patient was only evaluated by a single practitioner providing therapy (ie, their parent BT). However, our treatment delivery methods were evidence-based (eg, skill acquisition via manding [a request for a want or need], reinforcement, task analysis) and BCBAs performed ongoing supervision sessions with parent BTs and patients, thereby monitoring overall progress to ensure treatment was administered effectively and within the ABA standard of care [9]. Parent BTs performing ABA treatment were supervised by a BCBA for at least 5% of the treatment time (according to the BACB requirement) [25], or for any amount of treatment time required by state or insurance regulations [32-36].

For data analysis, we grouped skill acquisition goals into 4 FAs or categories: communication (COM), emotional regulation (ER), executive functioning (EF), and social skills (SS). Each FA aligned with a corresponding domain or subdomain utilized in the Vineland Adaptive Behavior Scale, 3rd Edition (Vineland-3), a widely used assessment tool targeting neurodevelopmental disorders, as follows [37]. COM FA corresponds to the Vineland COM domain; ER FA to the Coping Skills subdomain (Socializing domain); EF FA to the Daily Living Skills domain; and SS FA to the Vineland Interpersonal Relationships and Play and Leisure subdomains (Socializing domain). Vineland-3 domains and subdomains were used strictly for mapping the FAs (ie, assigning every skill acquisition goal to an FA) and were not employed as a data assessment scale for the data reported in this paper.

To evaluate the progress of patients and compare different cohorts, patients were first grouped into utilization rate, age groups, and treatment plan type cohorts. Within each group, goal success rate was measured across all skill acquisition goals and across each FA across cohorts (eg, success rate of all ER goals across all patients with a comprehensive care plan) for each patient. To evaluate the progress of goals over time, a correlation coefficient was computed for each FA for each cohort to determine the magnitude of change and the direction of the success rate trend for each cohort. A statistical significance test was then performed across all patient cohorts to determine if the correlation coefficient (*r*) was significant, indicating the change in performance over time did increase over the evaluation period of 16 weeks (Table 1).

Figure 1. Attrition chart. Figure created using Lucidchart [38].

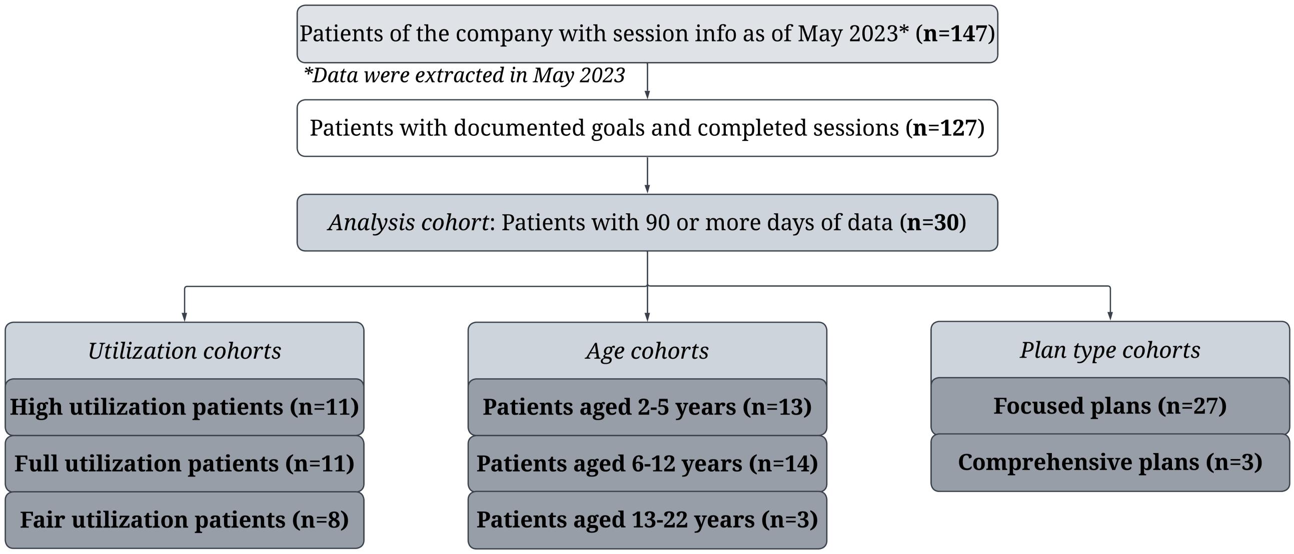


Figure 2. High utilization cohorts by (**A**) age and (**B**) weekly utilization. Goal achievement/success rate by utilization (**C**) overall and (**D**) for each focus area. Black lines aggregate all patients; each gray line represents a single patient; a vertical dashed line at 13 weeks denotes the cutoff for the minimum amount of data that each patient was required to have for inclusion in the study. This figure was created using Plotly in Python.

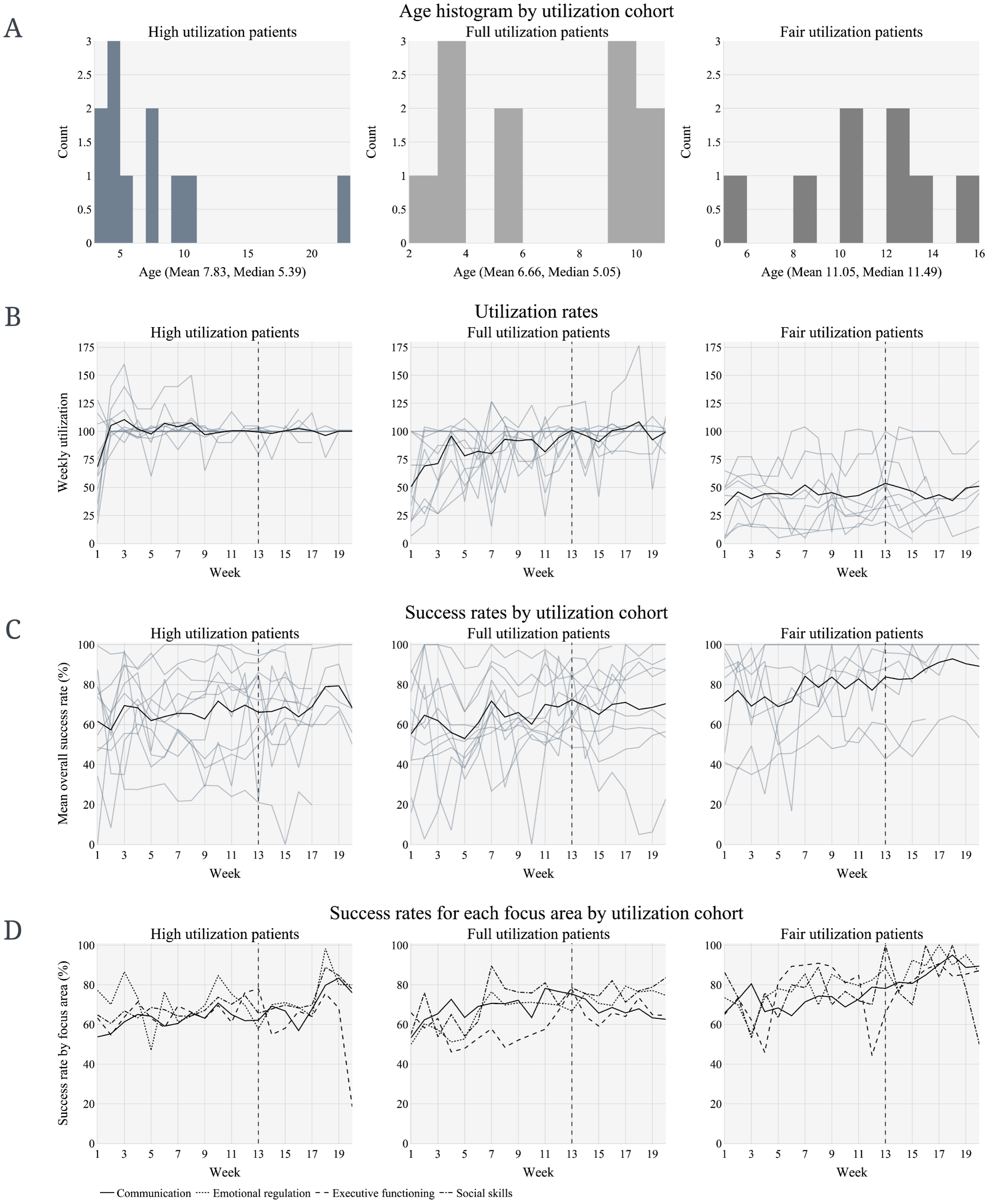


Table . Summary table indicating the net change in success rate overall and across each focus area for the different utilization, treatment plan type, and age cohorts (weeks 1 ‑ 16).[a]

		Utilization cohorts			Treatment intensity cohorts		Age cohorts (years)		
		High (n=11)	Full (n=11)	Fair (n=8)	Focused (n=27)	Comprehensive (n=3)	2 ‑ 5 (n=13)	6 ‑ 12 (n=14)	13 ‑ 22 (n=3)
Autism spectrum disorder severity breakdown									
	Mild	2	5	4	10	1	2	7	2
	Moderate	4	4	2	9	1	7	3	0
	Severe	5	2	2	8	1	4	4	1
Age (years), mean (SD)		8.2 (5.4)	6.7 (3.3)	11.0 (3.0)	8.9 (4.3)	4.0 (1.0)	4.3 (1.0)	10.1 (1.4)	17.0 (4.9)
Utilization percentage, mean (SD)		100.1 (3.4)	88.1 (4.6)	42.1 (24.3)	78.8 (28)	92.8 (8.8)	88.7 (23.1)	78.5 (24.5)	51.6 (41.7)
Prescribed hours, mean (SD)		21.8 (3.4)	21.4 (5.5)	23.1 (2.6)	21.1 (3.2)	30.0 (0.0)	23.5 (4.3)	20.7 (3.7)	21.7 (2.9)
Number of goals and associated targets, mean (SD)		18.5 (7.7)	21.5 (10.2)	24.0 (12.5)	21.0 (9.7)	21.7 (14.6)	18.5 (9.8)	24.6 (9.9)	16.3 (8.1)
Medication breakdown									
	None	7	3	4	13	1	6	7	1
	Meds^1[b]	0	2	1	3	0	2	0	1
	Meds^2[c]	1	3	1	4	1	2	3	0
	Meds^3[d]	3	3	2	7	1	3	4	1
Communication									
	r	0.500	0.450	0.748	0.645	0.719	0.455	0.616	0.153
	P value	.04	.07	.001	.05	.001	.07	.008	.62
Emotional regulation									
	r	−0.200	0.772	0.773	0.737	0.492	0.677	0.549	0.275
	P value	.44	<.001	<.001	.001	.045	.003	.03	.30
Executive functioning									
	r	0.136	0.410	0.305	0.544	0.382	0.224	0.536	−0.237
	P value	.60	.10	.23	.02	.13	.39	.03	.36
Social skills									
	r	0.570	0.537	0.370	0.664	0.466	0.510	0.516	0.592
	P value	.02	.03	.14	.004	.06	.04	.03	.09
Overall									
	r	0.020	0.798	0.597	0.646	0.358	0.319	0.330	0.360
	P value	.95	.001	.03	.02	.23	.29	.27	.23

[a] *P*<.05 indicates significant likelihood of data having a linear relationship.

[b] Meds^1: nonprescription medication.

[c] Meds^2: prescription medication, antipsychotics.

[d] Meds^3: prescription medication, other than antipsychotics.

Ethical Considerations

This work was deemed exempt by an independent Institutional Review Board per Food and Drug Administration 21CFR56.104 and 45CFR46.104(b)(4) and received a waiver of informed consent. The work was carried out in accordance with ethical standards and with the Declaration of Helsinki (revised in 2000). Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines have been applied in this study.

Results

Overview

Results are shown for goal achievement progress between weeks 1 (start of data collection) and 20. All patients had available data for the initial 13 weeks of the study and a minimum of 90 days of data total. All selected patients had >15 weeks of data (29 patients with ≥16 weeks, 1 patient with 15 weeks). The data between weeks 16 - 20 were less robust, as each patient had a different longitudinal dimension in that time period of data analysis, with some patients having only 16 weeks of data, and others having the full 20 weeks.

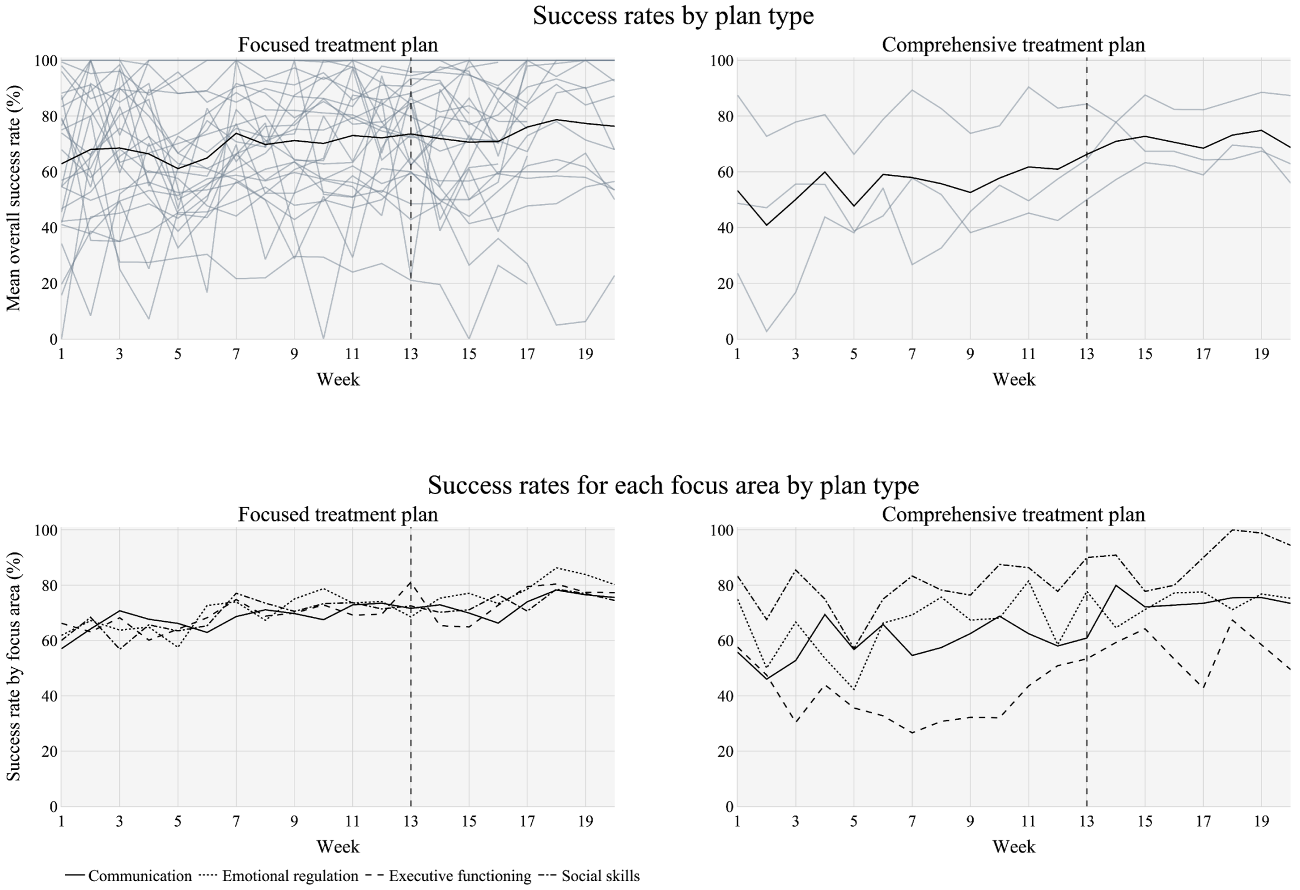
Goal Achievement/Success Rate by Utilization Rate and FA

As shown in Figure 2C, overall success toward skill acquisition increased for all 3 utilization cohorts. Overall success rate appears to be consistent and shows improvement over the 20-week period across all utilization cohorts. When examining the success rate for each FA by utilization cohort for the initial 16-week period, patients in each utilization cohort displayed growth in all 4 FAs, except ER for the high utilization cohort, which varied significantly during this period (Figure 2D). From weeks 16 to 20, patients in the high utilization cohort showed a distinguishable increase in success rate in ER, while remaining highly variable. In addition, patients in the high utilization cohort showed a drop in success for EF from weeks 19 to 20 after a steady increase during the initial 19 weeks. Further, patients in the fair utilization cohort displayed a substantial drop in success rate for SS from weeks 18 to 20, after having increased during the initial 18 weeks. Notably, EF and SS exhibited high variability.

Goal Achievement/Success Rate by Treatment Intensity (Plan Type) and FA

For patients in both treatment plan types, growth over time was displayed in the overall success toward skill acquisition (Figure 3, top panels). Success rates for each FA by treatment intensity (Figure 3, bottom panels) followed largely the same trend as the overall success rate (Figure 3, top panels), except EF for the comprehensive treatment plan cohort. Patients prescribed a focused treatment plan displayed consistent and similar growth in success rates over time for all 4 FAs. Patients prescribed a comprehensive treatment plan displayed growth in success rates over time in COM and SS. The success rate for ER and EF showed great variability for the comprehensive treatment plan cohort. However, this trend may be due to a smaller sample size (n=3) compared to the patient cohort prescribed a focused treatment plan (n=27).

Figure 3. Goal achievement/success rate by treatment intensity: overall (top panels) and for each focus area (bottom panels). Black lines aggregate all patients; each gray line represents a single patient; a vertical dashed line at 13 weeks denotes the cutoff for the minimum amount of data that each patient was required to have for inclusion in the study. This figure was created using Plotly in Python.



Goal Achievement/Success Rate by Age Cohort and FA

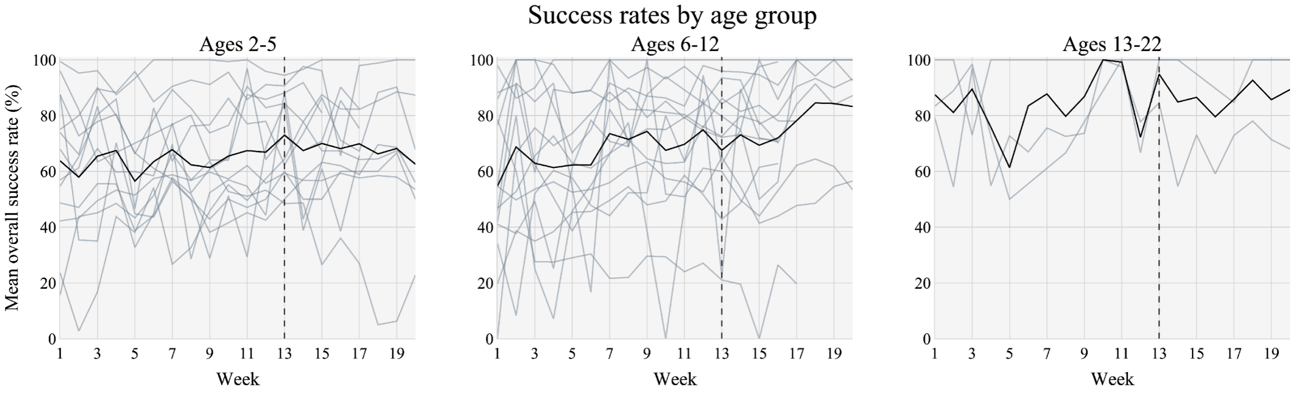
As shown in Figure 4 (top panels), overall success toward skill acquisition varied among the 3 age cohorts, with the most notable growth over time for the middle age cohort (6 - 12 years), followed by more modest growth for the oldest age cohort (13 - 22 years). The youngest age cohort (2 - 5 years) displayed growth for the initial 16-week period, where data were present for all but 1 patient. After 16 weeks, less data were available for the youngest and middle age cohorts; thus, statistical significance (as denoted by *P* value and *r*) of the results decreased by comparison with the initial 16-week period. Results after week 16 did not demonstrate statistical significance. The success rates for each FA by age cohort (Figure 4, bottom panels) followed largely the same trend as the overall success rate observed in Figure 4, top panels. The most notable and consistent growth over time was observed for the middle age cohort (6‑12 years) for all 4 FAs. When examining data for the oldest age cohort (13‑22 years) for each FA, no discernible pattern emerged; however, data appear to indicate a trend of increased performance with increasing treatment time. The youngest age cohort (2‑5 years) demonstrated growth for the initial 16-week period for COM, ER, and SS, with ER and SS maintaining growth after 16 weeks. The youngest age cohort struggled the most with EF. It is notable that 3 of the 13 patients in the youngest age cohort have been prescribed a comprehensive treatment plan, and that the EF FA displays the same trend with respect to the other 3 FAs for the comprehensive treatment plan cohort and for the youngest age cohort.

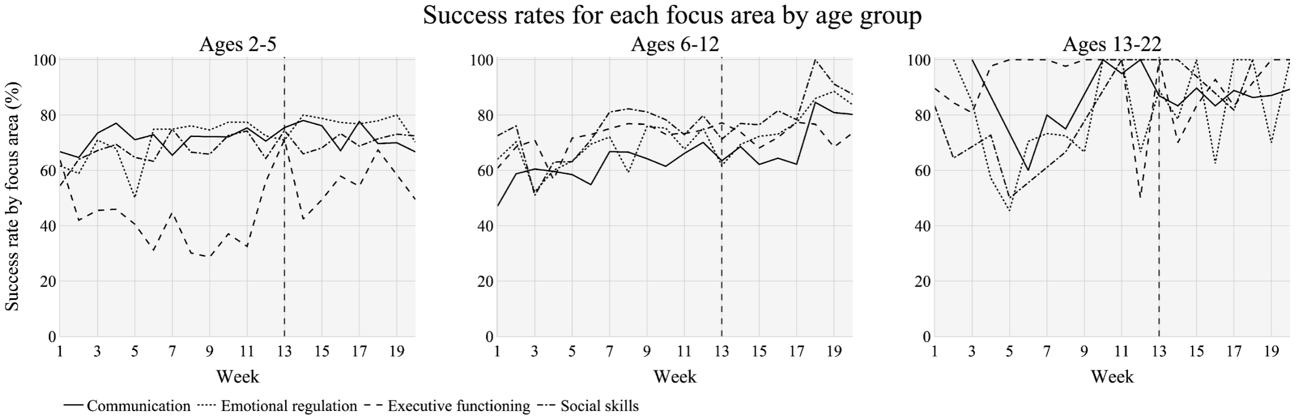
The results in Table 1 indicate the severity breakdown for each analysis cohort, as derived from DSM-5 severity level criteria, and the correlation coefficient (*r*) and *P* value for the cohort's success rate across each analysis cohort. The correlation coefficient represents the strength of the relationship of the cohort's success rate over time, with values closer to −1/1 indicating a stronger negative/positive relationship in success rate over time, and values closer to 0 indicating a flatter relationship over time. The corresponding *P* value indicates the likelihood of the relationship being flat (slope of a regression line equal to 0). For each analysis cohort, these values were computed across each FA, as well as overall (ie, in combination across all FAs).

Of the 40 unique combinations of analysis cohorts and FAs (Table 1), 20 showed statistically significant positive linear relationships (*P*<.05), with 26/40 having *r*>0.4, indicating at least a moderate-to-strong positive linear relationship in the data and 35/40 having *r*>0.2, indicating at least a weak-to-moderate positive linear relationship [39].

The mean age of patients between the treatment intensity cohorts indicates that patients with comprehensive treatment plans are younger than patients with focused plans, with all 3 patients in the comprehensive cohort being in the age range of 2‑5 years old. In addition, the youngest age cohort also had the highest mean number of authorized hours, with 3 of the 13 patients prescribed a comprehensive treatment plan. This aligns with literature indicating that younger children will gain more in ABA treatment with more hours [40]. Patients with comprehensive plans also had higher mean utilization, indicating not only a more intensive treatment plan, but also a more intense implementation of the treatment plan. Similarly, younger patients also have substantially higher utilization rates than older patients.

Figure 4. Goal achievement/success rate by age cohort: overall (top panels) and for each focus area by age (bottom panels). Black lines aggregate all patients; each gray line represents a single patient; a vertical dashed line at 13 weeks denotes the cutoff for the minimum amount of data that each patient was required to have for inclusion in the study. This figure was created using Plotly in Python.





Discussion

Principal Findings

This study examines outcomes for a small sample of Forta's patients receiving parent-led ABA treatment, where half of the cohort combinations demonstrated statistical significance in regard to positive linear relationships for skill acquisition. Within all cohorts, we generally observed growth toward overall success for skill acquisition for all 3 utilization cohorts, with a few exceptions. Additionally, we observed variability in success toward skill acquisition over the study period. Use of success toward skill acquisition as an outcome measure fills a gap in the literature, as a majority of studies utilize standardized measurements, such as Vineland-3, which do not reflect the granular changes that can be observed with behavior changes [8,27]. This is of particular value in clinical settings, as these changes can guide individualized treatment planning.

Separation of patients by age (cohort 1: 2 - 5 years, preschool; cohort 2: 6 - 12 years, elementary and middle school; cohort 3: 13 - 22 years, high school and older) reflects research indicating that these 3 age groupings master different skills at different rates within ABA treatment. This is particularly true for younger children, for whom the number of treatment hours directly impacts success toward skill acquisition [27].

When stratified by utilization, all 3 cohorts generally experienced growth in skill acquisition. The variability in success with ER within the high utilization cohort could be the result of parents having to spend a significant amount of time getting patients to become receptive to treatment during a session (owing to patient struggles with ER and EF).

Within cohorts stratified by age, there were several statistically significant positive linear relationships observed for the middle age cohort in all FAs, which may indicate that these patients were more receptive to treatment. The youngest age cohort struggled with EF; however, attaining EF skills is known to be a complex process that may be impacted by subtle differences between individual patients [41]. This cohort was the only age cohort for whom progress in EF goals declined between the start and conclusion of the study, which could be attributed to a number of factors. For example, this age cohort had the most patients with a high level of symptom severity, which may have impeded progress toward EF skill acquisition. Progress may also have been hindered if parents had to spend a greater number of hours acclimating their children to the treatment process.

Regarding the variability from week to week for skill acquisition success, research indicates that progress toward skill acquisition in ABA treatment does not typically follow a steady progression; thus, variability is expected [8,19,37,40]. Observing such fluctuations within different FAs may help a parent decide which skill to focus on for a given day, depending on their child's success level [27]. Although we also detected this weekly variability, several FAs followed linear trends in terms of progress within each cohort. Regarding the linearity that was observed within the focused treatment cohort across all FAs, this demonstrated that fewer treatment hours (focused treatment plans have fewer hours than comprehensive ones) can also lead to linear skill gains. Our results indicate that fewer treatment hours can also be beneficial; however, according to the existing literature, a higher number of hours (ie, comprehensive treatment) provides for better outcomes in terms of skill acquisition in ABA for individuals on the autism spectrum [42]. Linstead et al noted that when treatment intensity was either high or low, individuals did not gain as much per hour as individuals who received an intermediate number of treatment hours [30]. These two literature findings [30,42] are not mutually exclusive and both support the notion that treatment plans have to be highly individualized to provide the basis for achieving the most beneficial treatment gains. The linearity of gains for the patients in the focused cohort may indicate that the focused plan was appropriately assigned for the 27 patients. Further, even with only 3 patients in the comprehensive cohort (not providing much opportunity for averaging out data outliers), COM and ER displayed statistically significant positive linear relationships (*P*<.05, Table 1), which may also indicate that the focused treatment plan was appropriately assigned for the 27 patients.

When the patients were stratified by treatment intensity (plan type), there was more variation in the level of skills within all focus areas at both the start and conclusion of the study in the comprehensive versus focused cohorts.

Data regarding broad average utilization based on either prescribed hours of treatment or insurance-approved hours of treatment are not publicly documented, to the best of our knowledge. Therefore, the utilization rates that we present in this clinical outcomes study will fill a gap in the literature. Within research studies of ABA treatment, rates of utilization are highly variable. However, variability in the use of prescribed ABA hours and underutilization of prescribed ABA hours, which may impact a patient's ability to receive the "full dose" of treatment (at least 80% of prescribed treatment hours), is not uncommon. In a study by Yingling et al, patients on the autism spectrum who were prescribed a specific number of weekly hours for EIBI treatment only used a mean of 37% of those hours and the authors further noted that the most utilization was observed within the first week of EIBI treatment [43], a pattern that was not observed within our patient cohorts. By contrast, our overall utilization in the analysis cohort (n=30) was 80.2%, which is over twice as high when compared with the utilization reported by Yingling et al [43]. Choi et al examined ABA treatment utilization and noted that 28% of the patient population received the "full dose" of treatment in terms of hours or sessions [44], in contrast to our study, in which 70% of the patients used the "full dose" of authorized treatment hours. Croen et al [29] studied an ABA-based behavioral health treatment in which underutilization of prescribed treatment hours was observed, with only 15% of patients receiving the "full dose" of prescribed treatment hours. These studies examined treatment in clinical settings (as opposed to treatment delivered in-home by parents), and there may have been barriers that were prohibitive for initiating and maintaining care, such as a nationwide shortage of ABA treatment providers [45] or geographical limitations and/or costs associated with travel to obtain treatment in clinical settings, which are mitigated in our treatment approach [11]. Differences between the high utilization of the prescribed hours in our study and relatively poor treatment adherence in other studies could also be attributed to the parents' increased confidence in their ability to successfully deliver ABA treatment resulting from the receipt of ABA training [21,46].

This research highlights the potential value of parent-led ABA treatment in terms of impacting a patient's success toward goal acquisition, particularly as it relates to overcoming financial and logistical burdens of gaining access to ABA [16]. These factors impede the ability to obtain and sustain treatment, which prevents patients on the autism spectrum from receiving validated treatment that may improve outcomes [15,45]. At the time the data were analyzed for this study, Forta had almost 200 patients, a number which has seen continued and substantial growth in a small window of time. This may reflect the need for more service providers, as well as the need for alternative ABA treatment delivery methods that afford greater flexibility (ie, in-home and parent-led) for parents and families, which may ensure treatment uptake and adherence. By training parents to deliver treatment to their children on their own schedule and without having to leave their homes, parents can continue treatment regardless of the availability of BTs to sustain the gains that their child makes toward skill acquisition. Additionally, by allowing the BCBAs to perform monitoring virtually, logistical barriers are eliminated and the BCBAs can use time that may otherwise have been used for travel to patients' homes to see more patients. Parent-led ABA further allows treatment to be delivered in a culturally appropriate manner, which is important for treatment outcomes [16,47].

Study limitations are as follows. First, our study did not account for variables beyond age, utilization, and treatment intensity. Research suggests that sociodemographic traits can impact the utilization of ABA, which may impact progress toward goal achievement [48]. The severity of symptoms and the parent's skills for treatment delivery may also impact treatment outcomes [42]. In our 2 youngest cohorts, a higher number of patients were diagnosed with moderate and severe ASD. Though these cohorts accessed a "full dose" of treatment (>80% of prescribed hours), the severity of symptoms may require more time in treatment to progress at a pace similar to older patients. Individuals with greater severity of symptoms may also start treatment with limited baseline skills, which may impact rate of progress [49]. Individuals with more severe symptoms may have lower treatment adherence [50], which may impact outcomes. Future work should examine the effect of diverse variables/factors on treatment progression. As parents recorded the progress of their child, there is the potential that response bias may have impacted the internal validity of results. Future examination of patient outcomes may use a more research-focused design, including a control group, randomization of treatment intensity, or a larger number of patients to demonstrate statistical significance, the latter which may also improve upon generalizability. Though our study examined outcomes over a longer period of time than our previous pilot study, observing outcomes over a sustained period of time may elucidate different skill acquisition patterns, as patients are known to demonstrate better achievement in some skills over a longer treatment period (as opposed to intensity) [30]. Measuring such changes may be facilitated by the use of standardized assessments such as Vineland-3. Therefore, future work can incorporate validated outcome measurements to determine larger-scale, longitudinal changes resulting from ABA [8,27]. Last, there was a very small number of patients in the oldest cohort (13 - 22 years), which may have prevented the emergence of clearer trends. This cohort also had the lowest utilization, which may be the result of resistance to therapeutic treatments among adolescents (and a greater level of health care decision autonomy), fear of autism-related social stigma [51,52], and/or social and academic obligations. To better understand the extent that outcomes can be impacted in adolescents and young adults, future work should include a greater number of individuals within that age range.

Conclusion

This retrospective chart review study explored longitudinal trends related to patients' success toward achieving skill acquisition goals in parent-led ABA therapy within a real-world treatment setting. We examined the clinical outcomes of patients receiving parent-led ABA and noted overall growth in success for most cohorts and FAs. This study demonstrated the potential for parent-led ABA treatment delivery as an alternative approach to traditional ABA delivery in a clinical setting.

Acknowledgments

AG, MC, and QM originated the concept. AG, JG, MC, and QM did the data analysis. AG, JG, MC, NPS, QM, and RD are responsible for the design. AG, MC, GB, and FAD did the data interpretation. MC and QM supervised the work. MC, GB, FAD, and QM wrote the original draft. AG, MC, NPS, GB, FAD, JG, QM, and RD revised the writing. AG, MC, NPS, GB, FAD, JG, QM, and RD approved the final version.

Data Availability

The datasets generated during and/or analyzed during this study are not publicly available due to protection of patient privacy and confidentiality.

Conflicts of Interest

All authors are employees or contractors of Montera, Inc. dba Forta.

Multimedia Appendix 1
Demographics table showing patient information.
[DOCX File, 16 KB - pediatrics_v7i1e62878_app1.docx]

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Abbreviations

ABA: applied behavioral analysis
ASD: autism spectrum disorder
BACB: Behavior Analyst Certification Board
BCBA: board-certified behavior analyst
BT: behavior technician
COM: communication
DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
EF: executive functioning
EIBI: early intensive behavioral intervention
ER: emotional regulation
FA: focus area
SS: social skills
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
Vineland-3: Vineland Adaptive Behavior Scale, 3rd Edition

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Original Paper

Predictors of Participation in a Perinatal Text Message Screening Protocol for Maternal Depression and Anxiety: Prospective Cohort Study

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Abstract

Background: Universal screening for depression and anxiety in pregnancy has been recommended by several leading medical organizations, but the implementation of such screening protocols may overburden health care systems lacking relevant resources. Text message screening may provide a low-cost, accessible alternative to in-person screening assessments. However, it is critical to understand who is likely to participate in text message–based screening protocols before such approaches can be implemented at the population level.

Objective: This study aimed to examine sources of selection bias in a texting–based screening protocol that assessed symptoms of depression and anxiety across pregnancy and into the postpartum period.

Methods: Participants from the Montreal Antenatal Well-Being Study (n=1130) provided detailed sociodemographic information and completed questionnaires assessing symptoms of depression (Edinburgh Postnatal Depression Scale [EPDS]) and anxiety (State component of the State-Trait Anxiety Inventory [STAI-S]) at baseline between 8 and 20 weeks of gestation (mean 14.5, SD 3.8 weeks of gestation). Brief screening questionnaires, more suitable for delivery via text message, assessing depression (Whooley Questions) and anxiety symptoms (Generalized Anxiety Disorder 2-Item questionnaire) were also collected at baseline and then via text message at 14-day intervals. Two-tailed *t* tests and Fisher tests were used to identify maternal characteristics that differed between participants who responded to the text message screening questions and those who did not. Hurdle regression models were used to test if individuals with a greater burden of depression and anxiety at baseline responded to fewer text messages across the study period.

Results: Participants who responded to the text messages (n=933) were more likely than nonrespondents (n=114) to self-identify as White (587/907, 64.7% vs 39/96, 40.6%; *P*<.001), report higher educational attainment (postgraduate: 268/909, 29.5% vs 15/94, 16%; *P*=.005), and report higher income levels (CAD $150,000 [a currency exchange rate of CAD $1=US $0.76 is applicable] or more: 176/832, 21.2% vs 10/84, 11.9%; *P*<.001). There were no significant differences in symptoms of depression and anxiety between the 2 groups at baseline or postpartum. However, baseline depression (EPDS) or anxiety (STAI-S) symptoms did predict the total number of text message time points answered by participants, corresponding to a decrease of 1% (e^{β}=0.99; *P*<.001) and 0.3% (e^{β}=0.997; *P*<.001) in the number of text message time points answered per point increase in EPDS or STAI-S score, respectively.

Conclusions: Findings from this study highlight the feasibility of text message–based screening protocols with high participation rates. However, our findings also highlight how screening and service delivery via digital technology could exacerbate disparities in mental health between certain patient groups.

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KEYWORDS

perinatal mental health; digital screening; maternal depression; maternal anxiety; text messaging; mHealth; mobile health; pregnancy; mobile phone

Introduction

Perinatal Mental Health

Perinatal mood and anxiety disorders such as depression and anxiety are among the most common complications of pregnancy affecting as many as 20% of pregnant and postpartum individuals [1]. Failure to identify those at risk of adverse perinatal mental health outcomes can have negative consequences for both mother and child [2]. Maternal suicide is a leading cause of maternal death in high-income countries [3-5], while maternal prenatal depression and anxiety associate with an increased risk of preterm birth and low birth weight [6-9], child socioemotional and behavioral difficulties [10-17], and clinically significant psychiatric symptoms in adolescence and early adulthood [15,18-21]. Cost analyses from the United States, the United Kingdom, Australia, and Canada highlight the significant economic impact of untreated perinatal mood and anxiety disorders [22-25]. As such, the early detection and the appropriate treatment of maternal depression and anxiety are public health priorities [5].

Given the high prevalence and adverse consequences of perinatal mood and anxiety disorders, several countries now recommend universal screening for maternal depression and anxiety using validated questionnaires beginning in pregnancy [26-30]. In contrast, the Canadian Task Force on Preventive Health Care recently recommended against questionnaire-based screening [31], in part due to the time-consuming nature of these assessments. The use of brief screening instruments and remote screening approaches delivered using personal mobile devices may help overcome barriers to the implementation of universal screening for maternal perinatal depression and anxiety [32-34].

Mobile Health Perinatal Mental Health Screening

In Canada, approximately 96% of individuals aged 15 to 44 years own a smartphone [35], with comparable smartphone ownership rates in other countries including the United States [36]. The widespread availability of smartphone devices has led to increased interest in the use of personal mobile devices to deliver health care and public health services, termed "mobile health" (mHealth) [37,38]. mHealth encompasses a variety of approaches to identify, treat, or prevent adverse health outcomes including mental illness [39-46].

The most common mHealth approach is text messaging, which has been used for communication (eg, providing appointment reminders and improving patient adherence with treatment), intervention (eg, monitoring chronic conditions and providing psychological support), and patient data collection (eg, self-reported questionnaires screening for symptom levels) [39,47-51]. Text messaging allows for more timely and repeated self-report symptom capture with minimal burden [47]. A growing number of studies have used text messaging as a tool to collect self-report patient data in the perinatal period (pregnancy through 1 year postpartum) [40,52,53]. Studies in Canada and the United States have found text message–based mental health screening to be acceptable and feasible when compared to paper-based screening during the perinatal period [52-54], with increased participant satisfaction reflecting an increased perception of privacy and anonymity [52,54]. Few studies to date have examined potential selection biases (ie, sociodemographic and mental health factors) that may influence participation in a text message–based screening protocols [52]. In the United States, lower levels of participant engagement in digital health interventions were observed in racialized groups including Black and Latino communities [55]. To date, there are no Canadian reports on patient engagement in text message–based perinatal mental health screening particularly among racialized or low-income individuals [52,56-60].

In this study, we sought to identify factors that predict participation in a text message–based mental health screening protocol within a diverse, longitudinal cohort in Canada as a first step toward assessing the feasibility of using mHealth approaches to screen maternal mental health at the population level.

Methods

Ethical Considerations

Informed consent was obtained from all study participants, and the option to opt out of the study was provided to all participants. Ethics approval for the study was granted by Saint Mary's Hospital Research Ethics Board (SM-18-27, MP-18-20190500) in accordance with the Helsinki Declaration of 1975. Participants selected their preferred language (French or English) during enrollment with all subsequent data collected in their language of choice. Participants were compensated for completing self-report questionnaires at recruitment, in mid-late pregnancy, and 2 postpartum time points with a CAD $10 (a currency exchange rate of CAD $1=US $0.76 is applicable) e-gift card per time point.

Recruitment

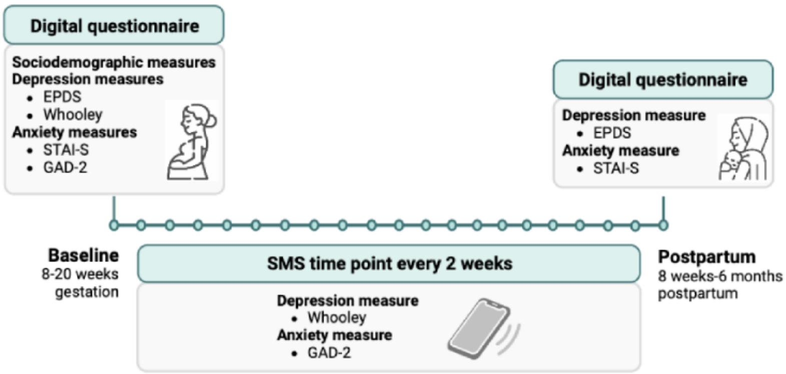
The Montreal Antenatal Well-Being Study (MAWS) is a cohort of 1130 pregnant participants recruited between August 2019 and March 2021. Participants were recruited from prenatal care clinics associated with 3 major birth centers in Montreal, Quebec (Saint-Mary's Hospital, Sainte-Justine Mother and Child University Hospital Center, and Lasalle Hospital). Following the onset of the COVID-19 pandemic, participants were also recruited through self-selection using targeted advertising on social media (Facebook). Eligibility criteria included being between 8 and 20 weeks of gestation; reading proficiency in French or English; aged 18 years or older; and owning a smartphone, tablet, or personal computer.

Measures

Sociodemographic Information

Sociodemographic data, including maternal age, race and ethnicity, immigration status, education level, income level, and history of mental health diagnosis were collected via self-report using a secure digital platform for data capture (REDCap [Research Electronic Data Capture]; Vanderbilt University) at baseline between 8 and 20 (mean 14.50, SD 3.80) weeks of gestation (Figure 1).

Figure 1. Data collection timeline of sociodemographic and mental health measures in the Montreal Antenatal Well-Being Study. EPDS: Edinburgh Postnatal Depression Scale; GAD-2: Generalized Anxiety Disorder 2-Item; STAI-S: State component of the State-Trait Anxiety Inventory.



Maternal Mental Health

Maternal depression and anxiety symptoms were assessed at baseline (recruitment) and at approximately 8 weeks postpartum (mean 8.73, SD 3.73 weeks) using validated clinical instruments through REDCap. Participants received a unique link via email at baseline and postpartum to complete their digital questionnaires on their own smartphones, tablets, or personal computers (Figure 1).

Maternal symptoms of depression were assessed using the Edinburgh Postnatal Depression Scale (EPDS). The EPDS is a widely used and validated 10-item self-report depression screening tool (Table S1 in Multimedia Appendix 1) with scores ranging from 0 to 30. EPDS sensitivity and specificity estimates range from 38% to 43% and 98% to 99%, respectively [61]. Maternal symptoms of anxiety were assessed using the State component of the State-Trait Anxiety Inventory (STAI-S). The STAI-S scale is a 20-item, self-report scale commonly used to measure an individual's anxiety symptoms at the time of assessment (Table S1 in Multimedia Appendix 1). Each item is measured on a 4-point Likert scale. Higher scores indicate greater state anxiety symptoms. Internal consistency coefficients for the scale have ranged from 0.86 to 0.95; test-retest reliability coefficients have ranged from 0.65 to 0.75 [62]. Depression and anxiety symptoms of clinical concern are defined as scores 13 on the EPDS and 40 on the STAI-S, respectively (Table S1 in Multimedia Appendix 1).

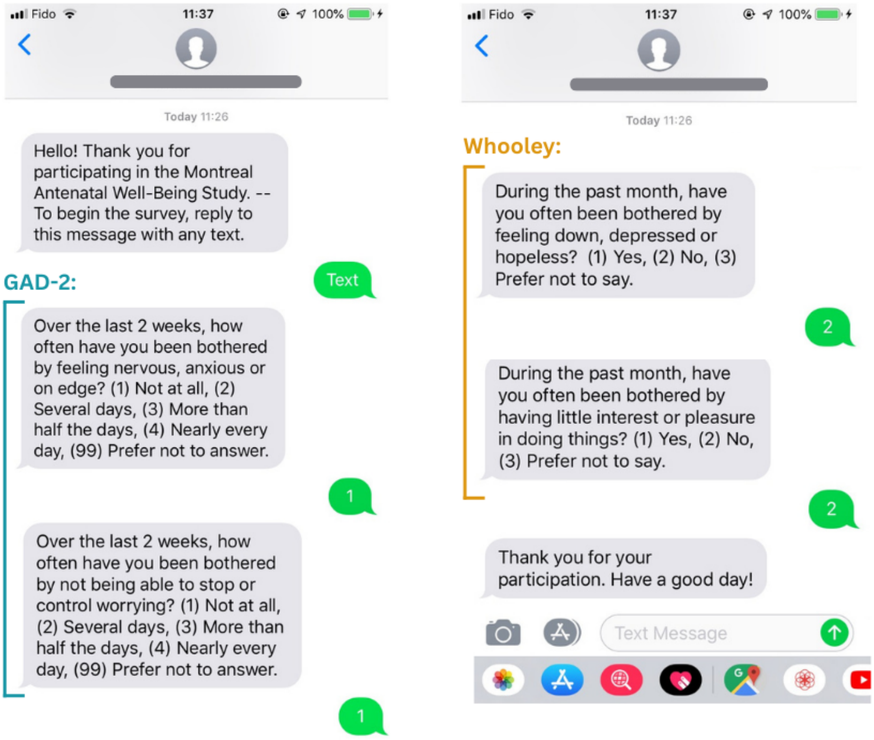
Text Message–Based Screening Protocol

Text message–based screening was performed using REDCap-Twilio integration (Figure 2 and Table S2 in Multimedia Appendix 1). Participants received their first text message time point 14 days after enrollment and then at 14-day intervals until the participant reached 8 weeks postpartum. If the survey was not initiated after the first text message, participants were prompted with a reminder text message sent 24 hours and then 48 hours after the initial text message. If participants failed to respond to 5 consecutive text message time points, no further messages were sent. A text message time point screening assessment consisted of 4 questions sent via separate text messages, which assessed symptoms of depression (Whooley Questions) [63] and anxiety (Generalized Anxiety Disorder 2-Item [GAD-2] questionnaire) [64], using 2 questions for each construct.

The Whooley Questions probe symptoms of depressed mood and anhedonia (Table S1 in Multimedia Appendix 1) and are used for routine screening of maternal depression in many countries including the United Kingdom [27]. Participants who respond "yes" to at least 1 of the 2 questions (score 1) may benefit from further evaluation (~95% sensitivity) [63]. Conversely, a negative screen suggests that no further evaluation is required. The Whooley Questions have a higher sensitivity compared to similar brief screening questionnaires for depression symptoms such as the 2-item Patient Health Questionnaire [65,66]. The GAD-2 assesses symptoms of anxiety and worry (Table S1 in Multimedia Appendix 1). Responses are scored using a Likert scale ranging from 0 to 3. An instrument score 3 has an 86% sensitivity and 83% specificity for identifying possible cases of generalized anxiety disorder and may warrant further evaluation by a clinician [64]. These 2 brief questionnaires were selected based on their suitability for delivery via text message and based on their existing use as part of universal perinatal mental health screening in the United Kingdom [27].

For this analysis, we included all maternal participants in the MAWS cohort who had received at least 1 text message time point, that is, one set of both depression and anxiety screening questions via text message. We excluded those who had withdrawn from the study prior to 8 weeks postpartum (n=60) and MAWS participants who did not receive a single text message because their area code was not covered by our service provider (n=23). This gave rise to a sample size of 1047, including 933 (89.1%) participants who responded to at least 1 text message time point and 114 (10.9%) participants who did not respond to any text message time points.

Figure 2. Text messages sent to Montreal Antenatal Well-Being Study participants' personal smartphones at 14-day intervals from enrollment in the study until 8 weeks postpartum. GAD-2: Generalized Anxiety Disorder 2-Item.



Hello! Thank you for participating in the Montreal Antenatal Well-Being Study. -- To begin the survey, reply to this message with any text.

Text

Over the last 2 weeks, how often have you been bothered by feeling nervous, anxious or on edge? (1) Not at all, (2) Several days, (3) More than half the days, (4) Nearly every day, (99) Prefer not to answer.

1

Over the last 2 weeks, how often have you been bothered by not being able to stop or control worrying? (1) Not at all, (2) Several days, (3) More than half the days, (4) Nearly every day, (99) Prefer not to answer.

1

During the past month, have you often been bothered by feeling down, depressed or hopeless? (1) Yes, (2) No, (3) Prefer not to say.

2

During the past month, have you often been bothered by having little interest or pleasure in doing things? (1) Yes, (2) No, (3) Prefer not to say.

2

Thank you for your participation. Have a good day!

Statistical Analyses

We defined "respondents" as participants who responded to at least 1 text message time point (n=933). "Nonrespondents" were defined as participants who did not respond to any text message time points (n=114). Fisher tests with Monte-Carlo simulations (categorical variables) and 2-tailed *t* tests (continuous variables) were used to investigate if any sociodemographic or mental health measures collected at baseline and postpartum significantly differed between respondents and nonrespondents.

In addition, hurdle regression models using a log link function were used to determine associations between participants' total number of text message time points completed and participants' sociodemographic variables or mental health, adjusting for the number of text message time points each participant received. Hurdle models considered the number of text message time points completed by participants according to its two possible outcomes: (1) zero time points completed, the outcome of nonrespondents (zero model); and (2) a positive number of time points completed, the outcome of respondents (count model) [67,68]. Binomial logistic regression with a log link was used for the nonrespondent zero model. On the other side of the "hurdle," a zero-truncated Poisson distribution was used for the respondent count model. For categorical sociodemographic variables, the relative difference between the data fitting a null model containing no predictor variables and a model containing each of the sociodemographic variables individually was tested with a likelihood ratio test. For continuous baseline mental health measures, Exp (β), or the exponential value of the unstandardized coefficient β (e^{β}), provided the incidence risk ratio for the count model, that is, the predicted ratio of the number of text message time points completed per unit increase in the predictor variables, whereas Exp (β) in the zero model provided the odds ratio. Adjusted hurdle models considered predictors of interest together with relevant covariates including self-reported race and ethnicity, income level, and education level.

Correlations (Spearman for ordinal and Pearson for continuous variables) were computed to determine the association of sociodemographic or mental health variables collected at baseline with participants' "response rate," which was defined as the number of text message time points they responded to divided by the number of text message time points they received. Thus, analyses of participant response rate account for variation in gestational age at recruitment, which determined the total number of possible text message screening time points.

Finally, linear regression models were used to determine if measures of anxiety or depression from brief text message screening assessments helped to better predict postpartum depression and anxiety symptoms than assessments of mental health at baseline. Participant response rate was also considered in these models to test whether participant compliance was a better predictor of mental health outcomes than symptom data. The Akaike Information Criterion was used as a measure of model fit to determine which of a set of predictors (ie, response rate, baseline mental health scores, or scores from the brief text message–based mental health screening questions) were the best predictors of elevated scores on validated clinical measures of postpartum depression and anxiety (EPDS and STAI-S). All analyses were run using R statistical software (version 4.2.2; R Foundation for Statistical Computing). The *pscl* package was used for the hurdle regression analyses.

Results

Overview

Over the course of the study, participants received an average of 14 (SD 4.66) text message screening assessments (text message time points) and responded to approximately 11 (SD 6.31) of these assessments. Some participants (n=40) received only the first 2 text message time points due to a REDCap configuration error. These participants were retained, and analyses account for the total number of text message time points received. Tables S3 and S4 in Multimedia Appendix 1 present the number of text message time points sent and answered by participants at each time point, and Table 1 shows the participant text message response rate per time point. Summary statistics of the text message time points sent and answered at each gestational or postpartum week (based on reported week of gestation at study entry) are included in Table S5 in Multimedia Appendix 1.

Table 1. Montreal Antenatal Well-Being Study participants' response rate per text message time point.

Time point	Response rate
1	0.78
2	0.8
3	0.77
4	0.76
5	0.74
6	0.8
7	0.81
8	0.81
9	0.82
10	0.82
11	0.84
12	0.83
13	0.82
14	0.79
15	0.76
16	0.74
17	0.74
18	0.79
19	0.65
20	0.76
21	0.8
22	0.6
23	0.6

Participation in a Text Message–Based Screening Protocol

Sociodemographic Characteristics of Respondents and Nonrespondents

Participants who responded to at least 1 text message screening assessment (ie, respondents) differed from nonrespondents on several sociodemographic factors (Table 2). Fisher tests indicated that, compared to the nonrespondent group, the respondent group was comprised of more individuals who identified as White (587/907, 64.7% vs 39/96, 40.6%; *P*<.001), who were Canadian citizens (603/768, 78.5% vs 41/77, 53.2%; *P*<.001), and who spoke 2 (483/917, 52.7% vs 46/98, 46.9%; *P*=.01) or more languages (286/917, 31.2% vs 24/98, 24.5%; *P*=.01), mainly French and English (425/566, 75.1% vs 29/53, 54.7%; *P*=.004). Respondents reported higher educational attainment (postgraduate: 268/909, 29.5% vs 15/94, 16%; *P*=.005) and higher household income (CAD $150,000 or more: 176/832, 21.2% vs 10/84, 11.9%; *P*<.001) than nonrespondents (Table 2). At baseline, respondents were more likely than nonrespondents to be primiparous (never given birth: 399/827, 48.3% vs 34/83, 41%; *P*=.049; Table 2).

Table 2. Baseline sociodemographic characteristics of respondents and nonrespondents.

	Full sample (n=1047)	Nonrespondents (n=114, 10.9%)	Respondents (n=933, 89.1%)	Fisher test *P* value
Maternal age—baseline (years), mean (SD)	31.92 (4.5)	31.52 (5.1)	31.96 (4.4)	.44[a]
Categorical characteristics				
Self-reported race and ethnicity, n/n (%)				*<.001*[b]
Arab and West Asian	55/1003 (5.5)	12/96 (12.5)	43/907 (4.7)	
Black	77/1003 (7.7)	18/96 (18.8)	59/907 (6.5)	
East Asian	36/1003 (3.6)	5/96 (5.2)	31/907 (3.4)	
Filipino	41/1003 (4.1)	6/96 (6.3)	35/907 (3.9)	
Latin American	37/1003 (3.7)	2/96 (2.1)	35/907 (3.9)	
South Asian	34/1003 (3.4)	5/96 (5.2)	29/907 (3.2)	
Southeast Asian	13/1003 (1.3)	2/96 (2.1)	11/907 (1.2)	
White	626/1003 (62.4)	39/96 (40.6)	587/907 (64.7)	
Other	22/1003 (2.2)	2/96 (2.1)	20/907 (2.2)	
Mixed	62/1003 (6.2)	5/96 (5.2)	57/907 (6.3)	
Immigration status, n (%)				*<.001*
Temporary resident	54/845 (6.4)	6/77 (7.8)	48/768 (6.3)	
Permanent resident	147/845 (17.4)	30/77 (39)	117/768 (15.2)	
Canadian citizen	644/845 (76.2)	41/77 (53.2)	603/768 (78.5)	
Number of languages spoken, n (%)				*.01*
1	176/1015 (17.3)	28/98 (28.6)	148/917 (16.1)	
2	529/1015 (52.1)	46/98 (46.9)	483/917 (52.7)	
3+	310/1015 (30.5)	24/98 (24.5)	286/917 (31.2)	
Spoken language (French vs English), n (%)				*.004*
French only	113/619 (18.3)	15/53 (28.3)	98/566 (17.3)	
English only	52/619 (8.4)	9/53 (17)	43/566 (7.6)	
French and English bilingual	454 (73.3)	29 (54.7)	425 (75.1)	
Education level, n (%)				*.005*
Secondary 5 or lower	80/1003 (8)	14/94 (14.9)	66/909 (7.3)	
Prebachelors	258/1003 (25.7)	30/94 (31.9)	228/909 (25.1)	
Bachelors	382/1003 (38.1)	35/94 (37.2)	347/909 (38.2)	
Postgraduate	283/1003 (28.2)	15/94 (16)	268/909 (29.5)	
Household income (CAD $)[c], n (%)				*<.001*
Less than 34,999	94/916 (10.3)	21/84 (25)	73/832 (8.8)	
35,000 to 49,999	67/916 (7.3)	10/84 (11.9)	57/832 (6.9)	
50,000 to 74,999	149/916 (16.3)	15/84 (17.9)	134/832 (16.1)	
75,000 to 99,999	164/916 (17.9)	12/84 (14.3)	152/832 (18.3)	
100,000 to 149,999	256/916 (28)	16/84 (19)	240/832 (28.8)	
150,000 or more	186/916 (20.3)	10/84 (11.9)	176/832 (21.2)	
Relationship status, n (%)				.07
In couple	947/972 (97.4)	85/90 (94.4)	862/882 (97.7)	
Single	25/972 (2.6)	5/90 (5.6)	20/882 (2.3)	

	Full sample (n=1047)	Nonrespondents (n=114, 10.9%)	Respondents (n=933, 89.1%)	Fisher test *P* value
Number of previous births, n (%)				*.05*
Never given birth	433/910 (47.6)	34/83 (41)	399/827 (48.3)	
1	316/910 (34.7)	25/83 (30.1)	291/827 (35.2)	
2	108/910 (11.9)	16/83 (19.3)	92/827 (11.1)	
3+	53/910 (5.8)	8/83 (9.6)	45/827 (5.4)	
Mental health diagnoses, n (%)				.15
Yes	225/1007 (22.3)	15/94 (16)	210/913 (23)	
No	782/1007 (77.7)	79/94 (84)	703/913 (77)	

[a] Two-tailed *t* test *P* value.

[b] Values in italics format indicate statistical significance.

[c] A currency exchange rate of CAD $1=US $0.76 is applicable.

Baseline and Postpartum Mental Health of Respondents and Nonrespondents

Respondents and nonrespondents reported similar levels of depression and anxiety symptoms both at baseline and postpartum (Table 3; see also Table S6 in Multimedia Appendix 1). The number of individuals who reported having received a mental health diagnosis was not significantly different between groups (*P*=.15; Table 2).

Table 3. Mental health measure scores of respondents and nonrespondents.

Continuous measures	Full sample (n=1047)		Nonrespondents (n=114, 10.9%)		Respondents (n=933, 89.1%)		*P* value[a]
	Participants, n	Mean (SD)	Participants, n	Mean (SD)	Participants, n	Mean (SD)	
Baseline							
EPDS[b] score	997	6.5 (4.79)	91	6.98 (4.55)	906	6.45 (4.82)	.30
STAI-S[c] score	985	33.97 (11.28)	88	35.67 (12.05)	897	33.81 (11.2)	.17
Postpartum							
EPDS score	854	6.07 (4.8)	54	5.74 (3.86)	800	6.09 (4.86)	.53
STAI-S score	827	32.48 (11.1)	46	30.96 (8.68)	781	32.57 (11.22)	.23

[a] Two-tailed *t* tests.

[b] EPDS: Edinburgh Postnatal Depression Scale (scores were prorated if ≥80% data available).

[c] STAI-S: State component of the State-Trait Anxiety Inventory (scores were prorated if ≥80% data available).

Predictors of the Number of Text Message Screening Time Points Completed

Next, we asked which factors predicted the total number of responses to regular (every 2 weeks) text message screening assessments across pregnancy (see Table S7 in Multimedia Appendix 1 for bivariate correlations). Unadjusted bivariate hurdle models indicated that there were significant differences in the number of text message time points completed based on self-reported race and ethnicity (*P*<.001), immigration status (*P*<.001), number of languages spoken fluently (*P*=.002), French-English bilingualism (*P*<.001), education level (*P*<.001), household income level (*P*<.001), relationship status (*P*<.001), and number of previous births (*P*=.01; Table 4), with self-reported race and ethnicity having the strongest effect. Table 4 also describes the results from the adjusted hurdle model where maternal race and ethnicity (*P*<.001), education (*P*=.001), household income (*P*=.02), and relationship status (*P*=.03) remained significantly and independently associated with the total number of text message time points completed by participants. Maternal age at baseline was not significantly associated with the likelihood of responding to one (or more) text message time points after considering relevant covariates (Table S8 in Multimedia Appendix 1).

Measures of maternal mental health at baseline also predicted the total number of text message time points completed across the duration of the study (Table 5 and Table S9 in Multimedia Appendix 1). A 1-point increase in EPDS and STAI-S scores at baseline was associated with a respective decrease of 1% (e^{β}=0.99) and 0.3% (e^{β}=0.997) in the average number of text message time points answered by participants (Table 5). Thus, for each SD increase in maternal depression or anxiety scores, the average number of text message time points completed was

4.7% and 3.3% lower, respectively. In hurdle models adjusted for self-reported race and ethnicity, education level, and household income level, baseline EPDS (*P*<.001) and STAI-S scores (*P*=.03) remained significant predictors of the total number of text message-based screening assessments completed (Table 5). In contrast, a previous mental health diagnosis (reported at baseline) did not improve the prediction of number of text message time points completed by participants in both the unadjusted (*P*=.17) and adjusted (*P*=.91) models (Table 4).

Table 4. Associations between baseline categorical sociodemographic variables and participants' number of text message time points completed.

Categorical variables	Participants, n	Log-likelihood null	Log-likelihood variable	*P* value
Unadjusted				
Self-reported ethnicity	1003	–2791.06	–2738.32	*<.001* [a]
Immigration status	845	–2343.97	–2321.83	*<.001*
Number of languages spoken	1015	–2841.3	–2832.65	*.002*
Spoken language (French vs English)	619	–1703	–1691.03	*<.001*
Education level	1003	–2804.16	–2778.46	*<.001*
Household income	916	–2519.26	–2486.46	*<.001*
Relationship status	972	–2720.14	–2710.38	*<.001*
Number of previous births	910	–2546.73	–2538.61	*.01*
Mental health diagnosis	1007	–2817.01	–2815.23	.17
Adjusted[b]				
Self-reported ethnicity	905	–2443.98	–2417.47	*<.001*
Immigration status	752	–1993.68	–1989.02	.05
Number of languages spoken	905	–2417.47	–2416.59	.78
Spoken language (French vs English)	573	–1510.95	–1509.17	.47
Education level	905	–2428.91	–2417.47	*.001*
Household income	905	–2427.83	–2417.47	*.02*
Relationship status	870	–2322.42	–2319.03	*.03*
Number of previous births	821	–2189.75	–2186.93	.46
Mental health diagnosed	903	–2412.25	–2412.16	.91

[a] Values in italics format indicate statistical significance.

[b] Adjusted log-likelihood null models (with categorical variables) include self-reported race and ethnicity, income level, and education level as covariates.

Table 5. Associations between baseline mental health measure scores and participants' number of text message time points completed.

Continuous variables	n	β Count	SE β count	Exp (β) count[a]	*P* value count	β Zero	SE β zero	Exp (β) zero[b]	*P* value zero
Unadjusted									
EPDS[c]—baseline	997	–0.01	0.002	0.99	*<.001* [d]	–0.02	0.02	0.979	.37
STAI-S[e]—baseline	985	–0.003	0.001	0.997	*<.001*	–0.01	0.01	0.988	.23
Adjusted[f]									
EPDS—baseline	893	–0.008	0.002	0.992	*<.001*	0.01	0.03	1.013	.62
STAI-S—baseline	885	–0.002	0.001	0.998	*.03*	–0.004	0.01	0.996	.69

[a] Exp (β), or the exponential value of β (e^{β}), provides the incidence risk ratio for the count model, that is, the association between baseline mental health measure scores and the incidence rate of participants responding to a positive number of text message time points.

[b] Exp (β) provides the odds ratio in the zero model, that is, the association between baseline mental health measure scores and the odds of responding to at least 1 text message time point.

[c] EPDS: Edinburgh Postnatal Depression Scale.

[d] Values in italics format indicate statistical significance.

[e] STAI-S: State component of the State-Trait Anxiety Inventory.

[f] Adjusted hurdle regression models include ethnicity, income level, and education level as covariates.

Text Message Response Rate Does Not Outperform Brief Symptom Measures in the Prediction of Postpartum Anxiety and Depression Symptoms

Given the associations we observed between baseline measures of maternal mental health and the number of text message time points participants responded to, we next asked if participant text message response rate was a better predictor of postpartum mental health than symptom data from brief screening tools. Specifically, these models tested if text message response rate was a better predictor of depression and anxiety symptoms (measured by EPDS and STAI-S) at approximately 8 weeks postpartum than scores derived from the Whooley and GAD-2 questionnaires. Text message response rate did not improve the prediction of postpartum depression or anxiety (Table S10 in Multimedia Appendix 1). Similar results were found in the adjusted models, suggesting that measures of selection bias (as reflected by text message response rate) were not a significant predictor of postpartum depression or anxiety symptoms (Table S10 in Multimedia Appendix 1). In contrast, we found that participant GAD-2 scores collected via text message proximal (average 7.3, SD 21.7 days) to the postpartum screening assessment provided the strongest prediction of maternal postpartum depression and anxiety symptom levels (Table 6).

Table 6. Comparison of predictors (based on model fit statistics) of postpartum depression and anxiety symptoms. Model fit was estimated using the Akaike information criterion (AIC) with lower values indicating a better fit or prediction.

Outcome	Predictor						
	Response rate	Baseline measures		Last gestation measures		Last postpartum measures	
		STAI-S[a] score	EPDS[b] score	GAD-2[c] score	Whooley score	GAD-2 score	Whooley score
EPDS score—postpartum	3959.3	3832.5	3829.27	3893.5	3917.27	*3722.56* [d]	3813.89
STAI-S score—postpartum	5063.27	4896.73	4963.46	4985.09	5002.80	*4840.15*	4920.96

[a] STAI-S: State component of the State-Trait Anxiety Inventory.

[b] EPDS: Edinburgh Postnatal Depression Scale.

[c] GAD-2: Generalized Anxiety Disorder 2-Item.

[d] The lowest AIC (best fit) for each outcome is set in italics format.

Discussion

Principal Findings

This study provides a comprehensive analysis of sociodemographic and mental health selection bias in participation in a text message–based perinatal mental health screening protocol. Overall, we found some evidence of selection bias that was patterned by maternal characteristics including race and ethnicity, income level, education, and parity. While we did not find strong evidence for an impact of maternal mental health on initial participation in our text message–based screening protocol, we did observe fewer total text message time points completed based on baseline maternal depression and anxiety symptoms. These findings suggest that text messaging may be a useful tool in the context of perinatal mental health screening. However, this study highlights important individual-level factors that may impact the effectiveness of text message–based mental health screening.

Sociodemographic and Mental Health Factors Predict Participation in Text Message–Based Screening

This study identified several sociodemographic variables that were associated with initial participation in a text message–based mental health screening protocol, and several of these factors also influenced the total number of text message time points completed over time. Specifically, respondents were more likely to identify as White, report Canadian citizenship, speak more languages (predominantly French-English bilingualism), have higher educational attainment, have higher income, and have fewer children. Self-reported race and ethnicity, education level, household income level, and relationship status were also associated with the number of text message time points answered by respondents. Our findings are consistent with previous studies, which have identified higher engagement with mobile-based health interventions among socially advantaged groups, reflecting potential challenges faced among disadvantaged groups, such as time constraints, differences in communication needs and preferences, and varying levels of literacy, trust, and comfort with digital technology [69,70]. Previous studies demonstrating the feasibility of text message– or mobile-based perinatal mental health screening have generally been performed in well-educated, higher-income cohorts [52] or in smaller cohorts than this study [71]. For example, a previous Canadian study focused predominantly on women with a university degree (865/937, 92%), which contrasts with this study (665/1003, 66% college-educated). Further empirical and qualitative studies are needed to parse the role of these factors and their interplay in the prediction of participation in text message–based screening. This work should include racially, culturally, and economically diverse samples and ideally incorporate qualitative studies to better understand individual-level factors that may act as barriers to participation in a text message–based screening of perinatal mental health.

Maternal depression and anxiety symptoms as well as previous mental health diagnoses were comparable across respondents and nonrespondents at baseline and postpartum. Thus, the likelihood of participation in a text message–based mental health screening protocol does not appear to vary as a function of maternal mental health. This finding provides supportive evidence of the utility of this approach to assess mental health symptoms in pregnant individuals. However, we did observe a significant negative association between maternal symptoms of depression and anxiety at baseline and the total number of text message time points answered over time. Our finding is consistent with a UK-based study that found that a history of depression and a history of use of psychiatric medication were negatively associated with the use of a postnatal depression screening app [71]. Similarly, a Japanese perinatal cohort reported that maternal psychological distress during pregnancy correlated with nonresponsiveness to follow-up questionnaires in the postpartum period [72]. Collectively, these findings suggest that the burden of repeated mental health assessments may lead to increased attrition among vulnerable groups. Thus, the frequency of mental health screening assessments is an important consideration for public health initiatives that seek to repeatedly assess maternal mental health across the perinatal period.

Response Rate and Brief Screening Scores as Predictors of Postpartum Depression and Anxiety Symptoms

Anxiety symptoms, as reported using the GAD-2 questionnaire sent via text message, emerged as the strongest predictor of postpartum symptoms, while participants' text message response rate was not significantly associated with postpartum mental health symptoms. Specifically, the GAD-2 score most proximal to the postpartum assessment of depression and anxiety, with an average interval of 7.3 days between these assessments, was the best predictor of postpartum symptom levels. This finding is unsurprising as closely spaced assessments of similar constructs are likely to be highly intercorrelated. However, we did note a stronger prediction of both postpartum depression and anxiety symptoms by GAD-2 scores than scores derived from the Whooley Questions, which assess symptoms of depression. This finding is consistent with a previous report highlighting a robust association between prenatal anxiety and postpartum depression [73]. Our multivariable analyses show that the GAD-2 is a helpful brief screening tool that captures additional variance in postpartum anxiety and depression symptoms (beyond that explained by sociodemographic factors) [64,74].

Overall, the adoption of digital, mobile-based short-form perinatal mental health screening has the potential to address clinical barriers such as time and resource constraints. Consistent with previous findings, the high rate of participation from the MAWS sample in the text message screening protocol (933/1047, 89.1%) also suggests that text message–based screening may be appealing to a broad section of pregnant and postpartum individuals [52-54]. Our findings emphasize the need to identify and remove the barriers that contribute to lower patient engagement in digital screening protocols among disadvantaged groups who are at higher risk of developing a perinatal mental health disorder [75]. Such barriers could include time constraints, reduced access to a mobile device, language barriers, mistrust of health institutions, and stigma associated with mental health, among others. Overcoming these barriers may help more fully realize the clear potential of text messaging technology to reduce inequitable access to perinatal mental health care.

Limitations

This study is not without limitations. First, this study only included participants who owned a smartphone, tablet, or personal computer, and due to the COVID-19 pandemic, 216 (20.6%) of the 1047 MAWS cohort sample participants were recruited using targeted advertisements on social media. Thus, the participation rate in our text message–based screening protocol (933/1047, 89.1%) may be higher than studies that focus on a more general perinatal population. However, we note that only 1 (0.03%) of 3761 individuals approached to participate in MAWS did not own a smartphone, tablet, or personal computer. Likewise, our participation rate was similar to Lawson et al [52] (930/937, 99%), who carried out a text message–based screening protocol in a postpartum cohort.

Second, although studies have previously demonstrated the high accuracy and internal consistency of existing clinical screening tools like those administered to MAWS participants (Whooley, GAD-2, EPDS, and STAI-S) across ethnically diverse populations [76-80], many of these instruments contain idioms that may not translate well to different languages and may lack sensitivity in the conceptualization of symptoms of perinatal maternal depression and anxiety across different cultures. Future studies would benefit from considering culturally relevant research methodologies and questionnaires for digital screening of perinatal mental health [32].

These limitations notwithstanding, a major strength of the study design is that it allowed us to collect longitudinal data on participants who did not participate in the text message component of the study. Studies whose sole focus is on testing the feasibility of a text message–based screening protocol are, by nature of their design, unable to collect longitudinal data on nonengaged participants. Our findings therefore bring much-needed insights into the sociodemographic and mental health profile of pregnant individuals who choose to participate in and consistently respond to text message–based mental health screening assessments.

Conclusions

New approaches are required to better identify and treat perinatal mood and anxiety disorders, which cause profound human distress and result in large economic costs. Our study provides preliminary support for the feasibility and utility of a text message–based perinatal mental health screening protocol; the first evidence of this kind derived from a bilingual Canadian cohort. However, our findings also highlight how digital technologies could contribute to further disparities in mental health screening and treatment, an equity issue that should be a central focus for health policy formation.

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Authors' Contributions

JB drafted the paper and contributed to the interpretation of the data. CHR, KPD, CG, and JB conducted the literature review. CHR and KPD contributed to the drafting and critical revisions of the paper. GE and HP conducted the data analysis and contributed to the interpretation of the data. KJOD, TCM, and TVN contributed to the study's conception and design. KJOD and TCM contributed to the interpretation of the data and critical revisions of the paper. All authors have read and approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Summary information and statistics on the Montreal Antenatal Well-Being Study's text message time points.
[DOCX File , 69 KB - pediatrics_v7i1e53786_app1.docx]

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Abbreviations

EPDS: Edinburgh Postnatal Depression Scale
Exp (β), eβ: exponential value of β
GAD-2: Generalized Anxiety Disorder 2-Item
MAWS: Montreal Antenatal Well-Being Study
mHealth: mobile health
REDCap: Research Electronic Data Capture
STAI-S: State component of the State-Trait Anxiety Inventory

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Original Paper

Refining the Universal, School-Based OurFutures Mental Health Program to Be Trauma Informed, Gender and Sexuality Diversity Affirmative, and Adherent to Proportionate Universalism: Mixed Methods Participatory Design Process

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Abstract

Background: Mental disorders are the leading cause of disease burden among youth. Effective prevention of mental disorders during adolescence is a critical public health strategy to reduce both individual and societal harms. Schools are an important setting for prevention; however, existing universal school-based mental health interventions have shown null, and occasionally iatrogenic, effects in preventing symptoms of common disorders, such as depression and anxiety.

Objective: This study aims to report the adaptation process of an established, universal, school-based prevention program for depression and anxiety, OurFutures Mental Health. Using a 4-stage process; triangulating quantitative, qualitative, and evidence syntheses; and centering the voices of young people, the revised program is trauma-informed; lesbian, gay, bisexual, transgender, nonbinary, queer, questioning, and otherwise gender and sexuality diverse (LGBTQA+) affirmative; relevant to contemporary youth; and designed to tailor intervention dosage to those who need it most (proportionate universalism).

Methods: Program adaptation occurred from April 2022 to July 2023 and involved 4 stages. Stage 1 comprised mixed methods analysis of student evaluation data (n=762; mean age 13.5, SD 0.62 y), collected immediately after delivering the OurFutures Mental Health program in a previous trial. Stage 2 consisted of 3 focus groups with high school students (n=39); regular meetings with a purpose-built, 8-member LGBTQA+ youth advisory committee; and 2 individual semistructured, in-depth interviews with LGBTQA+ young people via Zoom (Zoom Video Communications) or WhatsApp (Meta) text message. Stage 3 involved a clinical psychologist providing an in-depth review of all program materials with the view of enhancing readability, improving utility, and normalizing emotions while retaining key cognitive behavioral therapy elements. Finally, stage 4 involved fortnightly consultations among researchers and clinicians on the intervention adaptation, drawing on the latest evidence from existing literature in school-based prevention interventions, trauma-informed practice, and adolescent mental health.

Results: Drawing on feedback from youth, clinical psychologists, and expert youth mental health researchers, sourced from stages 1 to 4, a series of adaptations were made to the storylines, characters, and delivery of therapeutic content contained in the weekly manualized program content, classroom activities, and weekly student and teacher lesson summaries.

Conclusions: The updated OurFutures Mental Health program is a trauma-informed, LBGTQA+ affirmative program aligned with the principles of proportionate universalism. The program adaptation responds to recent mixed findings on universal school-based mental health prevention programs, which include null, small beneficial, and small iatrogenic effects. The efficacy of the refined OurFutures Mental Health program is currently being tested through a cluster randomized controlled trial with up to 1400 students in 14 schools across Australia. It is hoped that the refined program will advance the current stalemate in universal school-based prevention of common mental disorders and ultimately improve the mental health and well-being of young people in schools.

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KEYWORDS

mental health; prevention; school; depression; anxiety; proportionate universalism

Introduction

Background

Mental disorders, such as depression and anxiety, are the leading causes of disease burden among youth [1]. Almost two-thirds of those who experience a mental disorder are first diagnosed before the age of 25 years [2,3]. Global evidence suggests depressive and anxiety symptoms have been increasing among adolescents since the 1980s [4-7]. This was further compounded by the COVID-19 pandemic, culminating in a current crisis characterized by doubled prepandemic rates of depression and anxiety among youth and increased attempts at suicide [8,9]. These trends highlight the urgency of prioritizing efforts to address mental ill-health.

Alarmingly, many people experiencing mental health disorders do not receive the care they need. In high-income countries, it is estimated that only 33% of people with depression access treatment, while in low-income countries, just 8% of those in need access treatment [10]. Services are overburdened, with high out-of-pocket costs, lengthy wait times, and other barriers prohibiting access to treatment for our youth [11]. While improving access to ensure treatment coverage for those who need it is critical, greater attention and resources must also be directed to *preventing* these disorders.

Schools are an ideal setting for implementing mental health prevention programs [12], enabling broad reach before the peak age of onset of mental disorders (14.5 years [2]). Universal delivery of mental health programs is typically low cost and practical for schools, enables tailoring of programs to students' developmental level, facilitates scalability, and is nonstigmatizing [13,14]. However, meta-analyses and recent large-scale randomized controlled trials (RCTs) of universal school-based depression and anxiety prevention programs show mixed results, including null effects, small benefits on symptom reduction in the short term, and even potential iatrogenic effects, particularly for individuals with preexisting mental health symptoms [15-20]. Indeed, the consistent observation of small, null, and iatrogenic effects of universal school-based mental health prevention activities has garnered significant global attention [21-23], with several editorials calling for a shift in universal approaches for school-based prevention for depression [21,23].

Therefore, despite the promise of school-based, universal mental health prevention, existing evidence demonstrates a clear need to improve these interventions or rethink the approach used in universal school-based prevention. One solution that has been proposed is the use of targeted prevention approaches, which selectively target subgroups within the population that have been identified as being at an elevated risk for mental ill-health [12]. Meta-analytic estimates of targeted school-based depression and anxiety prevention programs consistently show larger effect sizes compared with universal programs [16,17]. However, targeted programs often incur greater implementation and resource burden, requiring sound identification and communication of individual risk, both in terms of sensitivity and specificity in allocating individuals to receive an intervention or not, as well as care to avoid labeling or causing stigma through this process [24].

One potential path forward that leverages the strengths of both universal and selective prevention is "proportionate universalism." This is the notion that universal public health policies or interventions be designed to proportionately (equitably) benefit those who need it the most [25,26]. A growing body of public health and health policy literature suggests that this is a pragmatic step toward achieving optimal global health by harnessing universal delivery but tailoring intervention dosage and content based on need [25]. By applying proportionate universalism to mental health prevention, those exhibiting elevated mental health symptomatology would receive or could opt in to receive additional intervention components, such as psychoeducation, skills training, and evidence–based early intervention resources. This has the potential to address a notable challenge in universal mental health prevention, whereby the same intervention is delivered to individuals with varying levels of preexisting symptoms and risk. For those with low symptoms or levels of risk, universal intervention may lack relevance and perceived usefulness, limiting engagement, while for those with preexisting symptoms, its low-intensity therapeutic content may raise awareness or discomfort of unpleasant thoughts and emotions but could be insufficient in helping these individuals manage their distress [20,27]. Providing flexibility in the dosage of the intervention, where individuals can choose to receive additional skills training or psychoeducation, could improve the relevancy of prevention SMS text messaging across the spectrum of preexisting symptomatology. Moreover, giving individuals a choice as to which intervention components they receive could improve adherence, retention, and ultimately, effectiveness [28]. In practice, however, literature is scant on real-life applications of this paradigm.

Another noticeable limitation of universal mental health prevention programs is a lack of attention to the social factors contributing to mental health difficulties. A wealth of literature has identified the elevated risk of mental health difficulties among young people exposed to trauma or adversity, such as child abuse, neglect, or exposure to domestic violence. Given that, up to 62% of Australians have experienced maltreatment or domestic violence during childhood and adolescence [29], programs aiming to address or prevent adolescent mental health problems must be trauma-informed. In addition, growing research has highlighted the disproportionate rates of mental ill-health among lesbian, gay, bisexual, transgender, nonbinary, queer, questioning, and otherwise gender and sexuality diverse (LGBTQA+) young people [30,31]. Nearly half of young LGBTQA+ Australians have ever received a diagnosis of generalized anxiety disorder and depression [32]. Transgender people and gender diverse people (binary and nonbinary; henceforth, "trans") are people with a gender identity different from the one presumed for them at birth. Relative to their sexuality diverse peers, transgender young people report even higher rates of generalized anxiety disorder and depression conditions [32]. Mental ill-health disparities affecting LGBTQA+ young people widen through adolescence [33]. LGBTQA+ young people experience daily, chronic discrimination based on their genders and sexualities and, moreover, are more likely than their cisgender, heterosexual peers to report nonidentity–related traumatic events, such as intimate partner abuse and sexual assault [34]. Notably, it is those experiences of daily, chronic discrimination and inability to feel safe that bear more mental health consequences than traumatic events [34]. Moreover, the mental health effects of both minority stressors and nonidentity–specific traumatic events are disproportionately shouldered by transgender young people [34]. Although schools can be affirming and supportive of LGBTQA+ young people [35], high rates of school-based bullying, harassment, exclusion, and isolation continue to be documented among contemporary LGBTQA+ young people [36]. Significant variability in school and staff-level preparedness to support underscores a dire need for additional school-wide LGBTQA+ affirmative initiatives [30]. Henceforth, to effectively respond to either the needs of young people exposed to trauma or adversity or LGBTQA+ young people necessitates an integrated approach, reflecting how young people undergo dynamic, interrelated experiences of trauma, adversity, gender, and sexuality. Therefore, a trauma-informed, LGBTQA+ affirmative approach that applies proportionate universalism may be effective in preventing and reducing the escalation of mental health symptoms among adolescents, particularly adolescents exposed to trauma or adversity and LGBTQA+ adolescents.

One universal, school-based OurFutures Mental Health program (formerly Climate Schools Mental Health) has similarly shown mixed effects for preventing anxiety and depression [37]. It was developed in 2009 as a web-based cognitive behavioral therapy (CBT)–based mental health education program. The content was delivered over six 30-minute lessons (including a 10-minute weekly revision) comprising skill acquisition; psychoeducation; and management of thoughts, emotions, and behaviors specific to depression and anxiety [38]. A feasibility trial demonstrated improvements in well-being and knowledge about stress and reductions in measures of distress [38]. The program was subsequently divided into 2 programs targeting depression and anxiety separately and was tested in a 3-arm, cluster RCT with 976 year 9 and 10 students from 12 Australian schools. Compared with health education as usual, the anxiety intervention resulted in significant reductions in anxiety symptoms, and the depression intervention reduced both anxiety and depressive symptoms [39].

In 2013, the depression and anxiety modules were amalgamated and condensed into six 40-minute lessons to create the Climate Schools Mental Health program to reduce content overlap and decrease time demands for schools [40]. Lessons included a 20-minute cartoon storyline, followed by optional teacher–delivered activities involving CBT–based skills practice. Teachers and students were also provided with downloadable lesson summaries to reinforce the content delivered in the lessons. The program was developed through input from an experienced clinical psychologist; focus groups with approximately 30 students from 2 independent schools in Sydney, Australia; and consultation with numerous health and educational professionals to verify the program's clinical and educational validity [40]. Between 2013 and 2016, a cluster RCT of >6000 students of grades 8 and 9 (aged approximately 13-15 years) investigated the effectiveness of 3 interventions, including Climate Schools Mental Health, Climate Schools Substance Use, and both Climate Schools Mental Health and Climate Schools Substance Use programs combined, for preventing depression, anxiety, and substance use, accordingly, compared with an active control (health education as usual). Additional detail regarding the components of Climate Schools Substance Use is published elsewhere [41]. Over a 30-month period, students in the combined group experienced increased knowledge of alcohol, cannabis, and mental health and decreased growth in anxiety symptoms [42]. However, further post hoc analyses revealed the students in the stand-alone Climate Schools Mental Health condition improved their knowledge of mental health but reported no improvement in other mental health outcomes compared with the control condition [37]. Moreover, the participants in the stand-alone mental health group also reported transient increased internalizing scores at the 6-month and 12-month postintervention time points compared with controls; however, these were not sustained at further follow-ups [37].

Objectives

In light of previous findings from RCTs of the OurFutures Mental Health program, as well as existing evidence from other universal school-based mental health prevention approaches, the OurFutures Mental Health program was refined from 2022 to 2023. This paper describes this refining process. We aimed to explore and understand young peoples' perceptions and experiences of the OurFutures Mental Health program within previous trials, source input from young people to refine the program to be trauma-informed and gender and sexuality inclusive, and incorporate the principles of proportionate universalism.

Methods

Overview

Program adaptation occurred from April 2022 to July 2023, using a four-stage approach: (1) analysis of evaluation data from the original Climate Schools Mental Health program; (2) focus groups and interviews conducted with young people, including LGBTQA+ youth; (3) content review by a clinical psychologist; and (4) expert team consultation and literature review.

This paper adheres to guidance for reporting intervention development studies in health research (Guidance for the Reporting of Intervention Development) [43].

Ethical Considerations

Ethics approval was granted by the University of Sydney Human Research Ethics Committee (2022/664) and for Stage 1 from the University of New South Wales Human Research Ethics Committee (HC13073). All participants provided written informed consent. In stage 1, participants were entered into a prize draw to win an iPad. In stage 2, focus group participants were entered into a prize draw to win an Aus $100 (US $65.84) gift card, and interview participants were reimbursed with an Aus $20 (US $13.17) gift card.

Stage 1: Analysis of Evaluation Data From the Original Climate Schools Mental Health Program

Between June 2022 and February 2023, we conducted a mixed methods analysis of student evaluation data (n=762, mean age 13.5, SD 0.62 y) collected immediately after the delivery of the Climate Schools Mental Health program (2015) in a previous trial. The full methodology of the trial is published elsewhere [42,44]. Students responded to seven 5-point Likert scale items regarding how strongly they agreed or disagreed with statements regarding satisfaction, relevance, and helpfulness of the program. Two open-ended items also asked students to identify “one good thing” and “one bad thing” about the program. Open-ended items were analyzed using a 6-step thematic analysis approach [45]. Differences in responses by sex and baseline mental ill-health symptoms (Generalized Anxiety Disorder questionnaire [46], Patient Health Questionnaire-9 [47], and Emotional Symptoms subscale of the Strengths and Difficulties Questionnaire [48]) were also tested using multivariate logistic regression models, which controlled for binary sex. Full information on the evaluation has been published elsewhere [27].

Stage 2: Focus Groups and Interviews Conducted With Young People, Including LGBTQA+ Youth

Overview

The adaptation involved extensive consultation with young people, including LGBTQA+ young people. Duty of care procedures were created, including having a clinical psychologist on standby, although these procedures were not required during the consultations. Specifically, this consultation process comprised 3 stages.

Stage 2.1: School-Based Focus Groups (General Population of Adolescents)

To seek input on current sources of stress experienced by young people, as well as feedback on the OurFutures Mental Health storylines, focus groups were conducted in 2 Australian high schools. Given that 1 school had a large student cohort, 2 separate focus groups were conducted within the school, resulting in 3 focus groups across 2 schools (n=39). It was determined that this is an appropriate number for data saturation [49,50].

Independent secondary schools in Sydney, Australia, were contacted in mid-2022 using publicly available email addresses and phone numbers and invited to participate in focus groups. Two schools agreed to participate and sent information and consent forms to parents of their grade 8 students (aged approximately 13-14 years). Students were required to sign their own information and consent form.

Focus groups were each cofacilitated by 2 researchers each and took place in November 2022 and February 2023. A semistructured focus group guide was used, comprising 12 questions (Multimedia Appendix 1) centered on major stressors, how they affect mental health, and strategies youth use to cope. Students were also shown scenes from the existing program, and facilitators sought specific feedback regarding the characters, storylines, and language. This set of discussion questions permitted flexibility for participants to expand on their responses and explore themes in greater depth.

School staff were not present in the room during the focus groups. Focus groups were audio-recorded and later transcribed using transcription software Otter (Otter.ai, Inc). Focus groups lasted for approximately 40 minutes, and participants could opt in to enter a draw to receive an Aus $100 (US $65.84) gift voucher (1 per school).

Stage 2.2: Consultations With an LGBTQA+ Youth Advisory Committee

An LGBTQA+ youth advisory committee (YAC) was established, comprising 8 LGBTQA+ young people aged 17 to 19 years across rural or regional and metropolitan areas in New South Wales, Australia. There was a diverse representation of gender and sexuality in the YAC membership. YAC members were recruited through advertisements shared through professional networks, including newsletters and social media channels. Targeted advertisements were further shared through collaborative efforts from local LGBTQA+ youth health organizations. LGBTQA+ YAC members were reimbursed with Aus $30 (US $19.75) gift vouchers for each meeting they attended. Over the course of intervention adaptation, the YAC met 3 times: August 2022, November 2022, and March 2023. Chaired by SB, these early meetings focused on high-level discussions about the process and ethics of adapting universal programs intended to reach all young people, to be simultaneously affirming, inclusive, and supportive of LGBTQA+ young people. In the interest of maintaining comfortable, confidential spaces, these meetings were not recorded; however, detailed independent field notes were taken by SB and RT for later comparison and review. Iterative discussion based on these field notes generated guiding principles and accompanying recommendations stemming from LGBTQA+ YAC discussions for the adaptation of OurFutures Mental Health to be LGBTQA+ affirming and inclusive.

Stage 2.3: Interviews With LGBTQA+ Youths

LGBTQA+ young people aged 16 to 21 years were invited to participate in individual, semistructured, in-depth interviews. Interview questions (Multimedia Appendix 1) were structured similarly to focus group items and aimed to explore 2 main domains: contemporary sources of stress experienced by LGBTQA+ young people and potential areas for making the OurFutures Mental Health program more affirming, inclusive, and supportive of LGBTQA+ young people. Young people were recruited through social media (Twitter; Twitter, Inc, subsequently rebranded as X and Facebook; Meta Platforms, Inc) and professional networks of youth and LGBTQA+ organizations. Interviews were conducted over Zoom or WhatsApp text messaging (participant's choice) and lasted for approximately 1 hour. These online channels were chosen as they offer LGBTQA+ young people increased flexibility, confidentiality, privacy, and anonymity to overcome key barriers to participation, including travel, cost, and parental support [51,52]. Interview participants were reimbursed with an Aus $20 (US $13.17) for their time. Interview facilitators had a script but had the flexibility to explore participant responses in depth and ask follow-up questions based on participant responses. Interviews were recorded and transcribed, and summative content analysis was conducted.

Stage 3: Clinical Psychologist Review of All Program Materials

From April to July 2023, a clinical psychologist provided an in-depth review of all program material to enhance readability (condensing text and simplifying language); improve utility (increasing use of role modeling techniques by characters) while preserving key CBT elements; and remove focus on overt symptoms and disorders, instead normalizing general stress and worry or feeling low; and differentiating between the universal experience of emotions and mental disorders, such as anxiety and depressive disorders [22]. The psychologist review also incorporated considerations of safety and privacy, suggestions for trauma-informed content, and reviewing trauma-informed refinements (refer to the Stage 4: Expert Team Consultation and Literature Review section).

Stage 4: Expert Team Consultation and Literature Review

From April 2022 to May 2023, a team of 12 research experts in adolescent mental health and a clinical psychologist engaged in fortnightly consultations on the intervention adaptation. Aligning with contemporary discussions regarding the future of universal, school-based mental health prevention programs, the team conscientiously discussed potential strategies to avoid potential iatrogenic harms associated with the program [21], including normalizing difficult emotions, discussing character examples rather than personal examples, and offering strategies for personal reflection and skills practice as optional and for discretionary individual use out of class. Discussions focused on the latest literature and findings from school-based universal mental health trials [19,23,37,40], as reviewed in the introduction of this study. These consultations drew on the latest evidence for trauma-informed prevention [53-55]. Specifically, these drew on 2 systematic reviews of the literature, which identified intervention targets to prevent psychopathology for young people exposed to trauma, as well as existing trauma-informed mental health prevention programs for young people aged 12 to 24 years [56,57].

Finally, consultations centered on restructuring the existing program and adapting it in line with the youth feedback described in stages 1 and 2.

Formative findings and insights from the aforementioned stages were collated and iteratively discussed among the research team. Adaptations were subsequently made to the OurFutures Mental Health intervention relating to the delivery of therapeutic content (classroom materials and take-home activities), storylines, and cartoons.

Results

Stage 1: Analysis of Evaluation Data From the Original Climate Schools Mental Health Program

Textbox 1 presents the identified areas for improvement arising from the formative evaluation and the corresponding intervention adaptation undertaken. Full results of the formative evaluation are presented in a separate publication [27]. Briefly, while most (453/759, 59.7%) students rated the OurFutures Mental Health program as good or very good, a considerable proportion of students did not perceive the original storylines to be relevant and were unsure whether they were likely to use skills and information from the program in their own lives (370/758, 48.8% and 290/757, 38.3%, respectively). Female participants were less likely to perceive the storyline as relevant compared with their male peers. Adjusting for participants' sex, participants with either probable anxiety disorder, probable depressive disorder, or elevated levels of emotional symptoms were significantly more likely to enjoy the project storylines compared with their peers without these 3 respective conditions [27].

Five broad themes emerged from participants' survey responses to open-ended questions regarding potential areas for improvement: (1) making content more realistic and relatable; (2) ensuring that the content is engaging and entertaining; (3) ensuring that the content covers wide aspects of mental ill-health, such as adversity, stigma, and diversity; 4) reducing the length of the program; and 5) ensuring that the materials are age appropriate.

Textbox 1. Areas for future improvement identified in previous program iteration.

Focus areas

- The stories seemed unrealistic or unrelatable, for example, having cognitive behavioral therapy skills delivered by 1 of the peer characters in the cartoon (Chloe, a student aged 14 years).
- The content was not engaging and entertaining.
- The program did not adequately cover the realities of living with mental ill-health, including adversity, stigma, and diversity.
- There was too much information, and the program was too lengthy.
- The content seemed to be aimed at younger audiences.

Stage 2.1: School-Based Focus Groups (General Population of Adolescents)

Three in-depth focus groups were conducted in 2 secondary schools in Australia, with youths aged 13 to 15 years (n=39). Predominant responses to the research questions eliciting the main causes of stress among Australian youths, ways of coping, and topics they believe should be covered in a mental health program are presented in Textbox 2 and Multimedia Appendix 1.

Some of the students' comments vividly described scenarios reflective of contemporary causes of stress and coping strategies. For example, 1 participant noted that "lash[ing] out... is a very common experience." Another focus group participant raised that "a lot of young people today report feeling rushed...." These discrete comments were addressed through specific changes and adaptations in the cartoon and learning materials. Other responses, which were more intangible and commentary in nature, were accordingly absorbed into the team's general outlook and approach to the intervention adaptation process. For example, when describing the therapeutic experience of successfully coping with a difficult time, 1 focus group participant described it as "...doing things so you can feel like out of your reality."

In addition to the common sources of stress mentioned above, focus group participants also identified discrete aspects of the OurFutures Mental Health cartoons and storylines that would benefit from improved relevance. These areas for improvement are listed below in Textbox 3.

Textbox 2. Focus group participants' common sources of distress, ways of coping, and topics they believe should be covered in a school-based mental health program.

Research questions and responses

- Concerns
  - Bullying
  - Gender and sexuality diversity
  - School work and pressures, for example, deadlines, time management, managing cocurricular activities, and relationships on top of school
  - Parent expectations
  - Sport (eg, how well you perform and relationships with members of the team)
  - Relationships, particularly peer relationships
- Ways of coping
  - Try not to think about it
  - Talking with friends
  - Seeking help from a professional (eg, psychologist)
  - Finding someone you can talk to who understands you
  - Telling someone (instead of being mean back, eg, bullying)
  - Being around supportive friends
  - Social media and games
  - "Breathing tricks to help"
  - Taking a broader perspective
  - Preparing the best you can
  - Avoiding distractions
  - Breaking things up with a run or seeing friends
  - Letting things go
  - Listening to each other
  - Asking for advice
- Topics and issues
  - Social media
  - How to be assertive
  - False information (eg, rumors), social media depictions, stereotypes, and stigma
  - How to seek help from an adult
  - Substance use, especially vapes
  - Diverse representations of gender and sexuality
  - Normalization of gender and sexuality diversity
  - Combating transphobia and racism
  - Trauma
  - Time management
  - Planning activities
  - Important role of friendships
  - Lack of support from friends
  - How to have and "manage" healthy relationships with friends
  - Mindset

Textbox 3. Focus group participants' suggestions for improvement.

Suggestions

- Remove curfew for characters as this is not realistic for young people, who are more likely to communicate with their parents via phone about where they are and what time they will be home.
- Need to increase engagement
- Trans and gay people in modules should "just be there" and not be different.
- Characters looked like Disney princesses. Clothes were "basic" and not realistic.
- Gender stereotypes of boys going to the beach and girls hanging out at home should be avoided.
- Inclusive, stigma-free language around mental health should be used.
- Animations appeared dated

Stage 2.2: Consultations With an LGBTQA+ YAC

Insights drawn from YAC meetings and accompanying field notes were distilled into key recommendations that were adopted by the researchers in their approach and activities to ensure that all program content and materials are affirming, inclusive, and supportive of LGBTQA+ young people and gender and sexuality diversity more broadly. These guiding principles and key recommendations are detailed in Textbox 4.

Textbox 4. Guiding principles and recommendations for making universal mental health prevention programs inclusive, supportive, and affirming of lesbian, gay, bisexual, transgender, nonbinary, queer, questioning, and otherwise gender and sexuality diverse (LGBTQA+) young people, as described by the LGBTQA+ youth advisory committee.

Guiding principles and recommendations

- LGBTQA+ young people experience life unrelated to their gender and sexuality.
  - Produce narratives that do not center LGBTQA+ young peoples' storylines around their gender and sexuality.
- Being inclusive of LGBTQA+ young people means letting LGBTQA+ young people "casually exist," that is, "inclusion through normalisation."
  - Normalize gender and sexuality diversity for an LGBTQA+ character by not making gender and sexuality a focal part of their personality.
- Avoid tokenistic stereotypes but portray genuine "touchstones" of trans and queer cultures.
  - Draw from real-life experiences to create authentic, relatable depictions of LGBTQA+ young people.
- Queer and transgender identities are diverse and intersectional.
  - Ensure representation of less represented LGBTQA+ young people, including trans and nonbinary people, as well as LGBTQA+ young people at different stages of their identity (eg, questioning).
- Queer and transgender identities cannot be seen by other people unless you choose to express and "show" it.
  - Ensure all storylines and characters reflect the complex nuance of gender and sexuality diversity rather than inauthentic, simplistic, or tokenistic expressions.

Stage 2.3: Interviews With LGBTQA+ Youths

Two LGBTQA+ youths, a gay transgender boy and a bisexual cis girl, consented to participate in interviews via WhatsApp text messaging and Zoom videoconferencing, respectively. Interviews highlighted how isolation is a common issue for LGBTQA+ young people. Moreover, both participants reflected on how their families and friends represented major support systems. For example, 1 participant noted:

> *I have my support systems for when I feel unsafe but I think the majority of the time there's only avoidance.*

Both participants noted that their sexuality and gender were not causes of distress but rather prejudice and discrimination from others due to their sexuality and gender caused distress. In addition, both participants noted that the current materials did not make any mention or representation of gender and sexuality diversity, with 1 participant suggesting that "...seeing other queer people comfortable and thriving is all a lot of kids need." Input from these interviews was combined with feedback from the YAC consultations (refer to the Stage 2.2: Consultations With an LGBTQA+ YAC section) to adapt the intervention accordingly.

Stage 3: Clinical Psychologist Review of All Program Materials

The review by a clinical psychologist was driven by key guiding principles and accompanying recommendations, as shown in Textbox 5.

Textbox 5. Guiding principles and recommendations following clinical psychologist review of the program materials.

Guiding principles and recommendations

- Difficult emotions are experienced by everyone and have a normal ebb and flow, just as pleasant emotions do. Emotions are informative.
    - Avoid pathologizing difficult emotions.
    - Acknowledge that while emotions can be unpleasant, they can also be informative.
    - Promote student understanding of emotions by encouraging them to think of other words to describe their emotions, for example, the color wheel.
    - Language such as “activities to combat depression” should be avoided. Provide coping strategies along with the knowledge that these are not intended to remove uncomfortable emotions but rather help tolerate when they are overwhelming.
- How we cope with our emotions and thoughts is important; this is the difference between low mood and depressive disorder and anxiety and anxiety disorder.
    - Educate students on the difference between the symptoms and a disorder. Reinforce that all students experience difficult emotions, but not all students experience depression or anxiety.
    - Provide strategies to promote healthy ways of coping when we inevitably experience periods of feeling anxious or down.
    - Include behavioral activation strategies to promote functioning when feeling low or anxious.
- Stressful life events have a strong impact on the symptoms of depression and anxiety.
    - Include psychoeducation, resources for teachers, and details of support services.
    - Reduce the focus on the individual and educate students on the social determinants of health and trauma. This will hopefully reduce shame, stigma, and self-stigma.
- Adolescent depression often includes dysregulated emotions, labile mood and can include suicidality and self-harm [58].
    - Provide guided examples to self-regulate in times of high emotions, such as breathing exercises, progressive muscle relaxation, and emotion surfing for all students and optional additional strategies, such as soothing activities and grounding techniques.
- There is a huge individual variability in strategies that young people find helpful for managing strong emotions [20,59,60]. Finding strategies that work for oneself enables empowerment and autonomy, which are key to adolescent development.
    - Make all skills practice apply to the cartoon characters, with any self-applied skills training to be optional only. Students do not have to discuss and practice their own experiences in class (also recommended from a trauma-informed perspective, see Stage 4: Expert Team Consultation and Systematic Reviews) but can learn the skills through peers in the cartoon characters and then can choose to use the strategies in their own time.
    - Rather than being prescriptive, phrasing refers to trying different strategies to see what helps them, and the characters use different types of strategies. This reinforces that not everything works for everyone and is hoped to reduce feelings of hopelessness if certain strategies do not help.
- Students have incredibly varied lived experiences, which influence their mental health in myriad ways.
    - Scenarios used in class activities apply to the cartoon characters only. Students only apply skills to their own personal scenarios in the privacy of their own homes. This is hoped to reduce the negative impact of social comparison, whereby students who experience elevated depressive symptoms may feel more isolated and concerned whether the other students in the classroom reflect on their own experience of never having experienced elevated symptomatology.
- Sources of support are crucial
    - Modeling characters seeking support
    - Ask students to write down the name of someone who they could talk to about a problem they are currently facing, or if they cannot think of anyone, a service from one of those provided to them in the program that they could call. Identifying the barriers to reaching out to this person to talk to them about the problem they are facing and some things they could do to overcome this barrier

Stage 4: Expert Team Consultation and Systematic Reviews

Program adaptation drew on the findings from 2 systematic reviews conducted from 2021 to 2023 and consultations among expert researchers and clinicians in the fields of childhood trauma and youth mental health. These systematic reviews identified intervention targets to prevent psychopathology for young people exposed to trauma, as well as existing trauma-informed mental health prevention programs for young people. Full details of these reviews are available elsewhere [56,57]. Guiding principles and recommendations derived from this literature and team consultations are presented in Textbox 6.

Textbox 6. Guiding principles and recommendations regarding embedding trauma-informed principles within the modified OurFutures Mental Health program generated from expert team consultation and systematic literature reviews.

Guiding principles and recommendations

- Trauma-informed practice recognizes the impact, signs, and symptoms of trauma; resists retraumatizing clients or students; and integrates understanding of trauma into practice and policies [61].
    - Traumatic events are commonly faced by young people and should be represented in program content. Psychoeducation around the impact of trauma on mental health and common signs and symptoms of trauma exposure should be included in accompanying student and teacher lesson summaries.
    - School practices and policies play an important role in avoiding retraumatizing youth affected by trauma. For example, disciplinary practices that provide support rather than exclusion (eg, suspension) reflect trauma-informed practice.
    - Provide information to teachers before program commencement via teacher summaries.
    - All skills practice in the classroom apply to the cartoon characters. Students do not discuss their personal experiences or practice skills for their own situations in class, where they may not feel safe (due to peers and teachers). Instead, skills are learned through the cartoon characters, and students can choose to access the optional, at-home activities to apply the skills to their own scenarios.
- Many young people exposed to traumatic events do not develop mental health problems. Trauma should not be considered deterministic of mental illness. The individual and social resources available to someone exposed to trauma can affect the development of mental ill-health.
    - Include information for teachers on the link between trauma and mental health and that it is not deterministic in the teacher summaries.
    - Provide psychoeducation material to students, illustrating the interconnected relationship between thoughts, feelings, and actions.
- Exposure to adversity can impact one’s ability to regulate their own emotions.
    - Empower students with skills of soothing, grounding techniques, imagery, and visualization techniques.
- There is a diverse range of exposures to adversity that impact young people differently.
    - Represent a range of adversities in the program content, for example, bullying, domestic violence, and gender-based and sexuality-based discrimination.
    - Similarly, represent a range of reactions, including feeling sad or down, anxious, and dysregulated.
- Safety is the first priority.
    - Consistently encourage young people to talk to a trusted adult when faced with traumatic or adverse experiences. List examples of trusted adults to whom they can reach out, for example, a school counselor, teacher, parent, or other relative. Provide information and contact details for third-party support services.
- The impacts of trauma can be long term, affecting attribution styles, emotions, and behaviors. There are high levels of shame and self-criticism in adolescents, especially for those exposed to adversity and discrimination.
    - Reflect on how experiences of past adversity can affect how we perceive ourselves, the world, and our relationships. Incorporate skills training and practice for students to identify thinking traps and challenge these with more helpful and realistic ways of thinking. Encourage self-compassion through student activities.

Adapted OurFutures Mental Health Module

In response to the youth perspectives and guiding principles described in Textbox 6, the following adaptations were made to the OurFutures Mental Health program. Storyline dialogue and lesson content were reduced in length (quantity and overall time taken to complete).

Storylines

To reflect best-practice principles of trauma-informed approaches to prevention (Textbox 6), the research team carefully expanded 2 characters’ storylines, including Will and Chloe, to reflect the backgrounds of domestic violence and bullying, respectively, in an authentic, trauma-informed manner. These 2 specific experiences reflect the most commonly experienced adverse events by young people in Australia [62,63] and are strongly associated with mental ill-health and substance use [53,64,65]. In addition to these major changes, several minor modifications were made to the program storylines:

- Elements of drama in the storyline (eg, friendship conflicts and suspenseful romance) were increased, and dialogue was significantly shortened to increase student engagement.
- Several key expansions were made to characters’ storylines to include more diverse life experiences. These include themes of bullying, domestic violence, household dysfunction, and identity exploration. More diverse representations of depression and anxiety, incorporated issues of stigma and discrimination, the role of friendships, and the physiological aspects of anxiety were included.
- School stress and time management were made central and peripheral themes in all main characters’ storylines.
- Scenes were revised and café and skate park (gender-neutral) settings were introduced. Transgender nonbinary queer character, Julia, was included in both.

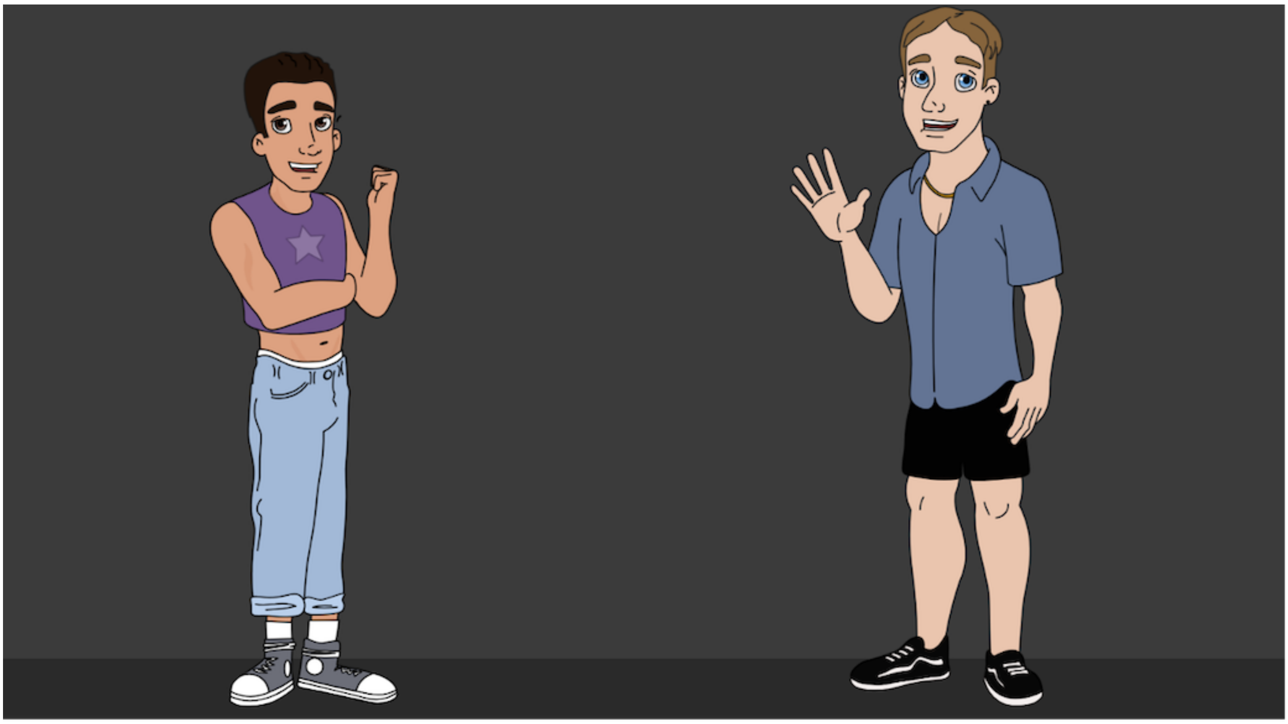
- Material was revised to remove curfews within characters' storylines.
- Two new narrators were introduced to add more layers to the main characters' respective storylines through focalizing narration from an outside character.
- Themes of peer relationships and intimate partner relationships were embedded and maintained throughout all character storylines.

Characters

Combining insights from interviews and consultation with LGBTQA+ youths, 3 new characters were created with the help of a professional graphic designer, reflecting a variety of genders, sexualities, and cultural backgrounds, whose mannerisms and clothes were inspired by contemporary media personalities. These new characters are displayed in Figures 1 and 2.

Figure 1. New character in the revised OurFutures Mental Health program: Julia.

Figure 2. New narrators in the revised OurFutures Mental Health program: Alex and Ryan (Alex presented in the left and Ryan in the right).



Julia is a transgender nonbinary queer person who is the love interest of Ella, a queer girl. Through normalizing Ella’s attraction to a transgender nonbinary queer person, these characters strive to normalize attraction, behavior, and feelings without self-doubt, self-stigma, and gatekeeping. Alex is a “femme slay queen of colour,” and Ryan is a “stereotypically hegemonically masculine-looking bro.” Together, this duo are the new story narrators who previously attended the same school as the other characters. This configuration was intentional to elevate voices within LGBTQA+ communities that have been historically underrepresented (eg, LGBTQA+ young people of color) to break down stigma and barriers to friendship and to demonstrate connection irrespective of gender and sexuality diversity. The appearances of these characters were inspired by popular television shows, including LGBTQA+ mainstays: the *Queer as Folk* reboot and *Heartbreak High*.

Feedback during stages 2.2 and 2.3 emphasized that LGBTQA+ young peoples’ stories in the past have largely revolved around surviving dysphoric adversity rather than celebrating the positive, euphoric, and mundane aspects of LGBTQA+ young peoples’ lives. Hence, Julia’s storyline does not feature any aspect of hardship in relation to their gender journey.

In addition to the 3 new characters, several minor modifications were made to the remaining cast of characters, as listed below:

- Revisions of characters maintained cultural diversity among the cast of characters.
- More realistic, discreet clothing options were sourced from popular influencers and television actors on social media.

Weekly, Manualized Program Content (Universal)

In response to feedback sourced from stages 1 to 4, the following adaptations were made to the content:

- We moved psychoeducation from being delivered by peers to being delivered by new older narrator characters. These narrators are alumni of the main storyline high school setting, retaining a youth voice and allowing peer-led SMS text messaging.
- We changed the character of Chloe to seem less regimented and formally trained in the way that she spoke about mental health and more of a compassionate peer who is a good listener. This ultimately allowed Chloe to more realistically represent a young person aged 14 years.
- By virtue of revising all dialogue and program content to be trauma-informed, all language used was sensitive to the impacts of adverse life experiences and how this might impact mental ill-health.

A comparison of the program content between the original and updated program is presented below in Table 1.

In the original OurFutures Mental Health, the teacher or school staff member responsible for program facilitation was provided with optional activities to administer to students after completing the cartoon component of each lesson. By contrast, the updated classroom activities contain skills practice and are, therefore, not described as optional but rather a key component of the intervention. Classroom activities are a mix of individual activity-style questions and class discussion and brainstorming activities facilitated by the teacher intended to reinforce the key concepts introduced in the cartoon storylines and provide an opportunity for skills practice using the cartoon characters’ scenarios. For each lesson, classroom activities are provided to teachers via the teacher portal of the website. These activities focus on applying the CBT strategies covered in that week’s lesson to the cartoon characters, allowing students to practice the skills learned while minimizing the potential for uncomfortable feelings that might arise when students discuss or reflect on their own personal examples in class. This adaptation reflects principles of trauma-aware schooling, which asserts that schools should promote a sense of safety among students [66]. In addition, this level of skills practice was expected to be sufficient for most children who do not experience elevated mental health symptoms, thus improving the relevancy of the program for these students.

Table 1. Comparison of weekly program content in original and updated versions of the OurFutures Mental Health program.

Lesson	Original content	Updated content
1	• Identify the signs and symptoms of anxiety and depression.	• Highlight the difference between symptoms of low mood or anxiety and depressive or anxiety disorders. Remove statistics on the prevalence of depressive and anxiety disorders to avoid students pathologizing normal experiences and to improve relatability. Encourage students to think of other words to describe low mood and anxiety to demonstrate these are common and normal emotions. • Introduce the CBT[a] model to understand how the characters' thoughts, feelings, and physical sensations affect their behaviors. Show how the characters' exposure to adversity (eg, bullying and domestic violence) affects their mental health. • Introducing pronouns and information about experiences of gender and sexuality diversity
2	• Identify unhelpful thoughts and practice skills to challenge these thoughts. • Explore more realistic and helpful ways of thinking.	• Identify negative thinking traps (eg, mind reading and catastrophizing) and learning strategies to challenge negative thoughts. Apply realistic thinking practice to Will's and Ella's scenarios, where Will's scenario incorporates examples of applying self-compassion in light of adverse situation happening in his home life.
3	• Identify behavioral strategies to improve mood and enhance mental health. Practice implementing these strategies through activity scheduling and stepladders.	• General updates but no substantive changes to content or activities
4	• Learn and practice skills for assertiveness. Practice skills for coping with intense emotions, for example, controlled breathing and emotion surfing.	• Reflect that our past or current experiences affect how we perceive others' communication and actions. For example, a previous experience of bullying can influence how we perceive others' actions in the present. • Assertiveness and other skills practice retained from original content
5	• Structured problem-solving and behavioral experiments: learn ways to tackle daunting scenarios by breaking them into smaller, more manageable components, such as managing several assessments alongside part-time employment.	• General updates but no substantive changes to content or activities
6	• Review and help-seeking: promotes the importance of seeking help and reminds students of the support available. Review of strategies to address feelings of anxiety and low mood.	• General updates but no substantive changes to content or activities

[a] CBT: cognitive behavioral therapy.

Optional at-Home Activities (Proportionate Universalism)

In the refined OurFutures Mental Health program, teachers are encouraged to additionally direct students to optional "at-home" activities that are available to download in the student portal of the website. In these activities, students are provided with psychoeducation focused on coping with adversity or traumatic events, seeking support, prioritizing safety, gender and sexuality diversity broadly, and support services specific to LGBTQA+ young people. These activities encouraged students to apply the strategies and coping skills learned in that week's lesson to themselves and their own scenarios. These included activities such as grounding exercises, soothing activities, imagery, and self-compassion. Teachers were informed that these activities were to be accessed by students outside of class time to ensure that this self-practice was voluntary and confidential. Specific content is presented in Textbox 7. These opt-in at-home activities were introduced to facilitate a restructuring of the program to provide low-intensity therapeutic content to *all* students, including students not exhibiting mental ill-health symptoms, while providing greater-intensity therapeutic content to students who might need it. Therefore, aligned with the concept of proportionate universalism, these optional activities facilitated an "opt-in" increased intervention dosage for students who perceived the need or wanted additional information and skills training while retaining a low-dose, universal mental health intervention for delivery within schools.

Textbox 7. Summary of optional, at-home activities available to students.

Summary

- Psychoeducation: apply the cognitive behavioral therapy model to self to identify the thoughts, feelings, and behaviors associated with recent feelings or low mood or anxiety and identify ways of coping with these. Identify which of these ways of coping were helpful or unhelpful. Provide psychoeducation about stressful life events, stigma and discrimination, and our environment on mental health. Identify sources of support for managing mental health and provide contact details for third-party support services.
- Cognitive strategies: apply realistic thinking and thinking traps to the student's own personal example.
- Behavioral strategies: complete behavioral strategies for oneself, for example, stepladder and activity scheduling.
- Assertiveness training: practice assertiveness in response to a situation the student is currently facing (or using an example from the past). Introduce and practice additional strategies (than those provided in the universal content) to cope with intense emotions, for example, grounding, soothing, imagery, and self-compassion. Encourage students to select and try some of these strategies and record which ones they found helpful.
- Problem-solving: apply structured problem-solving to a problem the student is currently facing (or one from the past). Encourage students to reflect on their progress or the success of their structured problem-solving attempt after they enact the solution they came up with and try a different strategy if needed.
- Review and sources of support: review the techniques and strategies learned throughout the program. Record sources of support available to the student and encourage them to identify barriers to reaching out to this person and ways to overcome barriers to reaching out.

Weekly Student and Teacher Lesson Summaries

Student and teacher lesson summaries were updated to include more guidance on trauma and gender and sexuality diversity, including the relationships between traumatic events and gender or sexuality stigma and discrimination on mental health; inclusive, trauma-informed language regarding gender and sexuality; and what schools and teachers can do to support the mental health of their students, particularly LGBTQA+ students and students exposed to adversity.

Quiz Questions to Reinforce Material

Multiple-choice quiz questions at the end of each module were also modified to reinforce key concepts regarding problem-solving skills, coping skills, and the interconnectedness of thoughts, behaviors, and emotions (eg, “True or false: Avoiding things you are anxious about can make anxiety worse in the long term.”). In addition, some items were included to promote principles of trauma-informed approaches, particularly related to recognizing the signs, symptoms, and impacts of exposure to adversity. Finally, quiz items were included that aimed to promote students' knowledge and acceptance of gender and sexuality diversity. The questions and answers specific to LGBTQA+ young people aimed to reinforce key skills of allyship, fostering acceptance, inclusion of LGBTQA+ young people, and affirming and validating LGBTQA+ young people. For example, 1 answer delivered by Josh is as follows:

> *Love is love! No matter if its cis people, hetero people, trans people, or queer people, relationships are the same for everyone.*

Discussion

Principal Findings

The updated OurFutures Mental Health program is a trauma-informed, LBGTQA+ affirmative program aligned with the concept of proportionate universalism. Program adaptations included (1) adding new characters and storylines to reflect gender and sexuality diversity and common adverse life events, youth perspectives, and expert advice; (2) updating teacher resources to include more guidance on trauma, guidance on LGBTQA+, and teaching social-emotional skills; and (3) restructuring the content in line with targeted universalism, by providing lower-intensity social-emotional skills and psychoeducation to all adolescents in the core modules or activities and additional content via voluntary, at-home activities (eg, LGBTQA+ and trauma resources and further skills for depression or anxiety). This universal, student-facing intervention will use proven strategies to enhance implementation and scalability in schools. This includes web-based delivery of the lesson content via a web portal, student and teacher summaries, and discussion guides (not requiring teacher training). The content of the program is also mapped to the Australian National Curriculum, allowing it to be embedded in teacher planning for mental health education.

The OurFutures Mental Health program adaptation responds to recent mixed findings of universal school-based mental health prevention programs, which include null, small beneficial, and small iatrogenic effects [19,20,23,37,42]. The reality of diverse school student populations presents a challenge for preventionists to ensure the relevance and utility of universal mental health prevention programs for all students. Our findings highlight that the heterogenous distributions of the severity of mental ill-health symptoms among young people are meaningful for how relevant and engaging universal mental health prevention programs are to end users [27]. This study highlights the importance of sourcing formative insights from a variety of stakeholders, especially young people themselves. Asking what works, for whom, and why it works is of crucial importance in determining the efficacy of prevention approaches [19,20].

The efficacy of the refined OurFutures Mental Health program is currently being tested through a cluster RCT with up to 1200 students in 12 schools across Australia [44]. We hypothesize that, compared with students in control schools, students in intervention schools will show improved mental health knowledge and reduced depressive and anxiety symptoms at 3 months after baseline. A planned subgroup analysis will also examine the program effects for those exhibiting elevated mental health symptoms at baseline, across the 3 main outcomes of knowledge, depression, and anxiety symptoms. Secondary outcomes to be measured include improvements in general well-being, help-seeking, and quality of life and reductions in psychological distress; functional impairment; social, emotional, and behavioral problems; and alcohol use. In conjunction with student-report indicators of mental health and well-being, the proposed trial will also administer brief evaluation surveys to students and teachers in intervention schools to assess their experiences (eg, perceived satisfaction, relevance, helpfulness of program materials, and potential areas for improvement) completing or delivering the OurFutures Mental Health program. Teachers in intervention schools will also complete weekly logbooks describing their implementation of the program and any associated barriers and facilitators. A formal process evaluation will analyze and summarize findings from both evaluation surveys and logbooks to identify areas for improved relevance and engagement in future program iterations, with particular attention to the acceptability and reception of intervention characteristics tailored to LGBTQA+ young people and young people exposed to adversity. These results will also be compared with process evaluation results related to the previous iteration of the program [27] to further identify strengths and weaknesses for future program design and adaptation.

The adaptation process described in this study is not without its limitations. First, focus groups with grade 8 students were conducted at 3 independent or private schools in Sydney, Australia, and only 2 LGBTQA+ young people agreed to participate in targeted interviews. While this overrepresentation of youth from independent schools, who are likely from higher socioeconomic backgrounds, and urban youth limits generalizability to diverse groups of youth, qualitative responses were detailed and aligned with evidence from national surveys on sources of concern among young Australians [67]. Similarly, the limited number of individual interviews with LGBTQA+ youth may not have captured the full diversity of experiences within this population. Future studies should aim to increase the sample size and diversity of students to allow for more generalizable findings. Second, there was a poor quality of audio recordings for certain focus groups, which, in turn, may have missed participant insights during transcription. Every effort was made to transcribe these focus groups accurately with careful double-checking of transcripts for quality assurance purposes. Ensuring high-quality recording equipment should be prioritized in future studies. Third, the original evaluation data sourced for stage 1 of the adaptation process are relatively dated (having been collected in 2015). The nonrepresentativeness of this cohort relative to more contemporary cohorts was mitigated by our sourcing of feedback from additional contemporary youth (stage 2). Finally, due to time and budgetary constraints, not all updates to cartoons could be executed.

Conclusions

To the best of our knowledge, our study is the first to represent a shift in thinking about the future of school-based, universal mental health prevention, adapting a universal mental health prevention program to be universally proportionate, thereby leveraging the strengths of both universal and targeted approaches. Specifically, our study thoroughly details the multistaged adaptation of a universal mental ill-health prevention program, OurFutures Mental Health, to be trauma-informed, LGBTQA+ affirmative, and relevant to contemporary youth, triangulating multiple sources of quantitative, qualitative, and evidence synthesis data. A school-based cluster RCT with grade 8 students in Australian secondary schools is currently underway to evaluate the effectiveness of the OurFutures Mental Health program for reducing depressive and anxiety symptoms and improving mental health knowledge. Our study proposes a novel solution to the global call to action issued to actors in the school-based mental health prevention space to decisively and innovatively respond and advance the current stalemate state of the literature to ultimately improve the mental health and well-being of young people in schools.

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MT and NCN are 2 of the developers of the OurFutures programs (formerly Climate Schools) and members of the OurFutures Institute, a not-for-profit charity, to distribute the OurFutures programs and maximize social well-being.

Conflicts of Interest

MT and NCN are cofounders of the OurFutures Institute. There are no other conflicts of interest to declare.

Multimedia Appendix 1
Focus group and interview guides.

[DOCX File , 384 KB - pediatrics_v7i1e54637_app1.docx]

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Abbreviations

CBT: cognitive behavioral therapy
LGBTQA+: lesbian, gay, bisexual, transgender, nonbinary, queer, questioning, and otherwise gender and sexuality diverse
RCT: randomized controlled trial
YAC: youth advisory committee

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Recruitment of Adolescents to Virtual Clinical Trials: Recruitment Results From the Health4Me Randomized Controlled Trial

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Abstract

Background: Preventive interventions are needed to provide targeted health support to adolescents to improve health behaviors. Engaging adolescents in preventive interventions remains a challenge, highlighting the need for innovative recruitment strategies. Given adolescents' lives are intertwined with digital technologies, attention should be focused on these avenues for recruitment. The evolving nature of clinical trials, including the emergence of virtual clinical trials, requires new recruitment approaches, which must be evaluated.

Objective: This study aimed to examine the effectiveness and cost of various digital recruitment strategies for recruiting adolescents to a virtual clinical trial, evaluate the progression of participants from screening to enrollment, and explore factors associated with nonparticipation. This was conducted using data from the Health4Me Study, a preventive digital health intervention to improve physical activity and nutrition behaviors among adolescents aged 12 to 18 years.

Methods: Participants were recruited into the Health4Me Study via social media advertisements on various contemporary platforms, emails to schools, emails to contacts within known networks, and emails to relevant youth organizations. Data were collected from social media advertisements, screening, and recruitment logs. Data analysis included summary and descriptive statistics, as well as chi-square tests to explore factors associated with nonparticipation.

Results: From 2369 expressions of interest, 390 (16.4%) participants were enrolled. A total of 19 advertisements were placed on social media, and 385 promotional emails were sent to schools, contacts within known networks, and relevant youth organizations. Social media advertisements reached 408,077 unique accounts. Advertisements mostly reached those living in populous states in Australia (306,489/408,077, 75.11% of unique accounts) and those identifying as female (177,698/408,077, 43.55% of unique accounts). A total of 24.97% (101,907/408,077) of advertisements were delivered to accounts with uncategorized genders. The total cost per participant enrolled was Aus $3.89 (approximately US $2.58). Most participants (1980/2305, 85.90%) found out about this study through Instagram. Differences in screening characteristics between eligible participants who did and did not enroll were found to be statistically significant for gender (*P*=.02), with fewer males and more individuals reporting their gender as "other" enrolling than expected by chance alone. The recruitment method also differed (*P*<.001), with fewer participants enrolling through Instagram and more enrolling through other methods (eg, known networks or word of mouth) than expected by chance alone.

Conclusions: This study found that virtual clinical trial recruitment was found to be low-cost, with the potential to increase trial participation. Social media was the most effective recruitment method, reaching all states and territories, including hard-to-reach populations. Future action is needed to explore recruitment methods that are more effective for males and to build trust among adolescents regarding clinical trial recruitment via social media.

Trial Registration: Australia New Zealand Clinical Trials Registry ACTRN12622000949785; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=383576&isReview=true

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KEYWORDS

adolescents; clinical trial; recruitment; digital health; prevention; adolescent health; health behavior change; health promotion; social media

Introduction

Adolescence is regarded as the second window of opportunity—a critical period to intervene and provide targeted support to improve health outcomes that have a profound impact on health and well-being throughout the life course [1]. Failure to invest in primary prevention among today's adolescents will increase the burden of chronic diseases and the existing sizable total health expenditure of Aus $24 billion (approximately US $15.9 billion) on potentially avoidable risk factors [2]. It is important that high-quality public health interventions that focus on primary prevention of chronic diseases are tested with adolescents through clinical trials. However, challenges exist with engaging adolescents in preventive interventions, including their health system disengagement making them hard to access for delivering such interventions [3], a prevention lens not being appealing to adolescents [4], and their evolving need for autonomy in providing informed consent [5]. Innovative methods to engage adolescents within preventive interventions are needed that can overcome identified barriers.

Adolescents' lives are increasingly intertwined with digital technologies such as mobile phones and the internet [6]. With that comes the opportunity to harness developments in digital technologies for innovative preventive interventions [7]. The use of digital methods for recruitment to clinical trials is increasing in popularity and they are particularly beneficial for recruitment to online clinical trials. Previous research has focused on comparing social media or other digital strategies to traditional in-person recruitment [8-13], and the use of digital tools for recruitment and retention of clinical trial participants [14,15]. While research shows that digital recruitment strategies are effective compared to traditional in-person recruitment, limited research is available to understand the efficiency of digital recruitment strategies alone and their impact on clinical trial participants and investigators (eg, helping investigators identify eligible trial participants) [14]. A previous review identified that Facebook (Meta) is effective for recruiting adolescent participants [16], and a cross-sectional study revealed that the use of Instagram (Instagram from Meta) and Snapchat (Snap Inc) may also be useful and cost-effective to recruit young people to surveys [17], but limited evidence is available for the use of these contemporary platforms for adolescent recruitment to clinical trials. As more social media platforms become available and others diminish in popularity, it is crucial that research is undertaken to understand their effectiveness for recruiting adolescents to research.

Additional complexities occur when there are no physical recruitment sites, otherwise known as remote [18], decentralized [19], or virtual [20] clinical trials, from hereon in called virtual clinical trials. Virtual clinical trials can leverage digital technologies for participant recruitment and retention, enabling online consent for participants, on-time data collection, and delivery of the intervention that is convenient for participants, as they do not have to travel to a physical site [21]. Virtual clinical trials among adolescent participants have the potential to overcome some of the previously identified barriers, including reaching those who are disengaged with the health system and reaching adolescents directly [22,23], allowing them autonomy in making decisions about their health [24], including providing informed consent (depending on ethics approvals). However, there is limited research to understand digital recruitment strategies for clinical trials among adolescents. Furthermore, it is also important to understand factors that may cause eligible participants not to engage in digital preventive interventions. Reporting will enable future research to tailor recruitment toward the most effective digital strategies and address factors that cause disengagement. Therefore, this study aimed (1) to examine the effectiveness and cost of various digital recruitment strategies for recruiting adolescents to a virtual clinical trial, (2) to evaluate the progression of participants from screening to enrollment, and (3) explore factors associated with nonparticipation.

Methods

Study Design

The Health4Me study was used as the context for this research. The full protocol is published elsewhere [25]. In brief, the Health4Me Study is a virtual clinical trial, based in Australia, of a community-based, 6-month text message intervention. The intervention aims to improve physical activity and nutrition behaviors among adolescents aged 12 to 18 years.

Ethical Considerations

Primary ethics approval was received from the University of Sydney Human Research Ethics Committee (2022/402), and the trial is registered at the Australia New Zealand Clinical Trials Registry (ANZCTR; ACTRN12622000949785; date registered: July 5, 2022).

Participants and Eligibility Criteria

Participants were eligible to take part in the Health4Me Study if they were (1) aged 12 to 18 years, (2) owned a mobile phone capable of sending and receiving text messages, (3) had an

Australian mobile phone number, (4) had sufficient English proficiency to read text messages pitched at a 7th grade reading level, and (5) provided electronic consent (or from their parents or guardians if they were aged <14 years). Participants were excluded from this study if they (1) had a diagnosis of type 1 or type 2 diabetes mellitus, (2) had a previous or current diagnosis of an eating disorder or were at high risk for an eating disorder as assessed in screening, (3) weighed <25th centile for their age, (4) had recent rapid weight loss, (5) had a medical condition that would preclude providing informed consent or ability to comply with this study's protocol, (6) were enrolled in an alternative randomized lifestyle management program, (7) were pregnant or planning to become pregnant during the 6-month intervention, and (8) were unable to read English at a 7th grade reading level. The eligibility criteria for the Health4Me Study have been published elsewhere [25].

Given the Health4Me Study was conducted virtually, several steps were embedded to ensure participants could safely enroll into this study. To complete screening procedures, the research team partnered with the InsideOut Institute for Eating Disorders, a team of researchers and clinician experts in eating disorders based at the University of Sydney. Potential participants first expressed interest to take part in this study by filling out the Expression of Interest (EOI) form on REDCap (Research Electronic Data Capture; Vanderbilt University), which included contact details and screening against the eligibility criteria, as well as screening for eating disorder risk using two validated questionnaires—InsideOut Institute Screener (IOI-S) and Eating Disorder Examination Questionnaire (EDE-Q) [26,27]. Study specific cut points were set for the IOI-S (≥16) and EDE-Q (>3 and any of behavioral questions 15 - 18 endorsed ≥1). Potential participants first completed the IOI-S, if they scored below the cut point and met all inclusion criteria, they were sent the e-consent form. However, if participants scored above the cut point on the IOI-S, they were directed to complete an EDE-Q. If potential participants scored under the cut point on the EDE-Q, they were deemed eligible and sent the e-consent form. If a potential participant was detected to be above the cut point on the EDE-Q, they were referred to the InsideOut Institute for Eating Disorders for an assessment to determine suitability to participate by eating disorder expert clinicians (clinical psychologist or registered clinical psychology students with expertise in eating disorders) via phone call. If they received clearance from the eating disorder expert clinicians, they were sent the e-consent form and deemed eligible to enroll in this study. If they did not receive clearance, they were sent an email with various resources for eating disorder support. If a potential participant did not meet other inclusion criteria, they were sent an email explaining why they were ineligible. All participants provided informed e-consent (and from their parents or guardians if they were aged <14 years) before baseline measures were collected [25]. Participants were randomized once all baseline measures were complete.

Recruitment

The protocol was to enroll 390 participants—195 per arm—based on detecting a mean difference in moderate to vigorous physical activity minutes per day of 14.8 (control: 42.55 and intervention: 57.36) with an SD of 21.45 for control and 37.79 for intervention or a 13.37% difference in the proportion of appropriate vegetable consumption (control: 4.85% and intervention: 18.22%) with 90% power and accounting for 30% dropout. The Bonferroni adjusted significance level of 0.025 was used to account for two primary outcomes. The participant information statement detailed that participants would receive an Aus $30 (approximately US $19.90) gift voucher at the completion of all baseline assessments as a reimbursement for their time. A recent review has suggested that financial incentives can be provided to children appropriately, and few studies suggest incentives are inherently harmful [28]. Recruitment methods are detailed below.

Recruitment Methods

Overview

Recruitment ran from February 2023 to February 2024 using a range of methods including social media advertising on Facebook, Instagram, TikTok, and Twitter/X, emails to schools, emails to contacts within known networks, and emails to relevant youth organizations. A dedicated study website was also created to establish legitimacy.

Social Media Advertisements

Initially, study-dedicated Facebook and Instagram pages were established with this study's logo, study contact information and detailed the purpose of this study. Posts were made on Instagram to establish this study as an authentic and active social media account. All content and this study logo were co-designed with adolescents [29]. All advertisements were created using ethics approved text and images on Meta Ads Manager, which simultaneously promoted advertisements on Facebook and Instagram or on TikTok for Business, which promoted advertisements on TikTok. Due to restrictions in advertising to people aged younger than 18 years [30], all advertisements were targeted only for people aged 13 to 18 years in Australia. Examples of the social media advertisements (images and text) are available in Multimedia Appendix 1. Advertisements on Meta were run for a maximum of 2 weeks, with a maximum budget of Aus $20 (approximately US $13.30) per day. The single advertisement on TikTok was run for 4 days, with a lifetime budget of Aus $50 (approximately US $33.20). A single post was made on Twitter/X by a member of the research team. All advertisements linked directly to this study EOI form, hosted on REDCap.

Emails

Emails were sent to schools, known networks and contacts of the research team and, relevant youth organizations, for example, headspace. Emails contained a link to this study's website and this study's REDCap page.

Study Website

Previous formative work by the research team revealed that adolescents desire online health information that is credible and reliable [31]. A study website was created to establish this study as legitimate and to build trust among adolescents. This study's website contained this study's logo, study contact information, detailed the purpose of this study, how to become involved (including a direct link to this study's REDCap page), photographs and names of the key researchers and names of the wider research team. Potential participants could also access the full participant information sheet through this study's website.

Data Sources

Social Media Advertisements

Data were available and collected from Meta Ads Manager. For each advertisement, data were collected on the number of days the advertisement ran, advertisement strategy used, reach, impressions, link clicks, cost per result, and total amount spent (Aus $). Deidentified advertisement audience demographic data included location, age, and gender. User's location was based on their state or territory (New South Wales [NSW], Victoria, South Australia, Queensland, Western Australia, Northern Territory, Tasmania, and Australian Capital Territory). Age and gender data were based on what social media users disclose on their user profiles and were summarized according to Meta Ads Manager categories (age: 13 - 17 or 18 - 24 years; gender: male, female, or uncategorized). Data were available and collected from TikTok for Business. For each advertisement, data were collected on the number of days the advertisement ran, reach, impressions, link clicks, cost per result, and total amount spent (Aus $). Post analytics were available and collected from Twitter/X. For the single post, data were collected on likes, reposts, impressions, and link clicks.

Recruitment Log

A log was kept of all dates on which emails were sent to schools, known networks and contacts, and youth organizations. Data were also collected on the number of people who visited this study's REDCap page each day to express interest and the number of enrollments. Detailed notes were kept on the log by the research team.

Screening Logs

A detailed log was kept of all participant inquiries. The secure online REDCap [32] database collected data, including age (12-14 years or 15-18 years), gender (male, female, other, or prefer not to say), high school attendance (yes or no), height and weight (for BMI calculations, categorized as underweight, healthy weight, above a healthy weight, or well above a healthy weight) [33,34], and recruitment method. The responses for recruitment method included (1) Facebook, (2) Instagram, (3) Twitter/X, (4) TikTok, (5) other social media platform, (6) headspace, (7) general practitioner or doctor, and (8) other. The screening log also contained details on eligibility and reasons for exclusion. A further screening log was also collected from the InsideOut Institute for Eating Disorders, which kept a detailed log of potential participants requiring screening for eating disorder risk. The secure online REDCap database allowed both the psychologists and research team to make comments. Potential participants were contacted a maximum of two times by the eating disorder expert clinicians. If contact was not established after two attempts, they were marked as ineligible and sent resources via email.

Data Analysis

Summary statistics regarding social media data are presented. Total costs (Aus $) are reported for social media advertisements, with the average cost calculated per participant eligible and per participant enrolled. Descriptive statistics for continuous measures, including counts and percentages for recruitment method, were used to summarize the breakdown of potential participants who inquired and participants screened by the InsideOut Institute for Eating Disorders.

To explore factors associated with nonparticipation, differences in screening characteristics between eligible participants who did and did not enroll in this study were compared using chi-square tests. The significance level was set at 5%. Characteristics included age, gender, BMI, high school attendance, and recruitment method. Adjusted standardized residuals (ASRs) were used to measure the strength of the difference between observed and expected values. Data were analyzed using IBM SPSS (version 29.0; IBM Corp).

Results

Effectiveness and Cost of Recruitment Strategies

A total of 2369 entries were made to the EOI form. Of those, 2305 respondents completed the question asking how they heard about this study. Most (1980/2305, 85.90%) found out about this study through Instagram, followed by other (182/2305, 7.9%) and then Facebook (112/2305, 4.9%). The full sample size of 390 adolescents was reached in 12 months.

For the Health4Me Study, there were 17 advertisements run on Meta Ads Manager over 12 months. The length at which the advertisements were running for ranged from 2 - 18 days, with advertisements running for a total of 146 days. Overall, advertisements reached a total of 408,077 unique Meta accounts and were viewed >2.3 million times. A cost-per-link-click strategy was employed in 16/17 advertisements, and one employed a cost-per-post-engagement strategy. Across 17 advertisements, 7211 link clicks were made. Advertisements mostly reached people in NSW, Victoria, and Queensland, accounting for 75.11% (306,489/408,077) of the audience. With regard to age, 96.89% (395,403/408,077) of the advertisement audience was 13 - 17 years old. For gender, advertisements mostly reached females (43.55%, 177,698/408,077); however, a quarter (24.97%, 101,907/408,077) of the advertisements were delivered to accounts with uncategorized genders. One advertisement was run through TikTok for Business, which ran for 4 days, reached 8386 unique accounts, and was viewed 14,832 times, with 144 link clicks made. No further data were available. One advertisement was placed on Twitter/X, which was viewed a total of 1041 times and reposted 11 times, with 15 link clicks made.

The overall cost of social media advertisements run through Meta was Aus $1478.63 (approximately US $965.69). Cost-per-link-click ranged from Aus $0.03 to Aus $0.87 (approximately US $0.02 to US $0.54). The overall cost of the advertisement through TikTok was Aus $39.97 (approximately US $26.10), with cost-per-link-click at Aus $0.28 (approximately US $0.18). In total, Aus $1518.60

(approximately US $991.80) was spent on social media advertisements. Cost per eligible participant was Aus $1.64 (approximately US $1.09), and cost per participant enrolled was Aus $3.89 (approximately US $2.58). A full breakdown of all social media data is available in Tables 1 and 2.

Emails requesting inclusion in school communications to students were sent to 367 high schools across NSW. One school announced this study at their school assembly. One email was sent to our mailing list of young people who have expressed interest in future research. Emails were sent to 17 other known networks, contacts, and youth organizations. Of those, the research team was made aware that one shared in their general practitioner newsletter, and one shared within their local health district. All sharing through schools, known networks, contacts, and youth organizations was at no cost to the research team.

Table . Breakdown of Meta advertisements reach by state or territory, age, and gender.

	Reach, n (%)
State or territory	
New South Wales	123,543 (30.27)
Victoria	95,954 (23.51)
Queensland	86,992 (21.32)
Western Australia	44,808 (10.98)
South Australia	31,814 (7.8)
Northern Territory	5633 (1.38)
Tasmania	9858 (2.42)
Australian Capital Territory	5377 (1.32)
Unknown	4098 (1)
Age (years)	
13 - 17	395,403 (96.89)
18 - 24	12,674 (3.11)
Gender	
Female	177,698 (43.55)
Male	128,472 (31.48)
Uncategorized	101,907 (24.97)
Total	408,077 (100)

Table . Breakdown of social media advertisements for the Health4Me study through Meta, TikTok, and Twitter/X.

Social media platform and advertisement start date	End date	Days advertisements live (n)	Advertisement strategy[a]	Reach[b]	Impressions[c]	Total cost (Aus $[d])	Daily budget (Aus $)	Link clicks[e] (n)	Cost per result (Aus $)	Post reactions (n)	Post saves (n)	Post shares (n)
Meta (Instagram and Facebook)												
February 10, 2023	February 28, 2023	18	Post engagement	14,128	36,340	112.96	10	68	0.03	3184	5	1
March 2, 2023	March 8, 2023	6	Link clicks	88,929	138,404	59.87	10	550	0.11	28	4	17
March 31, 2023	April 15, 2023	16	Link clicks	70,992	164,879	115.66	10	675	0.17	76	5	19
April 28, 2023	May 12, 2023	15	Link clicks	86,464	237,153	143.3	10	775	0.18	106	6	22
May 16, 2023	May 28, 2028	13	Link clicks	93,409	237,016	123.73	10	641	0.19	78	2	9
May 31, 2023	June 14, 2023	15	Link clicks	117,056	345,260	144	10	680	0.21	208	1	9
June 15, 2023	June 30, 2023	15	Link clicks	110,532	307,182	162.05	10	706	0.23	127	1	10
July 4, 2023	July 18, 2023	14	Link clicks	96,816	301,837	143.73	10	664	0.22	69	3	8
July 21, 2023	July 25, 2023	4	Link clicks	72,945	124,063	80.86	20	731	0.11	113	13	23
July 28, 2023	July 31, 2023	4	Link clicks	64,672	99,327	59.77	20	410	0.15	66	7	8
September 1, 2023	September 4, 2023	4	Link clicks	49,600	76,721	59.99	20	375	0.16	41	6	9
October 13, 2023	October 16, 2023	4	Link clicks	44,795	72,066	59.99	20	435	0.14	51	7	14
November 23, 2023	November 25, 2023	3	Link clicks	18,484	18,995	40	20	72	0.56	3	0	3
December 1, 2023	December 3, 2023	3	Link clicks	35,278	36,989	41.18	20	85	0.48	0	0	0
January 16, 2024	January 21, 2024	6	Link clicks	8185	13,463	62.74	15	103	0.61	3	0	3
February 2, 2024	February 5, 2024	4	Link clicks	15,311	19,940	44.35	15	51	0.87	10	1	1
February 22, 2024	February 23, 2024	2	Link clicks	114,365	134,196	24.45	20	190	0.13	61	1	0
Totals	N/A[f]	146	N/A	408,077	2,363,831	1478.63	N/A	7211	N/A	4224	62	156
TikTok												
August 25, 2023	August 29, 2023	4	N/A	8386	14,832	39.97	10	144	0.28	7	0	0
Twitter												
February 14, 2024	N/A	N/A	N/A	N/A	1041	0	0	15	0	15	0	11

[a] Post engagement: strategy aims to encourage users to like, share, comment on, or save the advertisement. Link clicks: strategy aims to encourage users to click on the advertisement URL link.

[b] Number of times the advertisement is delivered to a unique account.

[c] Number of times the advertisement is delivered in total (including being delivered multiple times to one account).

[d] The conversion rate over the time of the study was approximately Aus $1=US $0.65.

[e] Number of times the advertisement URL link was clicked.

[f] N/A: not applicable.

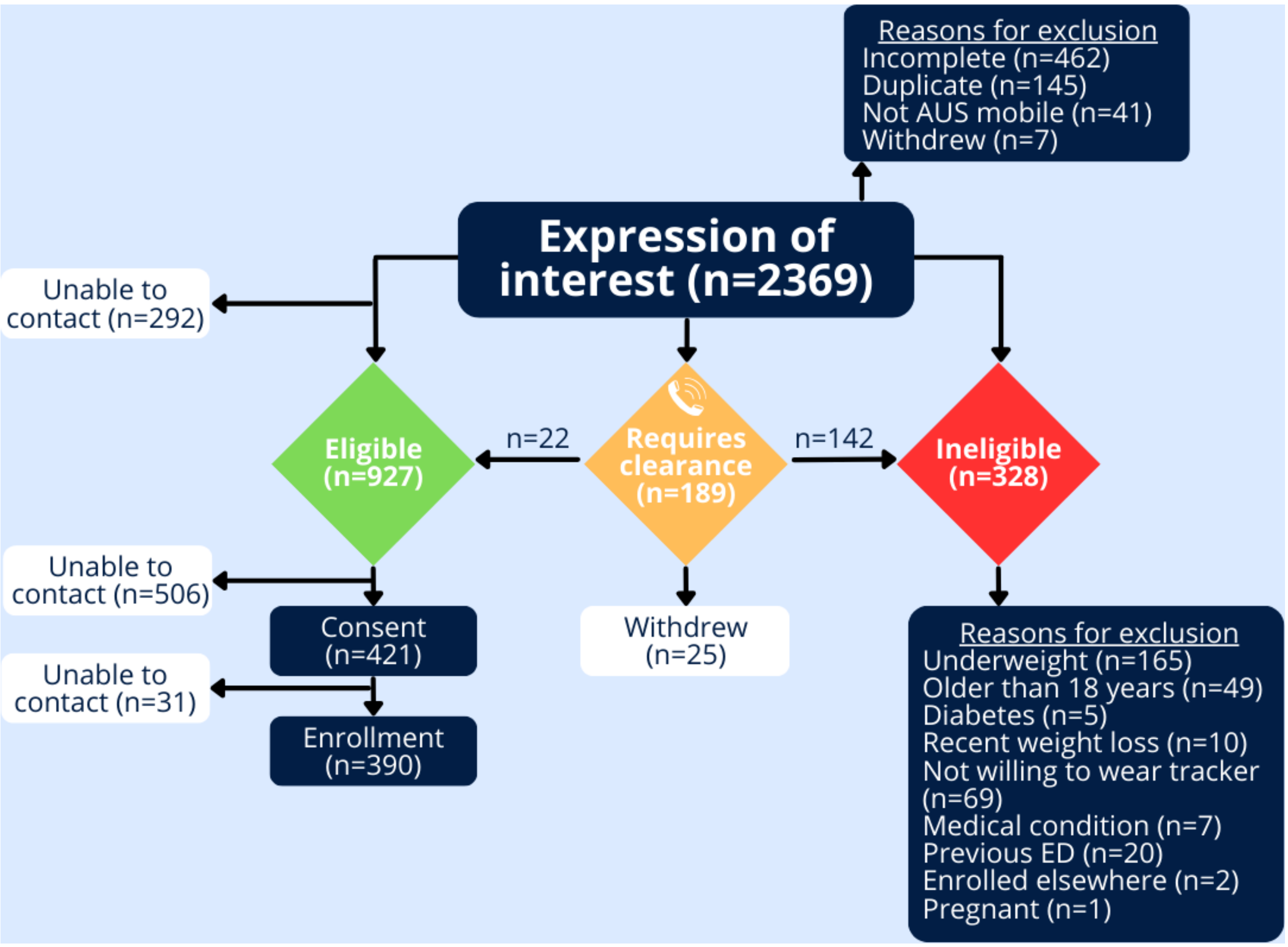
Progression of Participants From Screening to Enrollment

Figure 1 shows the progression of participants and dropout points from screening to enrollment. Of the 2369 entries on the EOI form, 655 were immediately excluded. Of the excluded entries, 41 did not have an Australian mobile number. These 41 entries were among the first 100 EOIs and were believed to be bots. After adding a reCAPTCHA to the REDCap screening survey, no further suspicious entries were received. Of the remaining, 462 entries were incomplete, 145 were duplicate entries, and 32 withdrew their EOI postscreening. In addition, 328 entries were ineligible, as they did not meet the inclusion criteria, with reasons for exclusion shown in Figure 1.

A total of 481 potential participants scored above the cut point on the IOI-S. A total of 292 participants were unable to be contacted to complete the EDE-Q (per protocol for further screening for eating disorder risk). A further 189 potential participants were referred to the InsideOut Institute for assessment from eating disorder expert clinicians. Of those, 104 were unable to be contacted by the eating disorder expert clinicians (and were therefore marked as ineligible), 38 were ineligible postcall as they were assessed as high risk. A further 25 potential participants withdrew at this step, and 22 potential participants were assessed as eligible by the psychologist and sent the e-consent form.

A total of 927 potential participants were eligible and sent the e-consent form. Of those, 506 were unable to be contacted and the e-consent form was never signed. The e-consent form was signed by 421 participants, and they were sent the baseline surveys, but 31 participants did not commence answering baseline questions, giving 390/2369 (16.4%) as participants enrolled in this study.

Figure 1. Progression of participants from screening to enrollment. AUS: Australian; ED: eating disorder.



Factors Associated With Nonparticipation

During screening, 537 potential participants were identified as eligible but did not proceed to enrollment, and 390 participants enrolled in the Health4Me Study. Chi-square tests indicated that there were statistically significant differences in screening characteristics between eligible participants who did and did not enroll in this study for gender and recruitment method. Gender differences were significant (χ^2_{3927}=9.8, *P*=.02); ASRs indicated fewer males and more individuals reporting "other" enrolled than expected by chance alone. Additionally, the recruitment method was significant (χ^2_{3925}=17.39, *P*<.001), ASRs indicated fewer participants enrolled through Instagram and more enrolled through other methods (eg, known networks or word of mouth) than expected by chance alone. No differences were observed for other screening characteristics. A full breakdown of screening characteristics between those who were eligible and did or did not enroll is available in Table 3.

Table . Comparison of screening characteristics between those who were eligible who did and did not enroll in the Health4Me Study.

	Total eligible and not enrolled (n=537)	Total enrolled (n=390)	Chi-square (*df*)	*P* value
Age (years)			3.8 (1927)	.05
12 - 14	80	41		
15 - 18	457	349		
Gender			9.8 (3927)	.02[a]
Male	166	92		
Female	347	274		
Other	11	17		
Prefer not to say	13	7		
BMI [b]			2.1 (3878)	.55
Underweight	21	16		
Healthy weight	410	279		
Above a healthy weight	60	51		
Well above a healthy weight	21	20		
Attending high school			0.5 (1927)	.82
Yes	464	339		
No	73	51		
Recruitment strategy [c]			17.3 (3925)	<.001[a]
Facebook	18	22		
Instagram	470	301		
Other social media platform[d]	4	5		
Other[e]	44	61		

[a] Statistically significant.

[b] Due to being asked gender during screening and not sex assigned at birth, we are unable to accurately calculate BMI for those who listed their gender as "other" or "prefer not to say."

[c] One record missing from each for recruitment strategy. Total eligible and not enrolled (n=536), and total enrolled (n=389).

[d] Due to small numbers, categories of Twitter/X, TikTok, and other social media platform were combined.

[e] Due to small numbers, categories of headspace, general practitioner or doctor, and other were combined.

Discussion

Principal Results

The Health4Me Study aimed at improving physical activity and nutrition behaviors among those aged 12 to 18 years. A total of 2369 EOIs were received, and 390/2369 (16.4%) participants were recruited in less than 12 months. Social media was the main source of recruitment. The research team did try to engage with schools, known networks, and relevant youth organizations via emails with limited success. Social media advertisements through Meta were effective, reaching 408,077 unique accounts across all states and territories in Australia. Overall, social media advertisements were low cost (Aus $3.89 per participant enrolled [approximately US $2.58]). From screening to enrollment, there were multiple points of dropout. Of the EOIs from potential participants who were eligible (927/2369, 39.1%), statistically significant differences were observed for those who did and did not enroll in terms of gender and recruitment method. Fewer males and more individuals reporting their gender as "other" enrolled than expected by chance alone. In addition, fewer individuals enrolled through Instagram and more enrolled through other methods (eg, known networks or word of mouth) than expected by chance alone.

Comparison With Prior Work

Virtual clinical trials have the potential to address challenges in traditional site-based recruitment and be cost-effective [20]. Yet, prevention programs among adolescents are known to have the lowest recruitment rates [35], and stakeholders have identified that a prevention lens may not be engaging for adolescents [4]. In the Health4Me Study, a digital preventive intervention, digital recruitment strategies that were employed were effective, recruiting 390 adolescents in less than 12 months. The Health4Me Study was guided by factors associated with successful recruitment from a previous virtual clinical trial [36], including (1) national recruitment, (2) self-referrals, (3) unmet need for trial intervention, (4) patient and public involvement, (5) regular monitoring and communication, and (6) reimbursement and early exclusion. In the Health4Me Study, a national sample was recruited and participants self-referred into this study. In addition, there are limited prevention programs currently available for adolescents [37], and the intervention and all advertising materials were co-designed with adolescents [29]. A small day-to-day research team was employed who communicated regularly through detailed screening and recruitment logs, and participants were reimbursed through online gift vouchers after completing all study activities at baseline and 6-month follow-up.

The costs reported in this study for social media advertising are lower per enrolled participant than what has previously been reported in reviews (approximately US $3-US $628) [9,38], however these studies mostly report on Facebook and compare social media to traditional in-person recruitment. Limited research is available reporting virtual clinical trial recruitment costs to recruit adolescents. A virtual clinical trial, which aimed to prevent and reduce cyberbullying among adolescents that used Instagram for study recruitment, found a higher consent rate than the Health4Me Study (24.4% vs 16.4%) yet had much higher social media advertisement costs (approximately US $19 versus approximately US $2.59 per enrolled participant) [39]. It is essential for future virtual clinical trials to report costs associated with recruitment to understand their cost-effectiveness for enrolling participants from the target population.

Virtual clinical trials allow remote access to research, potentially enhancing the diversity of participants, and recruiting from hard-to-reach populations [20]. In the Health4Me Study, it was observed that more individuals reporting their gender as "other" enrolled than expected by chance alone. This "other" category captures any gender other than male or female (eg, nonbinary or transgender). In another virtual clinical trial targeting cyberbullying found that nearly half of the participants recruited via Instagram identified as lesbian, gay, or bisexual [39]. It was also observed that less eligible males enrolled in the Health4Me Study than expected by chance alone. When looking at the social media advertisements, they reached less males overall. Evidence from large datasets demonstrates that females spend more time overall and more time per day on social media [40,41]. Additionally, another virtual clinical trial among an older population found that males were underrepresented [42]. Future efforts should be directed to identifying effective methods to recruit males to virtual clinical trials.

Another factor considered to attract hard-to-reach participants online is that those interested can self-refer into this study. A previous study, which aimed to assess effectiveness of online behavioral therapy for tics among young people, found that the majority of participants self-referred from online [36], enabling those who were not under the care of mental health clinicians to be included. The Health4Me Study is unique in that participants who are aged 15 years and older can consent themselves into this study, without the need for parent or guardian consent. This was approved by the ethics committee, with support from our youth advisory group as the Health4Me Study is a low-risk, preventive health intervention. This capacity to self-refer gives adolescents some autonomy around their health, especially given that preventive care is seldom given within primary care to this age group [43].

Within this study, less eligible adolescents enrolled through Instagram than were expected by chance alone, and more enrolled through other methods (eg, known networks or word of mouth) than what was expected by chance alone. Hypothesized reasons for this are around trust in health information that adolescents view online, adolescents being discouraged from sharing personal information online, and having poor knowledge and attitudes on clinical trials [44]. Previous reviews show that adolescents often distrust health information found online yet continue to engage with this information [45]. In terms of health information on social media, friends and networks are particularly important for gaining adolescents trust in this space [46]. Future studies planning to recruit adolescents through social media could explore the use of peer referral or endorsement from youth advisors or reputable organizations (eg, study sponsor) to gain an increased level of trust. In addition, adolescents are acutely aware of how their personal data are being used, and building trust and authenticity among this population is vital [31]. Partnerships with known youth health organizations and endorsement of the clinical trial through their own social media accounts may be useful to increase trust among adolescents.

Within the Health4Me Study, there were multiple points of dropout from screening to enrollment. The largest point of dropout was those who were eligible and sent the consent form but never responded. For all eligible participants, the research team sent the consent form twice via email, however after no response they were marked "unable to contact." Though emails are a highly acceptable form of communication among adolescents [47], future efforts should be directed to streamlining processes of screening and consent for scalability of future trials. Previous studies have aimed to do this using mobile apps, for example, ResearchKit (Apple Inc) [48], which is an open-source software framework designed to streamline the process of screening and consenting participants into research studies. Evidence of success is available for research studies among adults [49,50], yet no outcomes are currently available among adolescents [51]. Other strategies for enhancing communication with adolescents could also be explored in the future (with appropriate ethical approval), such as text messaging and direct messaging on social media platforms.

The second highest rate of dropout among participants was those who required further screening for a potential eating disorder. Out of 2369 potential participants, 292 (12.3%) did not complete an EDE-Q and were therefore excluded, and 189 (8.0%) required clearance through a phone call with this study's psychologist. When compared to the prevalence of eating disorders overall among Australian adolescents, this rate is lower than what has previously been reported (point prevalence of 22.2%) [52]. Thus, screening for eating disorders was not identified as a barrier to enrollment, rather an important safety precaution for potential identification of disordered eating among this population in a preventive intervention.

Limitations

Limitations in this study exist. First, this study is not representative of all adolescents due to inclusion criteria, which remove some groups. However, as this is a prevention intervention, the inclusion criteria aim to represent a large percentage of the adolescent population within Australia. Second, there are restrictions on advertising to adolescents via social media and changes are constantly occurring in this space. Though the inclusion criteria for age in this study was those aged 12 to 18 years, social media advertisements are unable to be targeted to adolescents aged younger than 13 years, as you can only establish a social media account if you are over 13 years. Advertisements were developed for distribution on Snapchat; however, advertising of clinical trials is not allowed on its platform. Therefore, recruitment of adolescents via social media is also a limitation to reaching adolescents aged <13 years. Third, adolescents report that they find recruitment via social media to be feasible and acceptable for recruitment and retention [53,54]. However, this was not assessed within this study as follow-ups are ongoing. Adolescent perceptions for using social media for recruitment will be assessed in the process evaluation for the Health4Me Study, by assessing retention rates and analyzing focus group data. The findings of this study require validation with studies among other adolescent populations and other types of interventions.

Conclusions

Within the Health4Me Study, it was observed that recruitment was most effective via social media, and this was low cost per participant enrolled. Throughout the screening to enrollment process, there were multiple points of dropout, and future efforts should be directed toward streamlining screening and enrollment processes for scalability of future trials. In addition, our results highlight the importance of building trust among clinical trials and health information generally among adolescents on social media for future success in recruiting adolescents via this digital strategy.

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Data Availability

The datasets generated or analyzed during this study are not publicly available due to ethical approvals that protect the data of participants who have taken part in the study.

Authors' Contributions

RR, S Maguire, KW, S Mihrshahi, MLH, JR, SRP, and The Health4Me Team conceptualized the study. RR, ART, S Barakat, SR and S Boulet conducted the investigation. RR conducted the formal analysis and wrote the initial draft. JR and SRP provided supervision. All authors reviewed and edited this paper. All authors approved the final version of this paper.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Health4Me social media advertisement examples.
[DOCX File, 1461 KB - pediatrics_v7i1e62919_app1.docx]

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Abbreviations

ANZCTR: Australia New Zealand Clinical Trials Registry
ASR: adjusted standardized residual
EDE-Q: Eating Disorder Examination Questionnaire
EOI: Expression of Interest
IOI-S: InsideOut Institute Screener
NSW: New South Wales
REDCap: Research Electronic Data Capture

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The Finnegan Score for Neonatal Opioid Withdrawal Revisited With Routine Electronic Data: Retrospective Study

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Abstract

Background: The severity of neonatal abstinence syndrome (NAS) may be assessed with the Finnegan score (FS). Since the FS is laborious and subjective, alternative ways of assessment may improve quality of care.

Objective: In this pilot study, we examined associations between the FS and routine monitoring data obtained from the electronic health record system.

Methods: The study included 205 neonates with NAS after intrauterine (n=23) or postnatal opioid exposure (n=182). Routine monitoring data were analyzed at 60±10 minutes (t–1) and 120±10 minutes (t–2) before each FS assessment. Within each time period, the mean for each variable was calculated. Readings were also normalized to individual baseline data for each patient and parameter. Mixed effects models were used to assess the effect of different variables.

Results: Plots of vital parameters against the FS showed heavily scattered data. When controlling for several variables, the best-performing mixed effects model displayed significant effects of individual baseline-controlled mean heart rate (estimate 0.04, 95% CI 0.02 - 0.07) and arterial blood pressure (estimate 0.05, 95% CI 0.01 - 0.08) at t–1 with a goodness of fit (R^2_m) of 0.11.

Conclusions: Routine electronic data can be extracted and analyzed for their correlation with FS data. Mixed effects models show small but significant effects after normalizing vital parameters to individual baselines.

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KEYWORDS

data science application; neonatology; Finnegan score; neonatal opioid withdrawal syndrome; mixed models; neonate; neonatal; abstinence; opioid; withdrawal; substance abuse; postnatal; pediatrics; electronic health record; EHR; monitoring; health record; finnegan; neonatal abstinence syndrome; NAS; opioid withdrawal

Introduction

When exposure to opioids ends, neonates may develop withdrawal symptoms [1]. Neonatal abstinence syndrome (NAS), also referred to as *neonatal opioid withdrawal syndrome*, can be subdivided into primary NAS due to prenatal opioid abuse by (or treatment of) the mother, and iatrogenic NAS (iNAS) when neonates are treated with opioids. Primary NAS may develop in more than 90% of infants after intrauterine opiate exposure [2]. Occurrence and severity vary interindividually and are influenced by several factors, such as prematurity [3], breastfeeding [4], and multisubstance exposure, which results in more severe symptoms and worse outcomes than exclusive exposure to a single substance [5]. Though primary NAS is typically understood as abstinence from opioids, neonates can also develop withdrawal symptoms after exposure to other substances or medication such as tobacco [6], alcohol [7], cocaine [8], selective serotonin reuptake inhibitors and other antidepressants [9], benzodiazepines [10], and a combination of opioids and other substances [5].

Many neonatal intensive care units monitor withdrawal symptoms using the Neonatal Narcotic Abstinence Scoring System, also called the *Finnegan score* (FS), which is composed of 32 clinical signs, each scored between 0 and 5 (maximum score 46) [11]. The FS was originally designed to assess withdrawal in otherwise healthy-term infants from mothers abusing opioids [11,12]. Thus, the validity of the FS in other patients receiving neonatal intensive care is unclear, particularly in preterm or term neonates experiencing iNAS [11,12].

The implementation of electronic patient data management systems (PDMSs) alongside the availability of digital data on vital signs allows using data science algorithms to reevaluate clinical scoring systems and to facilitate clinical decision-making using decision support algorithms [13]. Having provided the first examples in adult medicine, these methods have shown promising results in neonatology. For instance, algorithmic analysis of heart rate characteristics is used to generate the Heart Rate Observation score—an estimate of the risk of developing sepsis [14]. Other approaches for early detection of sepsis use more variables and extensive machine learning algorithms but have not yet been validated in prospective settings [15]. Other studies have attempted to use data science algorithms to predict neonatal mortality [16]. Regarding opioid exposure, the PoPPI (Procedural Pain in Premature Infants) trial assessed the possibility of minimizing procedural pain in neonates receiving morphine treatment [17]. These data have allowed for the successful establishment of models predicting whether cardiorespiratory instability occurs after morphine administration and whether it requires intensified treatment [17,18].

Considering the subjectivity and the effort in generating an FS, the exploration of data-driven alternative ways of monitoring withdrawal symptoms appears necessary. In this pilot trial, we analyzed the association between electronic health data—mostly continuously and routinely monitored vital parameters—and the FS as a measure of the severity of NAS. Strong associations would allow an objective and less laborious NAS assessment based on routinely available data.

Methods

Ethical Considerations

The institutional review board of the Charité – Universitätsmedizin Berlin approved the study (EA2/104/21). Due to the retrospective nature of the study, the need for patient consent was waived.

Data Export and Inclusion and Exclusion Criteria

Continuously and routinely monitored vital parameters were extracted from the electronic health systems and harmonized for further analysis.

Data were exported for all patients admitted to the clinic between January 1, 2013, and February 1, 2022. The data set was then refined on the basis of the following inclusion criteria, and all calculations were later performed within the refined data set. To include all patients with continued clinical suspicions of withdrawal symptoms but to exclude those with one-time-only suspicions or accidental documentation, we performed the export by selecting patients with at least 3 documented FSs, since a pharmaceutical intervention was usually not initiated on the basis of a single scoring result. We cross-referenced this export selection with patients classified as having NAS in accordance with *ICD-10* (*International Statistical Classification of Diseases, Tenth Revision*) criteria for quality control purposes. We categorized patients into subgroups of primary NAS and iNAS based on opioid medication, history of surgery, and time after birth before documenting the first FS for each patient. Primary NAS was coded when at least 1 FS was documented before any opioid medication was administered, any surgery was performed, and the patient had not yet approached postpartum day 8. iNAS was coded when any opioid medication was administered before the patient's first FS regardless of postnatal age. Patients with documented FS who did not meet any of these criteria were excluded. To design a sensitivity analysis, the analytic code was also applied to total study population without exclusion due to unclear NAS classification.

Review of Hospital Data Structure

Each variable was checked for availability within the hospital information system (SAP/Cerner) as well as the PDMS (COPRA) used in the neonatal wards (levels 1 ‐ 3).

Medication Data

Medications were not named consistently; hence, their names had to be preprocessed manually. We exported all unique medication entries from the PDMS and categorized them manually. The complete list of medication categories is provided in Multimedia Appendix 1.

Variables

To evaluate patients' demographics, we recorded their sex, gestational age at birth, birth weight, mode of delivery, number of documented FSs, and whether a time frame for individual baseline calculation was available and, if so, whether data were available within this time frame for the abovementioned vital parameters (including heart rate, respiratory rate, peripheral oxygen saturation, and mean blood pressure).

We calculated means for all variables listed below within specified time periods (t–1 and t–2, see the *Time Periods* section): heart rate, respiratory rate, peripheral oxygen saturation, and blood pressure.

Additionally, we generated an individual baseline for each patient by calculating the mean for each variable in a period of up to 5 days before documenting the first FS, which we defined as the relevant beginning of withdrawal (Figure 1). When calculating the individual baseline, we excluded spacer periods immediately post partum to minimize effects from postnatal adaptation and those immediately before documenting the first FS to minimize the effects of early-onset withdrawal. We set this spacer period to 1 day for patients with primary NAS and 3 days for those with iNAS (Figure 2). The sensitivity analysis was carried out with both spacer periods for the whole collective. We introduced the difference between this individual baseline and the mean of the respective vital parameter within the specified period before documenting any FS as a new variable to use as an alternative to the mean of the vital parameters and henceforth referred to this variable as the "baseline-controlled mean" (Figures 1 and 2).

Figure 1. Schematic representation of the calculation of an individual baseline-controlled mean of a given vital parameter—heart rate. To reduce the scattering of data in (**A**), we calculated the mean of the vital parameter for each patient (denoted with a green triangle, a blue dot, and a gray square) during the individual baseline period (**B**). The definition of this period is illustrated in Figure 2. We then calculated the difference from the baseline for each vital parameter of each patient, as shown in (**C**). When plotting this difference (**D**), we obtained individual baseline-controlled means for vital parameters plotted on a scale around zero and with a more linear grouping of all measurements, irrespective of patient identity.

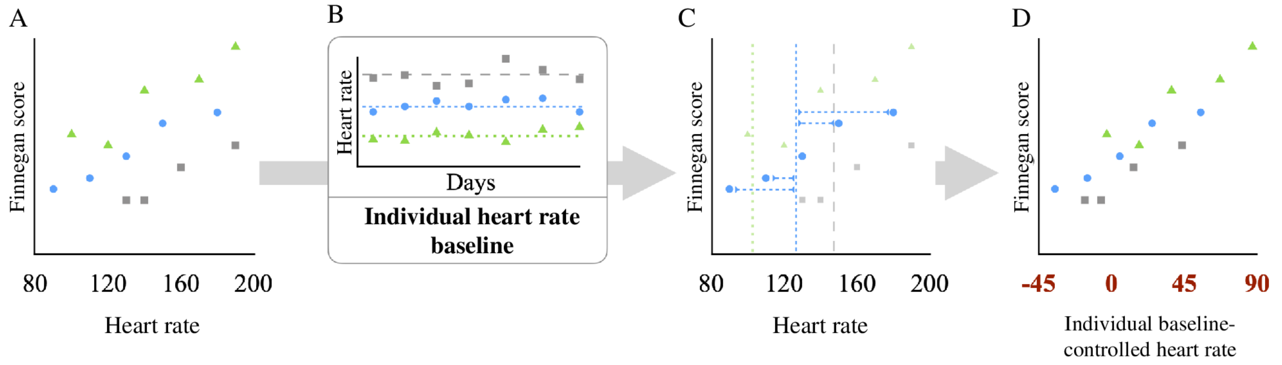
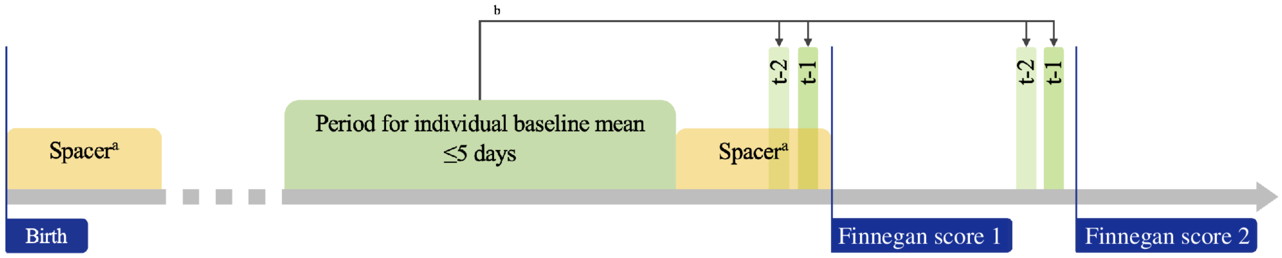


Figure 2. Time periods for the calculation of individual baselines (timeline not to scale). We defined a period to calculate an individual baseline for each patient of up to 5 consecutive days. After birth and before documenting the first Finnegan score, we introduced a spacer. [a]The spacer has a length of 1 day for patients with primary neonatal abstinence syndrome (NAS) and 3 days for those with iatrogenic NAS. [b]For all measurements within this period, we calculated a mean that is used to baseline-control measurements during every t–1 and t–2 for the respective patient; this baseline-control approach is illustrated in Figure 1.



Body temperature was assessed in variable patterns, and we calculated the mean and baseline-controlled mean body temperature within 1 day before documenting each FS and used these data for both time periods (t–1 and t–2).

Furthermore, we included the following variables. (1) The pharmacodynamics of buprenorphine—the first-line pharmacotherapy for NAS—is highly complex, and data on transferability to neonates are limited [19,20]. Hence, we did not attempt to estimate pharmacodynamics in neonates but considered the time between the last documented opioid medication and each FS instead. As these *hours since medication* can only be recorded for patients who have been administered any opioids before documenting the respective FS, either because of iNAS or because of treatment of any type of NAS, we used the date of birth as the date of the last opioid medication for infants with primary NAS if no opioid medication was documented more recently. (2) The last body weight measure before documenting each FS was considered as a percentage of the individual's birth weight. (3) The current gestational age at each FS documentation was recorded.

Time Periods

All graphs and models were created for 2 time periods. With the goal of exploring options for predicting withdrawal symptoms, we focused on time periods before each FS. The first time period, t–1, was set to 1 hour±10 minutes before each FS, resulting in a 20-minute period from 10 minutes before until 10 minutes after the time point of 1 hour prior of each FS documentation. The second time period was set in the same manner to 2 hours±10 minutes before the respective FS, resulting in an earlier time period, t–2. The time periods are visualized in Figure 2.

Data Analysis Software

Data analysis was carried out using RStudio (version 2022.07.1+554) and R (version 4.2.1; 2022-06-23 ucrt) [21,22] using the following packages and their dependencies in addition to the function included in R, RStudio, and the ::base-package R during data extraction and harmonization: cli [23], data.table [24], dplyr [25], lubridate [26], tibble [27], and tidyverse [28].

We used the consort package to generate Figure 3 [29]. Table 1 was created using the tableone package; significance was tested using chi-square tests for categorical variables, Wilcoxon tests for skewed variables and *t* tests for normally distributed metric variables [30]. Skewness was assessed using the summary-function from tableone in accordance with tableone documentation [30]. We generated graphs with ggplot2 [31] and fitted our mixed effects models using lme4 [32]. Goodness of fit parameters of the mixed effects models was calculated using MuMIn [33]. Table output from RStudio was facilitated using flextable [34]. All code is has been published previously [35].

Figure 3. Patient allocation and numbers. NAS: neonatal abstinence syndrome.

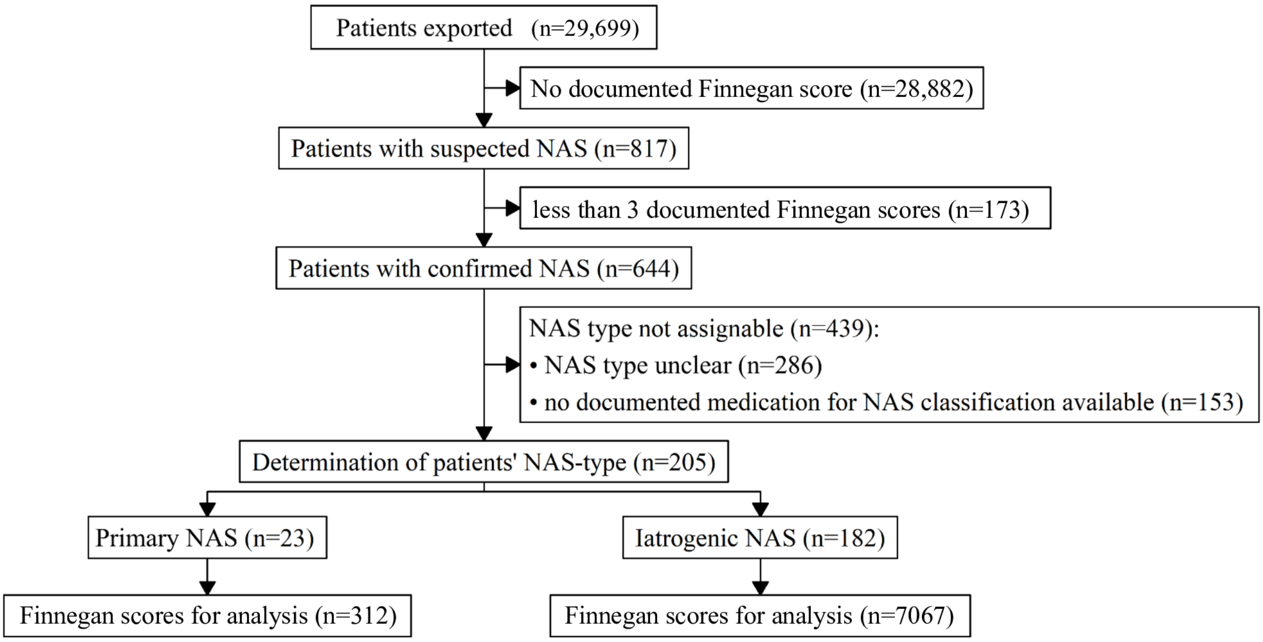


Table . Patient characteristics[a].

Characteristics	Total	Primary NAS[b]	Iatrogenic NAS	*P* value
Participants, n	205	23	182	N/A[c]
Sex, n (%)				>.99[d]
Female	72 (49.7)	8 (47.1)	64 (50.0)	
Male	73 (50.3)	9 (52.9)	64 (50.0)	
Median gestational age at birth in weeks (IQR)	37+1 (32+4 to 39+1)	38+4 (37+1.75 to 40+1.5)	37+0 (31+5 to 39+1)	.02[e]
Birth weight (g), median (IQR)	2663 (1758-3243)	3140 (2583-3366)	2585 (1695-3200)	.01[e]
Mode of delivery, n (%)				<.001[d]
Cesarean section	114 (55.6)	3 (13.0)	111 (61.0)	
Vaginal delivery	74 (36.1)	19 (82.6)	55 (30.2)	
Data not available	17 (8.3)	1 (4.3)	16 (8.8)	
Median number of documented Finnegan scores (IQR)	23 (10-47)	7 (5-14)	26 (12-50.75)	<.001[e]
Time frame for individual baseline, n (%)				.004[d]
Definable	172 (83.9)	14 (60.9)	158 (86.8)	
Not definable	33 (16.1)	9 (39.1)	24 (13.2)	
Individual baseline data for heart rate, n (%)				.005[d]
Available	166 (81.0)	14 (60.9)	152 (83.5)	
Not available[f]	6 (2.9)	0 (0)	6 (3.3)	
Individual baseline data for respiratory rate, n (%)				.005[d]
Available	164 (80.0)	14 (60.9)	150 (82.4)	
Not available[f]	8 (3.9)	0 (0)	8 (4.4)	
Individual baseline data for peripheral oxygen saturation, n (%)				.005[d]
Available	165 (80.5)	14 (60.9)	151 (83.0)	
Not available[f]	7 (3.4)	0 (0)	7 (3.8)	
Individual baseline data for mean blood pressure, n (%)				.004[d]
Available	162 (79.0)	14 (60.9)	148 (81.3)	
Not available[f]	10 (4.9)	0 (0)	10 (5.5)	

[a] All values rounded to integers except for pH.

[b] NAS: neonatal abstinence syndrome.

[c] N/A: not applicable.

[d] Categorial variables were assessed using the chi-square-test.

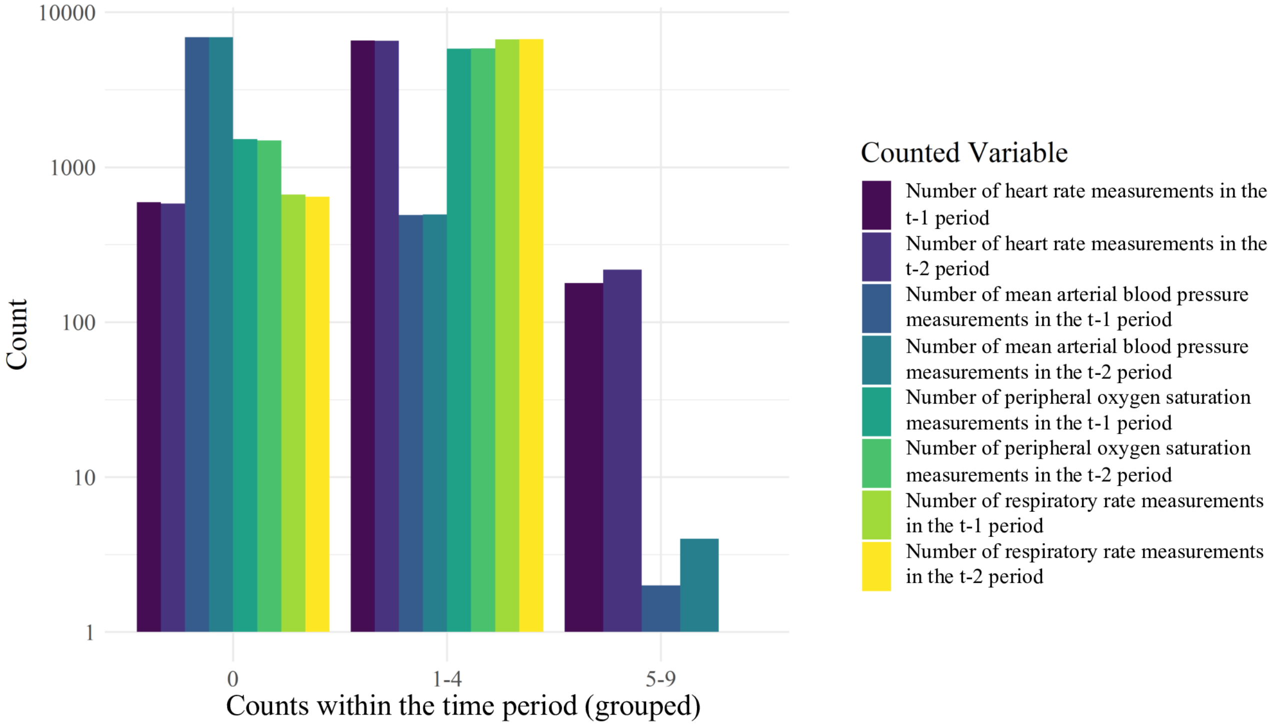
[e] Metric variables were assessed using the Wilcoxon–Mann-Whitney *U* test.

[f] Number of patients, for which a time interval for individual baseline calculation was definable but no data for the respective vital parameters were available within this interval.

Graphs

We visualized data availability in a clustered bar plot, reporting the number of data points per variable available for each patient within each period (Figure 4). By computing 2 statistical measures for each of the 4 vital parameter variables in each of the 2 time periods, we obtained a total of 16 graphs (see Multimedia Appendix 1). To visualize data distribution, we generated heat map plots. The color of each tile is set by the number of data points weighted by the number of measurements generating the data point so that data points based on more observations contribute more to the color scale. Hence, 2 data points based on 1 observation each and 1 data point based on 2 observations both result in the same color of the respective tile.

Figure 4. Distribution of data frequency within the time periods per variable. The y-axis is scaled logarithmically; the x-axis shows the groups of frequencies, starting with 0, corresponding to Finnegan scores for which there are no data points for the respective variables within the respective time period. All variables show counts within clusters 0 and 1 - 4. Within clusters 5 - 9, only counts for heart rate and blood pressure are available in both time periods.



Mixed Effects Models

We developed several mixed effects models. The models were fitted to descriptively analyze the relationship between the FS and vital parameters as well as NAS type, the time elapsed since the last opioid medication, gestational age, and the percentage of birth weight reached by the most recent body weight measurement. We controlled for interindividual differences by including the patient identifier as the random effect. We generally selected one set of vital parameter variables mixing neither means or individual baseline-controlled means nor the time periods of different vital parameters within a single mixed effects model. The models were not fitted to predict the FS; therefore, neither cross-validation nor bootstrapping were applicable. The regression equation for the full model was as follows, where “mean” could be substituted with “baseline-controlled mean” and “t–1” with “t–2” throughout the equation:

> *Value of Finnegan-Score~Intercept + Mean heart rate in the t–1 period + Mean peripheral oxygen saturation in the t–1 period + Mean respiratory rate in the t–1 period + Mean of the mean arterial blood pressure in the t–1 period + Mean body temperature within 1 day before documenting the FS + Hours between the last medication as specified and documentation of the FS + Percentage of birth weight + Gestational age + NAS type + (1 / patient identifier)*

We evaluated the goodness of fit again for models with a simplified set of variables, excluding variables with small effects (estimates of <0.05) and high degree of missingness (>30% missing values). Goodness of fit was determined using the Akaike information criteria (AIC), Bayesian information criteria (BIC), and R^2_m and R^2_c and is listed in Multimedia Appendix 1.

For the sensitivity analysis, we excluded the NAS-type variable from the full model. The model’s results and goodness-of-fit data from the sensitivity analysis can be found in Multimedia Appendix 2.

Results

Patient Characteristics and Data Composition

Patient demographic data are provided in Table 1, and patient allocation is demonstrated in Figure 3. Out of 205 neonates with NAS, 78 (38%) had been *ICD-10*–coded. Abstinence after intrauterine exposure (P96.1) was coded in 17.4% (n=4) of patients who were classified as having primary NAS and 5.5% (n=10) of patients who were classified as having iNAS. Abstinence after therapeutic exposition (P96.2) was coded in 21.7% (n=5) and 34.6% (n=63) of the respective patient groups. We obtained 7050 FS data points and calculated the baseline-controlled mean for up to 166 (81%) infants (Table 1). Two reasons prevented us from doing so in the other cases: no definable time period (as illustrated in Figure 2) or no data points within the time period to calculate upon.

Visual Interpretation

As shown in Figure 4, heart rate measurements showed the highest data density and mean blood pressure measurements showed the lowest. Heart rate measurements were the only variable for which at least 5 data points within a time period were commonly available, the only other variable being mean arterial blood pressure in very rare instances.

The plots show a widely distributed pattern for mean and baseline-controlled mean heart rate (Figure 5) and mean arterial blood pressure (Figure 6), each plotted against the FS. The tile color and different ranges shown in the color legends illustrate differences in the density of data available for heart rate and mean arterial blood pressure measurements; this corresponds to the data density described above and is shown in Figure 4.

While there was no direct relationship between the FS and the respective parameters visible, the graphs for the baseline-controlled version of each parameter showed a narrower spectrum on the x-axis. In particular, the baseline-controlled blood pressure shows a discernible trend of greater-than-zero values, indicating a rise in blood pressure in neonates in comparison with that before withdrawal assessment. However, this rise in baseline-controlled blood pressure does not clearly increase with an increase in the FS.

Figure 5. Heat maps of mean heart rate and baseline-controlled mean difference in heart rate during the t–1 time period (60±10 minutes before documenting the Finnegan score [FS]), values of children with iatrogenic neonatal abstinence syndrome. Left: the x-axis shows the mean heart rate in beats per minute (bpm); right: the x-axis shows the baseline-controlled mean difference in heart rate in bpm. Each tile has a width of 2 bpm and a height of 1 FS point; the opacity is generated from the amount of data points within the area of the respective tile weighted by the number of heart rate observations that each of those data points is calculated from.

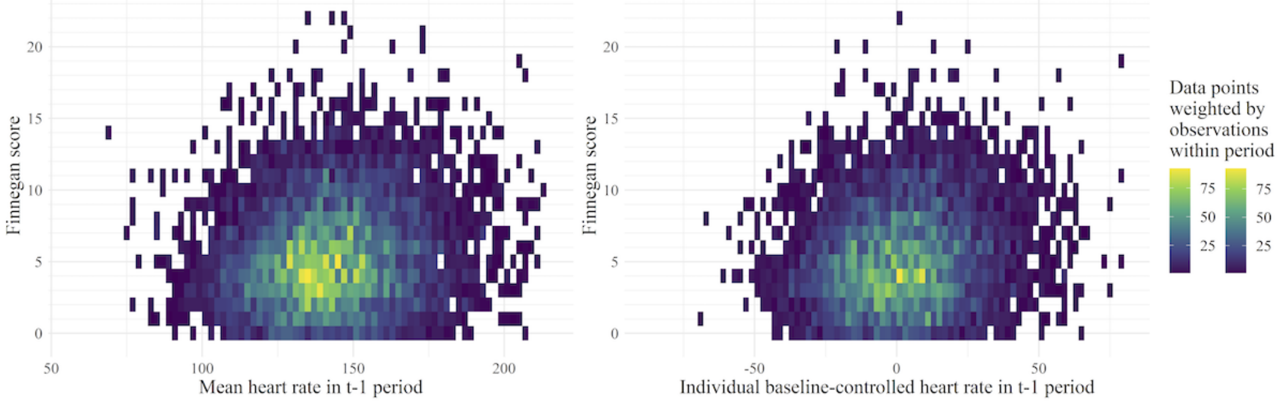
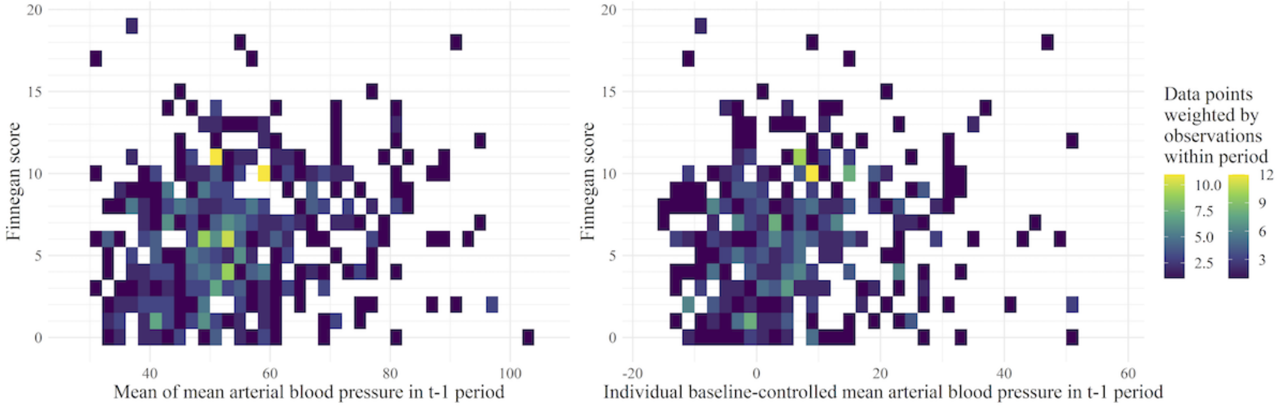


Figure 6. Heat maps of mean and baseline-controlled mean arterial blood pressure during the t–1 period (60±10 minutes before documenting the Finnegan score [FS]) for children with iatrogenic neonatal abstinence syndrome. Left: the x-axis shows the mean arterial blood pressure in mm Hg; right: the x-axis shows the baseline-controlled mean arterial blood pressure in mm Hg. Each tile has a width of 2 mm Hg and a height of 1 FS point; the opacity is generated from the amount of data points within the area of the respective tile weighted by the number of mean arterial blood pressure observations that each of those data points is calculated from.



Regression Analysis of Vital Parameters in Fitted Models

Estimates for vital parameters stayed either positive or negative across all fitted models and varied only in the corresponding SEs, CIs, and *P* values. Among all models, the model containing all variables, using the later time period of t–1 and the baseline-controlled mean as the statistical measure, yielded the highest R^2_c and R^2_m and second-lowest AIC and BIC (Table 2). This model was fitted on 357 observations obtained from 84 infants.

Table . Results of the mixed model using baseline-controlled means as statistical measures, t–1 as time period, and a complete set of variables (R^2_m=0.11; R^2_c=0.43; Akaike information criterion=1999.36; Bayesian information criterion=2045.89; 84 patients; 357 Finnegan scores).

Parameters	Estimate	SE	95% CI	*P* value
(Intercept)	9.31	2.88	3.51 to 14.92	.002
Individual baseline-controlled heart rate in the t–1 period	0.04	0.01	0.02 to 0.07	<.001
Individual baseline-controlled peripheral oxygen saturation in the t–1 period	–0.09	0.05	–0.19 to 0.01	.09
Individual baseline-controlled respiratory rate in the t–1 period	0.00	0.01	–0.02 to 0.03	.84
Individual baseline-controlled mean arterial blood pressure in the t–1 period	0.05	0.02	0.01 to 0.08	.005
Individual baseline-controlled body temperature within 1 day before documenting the Finnegan score	0.33	0.49	–0.63 to 1.28	.51
Hours between last medication as specified and Finnegan score	0.00	0.00	0.00 to 0.00	.46
Percentage of birth weight	0.00	0.00	–0.01 to 0.00	.19
Gestational age	–0.06	0.06	–0.18, to 0.06	.35
Iatrogenic (vs primary) neonatal abstinence syndrome	–0.27	1.64	–3.41 to 2.92	.87

An increasing individual baseline-controlled heart rate (estimate 0.04, 95% CI 0.02 to 0.07) and an increasing arterial blood pressure (estimate 0.05, 95% CI 0.01-0.08) correlated significantly with an increased FS.

Furthermore, a decreasing individual baseline-controlled peripheral oxygen saturation (estimate –0.09, 95% CI −0.19 to 0.01), decreasing gestational age (estimate −0.06, 95% CI −0.18 to 0.06) as well as increasing individual baseline-controlled respiratory rate (estimate 0.00, 95% CI −0.02 to 0.03), increasing hours since the last medication (estimate 0.00, 95% CI 0.00-0.00), increasing baseline-controlled body temperature (estimate 0.33, 95% CI −0.63 to 1.28), increasing percentage of birth weight (estimate 0.00, 95% CI −0.01 to 0.00), and the status of iatrogenic (vs primary) NAS (estimate −0.27, 95% CI −3.41 to 2.92) were associated with an increasing FS. However, while the inclusion of these variables improved the goodness of fit of the model, the estimates showed SEs and 95% CIs too large to be considered significant.

The irregularity and scarcity of blood pressure measurements in neonatal standard care resulted in missing values for the individual baseline-controlled mean arterial blood pressure and thereby reduced the amount of complete data on which the model could be fitted. Due to the large number of missing values (mean blood pressure unavailable for >90% of FS), imputation was not applicable. When blood pressure was not included—thereby reducing the complexity of the model but increasing the number of complete observations—all measures for goodness of fit decreased (worst model with blood pressure [R^2_m=0.08, AIC=2345]; best model without blood pressure [R^2_m=0.07, AIC=25,992]). On excluding the NAS type from our sensitivity analysis, these results were confirmed. Including previously excluded patients and using spacer periods of the same length for all patients during baseline calculation resulted in similar results (Multimedia Appendix 2).

The abovementioned estimated effects are small and may seem clinically irrelevant. However, due to the nomenclature of mixed effects models, the estimates refer to 1-unit changes of the respective variable. This implies that a heart rate increase of 10 beats per minute from the individual baseline would coincide with an FS increase of 0.4 and a 10-mm Hg increase (increase of 0.6) in the mean arterial blood pressure assuming that all other values remained constant.

Discussion

This pilot study shows a measurable association between withdrawal assessment based on FS and heart rate and blood pressure, which underlies heavy scatter and is only revealed when controlling for several other influencing variables in regression analysis. The unfiltered correlation between FS values and vital parameters was weak, and the analysis revealed heavily scattered data. Thus, we fitted mixed effects models that corrected for various variables. These models supported the hypothesis that opioid withdrawal measured by FS is associated with vital parameter readings if big data sets are considered. Multiple analyses revealed robust estimates with a small magnitude for the association of increasing FS with an increased heart rate and arterial blood pressure (Table 2) but not with the respiratory rate. However, even in the model exhibiting the best goodness of fit (R^2_m=0.11; Table 2), this association was found to be weak, likely because of heavily scattered input data. Notably, our analysis only revealed an association with the FS, which, while being the currently and widely used assessment tool for withdrawal, can only be understood as a resemblance of the latter, not withdrawal itself.

The use of electronic monitoring data and health records may become an attractive source for clinical decision-making (eg, for identifying the risk of sepsis) or multivariable predictive models (eg, for neurodevelopmental impairment) in neonatology [36-39]. While more conservative models perform similarly on the task of predicting sepsis in neonates, advanced machine learning techniques exhibit better performance in case of heterogenous big data pipelines [40].

Conceptually, it is appealing to develop such a big data–based prediction strategy, particularly if it can be validated by using a clinical scoring system. Since opioid withdrawal symptoms considered in the FS rely on the accuracy of reporting, detecting, and describing symptoms, adding monitoring or laboratory data might improve subsequent clinical decisions. However, items in the FS may be too complex per se for fitting common models of analyzing big data from electronic health records. In this regard, the density of electronic monitoring data, such as arterial blood pressure, was surprisingly low in our cohort. Other easily accessible data such as intrauterine growth restriction and maternal tobacco or multisubstance abuse also failed to sufficiently predict NAS severity in previous studies [41]. Success in using continuously monitored electronic data for decision-making in care of neonatal opioid withdrawal, however, may critically depend on the granularity of these data. At our institution, the heart rate may have been recorded with very low data granularity, for example (Figure 4), as these readings were previously summarized to means for storage capacity reasons. This is not unusual as hospital systems regularly do not save the highest available data frequency to reduce the required data storage space, all the while limiting its use for research at later stages [40]. Thus, we applied specific periods (t–1 and t–2; Figures 1 and 2) and identified an individual baseline of vital parameters to compile data with varying temporal resolution. Of note, temporal cross-correlation of vital parameters might have resulted in an improvement in predictive values on the severity of FS, as previously shown in other cohorts of preterm infants with sepsis, necrotizing enterocolitis, or retinopathy [38,42,43].

To date, our data did not offer sufficient temporal resolution to cross-correlate vital parameter data strings. However, based on the most the recent study by Poppe et al [38], we suggest that continuously logged electronic data sampled preferentially at 1 Hz should be obtained. For model development, such high-frequency data may also be obtained during prospective trials. For model validation, real-world data are required at a later stage. High temporal resolution also allows models to reach high levels of goodness of fit and significance with the use of relatively basic sets of variables, as demonstrated for both instability and requirement of treatment after morphine analgesia based on documented episodes of apnea, profound oxygen desaturation, the average heart and respiratory rates, and the postmenstrual age [18]. While our models based on our limited temporal resolution data did not show significant effects of changes in the respiratory rate, the addition of respiratory signals to heart rate characteristics also improved the performance of sepsis prediction models. The resulting model features an especially strong negative predictive value, and we suggest validating this model with larger cohorts [44]. Further research is necessary to not only validate the effects we observed in other cohorts but also analyze associations between high-frequency data and withdrawal, potentially using measures obtainable within these data, such as heart rate characteristics and variations. Most recently, our institution has begun to archive vital parameter data in real time and with high resolution, enabling us to pursue this path.

Our data do not allow considering the different (substance or dose) pharmacologic interventions for neonatal opioid withdrawal and variations in the half-life of such substances when computing the time elapsed since the last administration and the next FS. The complex metabolism of buprenorphine in neonates [19,20] may also affect the analytical mixed models' performance and be relevant for strategies using artificial intelligence for future clinical decision-making.

Despite these limitations, the discrepancy between the FS and data from electronic monitoring may also reflect an inherent weakness of the clinical score. Since the FS has been reported to be subjective, resulting in low interrater reliability, our study indirectly supports the "Eat, Sleep, Console" approach for neonatal opioid withdrawal as successfully shown in the recent cluster-randomized controlled trial of the ACT NOW Collaborative [45].

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Conflicts of Interest

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Multimedia Appendix 1

Extented set of figures on vital parameters and tables showing mixed effects model results.

[DOCX File, 2106 KB - pediatrics_v7i1e50575_app1.docx]

Multimedia Appendix 2
Sensitivity analysis.
[DOCX File, 2352 KB - pediatrics_v7i1e50575_app2.docx]

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Abbreviations

AIC: Akaike information criterion
BIC: Bayesian information criterion
FS: Finnegan score
***ICD-10*:** *International Statistical Classification of Diseases, Tenth Revision*
iNAS: iatrogenic neonatal abstinence syndrome
NAS: neonatal abstinence syndrome
PDMS: patient data management system

PoPPI: Procedural Pain in Premature Infants

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Original Paper

Provincial Maternal and Child Information System in Inner Mongolia, China: Descriptive Implementation Study

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Abstract

Background: After the implementation of 2- and 3-child policies, the rising proportion of high-age and high-risk pregnancies put enormous pressure on maternal and child health (MCH) services for China. This populous nation with an increasing population flow imperatively required the support of large-scale information systems for management. Municipal MCH information systems were commonly applied in developed cities of eastern provinces in China. However, implementation of provincial MCH information systems in relatively low-income areas is lacking. In 2020, the implementation of a regional maternal and child information system (RMCIS) in Inner Mongolia filled this gap.

Objective: This paper aimed to demonstrate the construction process and evaluate the implementation effect of an RMCIS in improving the regional MCH in Inner Mongolia.

Methods: We conducted a descriptive study for the implementation of an RMCIS in Inner Mongolia. Based on the role analysis and information reporting process, the system architecture design had 10 modules, supporting basic health care services, special case management, health support, and administration and supervision. Five-color management was applied for pregnancy risk stratification. We collected data on the construction cost, key characteristics of patients, and use count of the main services from January 1, 2020, to October 31, 2022, in Inner Mongolia. Descriptive analysis was used to demonstrate the implementation effects of the RMCIS.

Results: The construction and implementation of the RMCIS cost CNY 8 million (US $1.1 million), with a duration of 13 months. Between 2020 and 2022, the system recorded 221,772 registered pregnant women, with a 44.75% early pregnancy registry rate and 147,264 newborns, covering 278 hospitals and 225 community health care centers in 12 cities. Five-color management of high-risk pregnancies resulted in 76,975 (45.45%) pregnancies stratified as yellow (general risk), 36,627 (21.63%) as orange (relatively high risk), 156 (0.09%) as red (high risk), and 3888 (2.30%) as purple (infectious disease). A scarred uterus (n=28,159, 36.58%), BMI≥28 (n=14,164, 38.67%), aggressive placenta praevia (n=32, 20.51%), and viral hepatitis (n=1787, 45.96%) were the top factors of high-risk pregnancies (yellow, orange, red, and purple). In addition, 132,079 pregnancies, including 65,018 (49.23%) high-risk pregnancies, were registered in 2022 compared to 32,466 pregnancies, including 21,849 (67.30%) high-risk pregnancies, registered in 2020.

Conclusions: The implementation of an RMCIS in Inner Mongolia achieved the provincial MCH data interconnection for basic services and obtained both social and economic benefits, which could provide valuable experience to medical administration departments, practitioners, and medical informatics constructors worldwide.

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KEYWORDS

information system; maternal and child health care; system construction; system implementation; regional health; Inner Mongolia Autonomous Region

Introduction

In the Sustainable Development Goals issued by the World Health Organization (WHO), the most concerning targets related to good health and well-being were a reduction in the maternal mortality rate (MMR), neonatal mortality rate (NMR), and under-5 mortality rate (UMR), with the purpose of maternal and child health (MCH) improvement [1]. MCH and related measures, such as family planning and immunization, comprise one of the foundation stones for public health [2].

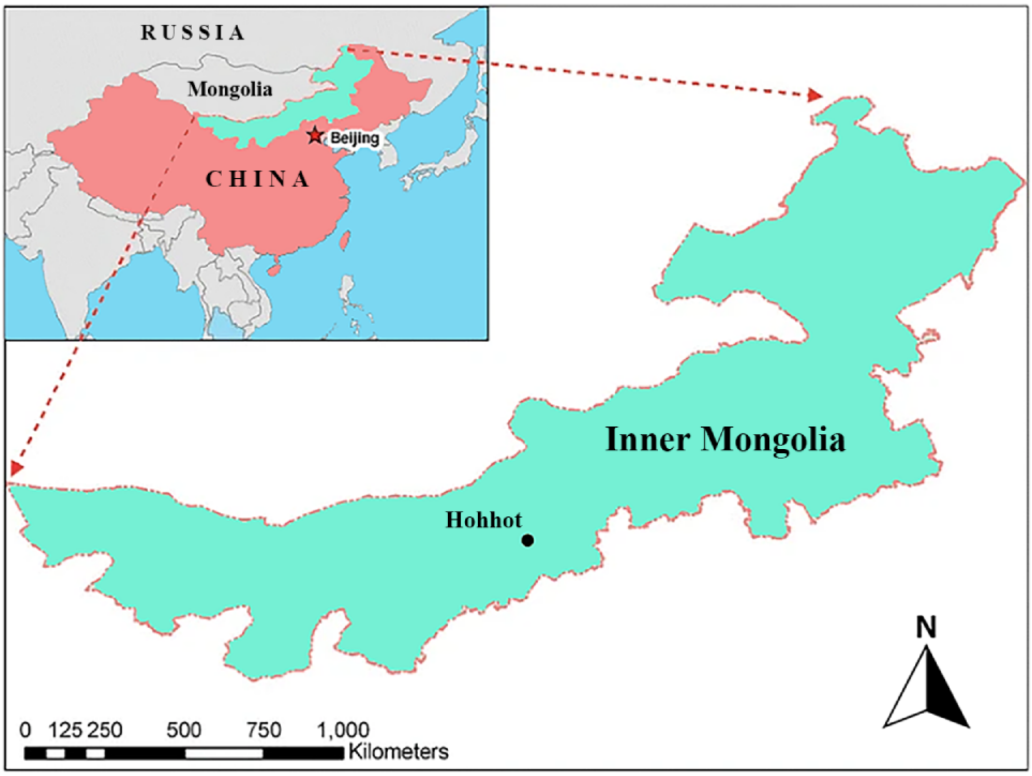
China has emphasized MCH as an essential component of China's health care system [3]. In October 2016, the Healthy China Action Plan (2019-2030) set clear requirements that the MMR and the NMR should be reduced to 12/100,000 and 5/1000 by 2030 [4]. In the past few years, the MMR of China has dropped from 23.2/100,000 in 2013 to 15.7/100,000 in 2022 [5,6]. After the implementation of the 2-child policy in 2016 [7] and the 3-child policy in 2021 [8], multiparous births exceeded primiparous births nationwide [9]. The rising proportion of high-age pregnancies (maternal age ≥35 years) resulted in a significant increase in pregnancy risks [9], putting enormous pressure on MCH services in China, with over 10 million newborns every year [6].

With the rapid development of medical informatization [10], the information construction for MCH has been a prominent development trend. Thanks to the similar gestation cycle and production inspection process, data types of MCH records are homogenous, which creates a positive precondition for the construction of a maternal and child information system (MCIS). In such cases, localized MCH informatization was launched worldwide. As early as in 1984, the Maternal and Child Health Information Network (MATCH) [11] was created to serve as a pilot project to manage data related to prenatal, child health, family planning, and genetic services in clinics in the state of Ohio in the United States. The South Western Sydney Area Health Service launched the Mother and Infant Network (MINET) in 1997 [12] in order to develop an integrated clinical data network to support a continuum of MCH care, including in-patient, ambulatory, and community-based services. However, all these systems were designed to be used only in a few clinics with limited features and served as a simple tool to record in-diagnosis information, leading to a relatively small application scope.

Given the disparity in economy and medical resources [13], China imperatively requires practical tools to integrate regional medical resources for MCH improvement, especially in low-income areas [14,15]. The increasing population flow with economic migration also demands higher-level resident information sharing in a wider scope [16]. However, although most medical institutions have already set up internal business systems, such as the hospital information system (HIS), the laboratory information system (LIS), and the imaging system, data noninteroperability has become a general problem [17], which poses difficulties for the construction of MCISs and the realization of full coverage of MCH services. In China, the initial attemps for MCISs started at the beginning of 21st century. The first version of the regional maternal and child information system (RMCIS) was implemented in the Xiamen Maternal and Child Health Hospital in 2003. In Shanghai, districts, such as Changning District in 2007 and Songjiang District in 2013, set up their own MCISs. Beijing established a citywide MCIS and a big data platform for MCH information in 2017. Prior interface and data standards for core functions were considered as common solutions to address the issues of data noninteroperability and ensure the realization of basic services. With the increasing requirements for geographical coverage, eastern provinces with high-income economies, such as Guangdong and Guangxi, took the lead in the construction of provincial MCISs. Conversly, due to the relatively poor economic development [18], implementation of provincial MCISs in western provinces is lacking. Challenges are significant because the relatively poor conditions are characterized by a weak economy, inconvenient transportation, a sparse population, and even insufficient medical resources, especially in rural and remote areas [19]. To address the imbalance issue and improve regional MCH services, Inner Mongolia, a western province in China, implemented a provincial RMCIS in 2020.

The Inner Mongolia Autonomous Region (hereafter referred to as Inner Mongolia) is an autonomous region of minorities located in north China, with 9 cities and 3 leagues. It covers 1.18 million square kilometers, with 12% of China's total land area and 24.05 million recorded residents (Figure 1) [20]. Due to the influence of the geographical location, a highly variable climate, and historical and cultural reasons, regional development disparity exists and the average economic development is behind that of eastern coastal regions in the country [21]. In 2021 and 2022, the gross regional product of Inner Mongolia ranked 21st among 34 provinces across the country [22]. This vast territory with a sparse population had a high demand for health service improvement, given the high turnover rate of medical workers in remote places and the limited access to tertiary hospitals for the residents. In such cases, a dense distribution of community health care centers is necessary for universal coverage health, which is the primary aim of the right care [23].

Figure 1. Geographical location map of Inner Mongolia (adapted from Xu et al [21], which is published under Creative Commons Attribution 4.0 International License [24]).



In recent years, Inner Mongolia has vigorously improved its MCH, focusing on the core task of prioritizing children and ensuring the safety of mothers. Before the implementation of the provincial RMCIS in 2020, two allied cities in Inner Mongolia, Wuhai in 2014 and Hohhot in 2017, constructed municipal MCISs for the purpose of MCH service management and data report. MCH outcomes were promoted, with the MMR decreasing from 20.64 to 9.92 for every 100,000 pregnant women and the NMR decreasing from 8.45 to 2.2 for every 1000 pregnant women from 2012 to 2021 [25]. During the 13th 5-year period (2016-2020), the MCH service capacity was also greatly enhanced. The rate of hospitalized deliveries for pregnant women continuously exceeded 99%, the systematic management rate of pregnancies rose from 93.77% to 94.68%, the systematic management rate of children under age 3 years rose from 92.82% to 94.72%, and the rate of screening for women's diseases rose from 68.84% to 82.73% [26]. Three-level preventive measures against birth defects were implemented, covering urban and rural residents. The maternal prenatal screening rate rose from 49.31% to 88.90%, the newborn disease screening rate rose from 65.04% to 96.86%, and the newborn hearing screening rate rose from 79.96% to 96.23% [26]. The medical service network was extended, maintaining 24,951 medical institutions in total, including 806 (3.23%) hospitals, 1251 (5.01%) community health care centers, 114 (0.46%) MCH hospitals, 1301 (5.21%) MCH and family planning service stations (township health centers), 13,000 (52.1%) village health offices, 15 (0.06%) maternity hospitals, and 2 (0.01%) children's hospitals [26]. In the 14th 5-year plan, Maternal and Child Health Care Development Plan for Inner Mongolia (2021-2025) [26], with the assistance of the RMCIS, a 5-level MCH service network is expected to cover the entire autonomous region, allied cities, flag counties (cities, districts), soum townships (streets), and gacha villages (communities).

In response to the increasing demand for large-scale service management and data report, the RMCIS would tremendously improve regional MCH with data interconnection. The implementation experience of the RMCIS in Inner Mongolia was a representative case in China, and even worldwide, which filled the gap of provincial MCISs in relatively low-income areas. This paper aimed to describe the construction process and evaluate the implementation effects of the RMCIS in improving provincial MCH in Inner Mongolia, which might provide helpful experience for the construction of RMCISs in other areas.

Methods

Role Analysis

The setup of an RMCIS covers extensive MCH services provided in all MCH service institutions. The regional MCH service network usually consists of community health care centers (stations), township health centers, village health clinics (rooms), MCH hospitals, midwifery institutions, child care institutions, and hospitals. In fact, the medical institutions also have the responsibility for other non-MCH–related services, but the design of the RMCIS only focused on MCH services. The collected MCH data are reported to health administration departments. Due to the complex relationships between MCH services and institutions, service role analysis was crucial at the initial stage of establishment.

According to the National Health Commission (NHC) [27], medical institutions can play 7 specific roles in the regional health care system. Due to the particularities of medical institutions' functional settings, 13 types of institutions were involved in MCH information interworking. The features included in each module for different institutions were clearly set. Furthermore, specific authorizations of different institutions were required for the privacy protection of public health and patients. The role analysis of the MCH service and medical institutions was presupposed in the Technical Program for Construction of Regional Maternal and Child Health Information System (Table 1).

Table 1. Role analysis of participating entities and MCH[a] services.

Institution	Pregnancy registry	Child care	Maternal care	Disease control	Disease management	Medical service	Administrative management
Community health care center	X[b]	X	X	X	X	X	—[c]
Health station	X	X	X	X	X	X	—
Clinic	—	—	—	X	X	X	—
Hospital	—	X	X	X	—	X	—
CDC[d]	—	—	—	X	X	—	—
MCH hospital	—	X	X	X		X	—
Emergency center	—	—	—	—	—	X	—
Blood center	—	—	—	—	—	X	—
Health education institution	—	—	—	—	X	—	—
Health administrative department	—	—	—	—	—	—	X
Health surveillance agency	—	—	—	—	—	—	X
FDA[e]	—	—	—	—	—	—	X

[a] MCH: maternal and child health.

[b] X: available.

[c] Not available.

[d] CDC: Centers for Disease Control and Prevention.

[e] FDA: Food and drug administration.

MCH service roles are classified into basic MCH services and administrative management. Basic health care services include most of the tabulated features and thus relate to the majority of medical institutions. Especially, community health care centers in the communities and health stations in the township take the responsibility of all basic services, which are the cornerstones for the hierarchical diagnosis and treatment system implemented in the country. The RMCIS integrates regional MCH resources and provides intelligent and intuitive tools for health administration departments, medical institutions, and patients. The RMCIS covers medical institutions from community health care centers to township hospitals to municipal hospitals and provides functions including high-risk intelligent assessment, automatic identification of high-risk children, self-collection of outpatient physical signs, and performance appraisal.

Business Architecture Design

The RMCIS renders continuous services for the entire MCH process. Health care service management is a closed-loop system, which means all actions and records from prediagnosis to in-diagnosis to postevent are traceable, ensuring system-wise efficiency, security, and quality.

A standard pregnancy care process protocol was set up by the NHC, according to the Pregnancy and Childbirth Health Care Work Administrative Regulation and the Pregnancy and Childbirth Health Care Work Principles [28] of 2011. To protect pregnant women's rights stipulated in the Maternal and Child Health Law of the People's Republic of China [29], the whole process of pregnancy and childbirth care was divided into 4 consecutive steps: preconception care, antenatal care, intrapartum care, and postnatal follow-up.

Preconception care mainly refers to a series of health services for a couple preparing for pregnancy, including health education and consultation, preconception medical examinations, health status assessment, and guidance.

Antenatal care is launched between the conception confirmation and the delivery, referring to health education and consultation, antenatal medical examinations, general examinations, obstetric examinations, and ancillary examinations (ie, basic examinations and recommended examinations). The regulation requires that every pregnant woman receive at least 5 antenatal visits: 1 first visit and at least 4 revisits. If conception is confirmed using ultrasonography, the pregnant woman is registered and managed in the system and receives a copy of the *Maternal and Child Health Handbook* (MCHH) developed by the Japan International Cooperation Agency originally in 1948 [30].

The frequencies of antenatal visits differ in every trimester. During the first trimester (ie, before the 13th gestational week) and the second trimester (ie, from the 13th to the 27th gestational week), pregnant women only receive antenatal care every 4 weeks, while in the third trimester (ie, after the 28th gestational week), the frequency reduces to 1 or 2 weeks. Each pregnant woman undergoes necessary basic and optionally recommended examinations, depending on her specific pregnancy conditions during antenatal care.

Five-color management for pregnancy risks was proposed by the Department of Maternal and Child Health of the NHC [31]. Pregnant women are classified into 5 levels of pregnancy risk using colors: green (low risk), yellow (general risk), orange (relatively high risk), red (high risk), and purple (infectious disease), as shown in Table 2. Pregnant women without risks are recommended to get registered and obtain a copy of the MCHH for recording in community health care centers in the first trimester, which is considered an early filing rate and is used during the performance appraisal of those centers. After the 21st gestational week of pregnancy, women who have never completed any maternity checkups in community health care centers should get registered in hospitals to undergo a proper medical examination. However, if a woman's pregnancy risk is high (ie, yellow, orange, red, or purple), arrangements will be made in a tertiary hospital even before the 21st gestational week. Regarding delivery, pregnant women are suggested to make an appointment for a bed in the first trimester (before the 14th gestational week) in a community health care center, but only hospitals are qualified to help them give birth.

Table 2. Risk levels and types in 5-color pregnancy risk management.

Risk color	Risk level	Risk types
Green	Low risk	No pregnancy complications
Yellow	General risk	Age≥35 or ≤18 years, genital malformation, pelvic stenosis, etc
Orange	Relatively high risk	Age≥40 years, severe preeclampsia, severe anemia, etc
Red	High risk	Dangerous placenta previa, placental abruption, severe anemia, etc
Purple	Infectious disease	Viral hepatitis, syphilis, AIDS, etc

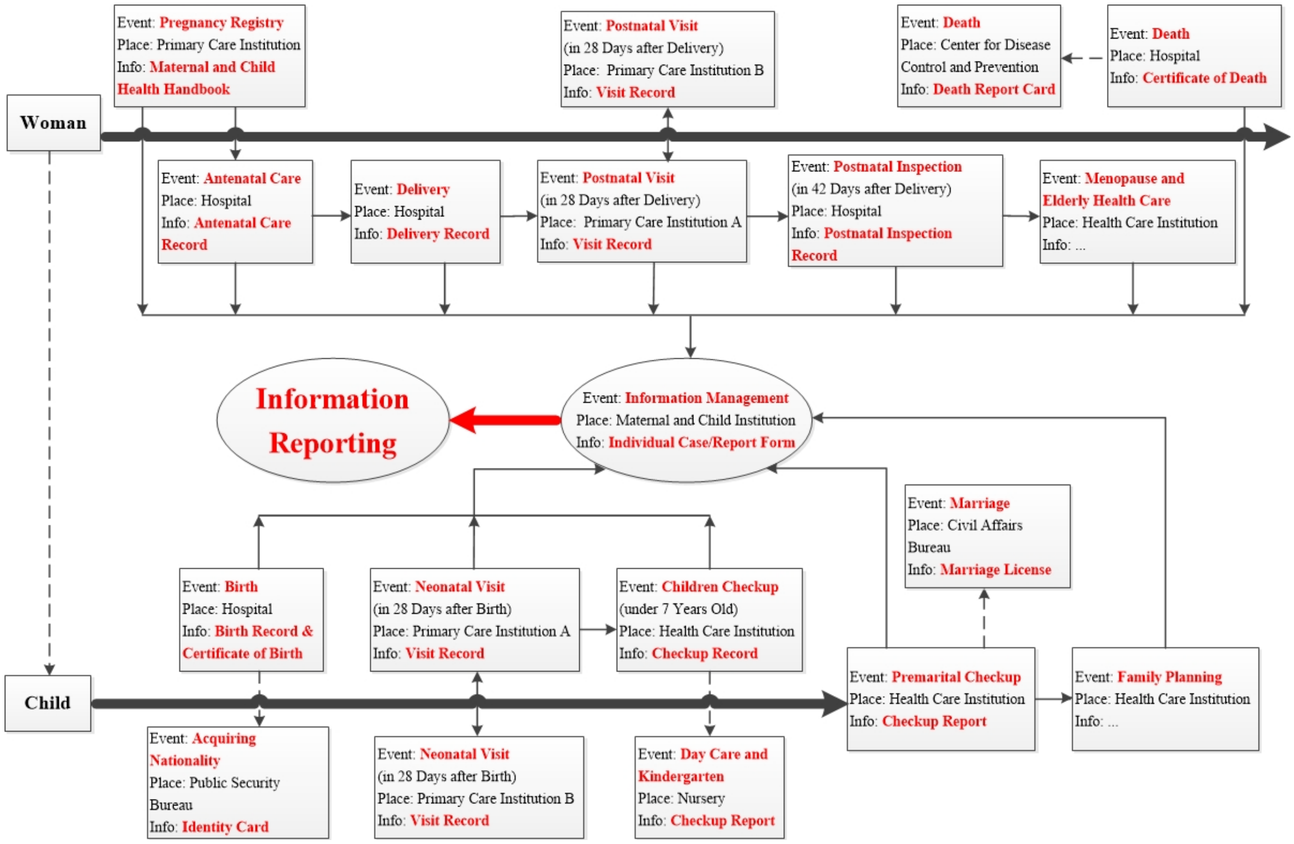
Intrapartum care refers to a process of comprehensive and dynamic assessment of maternal health, monitoring of mother and fetus, and prevention and treatment of complications during labor and delivery.

After delivery, the postnatal follow-up includes health care during hospitalization, postnatal visits for the mother and the newborn, and postnatal checks. Primary care workers offer 2 visits, one within 3-7 days and the other within 28 days after delivery. The postnatal check for mothers should be performed in a qualified maternity institution 42 days after delivery.

Following the whole preconception care, childhood follow-ups for newborns are conducted in the 1st, 3rd, 6th, 8th, 12th, 18th, 24th, and 36th months during the first 3 years. Later, follow-ups are conducted annually by kindergartens until the child becomes 6 years old.

The information reporting process of the RMCIS was designed according to the aforementioned closed-loop process. In addition to pregnancy and childbirth care, other maternal care services, such as premarital checkup, family planning, cervical cancer and breast cancer (CC and BC) screening, and childhood follow-up, are also included in this system. Every event occurs in the way of individual information forms created in the system. Based on the role analysis, each event takes place in a different medical institution, but all the data are uploaded to the same information system. In addition, the RMCIS is linked to other health data systems, such as public security bureaus, ensuring that vital statistics data, such as birth and death certificates, are accurately collected (Figure 2).

Figure 2. Business architecture design for the information reporting process.



Functional Modules and Services

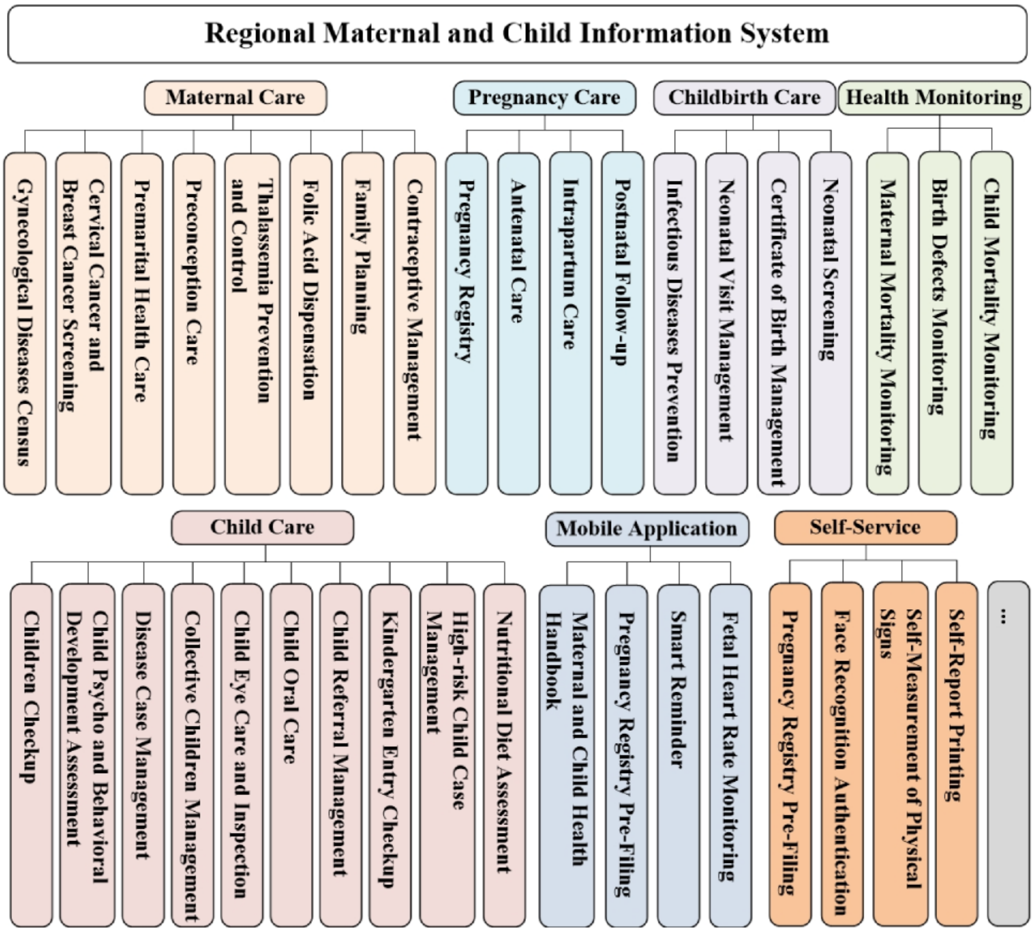
The essence of an RMCIS is to achieve data interconnection between medical institutions and provide coherent services for the whole health care process based on standardization. Core services were classified into 4 dimensions: basic health care services, special case management, health support, and administration and supervision. Compared to the basic health care services, which are the foundation for medical institutions and cover the whole life cycle of patients, other intelligent supplementary features of pregnancy and childbirth care, such as pregnancy risk surveillance and special case management of high-risk children, guarantee that patients with different medical needs receive proper treatments. Policy making and clinical decision support help medical workers comprehend the health status of patients and accordingly provide prescriptions. Databases for special cases, such as maternal anemia, weight gain during pregnancy, and high-risk newborns, are also built based on this system.

The RMCIS provides health support to users with self-service, but it still has great potential for development. The broadest application of self-service is pregnancy registry prefiling, which reduces the repetitive work of medical workers and ensures the authenticity of patients' personal information. Patients can fill their personal information in the prefilling forms through mobile apps or official WeChat accounts and conveniently complete pregnancy registry later in community health care centers. Common features (eg, health encyclopedia, daily service information and policies, automatic reminders, medical records, and examination result queries) and extensive services (eg, nutrition assessment, psychological assessment) have also been added to the mobile apps. In addition, daily personalized pregnancy knowledge and appointment reminders can be set in official WeChat accounts. Thanks to the telemedicine services provided by online hospitals, patients can further initiate interactive communications with health care experts online. Finally, the latest technologies, such as the internet of things (IoT), allow remote fetal heart monitoring to be applied broadly, even during an epidemic.

As mentioned in the *Role Analysis* section, most administration and supervision functions are directed to administrative departments, such as the NHC. The administrative departments can then extract data and display MCH surveillance indicators (maternal mortality and child mortality under age 5 years and neonatal birth defect surveillance) through queries. In this way, comprehensive statistics based on MCH can be easily gathered, contributing to period report writing. However, for administrative departments in medical institutions, special case management and supervision are crucial for the treatment of high-risk patients, while performance appraisal is a tool to assess medical workers.

Based on 4 core dimensions (basic health care services, special case management, health support, and administration and supervision), 10 modules were set up in the system: (1) maternal care, (2) pregnancy care, (3) childbirth care, and (4) child care for basic health care services; (5) mobile app and (6) self-service for health support; (7) health monitoring, (8) system management, (9) data center, and (10) other for the health administration department and the maintenance team. The maternal care module covers most of the services except pregnancy and childbirth care (which is divided into antenatal care and neonatal care), while the child care module only includes childhood follow-up services (Figure 3).

Figure 3. Functional module diagram for the regional maternal and child information system (RMCIS).



Intelligent Health Management and Decision Support

As concrete health care services can be divided into specific modules, intelligent health management and decision support are embedded in every feature of the RMCIS to assist medical workers with reasonable prescriptions. These intelligent services using new techniques make the RMCIS distinct from a simple information system.

The RMCIS can identify and assess the risk of a pregnant women based on her physical signs, report results, and *International Classification of Diseases, Tenth Revision* [32] diagnosis. Subsequently, the system estimates the pregnancy risk level and automatically implements 5-color management. Normal or low-risk pregnant women are further distinguished from high-risk patients by gestational diabetes, hypothyroidism, iron deficiency anemia, twin pregnancies, preeclampsia, etc, so that the system can make an intelligent diagnosis more precisely. Since the management of each patient is a closed-loop system, doctors can easily look up previous maternity checkup results according to the timelines and make a diagnosis with the help of the RMCIS. For high-risk pregnant women, the RMCIS reminds doctors and patients to carry out special case management and track on a regular basis.

The RMCIS also assesses children's growth status according to the measured data and alerts whether a child has a high-risk growth problem (wasting, obesity, anemia, etc). The system is interfaced with other in-hospital systems to extract data of physical signs and laboratory results, automatically calculates the child's growth and development status, and draws a WHO standard growth monitoring chart to assess the development level. In this manner, doctors can intuitively observe the child's growth status and give reasonable advice with intelligent health management guidance from the RMCIS. Special cases are highlighted in the system according to WHO and 9 Chinese provincial and municipal standards, effectively reducing deaths caused by untimely detection or resuscitation of high-risk diseases.

Furthermore, the traditional outpatient physical sign collection equipment has been transformed to an automatic one with the IoT technique. For instance, the automatic electronic blood pressure meter can be highly interconnected with intelligent equipment and an HIS, which can automatically upload blood pressure data to the system. It can also automatically fill in the patient's physical signs form, without manual entry, and thus simplifies the maternity checkup process. In addition, the remote fetal heart rate monitoring services have been extended to communities and families, closing the gap in out-of-hospital monitoring. Pregnant women can carry out fetal heart monitoring at home according to doctors' advice and upload the real-time monitoring data through their mobile phones. Hence, nursery stations can immediately uncover emergency conditions.

Technical Design

In the system design, feasibility, flexibility, robustness and scalability, and maintenance were considered as the basic design principles of system integration [33]. With reference to the guidelines of the NHC [34,35], the RMCIS was designed and constructed to achieve the whole life cycle management of MCH services for residents.

The RMCIS was deployed at a specialized network, while mobile services were deployed on the internet. Logical isolation separated the internet from the specialized network through firewalls and bastions. The system has realized docking with HISs, citizens' health platforms, management systems of primary health care institutions, and other systems, standardizing the management of MCH services in covered medical institutions and realizing the sharing and exchange of MCH resources. Large distributed databases, such as ORACLE (recommended for expandability and compatibility) and SQLServer, were supported, and centralized storage was adopted, with the builder providing the database server and specifying the storage location. In November 2020, the concept of the cloud-based maternal and child service was proposed and promoted by the NHC [16], and the latest technique (cloud computing) was recommended to be applied in MCH services. Data could be stored in either the cloud or the local data center, which improved the energy efficiency ratio of resource usage. Faster cross-institutional and cross-regional business collaboration and data interoperability became available. Three-layer browser/server (B/S) system architecture was adopted in the software based on service-oriented architecture consisting of an application layer, a service layer, and a data layer. Each layer only focused on its own tasks to successfully separate business from logic and client from database, which feasibly met system design requirements. The advantage of the B/S system architecture was obvious because users had the ability to access the system directly using the web browser, providing easy maintenance and high flexibility.

Budget Planning

The construction cost of the RMCIS was based on the provincial or municipal population number, since the population number determines the number of medical institutions and the workload of the system going live and docking. In addition, different function modules led to discrepant prices. The cost for medium-to-large cities with a population of more than 5 million was about CNY 4-6 million (US $555,609-$833,414), while that for small cities with a population of less than 5 million was about CNY 3-4 million (US $416,707-$555,609). This cost included system development, implementation, etc. The maintenance cost is 10% of the total cost per year.

Sustainability

To ensure the sustainability of the RMCIS, several actions were taken. Operation and maintenance management systems were established for all aspects, from funds to personnel. Data collection channels and data management regulations require fixed personnel and procedures to ensure stable and safe data sources. The data backup management system implements regular data backup and ensures that the system can be immediately accessed and restored after failure. The maintenance system monitors operation behavior to ensure correct operation status and avoid attacks, and system emergency plans can maintain business continuity in the case of an emergency. The maintenance fund guarantee system ensures that a certain amount of maintenance investment is kept to promote system updating and upgrading.

An operations and maintenance team was formed and provided by the technology company to ensure operation of the system without disruption. System operation and maintenance mainly include business operation consultancy, data maintenance, software maintenance, and hardware platform maintenance. Remote scheduled manual checking at regular intervals is the basic safeguard. If any system failure occurs, a text message and an email are directly sent to the duty personnel for notification. The time limit for a response to failure is 1 hour, and the repair time limit is 1 hour for major failures and 4 hours for general failures. Technical support is even offered to arrive on-site within a time limit to solve any problem.

As the lead department of the regional MCH system, the regional health care commission took the responsibility for user training. Centralized training and counseling for users was organized after system implementation. In addition, documents and videos of operation tutorial, as well as online support, were provided for users in need.

Data FLow

The RMCIS implemented in Inner Mongolia provides 2 modes of data collection, depending on the management requirements of local health commissions: direct upload mode and front-end processor collection mode. In the direct upload mode, medical institutions directly upload data through the web service interface after strict encryption. In the front-end processor collection mode, the business system of each medical institution first pushes data to the local front-end server, and then the collection client module automatically collects the data and submits them to the provincial maternal and child data center. The RMCIS supports the front-end processor collection mode with automatic data collection and submission. This way, connecting with the HIS, the LIS, the imaging system, financial systems, and other systems, the RMCIS deployed in individual medical institutions is able to collect data from health record information, tests, images, and reports of related MCH services. In addition, the RMCIS obtains information from personalized mobile apps and official WeChat accounts.

Following guidelines of the NHC [32,36], the data collection process of the RMCIS strictly follows standardized criteria to avoid ambiguous information exchange, including data elements, basic data sets, and data dictionaries. In real MCH business activity, relevant information and data are recorded in the form of record forms (eg, birth certificate, newborn disease screening record form, basic maternity registration form), making up 1 or more basic data sets (eg, birth certificate data set, newborn disease screening data set, maternal health services and high-risk management data set). The collection of standardized smallest units of health record data in unified formats, that is, data elements (eg, name, gender code, date of birth, detailed address), constitutes a data set as well as a record form. Taking the record form of birth certificates as an example, the corresponding data set is the birth certificate data set, which consists of the data elements newborn name, newborn gender code, newborn birth date and time, birthplace, etc.

To ensure the quality of collected data, the system automatically monitors and calibrates the uploaded data based on the data quality monitoring rules: accuracy, completeness, consistency, repeatability, and timeliness. In the face of various construction levels of HISs and the quality of data across the province, the provincial MCH data center needs to formulate a unified data set, data dictionary, business forms, quality control rules, etc.

All data are classified by category and regional distribution and displayed vertically from top to bottom, which means higher authorities are able to access the data of the corresponding affiliates. The RMCIS defines permissions for each user of each organization according to their role and authorizes management to access, download, and view statistical reports. In addition, case access and collaborative sharing functions are also provided, that is, as long as the resident's health card is inserted when they visit a health care institution within the province, the health care workers are able to access the resident's MCH information and records online with prior consent.

For data display and visualization, a surveillance module was developed to display relevant indicators, statistical reports, and graphs. Specific reports and graphs form the *Inner Mongolia Annual Report on Maternal and Child Health* [37] based on reporting specifications, including the annual report on maternal health care and health status, the annual report on the health care and health status of children under 7 years, the annual report on the health status of nonfamily children and pregnant women, the annual report on premarital health care, the annual report on the health care work of nurseries and kindergartens, the annual report on the work of midwifery service organizations, the annual report on the monitoring of deaths of children under 5 years, and the quarterly report on the number of perinatal babies. The RMCIS also provides the functions of single or multiple conditional combination queries, as well as printing and exporting query results. These MCH data visualization functions can help with health management decision-making and assist policy makers in determining future regulation outlines for further promotion.

Ethical Considerations

The First Affiliated Hospital of Xiamen University Ethics Committee approved this study (approval number SL-2021KY044-01). All the users consented to sharing the information for using the developed RMCIS. Privacy protection and data security were emphasized with technical support from technicians even before the system was implemented. Specific security solutions were determined by Technical Program for Construction of Regional Maternal and Child Health Information System.

A 3D information security protection system was built to ensure confidentiality, integrity, availability, and controllability spanning the hardware, software, network, system, data, application, and management. The security protection level was set to level 3 because any potential vulnerabilities might influence the social order and public confidence. Since the RMCIS was deployed on the government affairs' cloud, which met the requirements of information security level 3, the physical environment security, computing environment security, security boundary protection, communication network protection, and security management center required for the system all met the requirements.

To ensure data security, security access functions, including permission management, identity authentication, and access control management, were applied. Permission management allows the RMCIS to be controlled no matter what operations a specific user had undertaken, including editing, adding, and deleting. Identity authentication is also one of the main prevention and protection strategies to prevent the core information system from illegal access. Furthermore, access control management guarantee that permissions in the system are determined by user roles. Only specific users, such as government staff, are allowed to access functions with higher permission levels, while the rest of the users can only access modules of their own sections. For safety requirements, the system provides log management, recording modification and log queries. In terms of network security, the system supports links, such as private networks or virtual private networks, to ensure secure data transmission. Encryption and decryption technology, identity authentication, and security policy were used to guarantee the security of data transmission. Lastly, data set disaster recovery, customer data platform disaster recovery, data backup, and graded multiclass disaster recovery were designed and implemented in this study.

Data Collection and Statistical Analysis

This study collected summary data of the RMCIS implementation in 12 cities of Inner Mongolia. Since the system was implemented in Inner Mongolia since January 1, 2020, the speed of informatization construction of the 12 cities varied, so earlier data were not completely uploaded into the system. Partial data from Wuhai, Ordos, and Alaxa were absent because of inaccessibility. The experimental data used in this study only included those collected from Wuhai, Hohhot, and Tongliao in 2020, with partial 2021 data of Wuhai and Alaxa missing. Until October 31, 2022, all 12 cities in Inner Mongolia completed data interoperability with the RMCIS. Thus, the limitations of the data included data missing for extended services in some cities with a short duration.

The study followed the descriptive implementation methodology designed to demonstrate the construction process and implementation effects with the sample size of functional modules and the usage count of services. For distribution of specific users, the basic characteristics of pregnant women (ie, maternal age, gestational week at registration, maternal height, maternal weight, pre-pregnancy BMI, gestational week at delivery, gravidity, education level, parity, current smoking, current alcohol consumption, mode of delivery, multiple gestations) and that of newborns (ie, birth length and birth weight) were collected. Five-color management results were presented in a pie chart for ratios and a histogram for the top 10 factors as an example of high-risk management. The usage count per year for services (ie, pregnancy registry, delivery, newborn, premarital checkup, and CC and BC screening) and pregnancies (ie, total pregnancies and high-risk pregnancies) was displayed to demonstrate its application effects in each city. All these data were securely stored by Zoe Software Engineering Co, Ltd (Xiamen City), which cooperates with medical institutions to run the RMCIS. The company deidentified these data and constructed an internet environment for secure analysis, obtaining data according to the principle of minimum availability. After analyzing the data in the intranet security environment, the analysts exported the analytical results rather than the underlying data.

Project summary data, including duration, labor cost, and cost for each period, were provided by the project team of Zoe Software Engineering Co, Ltd. Other basic information, such as the MMR, NMR, and UMR, were shown on the website of the People's Government of Inner Mongolia Autonomous Region.

Descriptive analysis was performed using Microsoft Excel 2016. In addition, the aggregation and analysis of the top 10 factors of five-color management were performed using Python 3.10.7.

Results

Cost Summary

Project planning was initiated at the end of 2018, and the RMCIS was implemented in January 2020, with a duration of 13 months. The labor cost was 210 person-months, and the cost was CNY 8 million (US $1.1 million). In the 4-year maintenance, the first year was free and the later 3 years cost CNY 800,000 (US $111,142; 10% of the implementation cost) per year, leading to a total cost of CNY 10.4 million (US $1.4 million). See Table 3 for details.

Table 3. Duration, labor cost, and system construction cost.

Project period	Duration (months)	Labor cost (person-months)	Cost (million CNY)
Planning	2	10	0.5 (US $69,463)
Design, and research and development	8	140	5.5 (US $764,111)
Deployment	3	60	2.0 (US $277,858)
Total	13	210	8.0 (US $1.1 million)

Data Characteristics

In Inner Mongolia, the RMCIS covered 278 hospitals and 225 community health care centers in 12 cities. The main modules launched included pregnancy care, childbirth care, and maternal care. A total of 221,772 pregnancy registries, with a 44.75% (n=99,241) early pregnancy registry rate, were recorded in the system, along with 1,417,066 records of antenatal visits and 145,863 pregnancies for intrapartum care and delivery care. In addition, records of 147,264 newborns were maintained in the childbirth care module, with medical information including weight, height, newborn disease screening, etc. From January 1, 2020, to October 31, 2022, 56,430 people underwent premarital checkups and 256,659 women underwent CC and BC screening (Table 4).

Table 4. Usage count of main modules and services in the RMCIS[a] (January 1, 2020-October 31, 2022).

Module and services[b]	Data	Value
Pregnancy care		
Pregnancy registry	Pregnancies, N	221,772
Pregnancy registry	Early pregnancies, n/N (%)	99,241/221,772 (44.75)
Antenatal visit	Records, N	1,417,066
Antenatal visit	Pregnancies, n/N (%)	202,879/1,417,066 (14.32)
Intrapartum care	Pregnancies, n/N (%)	147,510/202,879 (72.71)
Intrapartum care	Deliveries, n/N (%)	145,863/147,510 (98.88)
Intrapartum care	High-risk pregnancies, n/N (%)	83,376/147,510 (56.52)
Childbirth care	Newborns, N	147,264
Maternal care		
Premarital health care	People, N	56,430
CC and BC[c] screening	Women, N	256,659

[a] RMCIS: regional maternal and child information system.

[b] For each service, the duration was from January 1, 2020 to October 31, 2022.

[c] CC and BC: cervical cancer and breast cancer.

The pregnancy registry, antenatal visits, and intrapartum care services had been put to use, while antenatal screening, postnatal follow-up, and kindergarten checkup data were still deficient. Note that the data of CC and BC screening were maintained in the RMCIS only from January 2022, because this service was applied using other systems previously.

The median maternal age was 30 (lower quartile [Q_L]-upper quartile [Q_U] 27-33) years, the median gestational week at pregnancy registration was 14 (11-22) weeks, and the median gestational week at delivery was 39 (38-40) weeks. The median birth length and birth weight of newborns were 50 (50-51) cm and 3300 (Q_L-Q_U 2990-3600) g (Table 5). Gravidity refers to the number of pregnancies, including current and past ones. A total of 20,165 (19.52%) pregnancies were multiparous, which meant a woman had more than 1 delivery of a fetus at or after the 24th gestational week, while the rest of the pregnancies (n=83,134, 80.48%) were nulliparous (no birth history). Only 926 (0.44%) pregnant women had a habit of smoking, and 724 (0.35%) currently consumed alcohol. A total of 48,135 (43.35%) deliveries were conducted by caesarean section, although WHO set a warning cutoff for the rate of cesarean section as less than 15% [38]. See Table 6 for the details.

Table 5. Numerical characteristics of pregnant women and newborns recorded in the RMCIS[a] (January 1, 2020-October 31, 2022).

Numerical characteristic	Median (Q_L-Q_U)[b]	Total pregnant women/newborns, n	Missing values, n (%)
Maternal age (years)	30 (27-33)	246,167	0[c]
Gestational weeks at registration	14 (11-22)	244,743	1424 (0.58)[c]
Maternal height (cm)	162 (158-165)	246,146	21 (0.01)[c]
Maternal weight (kg)	62 (55-70)	242,128	4039 (1.64)[c]
Pre-pregnancy BMI (kg/m^2)	23.83 (21.33-26.84)	242,128	4.39 (1.64)[c]
Gestational weeks at delivery	39 (38-40)	147,510	0[d]
Gravidity (times)	1 (1-3)	147,510	0[d]
Birth length (cm)	50 (50-51)	147,171	0[e]
Birth weight (g)	3300 (2990-3600)	147,171	0[e]

[a] RMCIS: regional maternal and child information system.

[b] Q_L: lower quartile; Q_U: upper quartile.

[c] N=246,167 (number of pregnancies in antenatal care).

[d] N=147,510 (number of pregnancies in delivery care).

[e] N=147,171 (number of newborns in childbirth care).

Table 6. Categorical characteristics of pregnant women recorded in the RMCIS[a] (January 1, 2020–October 31, 2022).

Categorical characteristics	Pregnant woman, n (%)	Missing values, n (%)
Education level	120,665 (100.00)	125,502 (50.98)[b]
No education or semiliterate	352 (0.29)	—[c]
Primary education	4777 (3.96)	—
Junior secondary education	29,253 (24.24)	—
Secondary education	16,312 (13.52)	—
Undergraduate	63,173 (52.36)	—
Postgraduate	6795 (5.63)	—
Parity	103,299 (100.00)	44,211 (29.97)[d]
Nulliparous	83,134 (80.48)	—
Multiparous	20,165 (19.52)	—
Current smoking	208,916 (100.00)	37,251 (15.13)[b]
Yes	926 (0.44)	—
No	207,990 (99.56)	—
Current alcohol consumption	208,916 (100.00)	37,251 (15.13)[b]
Yes	724 (0.35)	—
No	208,192 (99.65)	—
Mode of delivery	111,042 (100.00)	36,468 (24.72)[d]
Vaginal delivery	62,907 (56.65)	—
Caesarean section	48,135 (43.35)	—
Gestations	147,510 (100.00)	0[b]
Singleton	147,053 (99.69)	—
Multiple	457 (0.31)	—

[a] RMCIS: regional maternal and child information system.

[b] N=246,167 (number of pregnancies in antenatal care).

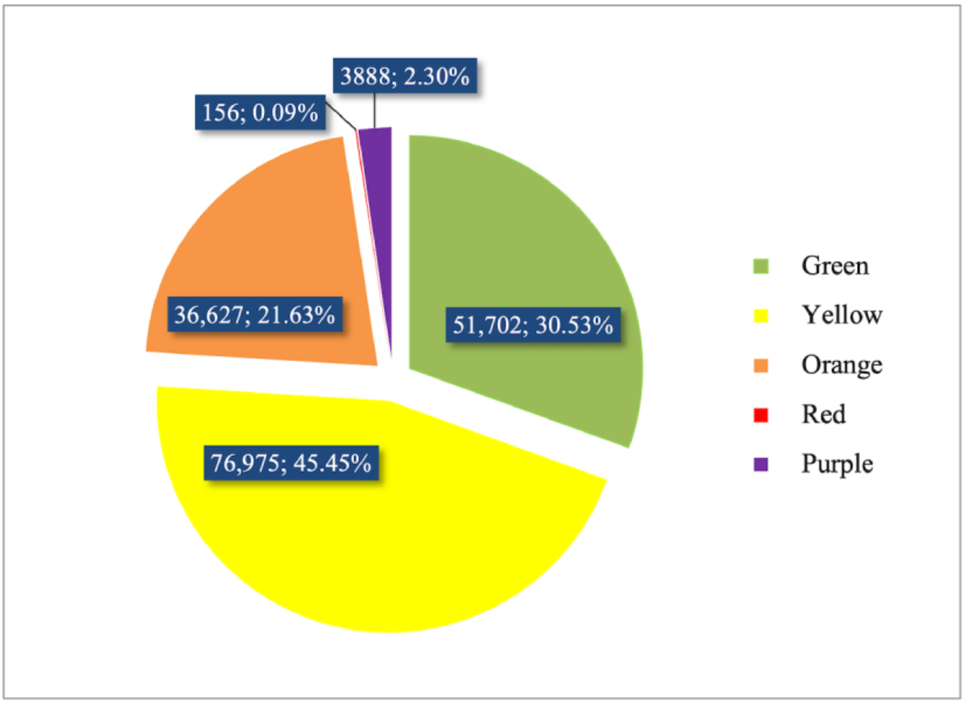
[c] Not applicable.

[d] N=147,510 (number of pregnancies in delivery care).

Pregnancy Risks and Factors

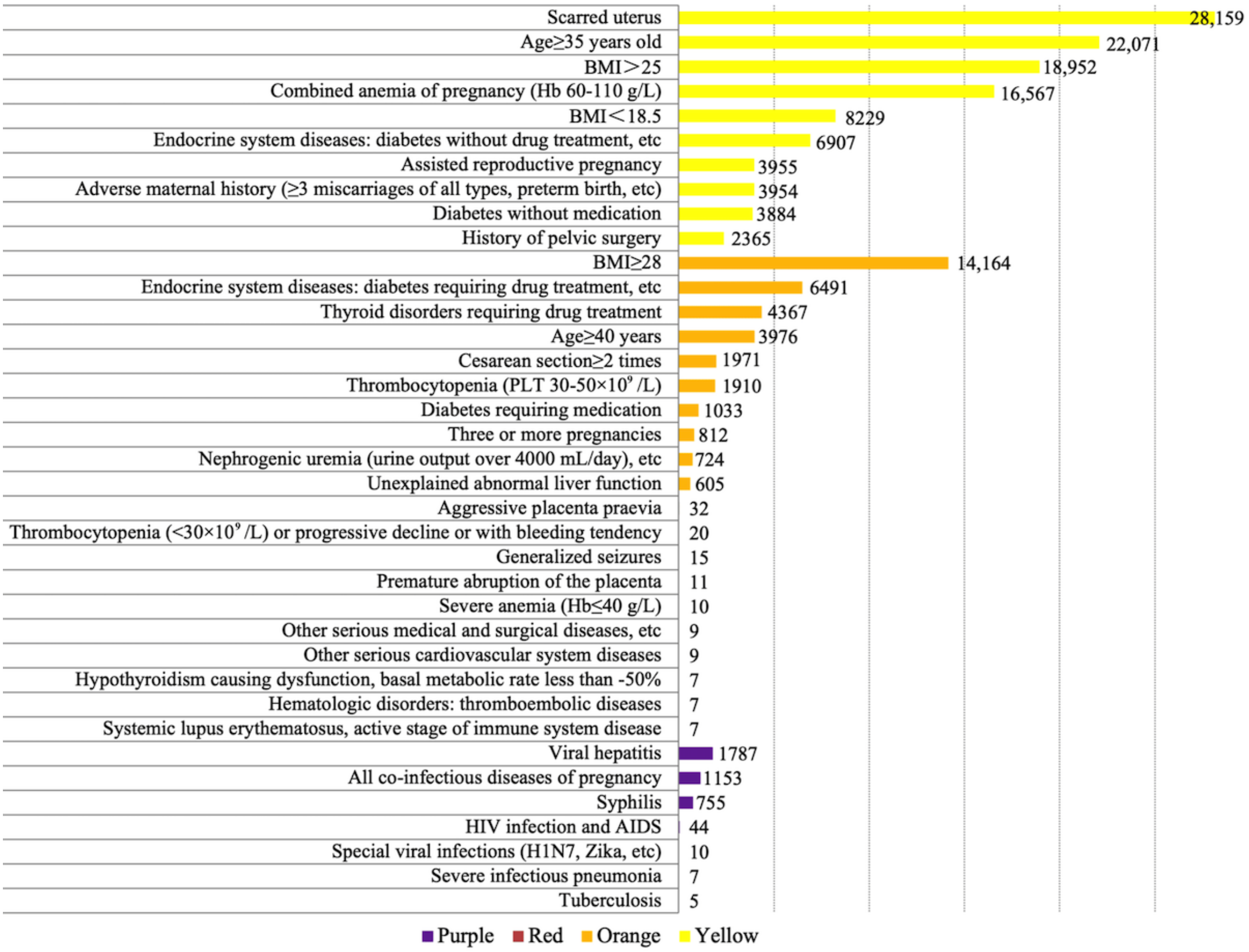
The RMCIS provided statistics for 5-color management. In total, 51,702 (30.53%) pregnancies were marked green (no pregnancy complications). Pregnancies marked yellow (general risk) accounted for the largest proportion (n=76,975, 45.45%), and 36,627 (21.63%) pregnancies were marked orange (relatively high risk). Only 156 (0.09%) pregnant women were marked red (high risk). Furthermore, pregnancies marked purple (infectious disease) were 3888 (2.30%) in total (Figure 4).

Figure 4. Numbers and percentages in 5-color pregnancy risk management (January 1, 2020–October 31, 2022).



For yellow risk, the top 4 factors accounting for 74.54% of cases were scarred uterus (n=28,159, 36.58%), age≥35 years (n=22,071, 28.67%), BMI>25 (n=18,952, 24.62%), and combined anemia of pregnancy (hemoglobin 60-110 g/L; n=16,567, 21.52%). For orange risk, BMI≥28 (n=14,164, 38.67%) accounted for almost 40% of cases and the 3 reasons were endocrine system disease (eg, diabetes requiring drug treatment, thyroid disease, pituitary prolactinoma, etc; n=6491, 17.72%), thyroid disorders requiring drug treatment (n=4367, 11.92%), and age≥40 years (n=3976, 10.86%). Red risk only accounted for 156 (0.09%) cases, and aggressive placenta praevia (n=32, 20.51%) was the most influencing factor. For purple risk (infectious disease), viral hepatitis (n=1787, 45.96%), all coinfectious diseases of pregnancy (n=1153, 29.66%), and syphilis (n=755, 19.42%) were the top 3 factors, accounting for over 98% of cases (Figure 5).

Figure 5. Top 10 factors and number of high-risk pregnancies (yellow, orange, red, purple) from January 1, 2020, to October 31, 2022..



Implementation and Popularity

Major modules and services were put into use in 2020, while the minor ones were not due to system transformation and various other reasons.

The 3 main modules put into use were pregnancy care, childbirth care, and maternal care. For pregnancy registry and delivery, the number of pregnant women doubled from 2020 to 2022. The number of newborns increased by almost 1000 every year. Premarital checkup data started to be recorded from 2021, and CC and BC screening was recorded from 2022, since previous data were maintained using other systems alternatively (Table 7).

In 2020, only 3 cities chose to apply and upload MCH data to the RMCIS, while in 2021, Wuhai and Alxa still used their own municipal MCH systems, and parts of cities only uploaded partial data to the system. Yet, now, all 12 cities have participated and contributed to the RMCIS construction in Inner Mongolia. Until October 2022, 132,079 pregnancies were registered in the system, with 65,018 (49.23%) high-risk pregnancies, compared to only 32,466 pregnancy registrations in 2020. The number of pregnancies managed in the system increased by 157.9% in 2021 and 57.74% in 2022 (until October). The popularity of RMCIS implementation is high, and the result of the whole regional MCH data interconnection is significant (Table 8).

Table 7. Annual usage count of major services (January 1, 2020-October 31, 2022).

Year	Pregnancy registries, n (%)	Deliveries, n (%)	Newborns, n (%)	Premarital checkup, n (%)	CC and BC[a] screening, n (%)
2020	45,374 (46.25)	30,211 (30.79)	22,520 (22.95)	0	0
2021	87,245 (47.20)	46,942 (25.40)	23,609 (12.77)	27,044 (14.63)	0
2022[b]	91,106 (19.36)	68,358 (14.52)	25,231 (5.36)	29,350 (6.24)	256,659 (54.53)

[a] CC and BC: cervical cancer and breast cancer.

[b] Until October 31, 2022.

Table 8. Annual and high-risk pregnancies in 12 cities of Inner Mongolia (January 1, 2020–October 31, 2022).

City	2020		2021		2022a	
	Pregnancies (n=32,466), n (%)	High-risk pregnancies (n=21,849, 67.30%), n (%)	Pregnancies (n=83,734), n (%)	High-risk pregnancies (n=39,466, 47.13%), n (%)	Pregnancies (n=132,079), n (%)	High-risk pregnancies (n=65,018, 49.23%), n (%)
Ordos	0	0	116 (0.19)	31 (0.08)	43,962 (33.28)	19,756 (30.39)
Baotou	0	0	4124 (4.93)	1977 (5.01)	5336 (4.04)	2866 (4.41)
Hohhot	27,806 (85.65)	20,301 (92.92)	24,330 (29.06)	16,697 (42.31)	20,834 (15.77)	10,678 (16.42)
Chifeng	0	0	36,596 (43.71)	11,756 (29.79)	17,753 (13.44)	9684 (14.89)
Tongliao	325 (1.00)	75 (0.34)	11,980 (14.31)	6323 (16.02)	15,063 (11.40)	8089 (12.44)
Hulunbuir	0	0	2413 (2.88)	833 (2.11)	6312 (4.78)	2455 (3.78)
Xilin Gol	0	0	847 (1.01)	450 (1.14)	3981 (3.01)	1916 (2.95)
Bayan Nur	0	0	112 (0.13)	59 (0.15)	5976 (4.52)	3531 (5.43)
Ulanqab	0	0	203 (0.24)	54 (0.14)	1180 (0.89)	231 (0.36)
Wuhai	4335 (13.35)	1473 (6.74)	0	0	2995 (2.27)	1368 (2.10)
Xingan	0	0	3013 (3.60)	1286 (3.26)	7982 (6.04)	4114 (6.33)
Alxa	0	0	0	0	705 (0.53)	330 (0.51)

Discussion

Principal Findings

This study described the construction process (system architecture, functional modules, and construction costs) of the RMCIS in Inner Mongolia and demonstrated the implementation effects with popularity (the usage of main services and 5-color management of pregnancy risks) and challenges. Based on the data collected, the RMCIS implementation was found to have many social and economic benefits, providing a feasible solution to RMCIS construction.

Social Benefits

The first social benefit was the achievement of MCH medical resource integration, providing supervision tools for governments, data sharing for medical institutions, and easy access to medical resources for residents. Basic services of pregnancy care, childbirth care, and maternal care were put into use. The whole MCH process was optimized through data interconnection and fast resource allocation (eg, hospital transfer, delivery bed appointment) [17]. Clinical decision support and intelligent health management helped health care providers make decisions and improve patient care [39]. The RMCIS also provided clear insight for users through calculated indicators, tables, and charts, leading to advanced performance appraisal tools for governments and administration departments. The quality, efficiency, and equity of regional MCH services were improved for the purpose of universal health coverage [40].

Furthermore, the RMCIS was linked to other public health data sets (eg, birth and death certificate data sets). Studies on MCH can be conducted based on the data collected by the system, and a few studies with a specific historical background have become available. Recently, the research priorities in MCH shifted to COVID-19 during the pandemic era worldwide [41]. Regarding domestic policies in China, the effects of the 1-child policy on MCH were also a hot topic [42]. Indicators or MCH outcomes can be compared within different regions of China or with other countries. Otherwise, since the system tries to cover the whole MCH care process for patients, long-term follow-up studies on sequela after delivery (eg, pelvic floor dysfunction after vaginal delivery [43] or uterus rupture after cesarean delivery [44]) or rehabilitation therapy effects on children with birth defects [45] are feasible. Thanks to large-scale data, techniques, such as big data, provide the basic foundation to build models to predict maternal outcomes. Some factors leading to death or birth defects can be explored [46,47]. Moreover, rare cases can be investigated due to the construction of special case databases. As Figure 2 shows, services, such as thalassemia prevention and control, neonatal defect screening, high-risk pregnancy case management, and high-risk children case management, were included in the RMCIS, and thus special case databases were built. After high-risk patients are detected during diagnosis and treatment, they are included in special case management and attract specific attention. Based on special case data, potential scientific studies focusing on rare cases can be conducted. Maternal anemia [48], gestational diabetes with weight gain [49], and high-risk newborn outcomes [50] are hot topics studied by medical workers. In addition, information about birth defects, children with medical handicaps, and growth retardation on stature or brain power is recorded and linked to other systems. Based on this, a new MCH data source profile can be built. For instance, a new data source profile, the Xiamen Registry of Pregnant Women and Offspring (REPRESENT), was developed [51], linking the 4 major health care data platforms: Resident Healthcare Management Platform, Primary Healthcare Management Platform, Electronic Healthcare Records Platform, and Maternal and Child Health Management

Platform. The profile provided further potential uses of pregnancy registry data.

Economic Benefits

The most important economic gain was the reduction in the operating costs for health care institutions and the medical fee for patients [17]. The workflow was further optimized within various institutions at all levels, and staff was streamlined. The problems of inner-hospital duplicate examinations and medications caused by the inability to share information were mitigated, directly reducing the wastage of health resources. Combined with the reform of medical insurance currently promoted in China [52], the medical fee charged became reasonable and acceptable. Finally, the operation efficiency of entire health care services was enhanced so that the sunk costs for institutions and patients decreased.

Challenges and Strategies

First, the biggest barrier to start-up was the huge financial requirement, since an MCIS does not generate direct economic effects but otherwise requires high operation and maintenance costs. The technology company seeks economic benefits, while medical institutions and governments only accept cost-effective ones. This benefit leverage between these parties can potentially hinder the migration of the system. Especially in low-income areas, deficient expenditure can lead to insufficient technical equipment, a lack of training opportunities, a high turnover rate of medical workers, and demotivation of patients. With a relative shortage of medical workers who even have to wear multiple hats, the use of helpful information systems can free them from tedious and repetitive tasks so that they can engage in more rewarding work. Investment at once with a low maintenance cost in exchange for a high degree of informatization helps with rationalization of staffing, MCH service quality improvement for residents, and more straightforward management for governments.

Second, a key factor affecting the RMCIS construction was technology compatibility and data interoperability, similar to the issues in other areas. Making the system compatible with other internal systems and public health databases demands high coordination between institutions and technology companies. On a policy level, strong policy support of governments is indispensable for participating parties to collaborate with clear objectives. On a technical level, standardized criteria of data collection should be predesigned. In fact, the implementation of the system does not indicate full coverage of MCH services. Prior interface standards for core functions are required to ensure the realization of basic services. Other interfaces for extended services (eg, postnatal follow-up, kindergarten checkups) can be further expanded and improved according to the experience in Inner Mongolia.

Third, the demotivation of health care workers was common during the implementation process. Since some medical institutions kept paper records, the application of the RMCIS was considered inferior than that of other basic information systems by staff. In addition, some of the health care workers preferred to provide medical instructions by experience, without intelligent decision-making support. The conversion of treatment habits was challenging. In Inner Mongolia, in addition to helpful tutorials and routine training opportunities, administrative tools, such as performance appraisal, were also used to regulate health care workers' behavior.

Fourth, after operation, requirements of rapid upgradation or optimization for the system were frequently raised to meet new needs, demanding capacity and efficiency from the maintenance team. During the CONVID-19 pandemic, measures, such as epidemiological investigation, real-time reporting of fever clinics, and polymerase chain reaction tests, were required to be added. The technical team was skilled, with ample experience. The RMCIS was used in 2 provinces (Inner Mongolian Autonomous Region and Jiangxi Province), in 6 cities (Xiamen, Fujian; Longyan, Fujian; Pingxiang, Jiangxi; Xinyu, Jiangxi; Jingdezhen, Jiangxi; and Dongying, Shandong) and 7 MCH hospitals. Engineers of the technology company and local technical teams are participating in development and maintenance work. The operation and maintenance management system (as mentioned in the *Sustainability* section) of the RMCIS is referenceable for other areas.

Fifth, network security and privacy security are nonnegligible. The network security law requires information security level protection and level assessment for compliance [53]. It also requires the implementation of sensitive data classification and classification protection. Protecting the data from attacks is a task. Considering the balance of convenience and security, B/S architecture with a private network was deployed in the RMCIS. Each medical institution can use the private network instead of the internet to access the system. This technical solution will provide a higher level of network and privacy security.

Finally, the direct upload mode of data collection (as mentioned in the *Data Flow* section) can lead to some issues. The RMCIS cannot automatically collect and submit data, requiring a data entry team to manually upload MCH records to the system. Every time after a routine production inspection, pregnant women need to take extra efforts to look for a data entry team member to enter her records in the MCHH, which demotivates patients. Since some information can be urgent, the manual uploading process impedes the data flow. Staff even have to call patients for verification if any data are missing. Such inconveniences occurred due to the management requirements of some local health commissions, resulting in duplicate work. Thus, the front-end processor collection mode used in Inner Mongolia is highly recommended for migration.

Due to the homogeneity of the maternal and child service process, the migration of the RMCIS seems feasible. In conclusion, governments should provide strong policy and financial support; medical infomatic constructors need to ensure data interoperability, security, and sustainable maintenance; administration departments in medical institutions should provide routine training opportunities and performance appraisal to motivate doctors; and medical workers are encouraged to keep pace with new techniques. These countermeasures have proven to be effective for the implementation of the RMCIS in Inner Mongolia, which might inspire other areas and even other countries.

Limitations of the Study

The study has several limitations. The period for which data were collected was relatively short, covering less than 3 years. Cities except Wuhai and Hohhot had not used a municipal MCIS before the implementation of the RMCIS, leading to missing data in 2020 and 2021. Extended services (eg, antenatal screening, postnatal follow-up, and kindergarten checkups) are still unused in the system, as further data interoperability with interfaces is awaited. Due to concerns of data security, the data collected in this study were deidentified and privacy-related data, including infectious diseases, were omitted. The artificial techniques used in the RMCIS are still immature, and the accuracy of clinical decision remains to be verified. Further studies can include benefits and outcomes, such as the impact on MCH outcomes, efficiency of health care delivery, patients' system management rate, and patient satisfaction, to evaluate the implementation effects of the RMCIS.

Conclusion

Based on the field study in Inner Mongolia, regional MCH improved through the effective implementation of an RMCIS. The system showed significant social and economic benefits, providing supervision tools for governments, provincial MCH data sharing for medical institutions, clinical decision support for health care workers, real-world data for researchers, and easy access to medical resources for residents. We can foresee that this large-scale application of an MCIS can further improve the quality, efficiency, and equity of MCH services in Inner Mongolia and provide valuable experience to medical administration departments, practitioners, and medical informatic constructors worldwide.

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Data Availability

The data sets including patients' individual information are not publicly available due to privacy protection and data security regulations. With the consent of the local health commission, the technology company in charge of system development and maintenance generated summary data according to the analysis requirements for this study, which have all been included in this paper.

Authors' Contributions

ZW and KG contributed to the study concept and design. JC and XL contributed to data acquisition. YZ and YL contributed to manuscript preparation and figure/table drawing. YY and CX performed data analysis and drafted the manuscript. All authors have contributed to the interpretation of the results and have approved the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

B/S: browser/server
CC and BC: cervical cancer and breast cancer
HIS: hospital information system
IoT: internet of things
LIS: laboratory information system
MCH: maternal and child health
MCHH: Maternal and Child Health Handbook
MCIS: maternal and child information system
MMR: maternal mortality rate

NHC: National Health Commission
NMR: neonatal mortality rate
RMCIS: regional maternal and child information system
UMR: under-5 mortality rate
WHO: World Health Organization

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Feasibility and Acceptability of Pediatric Smartphone Lung Auscultation by Parents: Cross-Sectional Study

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Abstract

Background: The use of a smartphone built-in microphone for auscultation is a feasible alternative to the use of a stethoscope, when applied by physicians.

Objective: This cross-sectional study aims to assess the feasibility of this technology when used by parents—the real intended end users.

Methods: Physicians recruited 46 children (male: n=33, 72%; age: mean 11.3, SD 3.1 y; children with asthma: n=24, 52%) during medical visits in a pediatric department of a tertiary hospital. Smartphone auscultation using an app was performed at 4 locations (trachea, right anterior chest, and right and left lung bases), first by a physician (recordings: n=297) and later by a parent (recordings: n=344). All recordings (N=641) were classified by 3 annotators for quality and the presence of adventitious sounds. Parents completed a questionnaire to provide feedback on the app, using a Likert scale ranging from 1 (“totally disagree”) to 5 (“totally agree”).

Results: Most recordings had quality (physicians’ recordings: 253/297, 85.2%; parents’ recordings: 266/346, 76.9%). The proportions of physicians' recordings (34/253, 13.4%) and parents' recordings (31/266, 11.7%) with adventitious sounds were similar. Parents found the app easy to use (questionnaire: median 5, IQR 5-5) and were willing to use it (questionnaire: median 5, IQR 5-5).

Conclusions: Our results show that smartphone auscultation is feasible when performed by parents in the clinical context, but further investigation is needed to test its feasibility in real life.

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KEYWORDS

respiratory sounds; respiratory; respiration; lung; lungs; pulmonary; breathing; sound; sounds; wheeze; crackle; child; children; pediatric; pediatrics; parent; parents; parenting; asthma; auscultation; smartphone; mobile applications; mHealth; mobile health; app; apps; applications; crackles; wheezes; wheezing; participation; patient participation; willingness; adoption; acceptance; usability; attitude; attitudes; opinion; perception; perceptions; smartphone; smartphones; intent; ease of use; survey; surveys; questionnaire; questionnaires; mobile phone

Introduction

Respiratory diseases are leading causes of morbidity and mortality worldwide, and infants and young children are particularly vulnerable. Asthma is the most common chronic respiratory disease in children, affecting approximately 14% of children globally, and its prevalence is increasing [1,2]. Health care costs associated with respiratory diseases are increasing burdens on the global economy, including primary and inpatient health care costs; disability-adjusted life-years; and lost productivity, with a high number of school and work days lost [3,4].

Remote monitoring strategies can play an important role in controlling symptoms, improving patients' quality of life, and detecting adverse events that are associated with significant morbidity [5,6]. Lung auscultation is a quick, inexpensive, and efficient way to assess the respiratory system and help monitor a child's respiratory status [7,8]. However, as auscultation with a stethoscope is commonly performed by a physician during in-person visits, there is a need for suitable alternatives that support teleconsultation and empower families to take control of their own health and others' health.

As the ownership of a smartphone is now extremely common, Reyes et al [8] and Ferreira-Cardoso et al [9] recently proposed using a smartphone to acquire lung sounds; the former used an electret microphone connected to a smartphone, and the latter used smartphone built-in microphones. Ferreira-Cardoso et al [9] showed that smartphone auscultation performed by a physician was feasible in children. However, it remains unknown whether smartphone auscultation would be feasible if performed by parents and whether they would accept the use of this technology outside the clinical setting [9,10].

The primary aim of our study was to compare the feasibility of smartphone auscultation when performed by parents versus physicians. As a secondary aim, we evaluated the acceptability and ease of use of this technology among parents.

Methods

Ethical Considerations

This study was approved by the ethics committee of Centro Hospitalar Universitário de São João (approval number: 316/20; September 18, 2020). This study was reported in accordance with the recommendations of the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) Initiative [11]. Written informed consent was obtained from the parents, and assent was obtained from the children. In accordance with national legislation, written informed consent was also obtained from the children if they were aged 16 years or older.

Study Design

We conducted a cross-sectional study with a convenience sample of children who were followed at the pediatrics department of the Centro Hospitalar Universitário de São João, a tertiary care public hospital in Porto, Portugal. This study took place between December 2022 and May 2023. During medical visits, the physicians invited the children and their parents to participate in this study.

Participants

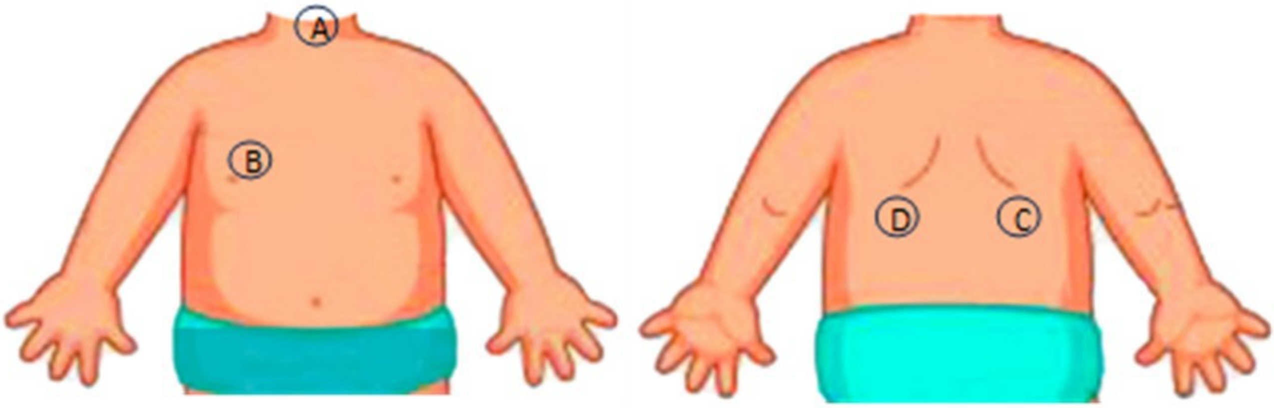
Children aged 5 to 17 years, with or without a respiratory disease (eg, asthma, cystic fibrosis, and other respiratory diseases), were included if they had a scheduled medical visit. The exclusion criteria were refusal to participate in this study and any health status or condition that interfered with the correct and safe collection of the children's lung sounds.

Data Collection

Data on children's sex, age, height, weight, and diagnosis were registered in a paper case report form. BMIs were calculated from the anthropometric data.

Smartphone lung auscultation was performed by the physicians, using the AIRDOC mobile app [10]. The app has multiple features, but only the lung auscultation feature was used for this study. A full description of the app can be found elsewhere [9,10]. During auscultation, the child was seated in an upright position. Auscultation was performed at the following four locations: the three minimum locations recommended for computerized respiratory sound analysis [12]—the trachea and the right and left posterior lung bases—and the right anterior chest, which is known to give a better sense of the presence of adventitious sounds in children (Figure 1) [13,14].

Figure 1. Lung auscultation locations: (A) trachea, (B) right anterior chest, (C) right posterior base, and (D) left posterior base.



Two 10-second recordings were made at each location, allowing for the inclusion of 1 to 5 respiratory cycles per recording [15]; 2 physicians (ie, 1 physician and 1 final-year medical student) were responsible for making the recordings, using their respective smartphones—an Apple iPhone XR (Apple Inc) and an Apple iPhone 14 (Apple Inc).

After the physicians completed the smartphone auscultations, the parents were invited to participate and were briefly instructed to perform the auscultation by using the same procedures and the same smartphones used by the physicians. Afterward, the parents completed a 3-item questionnaire to provide feedback on the app (app's ease of use for recording lung sounds, willingness to use the app to send lung sounds to the physician, and recommendation to others), using a Likert scale ranging from 1 ("totally disagree") to 5 ("totally agree").

Lung Sound Recording Classification

Each lung sound recording was listened to independently by 3 annotators—a physiotherapist and lung sound expert (CJ), a medical doctor (HFC), and a final-year medical student (CSS)—using Adobe Audition 2023 version 23.2 (Adobe Inc) and high-quality headphones (Marshall Major IV [Zound Industries], SONY Wh-H910Nl [Sony Group Corporation], and Sennheiser HD 380 Pro [Sennheiser electronic GmbH & Co. KG]). They also performed an analysis of sound spectrograms according to the default parameters of Adobe Audition. The three annotators were blinded to all data collected except child IDs and auscultation locations. Despite the shorter duration (10 s instead of the recommended 15 s), the quality of each lung sound recording was assessed according to the European Respiratory Society's criteria for sounds with quality (ie, minimal artifacts, visible respiratory phases, and a sound of interest could be demonstrated) [16]. The final decision on the quality of recordings was made by consensus among the three annotators. The next step was to evaluate only the lung sound recordings with quality in terms of the presence of adventitious sounds, namely, crackles and wheezes [17]. The final decision as to whether adventitious sounds were present was made by majority rule.

Data Analysis

Descriptive statistics were used to characterize the participants (ie, sex, age, weight, height, BMI, and diagnosis group [asthma, other respiratory disease, and no respiratory disease]). Shapiro-Wilk tests were used to assess the normality of the data. To explore the existence of differences among the three diagnostic groups, a chi-square test (sex), Kruskal-Wallis test (weight and BMI), and 1-way ANOVA (age and height) were applied.

The proportions of agreement and the proportions of specific agreement (specific agreement for each category) among the three annotators were calculated. Afterward, their interrater reliability was determined by using the Fleiss κ and its 95% CI. The Fleiss κ was interpreted as follows: 0 to 0.20 indicated slight agreement, 0.21 to 0.40 indicated fair agreement, 0.41 to 0.60 indicated moderate agreement, 0.61 to 0.80 indicated substantial agreement, and 0.81 to 1.0 indicated almost perfect agreement [18]. This was done for each auscultation group (ie, physicians and parents) and for each location. Differences in agreement among locations were explored with chi-square tests, and Bonferroni correction was used where necessary.

The proportions of quality recordings and recordings with adventitious sounds were calculated for each auscultation location and auscultation group. Chi-square tests, in which Bonferroni correction was used when necessary, were applied to assess differences among locations. All main analyses were based on the recordings, which were the de facto subjects of analysis in this paper. However, a secondary, more clinically oriented analysis was carried out in parallel by calculating the proportions of participants with at least 1 lung sound recording with quality and at least 1 lung sound recording with adventitious sounds. This was also done for each location and each auscultation group.

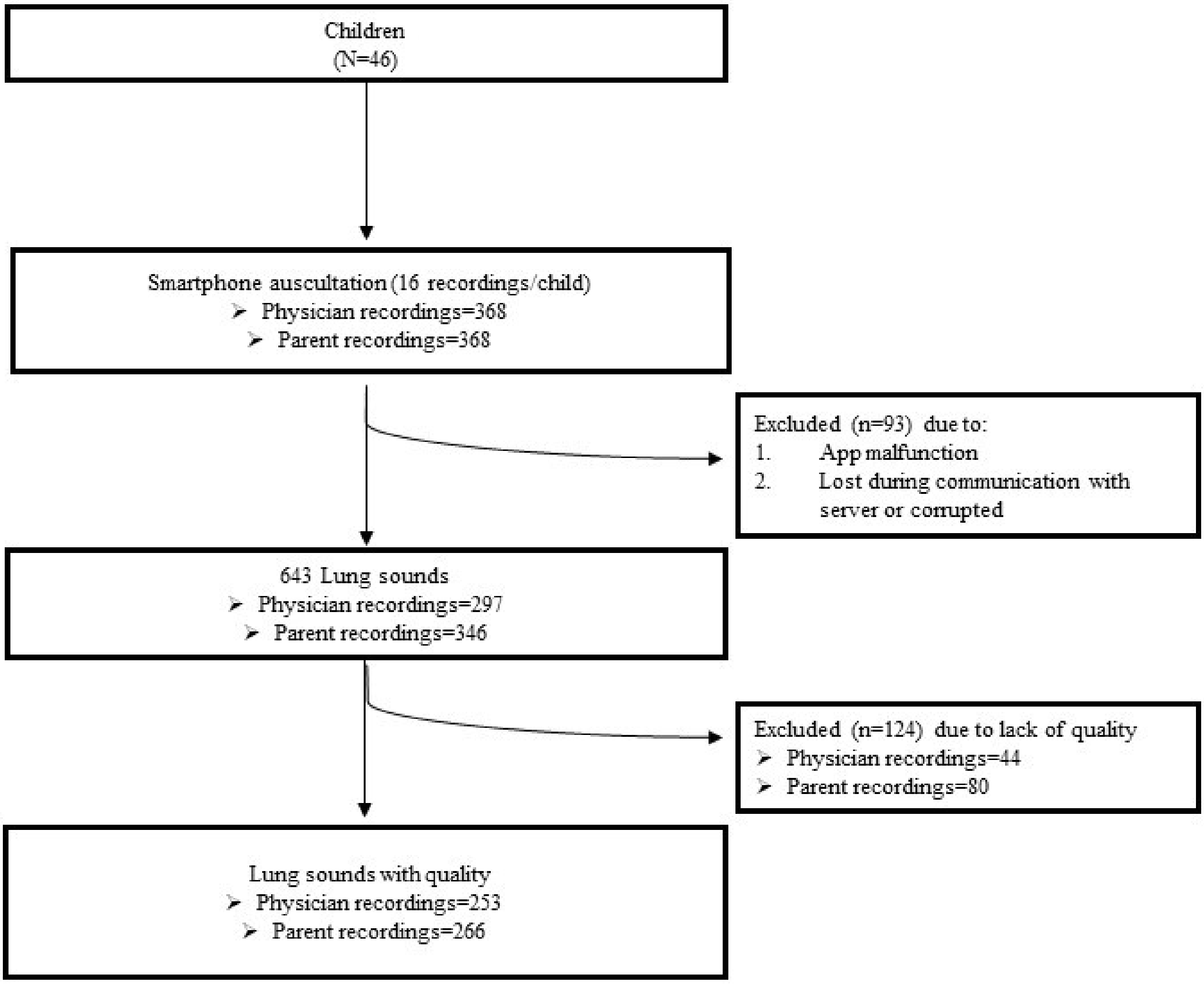
The statistics software used was IBM SPSS Statistics (version 28.0.0.0; IBM Corp). R software was used to compute the proportions of agreement with the "obs. Agree" package (R Foundation for Statistical Computing). The level of significance was set at .05.

Results

Participants' Characteristics

A total of 46 children were recruited. Most were male (n=33, 72%) and had asthma (n=24, 52%). The mean age was 11.3 (SD 3.1) years. The median BMI was 19.4 (IQR 16.4-21.5) kg/m^2. The characteristics of the participants are presented in Multimedia Appendix 1. A total of 736 recordings were expected from the 46 children (16 recordings/child), but due to some data losses, 641 (87.1%) recordings from 45 children were analyzed (Figure 2). All 45 children had recordings from both physicians and parents for each location except the right anterior chest, which was missed by the physician for one child and by the parent for another.

Figure 2. Flowchart showing the number of lung sound recordings and children considered throughout this study.



Lung Sound Quality: Agreement and Proportion

The proportion of agreement among the three annotators regarding the quality of the physicians' lung sound recordings (91%) was similar to that for the quality of parents' lung sound recordings (85%), corresponding to a Fleiss κ of 0.66 (95% CI 0.59-0.72) and 0.57 (95% CI 0.51-0.63), respectively (Table 1). With regard to the physicians' recordings, agreement for recordings taken at the trachea was greater than that for recordings taken at the right anterior and posterior locations (Multimedia Appendix 2). No statistically significant differences in the agreement among locations were found in the parents' recordings (Multimedia Appendix 2).

Table . Interrater reliability and proportions of agreement (PAs) among experts on the lung sound quality of physicians' and parents' lung sound recordings.

Location and quality of recordings		Physicians' recordings		Parents' recordings	
		Fleiss κ (95% CI)	PA (95% CI)	Fleiss κ (95% CI)	PA (95% CI)
Trachea		0.50 (0.37-0.63)	0.99 (0.97-1.00)	0.51 (0.39-0.63)	0.90 (0.84-0.95)
	No quality	N/A[a]	0.50 (0.50-0.50)	N/A	0.57 (0.37-0.73)
	Quality	N/A	0.99 (0.99-1.00)	N/A	0.94 (0.91-0.97)
Right anterior chest		0.58 (0.45-0.71)	0.84 (0.77-0.90)	0.51 (0.38-0.63)	0.81 (0.74-0.86)
	No quality	N/A	0.68 (0.53-0.80)	N/A	0.63 (0.51-0.74)
	Quality	N/A	0.90 (0.84-0.94)	N/A	0.87 (0.82-0.91)
Right posterior base		0.54 (0.40-0.67)	0.88 (0.82-0.94)	0.60 (0.47-0.72)	0.82 (0.75-0.88)
	No quality	N/A	0.61 (0.37-0.76)	N/A	0.73 (0.61-0.82)
	Quality	N/A	0.93 (0.89-0.96)	N/A	0.87 (0.80-0.92)
Left posterior base		0.81 (0.68-0.94)	0.94 (0.90-0.98)	0.58 (0.46-0.70)	0.88 (0.82-0.93)
	No quality	N/A	0.84 (0.70-0.94)	N/A	0.65 (0.48-0.79)
	Quality	N/A	0.97 (0.93-0.99)	N/A	0.93 (0.89-0.96)
All locations		0.66 (0.59-0.72)	0.91 (0.89-0.94)	0.57 (0.51-0.63)	0.85 (0.82-0.88)
	No quality	N/A	0.71 (0.62-0.78)	N/A	0.66 (0.59-0.72)
	Quality	N/A	0.95 (0.93-0.97)	N/A	0.90 (0.88-0.92)

[a] N/A: not applicable.

The proportion of quality recordings was high—85.2% (253/297) for recordings obtained by physicians and 76.9% (266/346) for recordings obtained by parents (Table 2). The proportion of quality recordings at the trachea was statistically superior to all other locations for the physicians' recordings and superior to the right posterior base for the parents' recordings (Multimedia Appendix 2). When using the participants (n=45) as the unit of analysis, the majority had at least 1 lung sound recording with quality per location when recordings were acquired by the physicians (n=30, 67%) and when they were acquired by parents (n=27, 60%).

Table . Proportions of physicians' lung sound recordings and parents' lung sound recordings with quality.

Location of recordings	Quality lung sound recordings, n/N (%)	
	Physicians' recordings	Parents' recordings
Trachea	75/76 (98.7)	64/74 (86.5)
Right anterior chest	57/76 (75)	53/75 (70.7)
Right posterior base	63/73 (86.3)	48/70 (68.6)
Left posterior base	58/72 (80.6)	59/70 (84.3)
All locations	253/297 (85.2)	266/346 (76.9)

Adventitious Sounds: Agreement and Proportion

The proportion of agreement among the three annotators regarding the presence of adventitious sounds was 91% (κ=0.60, 95% CI 0.53-0.68) for recordings obtained by physicians and 91% (κ=0.62, 95% CI 0.55-0.70) for those obtained by parents (Table 3). No statistically significant differences in the agreement were seen when considering locations separately (all *P* values were >.05).

Table . Interrater reliability and proportions of agreement (PAs) among experts on the presence of adventitious sounds in the physicians' and parents' lung sound recordings.

Recording location and presence of adventitious sounds		Physicians' recordings		Parents' recordings	
		Fleiss κ (95% CI)	PA (95% CI)	Fleiss κ (95% CI)	PA (95% CI)
Trachea		0.63 (0.49-0.76)	0.91 (0.86-0.95)	0.45 (0.31-0.59)	0.86 (0.78-0.92)
	Absent	N/A[a]	0.94 (0.91-0.98)	N/A	0.92 (0.87-0.95)
	Present	N/A	0.68 (0.45-0.83)	N/A	0.53 (0.25-0.71)
Right anterior chest		0.75 (0.59-0.91)	0.95 (0.89-0.99)	0.63 (0.48-0.79)	0.87 (0.79-0.94)
	Absent	N/A	0.97 (0.94-0.99)	N/A	0.92 (0.86-0.96)
	Present	N/A	0.78 (0.50-0.95)	N/A	0.71 (0.52-0.85)
Right posterior base		0.51 (0.35-0.66)	0.88 (0.82-0.95)	0.73 (0.57-0.90)	0.94 (0.88-0.99)
	Absent	N/A	0.93 (0.89-0.97)	N/A	0.97 (0.93-0.99)
	Present	N/A	0.57 (0.33-0.76)	N/A	0.76 (0.44-0.95)
Left posterior base		0.52 (0.37-0.67)	0.92 (0.86-0.98)	0.75 (0.61-0.90)	0.97 (0.92-1)
	Absent	N/A	0.95 (0.91-0.99)	N/A	0.98 (0.96-1)
	Present	N/A	0.56 (0.21-0.79)	N/A	0.77 (0.22-1)
All locations		0.60 (0.53-0.68)	0.91 (0.88-0.94)	0.62 (0.55-0.70)	0.91 (0.88-0.93)
	Absent	N/A	0.95 (0.93-0.97)	N/A	0.95 (0.93-0.96)
	Present	N/A	0.65 (0.54-0.75)	N/A	0.67 (0.55-0.77)

[a] N/A: not applicable.

Adventitious sounds were found in 13.4% (34/253) and 11.7% (31/266) of the recordings obtained by physicians and parents, respectively (Table 4). Comparisons between auscultation locations showed no significant statistical differences (all *P* values were >.05).

Table . Proportions of physicians' lung sound recordings and parents' lung sound recordings with adventitious sounds.

Location of recordings	Recordings with adventitious sounds, n/N (%)	
	Physicians' recordings	Parents' recordings
Trachea	12/75 (16)	8/64 (12.5)
Right anterior chest	7/57 (12.3)	9/53 (17)
Right posterior base	10/63 (15.9)	4/48 (8.3)
Left posterior base	5/58 (8.6)	3/59 (5.1)
All locations	34/253 (13.4)	31/266 (11.7)

When using the participants (n=45) as the unit of analysis, 19 (42%) participants had at least 1 lung sound recording with adventitious sounds (19 such recordings were obtained by the physician, and 17 such recordings were obtained by the parents).

Parents' App Feedback

As can be seen in Table 5, overall, the parents would recommend the app to others (questionnaire: median 5, IQR 5-5), found it easy to work with (questionnaire: median 5, IQR 5-5), and were willing to use it to send lung sounds to the physician (questionnaire: median 5, IQR 5-5).

Table . Parents' (n=45; 1 missing response) feedback about the app.

Questionnaire item	App feedback, n (%)				
	Totally agree	Agree	Neither agree nor disagree	Disagree	Totally disagree
App's ease of use for recording lung sounds	39 (87)	4 (9)	0 (0)	1 (2)	1 (2)
Willing to use the app to send lung sounds to the physician	38 (84)	3 (7)	3 (7)	0 (0)	1 (2)
Would recommend the app to others	38 (84)	5 (11)	1 (2)	0 (0)	1 (2)

Discussion

Principal Results

To our knowledge, this is the first study to assess the feasibility and acceptability of parents using a smartphone built-in microphone to capture lung sounds.

We found similar results when comparing the proportion of parents' quality recordings (266/346, 76.9%) with the proportion of physicians' quality recordings in this study (253/297, 85.2%) and that in a study by Ferreira-Cardoso et al [9] (73%). The same could be said for recordings with adventitious sounds; the proportion of parents' recordings with adventitious sounds (31/266, 11.7%) was similar to the proportion of physicians' recordings with adventitious sounds in this study (34/253, 13.4%) and that in the study by Ferreira-Cardoso et al [9] (14%).

Naturally, we attributed some of the differences in quality and adventitious sound proportion to the fact that the instructions on how to use the app were brief and the fact that parents were inexperienced and therefore misplaced the smartphone, pressed too gently, or even moved the smartphone or talked during the recordings.

Lung sounds were also recorded in a quiet but not soundproof room in the hospital. Therefore, the measured lung sounds might have been contaminated by ambient noise. However, with regard to the good overall agreement and moderate interrater reliability for the presence of adventitious sounds, the results were almost equal for recordings from physicians and parents and were similar to what has been reported in other studies [9,17].

With this study, we have confirmed the feasibility of using the AIRDOC app to record lung sounds with quality, as most participants had at least 1 recording with quality per location when recordings were acquired by physicians (30/45, 67%) and when they were acquired by parents (27/45, 60%). The results of our study are consistent with those of previous studies in which lung sound recordings were classified by experts [9,17,19]. For instance, the fact that recordings taken at the trachea have shown greater proportions of agreement (99%) and greater proportions of quality lung sounds (99%) has also been documented [9] and might be attributable to sounds having higher frequencies at this location, as the trachea has fewer tissues, which results in less filtering of sound signals [20,21]. These characteristics suggest that the trachea may be one of the best locations for the parental monitoring of respiratory status in real life. However, future studies with larger samples need to clarify whether adventitious sounds heard in the trachea are of clinical relevance for timely shared decisions. In adult patients with chronic obstructive pulmonary disease, sounds from this location could be used to predict exacerbations 5 days in advance [22].

Although only 13.4% (34/253) and 11.7% (31/266) of the physicians' and parents' recordings, respectively, had an identifiable adventitious sound, the percentage of participants with at least 1 lung sound recording with adventitious sounds (19/45, 42%) was similar to those found in previous works (35% in the study by Ferreira-Cardoso et al [9] and 28% in a study by Aviles-Solis et al [23]). The presence of adventitious sounds in the children without chronic respiratory diseases could be attributed to respiratory infections, as the recordings were made during the season with the highest incidence of respiratory infections. In addition, some of these participants were being followed up in the outpatient department due to a suspicion of a respiratory disease that had not yet been established, even though the presence of adventitious sounds has also been documented in healthy people [24,25]. The small difference between the presence of adventitious sounds in physicians' recordings and that in parents' recordings could be explained by the fact that the auscultations occurred some minutes apart rather than simultaneously (ie, the respiratory cycles differed among recordings) [26], which is a limitation of our study and should be addressed in further studies.

Although the parents' contact with the app was brief, they provided positive feedback on the auscultation feature with regard to its ease of use and their willingness to use it as a tool for communicating with the physician. Features related to an app's interface (eg, reduced number of screens and limited manual data entry) and communication with the health care team are among the features that are most valued by patients [27]. Parents' willingness to recommend the app to others was also high and similar to what has been reported in previous studies of asthma apps [28,29]. These findings are encouraging for the continued development of the AIRDOC app.

Limitations

This study has some limitations that need to be acknowledged. The results obtained from parents' recordings may not be generalizable to the real-life use of the app. Parents' performance in recording lung sounds was influenced by the fact that they were able to watch a demonstration of the procedure by observing physicians beforehand, and during parents' performance, physicians were able to give advice (how to press the smartphone, how to hold the smartphone, and no talking). However, the AIRDOC app is being developed for monitoring purposes in personalized follow-up care; therefore, demonstrations are being planned for parents. Another possible limitation was the use of the physicians' smartphones by the parents. We were aware of the possible effects of using an unfamiliar device; however, the decision to avoid the time-consuming process of installing the app on parents' smartphones was made, considering the internet connectivity limitations in the outpatient department. Additionally, comparing the smartphone auscultations performed by parents and physicians who used the same device allowed us to avoid the effects of differences among various embedded microphones. In the future, the feasibility of parents using the app should be evaluated in real life, with parents using their smartphones outside the clinical context. For this purpose, clear instructions on how to perform the auscultations should be made available in the app. With older children, we could have tested the self-recording of lung sounds, as they were old enough to manage their own diseases and treatment plans, but this would have increased the duration of the procedure, and it should be noted that data collection took place during routine medical visits. The self-recording of lung sounds by older children should however be carried out in further studies. Furthermore, the classification of adventitious sounds was based on broad classes (crackles and wheezes), without an attempt to distinguish subtypes, such as coarse crackles, fine crackles, high-pitch wheezes, and low-pitch wheezes. This decision was made in light of previous agreement studies, which showed that a broad classification was more reliable among experts than more detailed descriptions. We recognize that adventitious sound features are relevant to clinical decision-making, but it is sometimes very difficult for the human ear to discriminate these features [17]. The development of automated lung sound analysis methods will help us to overcome this limitation [30]. In addition, the proportions of recordings with crackles and recordings with wheezes were not analyzed separately; instead, our results are based on the proportions of recordings with adventitious lung sounds. This strategy was related to the small sample size and the small proportion of adventitious sounds (ie, crackles) in the recordings. The small sample size also hindered the comparison of smartphone auscultation performance among diagnosis groups; therefore, the project will continue to recruit children to strengthen the current findings. Another limitation is that other factors that may have been assessed by the physicians during the medical visits, such as respiratory rate, thoracic perimeter, and abdominal perimeter, were not included in our data collection. These parameters may be related to lung sound features and should be considered in the future.

Conclusions

The main findings suggest that lung auscultation via a smartphone built-in microphone is feasible when performed by parents, as they can record lung sounds with quality and can successfully capture adventitious sounds. This study also shows that parents are willing to use this technology in real life to provide feedback to physicians. Thus, smartphone lung auscultation can potentially be performed by parents to monitor children's respiratory status in real life. Additional research is needed to develop this technology further.

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Conflicts of Interest

JAF is a cofounder of MEDIDA, a small medium enterprise that develops mobile technologies for monitoring chronic diseases.

Multimedia Appendix 1
Participants' (N=46) characteristics.
[DOCX File, 23 KB - pediatrics_v7i1e52540_app1.docx]

Multimedia Appendix 2
Comparisons of the agreement for and the proportions of physicians' and parents' quality recordings.
[DOCX File, 23 KB - pediatrics_v7i1e52540_app2.docx]

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Abbreviations

STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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Digital Health as a Mechanism to Reduce Neonatal Intensive Care Unit Admissions: Retrospective Cohort Study

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Abstract

Background: Admission to the neonatal intensive care unit (NICU) is costly and has been associated with financial and emotional stress among families. Digital health may be well equipped to impact modifiable health factors that contribute to NICU admission rates.

Objective: The aim of the study is to investigate how the use of a comprehensive prenatal digital health platform is associated with gestational age at birth and mechanisms to reduce the risk of admission to the NICU.

Methods: Data were extracted from 3326 users who enrolled in a comprehensive digital health platform between January 2020 and May 2022. Multivariable linear and logistic regression models were used to estimate the associations between hours of digital health use and (1) gestational age at birth and (2) mechanisms to reduce the risk of a NICU admission. Multivariable logistic regression models estimated the associations between (1) gestational age at birth and (2) mechanisms to reduce the risk of a NICU admission and the likelihood of a NICU admission. All analyses were stratified by the presence of any gestational conditions during pregnancy.

Results: For users both with and without gestational conditions, hours of digital health use were positively associated with gestational age at birth (in weeks; with gestational conditions: β=.01; 95% CI 0.0006-0.02; *P*=.04 and without gestational conditions: β=.01; 95% CI 0.0006-0.02; *P*=.04) and mechanisms that have the potential to reduce risk of a NICU admission, including learning medically accurate information (with gestational conditions: adjusted odds ratio [AOR] 1.05, 95% CI 1.03-1.07; *P*<.001 and without gestational conditions: AOR 1.04, 95% CI 1.02-1.06; *P*<.001), mental health management (with gestational conditions: AOR 1.06, 95% CI 1.04-1.08; *P*<.001 and without gestational conditions: AOR 1.03, 95% CI 1.02-1.05; *P*<.001), and understanding warning signs during pregnancy (with gestational conditions: AOR 1.08, 95% CI 1.06-1.11; *P*<.001 and without gestational conditions: AOR 1.09, 95% CI 1.07-1.11; *P*<.001). For users with and without gestational conditions, an increase in gestational age at birth was associated with a decreased likelihood of NICU admission (with gestational conditions: AOR 0.62, 95% CI 0.55-0.69; *P*<.001 and without gestational conditions: AOR 0.59, 95% CI 0.53-0.65; *P*<.001). Among users who developed gestational conditions, those who reported that the platform helped them understand warning signs during pregnancy had lower odds of a NICU admission (AOR 0.63, 95% CI 0.45-0.89; *P*=.01).

Conclusions: Digital health use may aid in extending gestational age at birth and reduce the risk of NICU admission.

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KEYWORDS

digital health; education; gestational conditions; Maven Clinic; mental health management; neonatal; NICU admissions; neonatal intensive care unit; mobile phone

Introduction

In the United States, most newborns who are born prematurely (before 37 weeks, 0 days gestation), with low birth weight (<2500 g), or with a health condition requiring special care are admitted to the neonatal intensive care unit (NICU) [1]. In 2022, approximately 9.5% of all infants born in the United States were admitted to the NICU [2]. NICUs are essential, as they improve infant survival and reduce morbidity for premature and sick infants [3]. However, admission to the NICU is costly and has been associated with financial and emotional stress among parents [4,5]. The parent-infant separation and parental stress resulting from NICU admission have been associated with poor maternal-infant attachment [6], lower breastfeeding rates [7], and higher rates of postpartum depression and anxiety [8], all of which may compromise subsequent pediatric health and development.

Several risk factors at the maternal level contribute to a higher likelihood of premature birth, which in turn increases the risk of NICU admission [9-11]. Primary maternal risk factors for a NICU admission include advanced age, chronic disease, substance use, preeclampsia, and peripartum infection [12-14]. Further, maternal stress, anxiety, and depression during pregnancy are associated with low birth weight and preterm birth [15-17]. At the institutional level, otherwise healthy infants who are born at hospitals with a high number of NICU beds have an increased likelihood of a NICU admission [10,18].

Previous interventions have successfully reduced the likelihood of a NICU admission with programs centered around increased patient education, access to care, and care coordination [19-21]. Digital health, including telemedicine and mobile apps, is increasingly used during pregnancy and may help address current gaps in prenatal care education by making pregnancy services more accessible and affordable [22,23]. By providing care coordination, continuous access to health care providers, and pregnancy-related educational materials, digital health may be well equipped to impact modifiable factors that contribute to NICU admission rates, including disease and mental health management.

In this study, we use data from Maven, a digital health platform, to explore how the use of a prenatal digital health platform that provides access to educational materials, telehealth through care providers, and care coordination is associated with gestational age at birth and mechanisms that may mitigate the risk of a NICU admission. First, we aimed to investigate the association between digital health use with gestational age at birth and mechanisms that could reduce the risk of a NICU admission (ie, mental health management and pregnancy education). Second, we explored whether gestational age at birth and the mechanisms to reduce risk are associated with a decreased likelihood of a NICU admission.

Methods

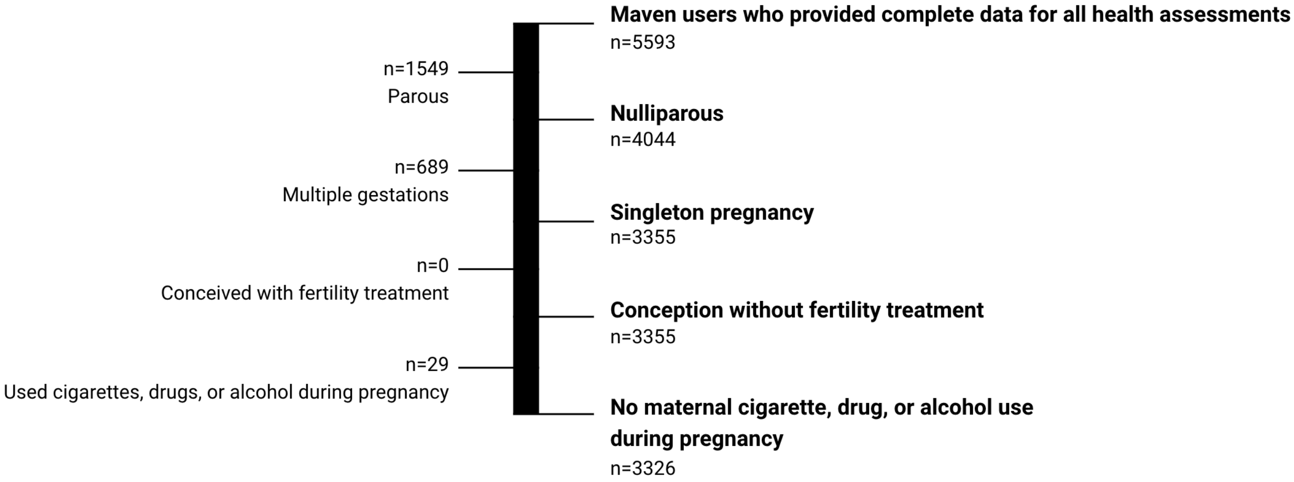
Ethical Considerations

All users consented to the use of their deidentified data for scientific research upon creating a Maven account. This study used deidentified data only, and the protocol was designated as exempt by WCG IRB (waiver 45 CFR § 46.104(d)(4)), an independent ethical review board.

Study Setting and Design

This retrospective cohort study examined the associations between digital health use and NICU admission among pregnant individuals enrolled in Maven. Maven is a comprehensive digital health platform designed to support women’s and family’s health and complement routine prenatal care. Users receive free and unlimited access to Maven as an employer or health plan–sponsored benefit through their own or their partner’s employer. Maven provides a range of digital health education and support services within its platform. Users have access to a care advocate—an allied health professional such as a nurse or social worker—who serves as their primary point of contact within the platform. This advocate helps coordinate digital prenatal services and directs users to relevant providers and resources. Additionally, within the platform, users have access to articles, videos, live classes, and appointments with providers across a variety of specialties, including obstetrics and gynecology, mental health, nutrition, and others. This analysis used both platform-use data and user-reported data from the enrollment questionnaire (completed during pregnancy upon enrollment in Maven) and the postbirth questionnaire (completed after birth). Together, the enrollment and postbirth questionnaires collected data on user demographics, health characteristics, pregnancy outcomes, and the impact of the digital health platform during pregnancy. Data were extracted from 5593 Maven users in the United States who enrolled in Maven’s pregnancy program and completed both health questionnaires between January 1, 2020, and May 27, 2022 (Figure 1). We excluded users who had previously given birth (n=1549), had a multiple pregnancy (n=689), conceived with fertility treatment (n=0), or reported any cigarette, drug, or alcohol use during pregnancy (n=29). These exclusion decisions were made due to the strong associations between experiences in a previous pregnancy or birth [24], multiple gestation [25], and drug or alcohol use with NICU admission [26], independent of other factors.

Figure 1. Flowchart of the users included in the current analysis.



Outcome: NICU Admission

The primary study outcome was the birthing parent report of a NICU admission on the postbirth questionnaire. After birth, users were asked “Did you experience any of the following complications during delivery?” and could select all that apply from a list of complications. Any users who selected “My baby went to the NICU” were considered to have a NICU admission in this analysis.

Hours of Maven Use

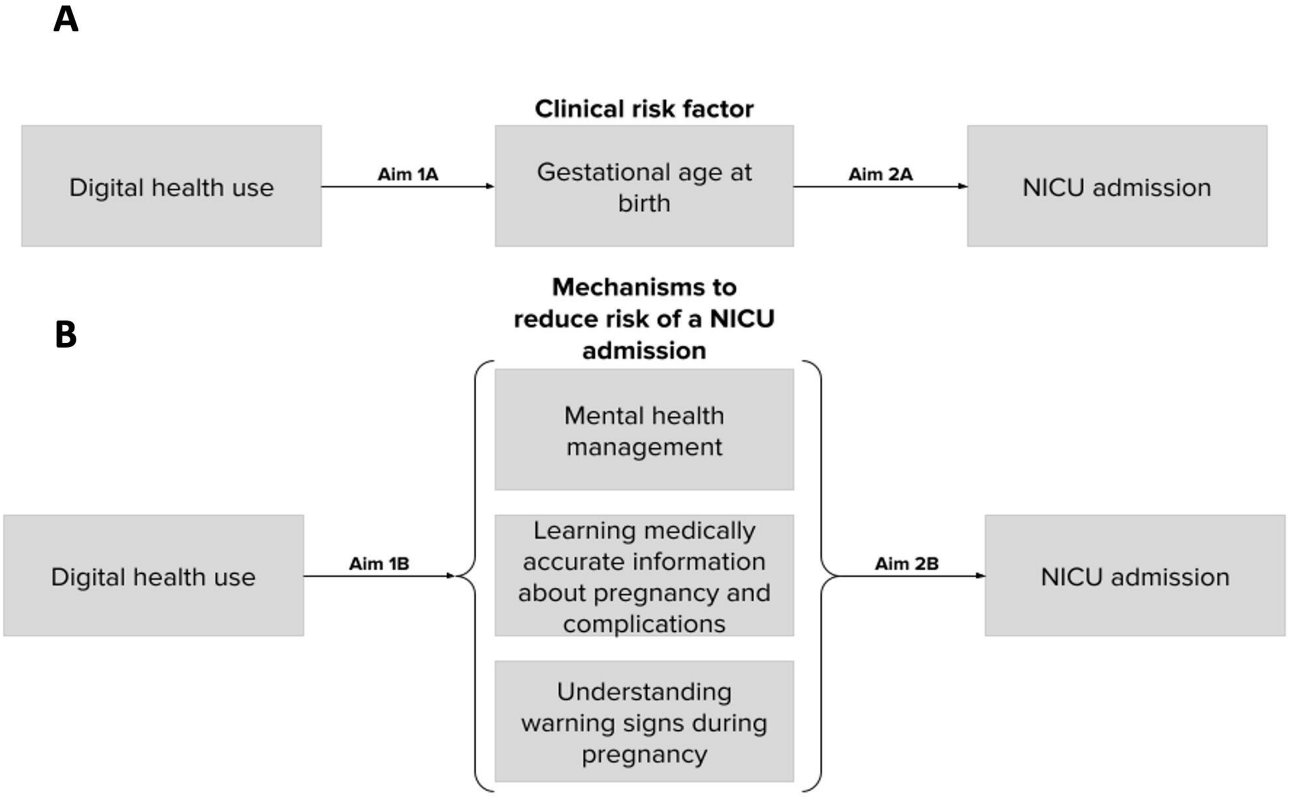
Hours of Maven use was the primary exposure in this analysis. The total number of active hours that each user spent on Maven was calculated from use data (automatically tracked within the platform) by summing the time spent with a care advocate, with a provider, messaging a provider, reading papers, attending web-based classes, or watching class recordings.

Impacts of Digital Health Use

This analysis examined the association between time spent on the platform with gestational age at birth and 3 pathways by which digital health may reduce the risk of a NICU admission (Figure 2A and B). Gestational age at birth was a continuous variable calculated from the difference between the user-reported due date (collected on the enrollment questionnaire) and the user-reported baby date of birth (collected on the postbirth questionnaire).

The three mechanisms of NICU admission risk reduction were (1) mental health management, (2) learning medically accurate information about pregnancy and complications, and (3) understanding warning signs during pregnancy. Each of the mechanisms was assessed on the postbirth questionnaire. To assess mechanisms 1 and 2, users were asked “In what way did Maven influence your experience?” and could select all that apply from a list of ways Maven may have influenced their pregnancy, including “Maven helped me manage anxiety and/or depression” and “Maven helped me learn medically accurate information about pregnancy and complications.” If either of these options were selected, the item was coded as “yes,” and the items were coded as “no” if they were not selected. To assess mechanism 3, users were asked “Did Maven help you understand warning signs during pregnancy?” and users selected “yes” or “no.”

Figure 2. Conceptual model to explore the associations between digital health use and likelihood of an infant NICU admission. (A) Conceptual model to explore the associations between digital health use, gestational age at birth, and likelihood of an infant NICU admission. (B) Conceptual model to explore the associations between digital health use, mechanisms to reduce the risk of a NICU admission, and likelihood of an infant NICU admission. NICU: neonatal intensive care unit.



Gestational Conditions

Given the strong associations between gestational conditions and infant health outcomes [27], all analyses were stratified by the presence of gestational conditions. To capture information on conditions that developed both before and after enrollment into Maven, the following conditions were assessed on both the enrollment and postbirth questionnaires: cholestasis, gestational diabetes, intrauterine growth restriction, high blood pressure, preeclampsia, eclampsia, vaginal blood loss (nonlabor related), problems with the placenta, issues with the cervix, excess or diminished amniotic fluid, infant large for gestational age, perinatal mood disorder, or hemolysis, elevated liver enzymes, and low platelet count syndrome. If a user reported the presence of any of the above conditions during their current pregnancy, they were coded as “Had at least one gestational condition” versus “No gestational conditions.”

Covariates

Data from the enrollment questionnaire were used to create covariates. Ethnicity and race were categorized into “Hispanic or Latinx” and non-Hispanic or Latinx: “Asian or Pacific Islander,” “Black,” “White,” and “other” (comprised of users who reported their race as multiracial or American Indian. This category was created due to a small sample size of users who identified as multiracial or American Indian). To account for the societal and geographical factors that contribute to a NICU admission, we used the Centers for Disease Control and Prevention’s Social Vulnerability Index (SVI) [28]. SVI is a geographic measure of community vulnerability by using data from 4 domains: socioeconomic status, household composition and disability, minority status and language, and housing type and transportation. A continuous SVI score was assigned to each user based on their ZIP code, with an SVI closer to 1 representing high vulnerability. Chronic conditions were assessed as cumulative risk scores, calculated by adding the number of medical conditions reported by each user. Users reported their mode of birth (vaginal or cesarean) on the postbirth questionnaire.

Statistical Methods

We conducted descriptive analyses to explore user demographic and medical characteristics stratified by the presence of gestational conditions. Chi-square or Fisher exact tests were used to assess categorical variables, and 2-tailed *t* tests and Wilcoxon rank-sum tests were used to assess continuous variables.

Adjusted linear regression was used to assess the association between time spent on the digital health platform and gestational age at birth (Figure 2; aim 1A). Adjusted logistic regression was used for all other aims. For aims 1A and 1B (Figure 2), assessing the associations between time spent using the digital health platform, gestational age at birth, and the 3 mechanisms to reduce the risk of NICU admission (mental health management, learning medically accurate information during pregnancy, and understanding warning signs during pregnancy), each component was assessed as an outcome in its own model. For aims 2A and 2B (Figure 2), examining whether gestational age at birth and mechanisms to reduce NICU admissions are associated with the likelihood of a NICU admission, each of the 4 components was assessed as the primary exposure in its own model with a report of a NICU admission as the outcome. Adjusted regression models controlled for age, race and ethnicity, mode of delivery, chronic conditions, SVI, and the number of days enrolled in Maven. All models estimated the effect with 95% CIs, and significance was determined when *P*<.05. All statistical analyses were performed using RStudio (Posit Software, PBC).

Results

Sample Characteristics

Our analytic sample consisted of 3326 pregnant individuals enrolled in the maternity program on the digital health platform. The mean age of our sample was 32.3 (SD 3.89) years. In total, 22.5% (747/3326) of users identified as non-Hispanic Asian or Pacific Islander, 46.5% (1547/3326) as non-Hispanic White, and 14.3% (475/3326) preferred not to disclose their race and ethnicity status (Table 1). Relatively few users reported the presence of any chronic medical conditions, with thyroid disease being the most prevalent (248/3326, 7.5%). During pregnancy, high blood pressure (482/3326, 14.5%) and gestational diabetes (357/3326, 10.7%) were the most common gestational conditions reported. The mean infant gestational age at birth was 39.3 (SD 1.57) weeks. A total of 68.9% (1799/3326) of users reported the digital health platform helped them learn medically accurate information about pregnancy and complications, 59.7% (1912/3326) reported the platform helped them understand warning signs during pregnancy, and 13.8% (361/3326) reported the platform helped them manage their mental health. A majority of 70.8% (2354/3326) of users reported having a vaginal birth, and 10.6% (353/3326) reported their infant was admitted to the NICU.

Compared to users who did not develop any gestational conditions during their pregnancy, users who developed one1 or more gestational conditions were less likely to be non-Hispanic White (44.1% [nn=613/1390], 44.1% vs. 48.2%[nn=934/1936], 48.2%) and more likely to be older (32.8 years y vs. 32.0 years); obese (21.3% [nn=296/1390], 21.3% vs. 9.4%[nn=182/1936], 9.4%); and have a a history of type 1 or type 2 diabetes (2.2% [nn=30/1390], 2.2% vs. 0.2%[nn=3/1936], 0.2%), hypertension (5.5% [nn=77/1390], 5.5% vs. 0.2% nn=3/1936], 0.2%), thyroid disease (8.9% [nn=124/1390,]8.9% vs. 6.4% [nn=124/1936], 6.4%), anxiety (27.3% [nn= =379/1390], 27.3% vs. 18.5% [nn=359/1936], 18.5%), and depression (15.5% [nn=216/1390], 15.5% vs. 9.1% [nn=177/1936], 9.1%). Users with gestational conditions were more likely to report that the digital health platform helped them manage their mental health (15.9% [nn=177/1390], 15.9% vs. 12.3% [nn=184/1936, 12.3%]), deliver preterm (8.7% [nn=121/1390], 8.7% vs. 3.4% [nn=65/1936], 3.4%), have a baby who was admitted to the NICU (15.6% [nn=217/1390], 15.6% vs. 7.0% [nn=136/1936], 7.0%), and less likely to have a vaginal birth (62.7% [nn=872/1390], 62.7% vs. 76.5% [nn=1482/1936], 76.5%). The average amount of digital health use during pregnancy was 8.1 (SD 7.9) hours. Digital health use did not vary by the presence of gestational conditions.

Table . User demographic characteristics and select chronic conditions across gestational conditions groups[a].

		Whole sample (N=3326)	0 gestational conditions (n=1936)	≥1 gestational conditions (n=1390)	*P* value
User characteristics					
	Age, mean (SD)	32.3 (3.89)	32.0 (3.63)	32.8 (4.18)	<.001
	Race and ethnicity, n (%)				.03
	Hispanic	325 (9.8)	179 (9.2)	146 (10.5)	
	Non-Hispanic Asian	747 (22.5)	419 (21.6)	328 (23.6)	
	Non-Hispanic Black	147 (4.4)	71 (3.7)	76 (5.5)	
	Non-Hispanic multiracial or American Indian	85 (2.6)	49 (2.5)	36 (2.6)	
	Non-Hispanic White	1547 (46.5)	934 (48.2)	613 (44.1)	
	Prefer not to say	475 (14.3)	284 (14.7)	191 (13.7)	
	Social Vulnerability Index, mean (SD)	0.38 (0.20)	0.38 (0.20)	0.38 (0.20)	.25
	BMI (kg/m^2), n (%)				<.001
	Underweight (<18.5)	139 (4.2)	92 (4.8)	47 (3.4)	
	Normal weight (18.5 - 24.9)	1906 (57.3)	1229 (63.5)	677 (48.7)	
	Overweight (25.0 - 29.9)	803 (24.1)	433 (22.4)	370 (26.6)	
	Obese (≥30)	478 (14.4)	182 (9.4)	296 (21.3)	
History of chronic conditions, n (%)					
	Thyroid disease	248 (7.5)	124 (6.4)	124 (8.9)	.01
	Autoimmune disease	99 (3)	49 (2.5)	50 (3.6)	.07
	Hypertension	80 (2.4)	3 (0.2)	77 (5.5)	<.001
	Diabetes (type 1 or type 2)	33 (1)	3 (0.2)	30 (2.2)	<.001
	Blood disorder	24 (0.7)	10 (0.5)	14 (1)	.10
	Heart disease	19 (0.6)	8 (0.4)	11 (0.8)	.15
	Thrombophilia	16 (0.5)	6 (0.3)	10 (0.7)	.09
	Kidney disease	11 (0.3)	7 (0.4)	4 (0.3)	.77
	HIV/AIDS	1 (0)	0 (0)	1 (0.1)	.42
History of reproductive conditions, n (%)					
	Abnormal pap	322 (9.7)	176 (9.1)	146 (10.5)	.17
	Polycystic ovarian syndrome	223 (6.7)	117 (6)	106 (7.6)	.07
	Sexually transmitted disease	104 (3.1)	55 (2.8)	49 (3.5)	.26
	Endometriosis	74 (2.2)	36 (1.9)	38 (2.7)	.09
History of mental health conditions, n (%)					<.001
	Anxiety	738 (22.2)	359 (18.5)	379 (27.3)	
	Depression	393 (11.8)	177 (9.1)	216 (15.5)	
Gestational conditions, n (%)					—[b]
	High blood pressure	482 (14.5)	—	482 (34.7)	
	Gestational diabetes	357 (10.7)	—	357 (25.7)	

	Whole sample (N=3326)	0 gestational conditions (n=1936)	≥1 gestational conditions (n=1390)	*P* value
Problems with the placenta	217 (6.5)	—	217 (15.6)	
Preeclampsia, eclampsia, or HELLP[c]	212 (6.4)	—	212 (15.3)	
Vaginal blood loss (excluding labor)	198 (6)	—	198 (14.2)	
Infant large for gestational age	145 (4.4)	—	145 (10.4)	
Excess or diminished amniotic fluid	134 (4)	—	134 (9.6)	
Issues with the cervix	100 (3)	—	100 (7.2)	
Intrauterine growth restriction	90 (2.7)	—	90 (6.5)	
Perinatal mood disorder	70 (2.1)	—	70 (5)	
Cholestasis	56 (1.7)	—	56 (4)	
Pregnancy outcomes and complications				
Gestational age at birth (weeks), mean (SD)	39.3 (1.57)	39.6 (1.25)	38.9 (1.86)	<.001
Gestational age at birth category (weeks), n (%)				<.001
Preterm (<37)	186 (5.6)	65 (3.4)	121 (8.7)	
Early term (37-<39)	717 (21.6)	334 (17.3)	383 (27.6)	
Full term (39-<41)	2119 (63.7)	1320 (68.2)	799 (57.5)	
Late term (41-<42)	295 (8.9)	211 (10.9)	84 (6)	
Postterm (≥42)	9 (0.3)	6 (0.3)	3 (0.2)	
NICU admission[d], n (%)	353 (10.6)	136 (7)	217 (15.6)	<.001
Vaginal birth, n (%)	2354 (70.8)	1482 (76.5)	872 (62.7)	<.001
Mechanisms to reduce risk of a NICU admission, n (%)				
Mental health management	361 (13.8)	184 (12.3)	177 (15.9)	.01
Learning medically accurate information about pregnancy and complications	1799 (68.9)	1018 (67.9)	781 (70.3)	.19
Understanding warning signs during pregnancy	1912 (59.7)	1131 (60.7)	781 (58.2)	.15
Digital health use				
Digital health use during pregnancy (hours), mean (SD)	8.10 (7.88)	8.02 (7.64)	8.21 (8.21)	.70

[a] Data are displayed for users who enrolled in Maven Clinic and gave birth between January 1, 2020, and September 19, 2022.

[b] Not applicable.

[c] HELLP: hemolysis, elevated liver enzymes, and low platelets.

[d] NICU: neonatal intensive care unit.

Associations Between Digital Health Use, Gestational Age at Birth, and Mechanisms to Reduce Risk of a NICU Admission

In analyses of users who did not develop any gestational conditions during pregnancy, adjusted models revealed that for every 1-hour increase in digital health use, users experienced an increase in gestational age by 0.01 weeks (β=.01; 95% CI 0.0006-0.02; *P*=.04); a 9% increase in their odds of understanding warning signs during pregnancy (adjusted odds ratio [AOR] 1.09, 95% CI 1.07- 1.11; *P*<.001); a 3% increase in their odds of reporting that the platform helped the user manage their mental health (AOR 1.03, 95% CI 1.02-1.05; *P*<.001); and a 4% increase in their odds of reporting that the platform helped the user identify medically accurate information (AOR 1.04, 95% CI 1.02-1.06; *P*<.001; Table 2).

In analyses of users who developed 1 or more gestational conditions during pregnancy, adjusted models revealed that for every 1-hour increase in digital health use, users experienced an increase in gestational age by 0.01 weeks (β=.01; 95% CI 0.0006-0.02; *P*=.04), an 8% increase in their odds of understanding warning signs during pregnancy (AOR 1.08, 95% CI 1.06-1.11; *P*<.001), a 6% increase in their odds of reporting that the platform helped the user manage their mental health (AOR 1.06, 95% CI 1.04-1.08; *P*<.001), and a 5% increase in their odds of reporting that the platform helped the user identify medically accurate information (AOR 1.05, 95% CI 1.03-1.07; *P*<.001).

Table . Associations between hours of digital health use, gestational age at birth, and mechanisms to reduce risk of a neonatal intensive care unit admission[a].

	No gestational conditions (n=1936)								≥1 gestational conditions (n=1390)							
	Gestational age at birth (weeks)		Understanding warning signs during pregnancy		Mental health management		Learning medically accurate information		Gestational age at birth (weeks)		Understanding warning signs during pregnancy		Mental health management		Learning medically accurate information	
	Adjusted β (95% CI)	*P* value	AOR[b] (95% CI)	*P* value	AOR (95% CI)	*P* value	AOR (95% CI)	*P* value	Adjusted β (95% CI)	*P* value	AOR (95% CI)	*P* value	AOR (95% CI)	*P* value	AOR (95% CI)	*P* value
Digital health use (hours)	0.01 (0.0006-0.02)	.04	1.09 (1.07-1.11)	<.001	1.03 (1.02-1.05)	<.001	1.04 (1.02-1.06)	<.001	0.01 (0.0006-0.02)	.04	1.08 (1.06-1.11)	<.001	1.06 (1.04-1.08)	<.001	1.05 (1.03-1.07)	<.001

[a] Adjusted for age, Social Vulnerability Index, mode of delivery, race and ethnicity, chronic conditions, and days on Maven.

[b] AOR: adjusted odds ratio.

Associations Between Gestational Age at Birth, Mechanisms to Reduce Risk of a NICU Admission, and the Likelihood of a NICU Admission

In analyses of users who did not develop any gestational conditions during pregnancy, adjusted logistic regression models found that for every 1-week increase in infant gestational age at birth, users experienced a 41% reduction in the odds of their infant being admitted to the NICU (AOR 0.59, 95% CI 0.53-0.65; *P*<.001; Table 3). Understanding warning signs during pregnancy (*P*=.05), learning medically accurate information about pregnancy and complications (*P*=.33), and mental health management (*P*=.83) were not significantly associated with the odds of a NICU admission at birth.

Table . Association between gestational age at birth, mechanisms to reduce risk of neonatal intensive care unit (NICU) admission, and the likelihood of a NICU admission[a].

	0 gestational conditions (n=1936)		≥1 gestational conditions (n=1390)	
	Adjusted odds ratio of a NICU admission (95% CI)	*P* value	Adjusted odds ratio of a NICU admission (95% CI)	*P* value
Gestational age at birth (weeks)	0.59 (0.53-0.65)	<.001	0.62 (0.55-0.69)	<.001
Understanding warning signs during pregnancy	0.73 (0.53-1.01)	.05	0.63 (0.45-0.89)	.01
Learning medically accurate information	1.22 (0.83-1.83)	.33	0.92 (0.61-1.42)	.71
Mental health management	0.95 (0.56-1.52)	.83	1.45 (0.83-2.42)	.17

[a] Adjusted for age, Social Vulnerability Index, mode of delivery, race and ethnicity, chronic conditions, and days on Maven.

In analyses of users who developed 1 or more gestational conditions during pregnancy, adjusted logistic regression models found that for every 1-week increase in infant gestational age at birth, users experienced a 38% reduction in the odds of their infant being admitted to the NICU (AOR 0.62, 95% CI 0.55-0.69; *P*<.001; Table 3). Additionally, users who reported understanding warning signs during pregnancy experienced a 37% reduction in the odds of their infant being admitted to the NICU (AOR 0.63, 95% CI 0.45-0.89; *P*=.01; Table 3). Learning medically accurate information about pregnancy and complications (*P*=.71) and mental health management (*P*=.17) were not significantly associated with the odds of a NICU admission.

Discussion

Principal Results

The results of this retrospective cohort study suggest that the use of a comprehensive digital health platform during pregnancy helps users with and without gestational conditions extend their gestational age at birth, learn medically accurate information, manage their mental health, and identify warning signs during pregnancy. For all users, an increase in gestational age at birth was associated with a decreased likelihood of a NICU admission. Additionally, among users who developed 1 or more gestational conditions during pregnancy, those who reported that the digital health platform helped them identify warning signs during pregnancy had a 37% reduction in the odds of their infant being admitted to the NICU.

Comparisons With Prior Work

Studies have found that birth outcomes can be improved through resources that support and complement traditional prenatal care. Previously, these influential resources have involved care coordination, transportation to appointments, and education [19-21]. Similarly, digital health can provide continuous care coordination and increased access to providers and educational materials [29]. This type of continuous support has been shown to have several benefits: improving in-clinic conversations with providers, influencing one's mode of delivery and birth plan [30,31], managing mental health throughout pregnancy [32], and enabling users to identify and address problems immediately (vs waiting until their next in-person appointment) [33]. Additionally, digital health provides a patient-centered approach to complement routine prenatal care throughout pregnancy [34]. While routine prenatal care is limited by time constraints and other clinical needs of each visit, digital health is especially equipped to provide patient education and offer individualized content that may address patient concerns between in-person appointments [35]. In our study, using a digital health platform was linked to mental health management, learning medically accurate information, and understanding warning signs during pregnancy. Additionally, understanding these warning signs was associated with a reduced likelihood of NICU admission. While mental health management and learning medically accurate information about pregnancy were not associated with NICU admission, improvement in perinatal mental health and education may still be important in mitigating the risk of adverse obstetric outcomes including NICU, and these factors should continue to be investigated in future work.

In our sample, higher levels of digital health use were associated with an increase in gestational age at birth. It is important to note that while statistically significant, our effect size is quite small. For every 1 hour of digital health use, we saw an increase in gestational age by 0.01 weeks (approximately 2 hours). While the effect itself is small, identifying any signal is encouraging, given that an increase in gestational age decreases the risk of preterm birth and related complications, including a NICU admission [1]. This finding is consistent with previous research, which has shown that among pregnant individuals with gestational conditions, access to telehealth care is associated with a decreased likelihood of preterm birth [36,37]. Our results are especially promising because in this sample, digital health use was self-directed by the users. While the digital health platform offered resources and services aimed at reducing the risk of NICU admission, users were not given instructions on how frequently to use the platform and were not required to use specific types of care or resources. Future interventions with targeted protocols may yield even greater impacts.

Among users with 1 or more pregnancy-related conditions, users who reported that the digital health platform helped them understand warning signs during pregnancy had a reduced likelihood of a NICU admission. Given the rapid changes that occur as a pregnancy progresses, a diagnosis of a clinical condition like gestational hypertension or diabetes in an otherwise healthy individual may yield questions or concerns that arise outside of a monthly prenatal care appointment [34,38]. Digital health platforms can offer access to providers as well as educational content to help users manage their diagnosis outside of traditional in-person care [39,40].

Limitations

Limitations of this study should be considered. First, our study population consisted primarily of commercially insured individuals who had internet access on a smartphone device or computer. Second, the majority identified as White and non-Hispanic, potentially limiting the generalizability and scalability of these findings.

Conclusions

Digital health use may aid in reducing the risk of a NICU admission by extending gestational age at birth and helping individuals recognize warning signs during their pregnancy. As the use of digital health during pregnancy increases, this model of care may serve as a blueprint for how digital services may contribute to disease management during pregnancy and improve birth outcomes.

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Conflicts of Interest

This research was funded by Maven Clinic through the employment of authors. HRJ, NH, CM, and NS hold positions at Maven Clinic and have equity in Maven Clinic, and AKB is a paid consultant for Maven Clinic.

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Abbreviations

AOR: adjusted odds ratio
NICU: neonatal intensive care unit
SVI: Social Vulnerability Index

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Evaluating a Mobile App Supporting Evidence-Based Parenting Skills: Thematic Analysis of Parent Experience

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Abstract

Background: Disruptive behavior disorders are among the most common disorders of childhood, and evidence-based parenting programs are the first-line treatment. Digital microinterventions have been proposed as one possible means of supporting parenting style change by giving parents in-the-moment advice about how to respond to challenging behavior. Until now, no digital microintervention supporting evidence-based parenting skills programs has been evaluated.

Objective: The aim of this study is to evaluate the subjective experience of parents using a digital microintervention to support evidence-based parenting skills, with particular attention to acceptability, usability, family relationships, and parents' values.

Methods: We conducted serial interviews with 11 parents of 33 children before and after spending 3 weeks using an app including 3 digital microinterventions. Parents were recruited via local authorities in the Midlands region of the United Kingdom. Previous participation in a parenting program was an inclusion criterion. Interviews explored family composition; child behavior problems; and experience of using the mobile app, including barriers to use. Thematic analysis was conducted from a user-centered design perspective, and illustrative case vignettes were produced.

Results: Many parents used the app in ways that helped them rather than strictly following the instructions they were given. Parents described a range of barriers to using the app including practical problems and failure to change child behavior. Parents and children responded in a variety of ways to the use of the phone, with many wholeheartedly embracing the convenience of technology. Case vignettes illustrate the uniqueness of each family's experience.

Conclusions: Parents' use of a mobile app supporting evidence-based parenting skills is difficult to predict due to the unique challenges each family encounters. Many parents found it an acceptable and helpful addition to family life, but increased personalization is likely to be key to supporting parents. Future digital microintervention developers should keep in mind that parents are likely to use the app pragmatically rather than following instructions, may struggle to use a complex app under pressure, and are likely to hold complex feelings about parenting with an app.

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KEYWORDS

digital microintervention; parenting app; product management; parent; parents; parenting; app; apps; usability; acceptability; family; families; interview; interviews; pediatric; pediatrics; child; children; youths; experience; experiences; attitude; attitudes; opinion; perception; perceptions; perspective; perspectives; acceptance; behavior; behaviors; disruptive behavior; thematic analysis

Introduction

Disruptive behavior disorders such as conduct disorder and oppositional defiant disorder are among the most common mental health conditions of childhood [1]. Untreated children with conduct disorder persistently violate the rights and boundaries of other children as well as adults [2]. Although phenotypes vary, young people presenting with some of the criteria for conduct disorder are at high risk for future mental illness, educational failure, and contact with the criminal justice system [3-5].

This study evaluated an app that was designed to help parents to use evidence-based parenting skills (including praise, age-appropriate time-out, and relaxation exercises), which are shown to improve children's behavior problems such as angry outbursts, violence, and refusing to follow instructions.

Evidence-based parenting skills programs are the first-line treatment for disruptive behavior disorders according to the National Institute for Health and Care Excellence [6]. Triple P, Incredible Years, and Chicago Parenting Program are supported by evidence from systematic reviews and meta-analyses. Changes in parenting style can lead to children building stronger self-esteem and learning to understand and respond to limits [7,8]. These programs can have long-term benefits; randomized controlled trials have shown that they set children on a path for better relationships, reduced criminal activity, and fewer behavioral diagnoses up to 8 years later [9].

Incredible Years, Triple P, and Chicago Parenting Program tend to draw on a range of didactic approaches to equip parents with new skills. The programs are frequently run as groups with 6 - 12 parents meeting weekly for 3 or 4 months, during which time, they use roleplay, videos, and group discussions to learn new skills [10]. Programs generally begin by supporting parents to improve their relationship with their child through positive play and showing warmth before moving to equip parents with proportionate and effective approaches to setting limits such as ignoring unwanted behavior, distracting the child, and introducing natural or logical consequences.

This paper focuses on 3 particular skills. The first is praise: praising a child's successes is an important part of building self-esteem, but vague praise of children with low self-esteem or, worse, backhanded praise, can damage the parent-child relationship [11]. The second is mindfulness: learning to calm raised emotions is a valuable skill for children with behavior problems, but there is a limited emotional window where children are responsive to mindfulness [12]. The third is a skill called "time-out" in Incredible Years and "quiet time" in Triple P, which provides an effective means of setting limits when carried out correctly. However, parents often struggle to use this skill, and resources available on the web conflict with the evidence for an effective time-out [13].

Changing parent behavior remains a significant challenge. One important consideration is that children's behavior often begins to get worse as parents introduce evidence-based parenting techniques, so-called "extinction bursts," which can wrongly give parents the impression that the techniques are not working [14]. A systematic review of face-to-face parenting programs for disruptive behavior found that only half of parents who start programs finish them [15].

The advice offered on apps and websites sometimes runs contrary to the evidence [13,16]. Although online programs provide an alternative to face-to-face programs, engagement appears to be even lower than in face-to-face programs, and evidence of lasting behavior change is weaker [17,18]. Extinction bursts are one reason for poor engagement: worsening behavior means parents lose faith in the program and quit. One parenting skills practitioner described to us the period between parental behavior change and child behavior improvement as the "giving-up gap." At the same time, many parents fail to implement parenting techniques learned in a calm classroom once they are in a hectic home environment. This is in keeping with Loewenstein's concept of the hot-cold empathy gap: in a calm state, people struggle to imagine the challenges they will face when they are emotionally aroused [19].

Given these 2 challenges, it is worthwhile considering whether more engaging digital interventions could change behavior. Baumel et al [20] called for digital microinterventions to help parents achieve change in parenting style and downstream improvements for parents. They define digital microintervention as "highly focused interventions delivered in the context of a person's daily life with little burden on the individual" [20]. Parents report lacking free time and having limited cognitive bandwidth for learning new skills, and as such, immediate interventions with little burden have great potential [21]. Digital microinterventions have the potential to address the giving-up gap by helping parents notice their achievements and overcome the hot-cold empathy gap by giving guidance in the heat of the moment.

Despite Baumel et al's [20] call to action, several unknowns remain. The cognitive constraints parents face may make an app overwhelming or may make prompts on an app particularly useful. Parents may prefer not to use a digital device to support parenting or may find it convenient. Parents may find that they prefer comprehensive instructions on parenting rather than a highly focused intervention. No digital microintervention has previously been used to guide parents through evidence-based skills in the moment when children are displaying disruptive behaviors.

In this paper, we aimed to evaluate the subjective experience of parents using a digital microintervention to support evidence-based parenting skills, with particular attention to acceptability, usability, family relationships, and parents' values.

Methods

Context and Target Population

Participants were recruited through several parenting programs run by local authorities across the Midlands region of the United Kingdom. Recruitment was supported by parenting program practitioners who advertised the study by emailing the study invitation to parents who had recently completed a program or by directly inviting parents who attended their final sessions. Others were recruited by word of mouth around the local authority. A participant information leaflet was shared with interested parents. We aimed to establish a sample of 10 participants in keeping with other recent pilots of parenting apps and following the 10±2 rule in usability testing [22,23]. Included parents were aged 18 years and older and had a child aged 2 - 10 years. Parents were included if they had sufficient concerns about their child's behavior to be referred to a parenting skills program. By only including parents who had previously benefited from a parenting skills program, we ensured that they had received support with the basic components of parenting skills. The intervention is intended for use by parents who have attended a parenting skills program so this inclusion criterion was essential to the external validity of the intervention. Parents were excluded if they did not have an Android or iOS smartphone, which could use the app.

Intervention

We previously developed a mobile app for iOS and Android through an iterative coproduction process involving 42 parenting skills practitioners reported elsewhere [24]. This app guided parents through using praise, mindfulness, and time-out or quiet time. It guided parents through using praise with a list of scrollable images with simple instructions on them. It guided parents through mindfulness by including a visual graphic helping children use "box breathing" as well as a guide walking parents through using a sensory grounding technique [25].

Procedures

Each participant was interviewed twice in order to develop a rich understanding of how the digital microintervention fitted into family life [26]. At interview 1, participants completed a consent form, were offered a participant information form, and had the opportunity to ask any questions about the research. Then, they answered questions about their family composition, parenting style, and experience of parenting skills. They also talked about their child's behavior problems and the strategies they use to manage these. Then, they were given a tour of the app and supported to download it to their own mobile device. They were asked about their initial responses to the app, including which features they thought could be useful or unhelpful. Topic guides are reported in Multimedia Appendix 1.

When they were shown the app, little specific psychoeducation was delivered, as they had already attended a parenting program. However, the app included suggestions to only use time-out or time in under circumstances of oppositional behavior or violence in keeping with best practice. Parents were encouraged to use the mindfulness activities with and without their children as they wished. They were encouraged to review the praise guidance, which offered very simple prompts to praise children frequently.

At the end of interview 1, participants received a US $32 shopping voucher and were invited to use the app and book a second interview about 3 weeks later following similar app pilots [27,28]. At interview 2, parents were asked whether they had used the app and how they had found the experience. Parents were prompted to talk about any features they had found helpful and any problems they had encountered. The whole incentive for participating was given during interview 1 to make it easier for parents to exit the study if they wished to.

All interviews were conducted remotely by NH and CT via Microsoft Teams or WhatsApp Voice Call and recorded with consent. All interviews were audio recorded and transcribed. If participants wished to have a friend or family member present during the interviews, this was accommodated. Transcripts were not returned to participants for comments.

Analysis

Analysis was conducted by NH and JLS. Thematic analysis was conducted using NVivo (version 1.5; Lumivero) and followed the principles set out by Braun and Clarke [29,30] using an inductive approach with a theoretical underpinning in user-centered design. Analysis was also informed by a narrative lens in order to develop a richer understanding of how the digital microinterventions had interplayed with the dynamic stories of the families because "narratives provide us with access to people's identity and personality" [31]. The narrative approach also helps present the uniqueness of each family's story. Both NH and JLS read and reread the data before generating initial codes and searching for themes. Themes were reviewed discursively and named by NH. The coding framework is given in Table 1 and findings are discussed in detail below.

Table . Coding framework and illustrative quotations.

Themes		Representative quotations
Theme 1: Unexpected uses of the app		
	1.1: Different children	“I only tried it twice in my 10 year old cause I found he got more annoyed. I probably used it about five times with my 4 year old.”
	1.2: Learning the app	“I spent the next day like on the app, seeing what was on there and stuff”
	1.3: Different timers	“I’ve just remembered what it said and it’s like if it’s three minutes, or whatever, I’ve just put on my Google (dot)”
	1.4: Specific contexts	“I’ve used it generally every night, before she goes to bed, with my little one. We do a little bit of breathing to like, calm down”
Theme 2: Not using the app		
	2.1: Phone unavailable	“It’s been hard if my phones dying of battery”
	2.2: Forgetting	“I think it’s remembering in the moment to actually pick up my phone and think to use it when it’s happening.”
	2.3: Urgency	“I don’t know if you’re able to do voice activation or just an easier way to access those particular parts where you need them in that moment.”
	2.4: Not getting good results	“He got put in time out cause he’d hit me and he’d hit his younger brother. And I had to keep putting him back in time out, like because he kept going. And I kept making him sit. But like even after the time he just, he was just really upset.”
Theme 3: Parenting with a mobile app		
	3.1: Surprised by mobile parenting	“Before I knew about this, I never even considered there would be an app for this sort of thing”
	3.2: Using a phone is inappropriate	“I have issues as a professional with electronics and devices and as a parent and I can limit it, but in this case I don’t see it as a problem”
	3.3: Phones are helpful and convenient	“It’s not a distraction. it’s a useful tool to have”

Full transcripts include extensive personal content relating to children so they are not presented. Instead, anonymized brief narrative case studies illustrate the individuality of each included family. Each relates to a specific interviewee and draws together examples of their family life. Two brief case studies are presented in the *Results* section (see Multimedia Appendix 2 for others). The results were presented in keeping with the COREQ (Consolidated Criteria for Reporting Qualitative Research) [32].

Ethical Considerations

Ethics approval was obtained from the Biomedical and Scientific Research Ethics Committee at the University of Warwick (BSREC 34/22 - 23). Informed consent was obtained from all participants, and data were anonymized.

Research Team and Reflexivity

NH and CT conducted the interviews, and participants were aware that NH was a psychiatrist with experience supporting parents concerned about their children’s behavior and well-being. Participants were referred to the research from a trusted source, the parenting team already supporting them, so participants may have expected the digital microintervention to be useful. NH and CT therefore actively sought to draw out the problems with the digital microintervention, but 2 participants nevertheless made apologetic comments including “I’m not saying that this is any reflection on the app at all” and “I looked through it like last night just kind of to refresh it. I wouldn’t say I look at it every, like every day.” When participants made comments along these lines, they were reminded that the aim of the research was to identify any problems, not just strengths.

The analysts who contributed to the thematic analysis and editing of the brief case studies, PW and JLS, had limited previous contact with these particular families but were involved in developing the app so they contributed a more technology-focused perspective than NH. DG was not directly involved in data collection or analysis or software development so he provided a different set of perspectives.

Results

Participants

Overview

In total, 11 parents of 33 children were included. All were female, and all had at least 1 child aged 2 - 10 years. Among the participants' 33 children, 1 was 18 years, and 6 others were 10 years and older. One was younger than 2 years. Only 1 was an only child. All used social media, most commonly Instagram, Facebook, and WhatsApp. Table 2 gives the characteristics of the included parents.

On average, interview 1 lasted 38 minutes and 42 seconds, and interview 2 lasted 21 minutes and 8 seconds. One participant did not attend a second interview and did not give a reason. All 10 parents who attended interview 2 reported that they had used the app in some form.

Table . Characteristics of included parents.

Topic	Parents (N=11), n (%)
Parents with more than 1 child	10 (91)
Any child with autistic spectrum disorder or attention-deficit/hyperactivity disorder	4 (36)
Use of time-out or naughty step or quiet corner	10 (91)
Past use of parenting app	2 (18)
Past use of parenting books	4 (36)
Use of social media	11 (100)
Lived with partner	7 (63)

Parenting Skills Background

Four children had diagnoses of attention-deficit/hyperactivity disorder or autistic spectrum disorder. Four participants were the only adults living at home. In total, 4 had used parenting books in the past, but only 2 had used a parenting app before. Only 1 had never used any variant of time-out or quiet time.

Participants reported a range of techniques or methods they took to managing behavioral and emotional problems prior to being offered the app. These included evidence-based techniques like distracting children, ignoring unwanted behavior, or using star charts. Some focused on managing emotions through calming breathing, coloring, or using an anger scale to notice when they are becoming upset. Other parents mentioned negative reinforcement through shouting, and one suggested other parents used corporal punishment. Encouraging physical touch was also identified as a useful emotion regulation technique, and predictable meal plans were important to another family. One parent mentioned using melatonin to manage behavior problems.

Comments Particular to This App

Reported strengths of the app including the mindfulness techniques and the advice on using praise, reducing excessive punishment, impulsivity, and inconsistency. They also approved of the prompts to remind parents to use positive parenting skills. They noted some weaknesses of the app including technical bugs, navigation difficulties, as well as the calming breathes being too slow for small children.

Thematic Analysis: Parents' Experience of Using a Parenting App

To address out main research question, we conducted a thematic analysis of the interviews in relation to parent's experience of using the app. Table 1 shows the coding framework.

Theme 1: Unexpected Uses of the App

Theme 1.1: Different Children

Parents reported that they had used the app with some children but not with others. This is certainly appropriate for parents with older or younger children, but parents even found that not all of their children in the age range 2 - 10 years had been responsive to the app. This ran contrary to our expectation that the app would increase consistency between children by supporting parents to use the same activities with all age-appropriate children. Several had tried the app with more than 1 child before deciding which one it was best suited to.

> *I've tried it once with (child 1) because she doesn't tend to get to a point where she needs it. Normally if I say to her "calm" it stops. It's more for (child 2) I've used it for the calming time which has worked quite nicely and I think he's liked it.* [Participant 4, interview 2]
>
> *I think I only tried it twice in my 10 year old cause I found he got more annoyed. I probably used it about five times with my 4 year old.* [Participant 9, interview 2]

Theme 1.2: Learning the App

Although we expected the app to be used as a digital microintervention in the heat of the moment, some parents used it as a way of learning instead. Some read the information and memorized the approaches to the problems. Others used it like a game to "play through" the possible problems and prepare a strategy. One parent described it as "almost like, you know, pretending to click through to the options to see what was behind it" [Participant 11, interview 2].

> *After our discussion, yeah, I spent the next day like on the app, seeing what was on there and stuff. And*

> *I was like. OK, that’s handy.* [Participant 9, interview 2]

The praise section was particularly well suited to being used for learning only and then applying the skills at another time. Although the app included prompts and reminders to use praise, many parents primarily read through the praise advice.

> *It’s like a slideshow of pictures and with some information and it’s regarding when to give children praise and there was a few other things on there, which I found was a really good read.* [Participant 2, interview 2]

Theme 1.3: Different Timers

Although parents used the mindfulness and praise advice as recommended, they often took the time-out information but used different timers around the home instead of the app’s built-in timer. Once they had learned how the app worked, some preferred to link it to a timer that their child could see as well or a timer in a different space in the house.

> *So I’ve just remembered what it said and it’s like if it’s three minutes, or whatever, I’ve just put on my Google and just been like “Ohh hey Google, set the timer for three minutes.”* [Participant 6, interview 2]

> *We have some egg timers and we have the ticking timers as well so I tend to use them anyway. So I wouldn’t necessarily use it on via the app. But if I was a parent who wasn’t already using the timers that I’ve got, then I think it was a good idea on the app.* [Participant 2, interview 2]

Theme 1.4: Specific Contexts

Some parents reported that they primarily used the app in particular settings. The mindfulness section was intended for parents to use with their child in a relaxed state so they would be prepared to apply the same skills in a difficult context. This may have been due to a change in the environment or a daily routine.

> *We’ve used it out and about we used it on holiday. We used it in the airport. We’ve used it like when we’ve been out in the car and things like that, and she’s getting really good at using it herself.* [Participant 10, interview 2]

> *I’ve used it generally every night, before she goes to bed, with my little one. We do a little bit of breathing to like, calm down and calm down function quick timer and she seems to like that.* [Participant 5, interview 2]

Theme 2: Not Using the App

Theme 2.1: Phone Unavailable

Some parents reported that they did not use the app because their phone was not in hand at the moment when they needed it. This was generally because it was somewhere else around the house, possibly on charge or being used by another child.

> *Maybe one of the kids is watching YouTube on the phone or like kids tube or whatever, so I can’t just take it off one of the other children because one of them’s misbehaving.* [Participant 6, interview 2]

> *It’s been hard if my phones dying of battery and stuff like that.* [Participant 9, interview 2]

Theme 2.2: Forgetting

Several parents reported forgetting to use the app. The app required a change of routine and parenting approach for them. Emotional and behavioral problems did not immediately trigger parents to pick up their phones.

> *I think it’s remembering in the moment to actually pick up my phone and think to use it when it’s happening.* [Participant 11, interview 2]

> *I think I could use it, but I just think I've forgotten about it and I just need to get it in my head to use it as a strategy more in the house as well.* [Participant 10, interview 2]

Theme 2.3: Urgency

Rather than interpreting their experience as “forgetting,” some parents reported that the situation had been too urgent for them to get their phones out. They described it as a rational and deliberate choice not to use the app in the heat of the moment. One parent suggested that a voice-controlled app would be easier to use when emotions are raised.

> *If (child 1) is hitting (child 2), I wouldn’t necessarily think “I’ve got go and get my phone” or “I’m gonna have to look at my phone at the app”, I’d just be like try and think about like what I need to do or try to manage the situation.* [Participant 6, interview 2]

> *I don’t know if you’re able to do voice activation or just an easier way to access those particular parts where you need them in that moment.* [Participant 2, interview 2]

Theme 2.4: Not Getting Good Results

Some parents did not use the time-out or quiet-time components because they did not achieve a change in behavior and because children were resistant. In some children, this was due to feeling that time-out was age-inappropriate, and in others, it was due to time-out being too difficult. There was no indication that children’s resistance was specifically linked to the app.

> *He got put in time out cause he’d hit me and he’d hit his younger brother. And I had to keep putting him back in time out, like because he kept going. And I kept making him sit. But like even after the time he just, he was just really upset.* [Participant 6, interview 2]

> *When my son was in a real mood he’d pick (a chair) up and, you know, smash it against a door or something.* [Participant 5, interview 2]

Theme 3: Parenting With a Mobile App

Theme 3.1: Surprised by Mobile Parenting

Some parents were surprised that they were being offered an app to help with parenting. They reported that some of their children were surprised to find their parents using an app to guide evidence-based parenting rather than entertainment. Although initially surprised by the app, they reported rapidly becoming used to the phone and seeing it as an implement, which parents could use well or not.

> *Before I knew about this, I never even considered there would be an app for this sort of thing.* [Participant 3, interview 1]
>
> *First time I got it out, he thought I was gonna let him watch YouTube. But no, no, this is something different.* [Participant 9, interview 1]
>
> *It's a tool, isn't it? You're using it as a tool just the same you would as a as a piece of paper.* [Participant 4, interview 2]

Theme 3.2: Using a Phone Is Inappropriate

Some parents were worried about using a phone as part of parenting. Only 1 parent strongly believed it was wrong, suggesting that a phone could form a barrier. Other parents expressed qualified concerns, which were overall outweighed.

> *I also don't think it's good practise to be using your phone when you're trying to sort that. If my children need attention and they're needing intermediate intervention there and then, it's not good for me to be having my phone in my hand.* [Participant 2, interview 2]
>
> *Some people don't like to see phones and stuff right before bed, but it doesn't seem to really affect her.* [Participant 5, interview 2]
>
> *I have issues as a professional with electronics and devices and as a parent and I can limit it, but in this case I don't see it as a problem.* [Participant 4, interview 2]

Theme 3.3: Phones Are Helpful and Convenient

Parents who compared the phone with other parenting resources could also identify advantages to using phones. The responsiveness and graphic interface of smartphones were seen as advantages. The possibility of a prompt card they could take anywhere was also seen as a strength. The use of the phone also created a warning sign, giving children a chance to de-escalate.

> *There's only so many visual aids I can have, you know? I mean, I know I printed out something that was like quite a nice little caption type stuff with the plan to laminate it, to put it in his room. But I'm like…actually in the heat of the moment…he doesn't tend to go to sit in his room in his day.* [Participant 11, interview 2]
>
> *It's not a distraction. it's a useful tool to have, especially when you're thinking "what should I do?" or "how should I do it?"* [Participant 1, interview 2]
>
> *I think even (child), when he's watching me, he knows the phone comes out, he knows what's coming next as well.* [Participant 4, interview 2]

Illustrative Case Vignettes

The case vignettes illustrated the way parents talked about their family life and the challenges they faced as well as capturing the personality of the parents and the way the relationships within their families impacted the response to the app. The vignettes draw attention to how siblings who display less prominent behavioral problems were sometimes able to use the app to regulate their emotions. The humor and closeness within families are highlighted by the way parents and children respond to the app. Textboxes 1 and 2 give illustrative examples of the case vignettes, and Multimedia Appendix 2 gives all 10 case vignettes.

Textbox 1. Illustrative case vignette 1 (participant H).

Before she had her twins - both 3 years old now - H used to work at a parenting assessment centre. She also has a 6 year old who can become violent and sometimes hits her. She finds it hard to know how to react. She's completed Triple P in the past and he is awaiting a neurodevelopmental assessment. H was interested in trying out the app to give her new ideas and resources for managing this violence. She sometimes used time outs, but she found it difficult because their house is quite open plan so there's not much privacy. More likely, her 6 year old announces his own time out and takes himself off to his bedroom.

She read through the information pages when she got the app and tried to start using more praise. She was surprised to see that she didn't have to insist her children apologised when they were done and found that this change made life easier. She mentioned she had re-read the information pages before we met. In fact, she had memorised so much of the information on the app that she did not use the timer; instead she used the kitchen Alexa and the Google Home in the lounge to set the timers. The main problem with the app is that she doesn't always have her phone on her; then again sometimes the smart speakers do not recognise her voice so no technology is perfect.

Textbox 2. Illustrative case vignette 2 (participant V).

Sometimes when your child is really winding you up and upsetting her siblings, V explains, it is hard to manage your own emotions. When everybody has fallen out, you know what they really need is a hug to make everything ok again, but you don't really feel like hugging them. It's good to have the app as a reminder to do that.

V has four children. It's not that they're naughty children but they do get really upset if she buys the wrong things from the shop. She tries to take their PS5 off them when they are badly behaved. She doesn't smack her children but she thinks some people probably do and reckons that the app creates an alternative model for their relationship, even suggesting that ending with a hug will have positive oxytocin effects on family life.

She used the app 2 - 3 times each week, including half term, but didn't need it the week before we spoke. Her son got the hang of taking 30 seconds of calming down, but her daughter was a little confused about what she was supposed to do. By the end of the three weeks her son knew what was going to happen when she took her phone out and could anticipate calming time.

Discussion

Summary of Results

This study aimed to evaluate the subjective experience of parents using a digital microintervention to support evidence-based parenting skills. In total, 11 parents of 33 children were interviewed before and after using a mobile app hosting 3 digital microinterventions, and thematic analysis was performed. Many parents used the app in ways they found convenient rather than strictly following the instructions they were given. Several parents experienced barriers to using the app including not having the phone to hand, forgetting about the app, the situation being too urgent, or not finding they were getting good results. Parents and children responded differently to the use of the phone; some were surprised, others explained nuanced concerns, and others wholeheartedly embraced the convenience of mobile technology. Future digital microintervention developers should keep in mind that parents are likely to use the app pragmatically rather than following instructions, may struggle to use a complex app under pressure, and are likely to hold complex feelings about parenting with an app.

Comparison With the Literature

The main problems parents noticed related to user interface problems including occasional freezing and navigation problems. Similar problems have been described in depth by MacKinnon et al [33], who described many practical challenges that arise in the implementation of an app for parents. As in their study, the app contained bugs due to the rapid build of the app under cost pressure. However, we suggest it is more efficient to run early tests of rapidly developed apps, which may contain bugs, in order to evaluate whether the underlying theory of behavior change works well rather than build a perfect app before testing it, in keeping with the principle of continuous innovation [34].

Many parents used the app in ways that were unexpected by researchers and out of keeping with the instructions they were given. Our intervention differed from common modes of parenting skills training, such as facilitator-led groups or e-learning videos, in that our intervention could be used in different ways [8,35]. We suggest digital microinterventions aiming to empower parents with digital tools are likely also to benefit from a group facilitator.

Parents held diverse views over whether using their phones to support their child’s behavioral and emotional well-being was appropriate, both in terms of whether they supported or opposed it and how far their views were nuanced or rigid. Previous research has revealed wide heterogeneity of attitudes throughout digital parenting, but there is little previous research on attitudes to using parenting apps, partly because the rapid pace of technological change precludes the formation of social norms [36]. Given the complex interaction of difficult family circumstances and shifting social norms, it is perhaps unsurprising that attitudes to technology have been uncorrelated with parenting app uptake [37]. The case vignettes illustrated how included parents had explored many other solutions in the past but maintained hope that the next solution would improve family life, and this is valuable in itself, in that when parents are more hopeful, there is greater parental well-being, child adjustment, and family resilience [38].

Strengths and Limitations

This study provides novel insights into how parents use an app with in-the-moment advice for supporting children through behavioral and emotional challenges. The use of qualitative analysis captured the diversity of views and uncovered some unexpected results. The use of illustrative case summaries illustrated how the app fitted into the wider context of family life, a feature often missing from pilot studies. However, app use was all self-reported, and no objective analytics were used, and as such, there is a risk that social desirability bias could lead to upwardly biased reports. Moreover, the way parents used the app in unexpected ways would have confounded objective analytics. The sample size was appropriate to evaluate the way parents used the app and to inform future development, but it was too small to draw conclusions about the proportions of parents who used the app in different ways or to make inferences about changes in child behavior [22,23]. This study used a self-selecting sample who may be more open to parenting apps than the general population of parents seeking parenting support, potentially leading to greater reported enthusiasm for the app than would be found with a general population sample. In addition, we were unable to recruit any fathers into this study, limiting the generalizability of this study to mothers.

Implications for Future Research

This study has implications for people developing apps to support parenting skills. Scholars should expect some resistance from parents who are wary of digital interventions but should also anticipate that other parents will nevertheless be open to using an app. Apps should facilitate several different levels of engagement (perhaps covering information, reflection, and in-the-moment guidance) that would allow parents with some qualms to begin to benefit from the app. This way, the largest number of parents can be supported by digital parenting interventions in a way they feel comfortable with. Alternatively, insights from behavioral science such as reminder notifications and incentives may be incorporated to prompt people to use parenting apps in keeping with suggestions, as has been attempted elsewhere in mental health care [39].

For a range of reasons, some parents occasionally found it impractical to use the phone in the heat of the moment. Some parents found a workaround in the use of home speakers. We suggest that future digital parenting skills programs incorporate home speakers. Although individual parenting skills have been built into home speaker apps in the past, families would benefit more from support integrating home speakers, smartwatches, and tablets with mobile apps [16].

Similarly, parenting apps should be designed to make it easy for parents to achieve their own personal goals, otherwise, parents will use the app in unintended ways that suit their family. Incorporating more personalization into parenting apps can support parents to use generic digital tools in ways that target the particular challenges affecting their families. Apps should provide evidence-based advice alongside useful tools.

Future studies should explore whether the finding that parents use digital microinterventions differently than guided is replicated among other groups of parents.

Conclusions

This study has described how a sample of mothers used an app designed to support evidence-based parenting skills following previous attendance at a parenting program. Digital parenting support is a rapidly growing area, and it is important that a wide range of possible interventions are offered to parents so they can find an approach that suits the needs of their families. Rapid pilots, such as this study, offer a comparatively cheap way of evaluating whether an app is suitable for parents and provide an opportunity to screen for areas to improve the intervention. In the future, we recommend researchers ensure parents' preferred approaches match up with the directions they are nudged toward by digital interventions.

Conflicts of Interest

NH and PW are named in a division of proceeds agreement for a parenting app owned by University of Warwick. The other authors declare no conflicts of interest.

Multimedia Appendix 1
Topic guides for interviews.
[DOCX File, 15 KB - pediatrics_v7i1e53907_app1.docx]

Multimedia Appendix 2
Case studies for Time Out Timer app.
[DOCX File, 20 KB - pediatrics_v7i1e53907_app2.docx]

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Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research

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Original Paper

Moderators of the Effects of a Digital Parenting Intervention on Child Conduct and Emotional Problems Implemented During the COVID-19 Pandemic: Results From a Secondary Analysis of Data From the Supporting Parents and Kids Through Lockdown Experiences (SPARKLE) Randomized Controlled Trial

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Abstract

Background: A smartphone app, Parent Positive, was developed to help parents manage their children's conduct and emotional problems during the COVID-19 pandemic. A randomized controlled trial, Supporting Parents and Kids Through Lockdown Experiences (SPARKLE), found Parent Positive to be effective in reducing children's emotional problems. However, app effectiveness may be influenced by a range of child, family, socioeconomic, and pandemic-related factors.

Objective: This study examined whether baseline factors related to the child, family, and socioeconomic status, as well as pandemic-related disruption circumstances, moderated Parent Positive's effects on child conduct and emotional problems at 1- and 2-month follow-up.

Methods: This study was a secondary exploratory analysis of SPARKLE data. The data set included 646 children (4-10 years of age) with parents randomized to either Parent Positive (n=320) or follow-up as usual (n=326). Candidate baseline moderators included child age, gender, attention-deficit/hyperactivity disorder symptoms, parental psychological distress, family conflict, household income, employment status, household overcrowding, and pandemic-related disruption risk (ie, homeschooling, lockdown status, and isolation status). Child conduct and emotional problem outcomes measured at 1- (T2) and 2-months (T3) post randomization were analyzed using linear mixed-effects analysis of covariance models adjusting for baseline (T1) measure of outcome and including intervention and intervention by time point interaction terms allowing for different effects at the 2 time points. Moderation of intervention effects by baseline factors was assessed by replacing the intervention by time interaction terms with intervention by time point by baseline moderator interaction terms.

Results: Child gender was a significant moderator of the Parent Positive versus follow-up as usual effect on emotional problems (B=0.72, 95% CI 0.12-1.33; P=.02). Specifically, the effect of Parent Positive was close to significant (T2: B=–0.41, 95% CI –0.82 to 0.0004; P=.05) or significant (T3: B=–0.76, 95% CI –1.22 to –0.30; P<.001) in males only when compared with females, and males experienced a significantly larger reduction in emotional problems than females in the Parent Positive arm at the 2-month post randomization time point. None of the other investigated baseline factors moderated effects on emotional problems, and no factors moderated effects on conduct problems.

Conclusions: This study highlights Parent Positive’s potential for effectively reducing emotional problems in primary school-aged male children across a wide range of families. However, due to limited variability in the demographic background of the families, cautious interpretation is required, and replications are necessary in diverse samples with longer follow-up times.

Trial Registration: ClinicalTrials.gov NCT04786080; https://clinicaltrials.gov/ct2/show/NCT04786080

(JMIR Pediatr Parent 2024;7:e53864) doi:10.2196/53864

KEYWORDS

parenting; intervention; smartphone app; randomized controlled trial; COVID-19 pandemic; moderators; conduct problems; emotional problems

Introduction

Background

Child conduct and emotional problems are a public health concern due to their negative impact on individuals, their families, and society [1]. Conduct problems are characterized by oppositional, disruptive, or aggressive behaviors [2], while emotional problems include anxiety and depression [3]. Conduct and emotional problems frequently co-occur [4] and can disrupt daily functioning, mental health, and social interactions [5]. If left untreated, these issues may elevate the likelihood of mental disorders, substance use, and delinquency in childhood and adolescence [6], as well as criminality in adulthood [7]. Children were particularly vulnerable to mental health difficulties during the global COVID-19 pandemic, likely due to COVID-19 mitigation strategies imposed on families by governments (eg, lockdowns, social isolation, and school closures) [8]. In a large cohort study conducted in the United Kingdom—COVID-19: Supporting Parents, Adolescents, and Children During Epidemics (Co-SPACE) [9]—lockdowns coincided with increased conduct and emotional problems in participating primary school-aged children.

Child conduct and emotional problems can be effectively reduced by behavioral parenting training that aims to enhance parenting practices [10]. However, financial costs, lack of access to transport, and stigma limit participation in these interventions, which are typically delivered face-to-face [11], and there were particular access issues during lockdowns. To increase accessibility, such interventions have shifted to smartphone app–based delivery formats [12,13]. Recently, Kostyrka-Allchorne et al [14] developed an evidence-based smartphone app, Parent Positive, that aimed to support parents and carers (henceforth referred to as parents) within the general population during the COVID-19 pandemic. Results from a randomized controlled trial (RCT)—Supporting Parents and Kids Through Lockdown Experiences (SPARKLE) evaluating the effects of Parent Positive versus a follow-up as usual arm (FAU)—showed that Parent Positive significantly reduced child emotional, but not conduct, problems [15] at 1- and 2-month follow-ups as compared with FAU.

While there were benefits of Parent Positive for the whole sample, as common for many interventions, there may be considerable variation in its benefits between individuals. In this case, it becomes important to identify factors influencing intervention outcomes to support a more targeted intervention approach. The literature describes such factors as intervention moderators, as they interact with the intervention and improve outcomes for some over others [16,17]. Exploring these moderators could improve understanding of which interventions are beneficial for whom, enabling clinicians to tailor recommendations to the most effective interventions [17,18]. We note that 1 moderation hypothesis was evaluated as part of the main SPARKLE trial analysis and was published in the main results paper: the effect of Parent Positive on conduct problems did not differ by levels of conduct problems at baseline [15].

The examination of moderator effects on child outcomes in previous studies of parenting interventions has been somewhat limited. Rather than conducting moderation analyses, some studies have primarily focused on assessing associations between various factors and outcomes only within groups exposed to interventions, or across the trial sample as a whole [16,19]. It is essential to distinguish this approach from moderation analyses, which involve investigating whether the effect of an intervention differs by the level of baseline characteristics or factors [16]. In this regard, there has been a somewhat limited number of studies explicitly exploring moderation effects in parenting interventions.

Most of the research on moderating factors in parenting interventions has examined how child, family, and socioeconomic factors influence the effectiveness of these interventions in addressing child conduct problems. Overall, the evidence regarding which moderators of parenting interventions are impactful on child conduct problems is somewhat mixed. The consensus from most meta-analyses suggests that child age [20-22] does not significantly moderate the effects of parenting interventions. Regarding child gender, while a meta-analysis found that boys benefitted more than girls from a parenting intervention [20], 2 RCT studies did not find any moderation effects related to child gender [23,24]. In the context of attention-deficit/hyperactivity disorder (ADHD) symptoms, multiple meta-analyses did not identify ADHD as a significant moderator of parenting intervention effects on child conduct problems [20,25,26].

Recent systematic reviews [19,27] exploring moderating effects of family risk factors, such as parental psychopathology, life stress, and family conflicts, reported no impact of these factors on effectiveness of parenting interventions for child conduct problems. Conversely, 1 meta-analysis indicated that children exhibited greater improvements when their mothers displayed elevated levels of depressive symptoms [26].

When examining socioeconomic status as a moderator in parenting intervention studies, the results have been less consistent. Most research indicates that these interventions maintain their effectiveness across different socioeconomic backgrounds [19,27], with recent meta-analyses and reviews [20,25] finding no significant moderation effects of socioeconomic characteristics on child conduct problems. However, other studies have suggested that socioeconomic disadvantage may lead to less positive child outcomes [21,28].

However, several of these moderator analyses faced limitations attributed to small sample sizes (ie, fewer than 70 participants in each arm of an RCT study [23]), likely lacking power to detect an effect that exists (type II error) [19]. In addition, there were variations in intervention components, including content, delivery format, length, and therapist contact [19]. These variations may have contributed to a lack of clear results, as what moderates intervention effects on outcomes likely varies across different interventions [19]. Furthermore, while previous research on parenting interventions has primarily examined moderation effects of child, family, and socioeconomic characteristics [19], recent pandemic-related disruptions could also influence intervention outcomes on children during the pandemic due to associated challenges. Consequently, the negative impact of mitigation policies [29] could influence how children and families respond to parenting interventions. For example, joint confinement and isolation from support networks, with parents often having to manage competing homeschooling and work demands have placed great pressure on parent-child relationships. In turn, it could have been more difficult for parents to engage within a self-directed universal intervention. This highlights the importance of examining moderating factors of a digital intervention within the context of the COVID-19 pandemic, even if previously studied and not found to be significant moderators, as the distinctive circumstances may yield diverse outcomes.

Objectives

This study aimed to test whether child, family, socioeconomic, and pandemic-related circumstances at baseline moderated Parent Positive effects on child conduct and emotional problems at 1- and 2-month follow-up in the SPARKLE trial. Given the inconsistent previous findings regarding moderators of parenting interventions and the novelty of the intervention [19], we chose an exploratory approach. The following factors, thought to be potential moderators, were used to construct a multivariate model: child age, gender, ADHD symptoms, parental psychological distress, family conflict, household income, employment status, household overcrowding, and pandemic-related disruption risk.

Methods

Study Design

This study was a secondary analysis using repeated-measures data from SPARKLE—a parallel, 2-arm, superiority RCT [14]. SPARKLE tested the effects of Parent Positive compared with FAU. Recruitment commenced in May 2021 during the COVID-19 pandemic and was a Trial within a Cohort [30] embedded in the general population Co-SPACE study [29]. The primary outcome variable was parent-reported levels of child conduct at 1- and 2-month post randomization, with emotional problems measured at the same time points as an important secondary outcome. Throughout the paper, we will refer to the "main analysis" or "main analysis models." By this, we mean the analysis we used to obtain the main trial results [15]. The main trial outcomes indicated that Parent Positive significantly reduced emotional problems but not conduct problems [15] when compared with FAU at both the 1- and 2-month follow-ups.

Ethical Considerations

Ethics approval was granted by King's College London (reference: HR–20/21-21451) and the University of Oxford (SPARKLE reference: R73153/RE001; Co-SPACE reference: R69060/RE001).

Written informed consent was originally provided by participants for the primary trial, covering the use of their data in secondary analyses without requiring additional consent. Participants were fully informed of their rights, including the ability to withdraw from the study at any time without consequence. Participant data were deidentified using unique study IDs, with raw data from the SPARKLE trial deposited in the UK Data Service repository [31]. A data privacy notice was made available on the study website. As compensation for their time, participants received 2 £5 (£1=US $1.26 at time of conversion) web-based shopping vouchers upon completing each follow-up questionnaire. Further information can be found in the SPARKLE protocol [14] and the main trial results article [15].

Participants

A total of 100% (646/646) children with parents were recruited into SPARKLE between May 19, 2021, and July 26, 2021. Parents were either part of the Co-SPACE cohort before the trial or were eligible to join Co-SPACE (aged 18 years and older, UK residence, informed consent) and SPARKLE after the start of the trial. In addition to the Co-SPACE criteria, SPARKLE participants were required to have a child aged 4-10 years and a smartphone to access Parent Positive (Android: operating system OS 8-9 or higher; Apple: iOS 12-13 or higher).

Procedures

Data Collection

Participants were invited to SPARKLE via a Qualtrics Co-SPACE survey between May 19, 2021, and July 26, 2021, and confirmed their eligibility before giving written e-consent. After completing baseline measures, participants were randomized to either Parent Positive or FAU and automatically informed about their allocated group through the Qualtrics Randomizer function. Participants (320/646, 49.5%) allocated to the Parent Positive arm received free access to Parent Positive from randomization until November 30, 2021. Data were collected at baseline (T1), 1-month (T2), and 2-months (T3) post randomization (via Qualtrics as part of Co-SPACE). Further details about the procedures, including the trial CONSORT (Consolidated Standards of Reporting Trials) diagram, can be found in the main trial results paper [15].

Interventions

Parent Positive

Parent Positive is an evidence-based self-directed smartphone app delivering support to parents with content organized in 3 zones. The first zone, Parenting Boosters, provided parenting advice on common challenges through 8 animations narrated by celebrity parents. The second zone, Parenting Exchange, provided access to a moderated support platform to connect with other parents and submit questions to experts in the field of child behavior and mental health. The third zone, Parenting Resources, provided parents with links to evidence-based parenting resources. No specific order or time was necessary for accessing the zones. Further details about the intervention can be found in the main trial results paper [15].

Follow-Up as Usual

Participants (326/646, 50.5%) randomized to FAU received no intervention during data collection. After their follow-up at T3, they received free access to Parent Positive until November 30, 2021.

Measures

Clinical Outcomes

This section describes the clinical outcomes assessed in the study, focusing on child conduct and emotional problems.

Child Conduct and Emotional Problems

The clinical outcomes were parent-reported levels of child conduct and emotional problems measured by the conduct and emotional subscales of the Strengths and Difficulties Questionnaire (SDQ) [32]. Each subscale consists of 5 items with response options ranging from 0 (Not true) to 2 (Certainly true). An overall subscale score was derived from summing the scores of individual items for each subscale, with higher scores indicating greater severity. The internal consistency of the SDQ is good (Cronbach α=0.73) [33].

Candidate Moderators

The key candidate baseline moderator variables were child age, gender, ADHD symptoms, parental psychological distress, family conflict, household income, employment status, household overcrowding, and pandemic-related disruption index. The following section provides a detailed description of these child, family, and socioeconomic characteristics.

Child Characteristics

Child Age and Gender

Child age and gender were provided by parents at baseline in a form asking about background demographics. When responding regarding the gender of their child, 3 parents chose the option “prefer not to say.” Given the limited number of participants in this category, mean imputation was conducted to include these participants. However, when we explored gender-specific moderation effects, data of only the more prevalent categories of males and females were used due to the limited number of participants in the “prefer not to say” category.

Child ADHD Symptoms

Child ADHD symptoms were measured by the 5-item hyperactivity-inattention subscale of the SDQ as described in the “Clinical Outcomes” section [32], with response options ranging from 0 (Not true) to 2 (Certainly true). An overall subscale score was derived from summing the scores of individual items, with higher scores indicating greater severity.

Family Characteristics

Parental Psychological Distress

Parental psychological distress was assessed using the 21-item Depression, Anxiety, and Stress Scale (DASS-21) [34]. The DASS-21 is a self-reported measure of depression, stress, and anxiety symptoms [35], consisting of 3 subscales (7 items each) and response options ranging from 0 (Never) to 3 (Almost always). The total score was multiplied by 2 to obtain a DASS-42 equivalent score [14], ranging from 0 to 126. Higher scores indicate higher severity. It has excellent internal consistency (Cronbach α=0.93) in community samples [36].

Family Conflict

The Family Conflict Scale was developed for the Co-SPACE study [29] to assess family conflict. It is a self-reported 3-item measure of arguments and disagreements between family members (parents, parents-children, and siblings). In the Co-SPACE study, family conflict was associated with mental health symptom trajectories during the pandemic [37]. Response options range from 0 (Not at all) to 3 (Completely) and the total score ranges from 0 to 9, with higher scores indicating greater family conflict. The internal consistency in the Co-SPACE sample was Cronbach α>0.54 [14], indicating moderate reliability.

Socioeconomic Characteristics

Household Income

Household income, collected at baseline, was recoded into 2 categories: less than £29,999 (US $38,600.66) per year and greater than £30,000 (US $38,603.78) per year. To create similar-sized groups, this cutoff was chosen due to less representation of families from lower-income backgrounds.

Employment Status

Due to limited numbers, participants’ employment status recorded at baseline was recoded into two categories: (1) not in paid employment, which encompassed parents who were at university, unable to work due to disability, homemakers or full-time parents, unemployed and actively seeking work, or retired, and (2) in paid employment—which included those who were self-employed, working part-time, or engaged in full-time employment.

Household Overcrowding

Three demographic variables, collected at baseline, were used to compute the household overcrowding index. The number of adults and children (excluding the parent and child in SPARKLE) was each assessed using a single-item measure, with response options ranging from 1 (None, I am the only adult in the household; None, the child I am answering about is the only child in the household) to 7 (6 or more). To calculate the household overcrowding index, the total number of people was divided by the number of rooms where the family resided. A higher overcrowding index reflects a greater degree of household overcrowding.

Pandemic-Related Disruption Characteristics

Pandemic-Related Disruption Index

Several variables pertaining to pandemic-related disruption circumstances at baseline were available for this analysis. Among them, 3 variables were selected due to their significant variation in responses and aggregated to calculate a pandemic-related disruption index. The selected variables were lockdown status (no=0; yes=1), isolation status (living life as normal=0; social distancing=1; self-isolating=1), and physical school attendance (yes=0; no=1). Scores ranged from 0 (low disruption) to 3 (high disruption), with higher scores indicating a greater disruption. For the purposes of analysis, the 2 highest scores (2 and 3) were collapsed into 1 category due to the small numbers in these 2 groups. While interpreting values of the pandemic-related disruption index, it is important to consider that the trial commenced during a period when COVID-19–associated lockdown measures had somewhat subsided. Thus, the pandemic-related disruption index exhibited lower values, indicative of a reduced degree of disruption compared with the initial phases of the pandemic.

Statistical Analysis

The analysis plan was registered prior to completion of the analysis [38]. Data analysis was done using Stata (version 17.0; StataCorp) [39].

Base Model

Linear mixed-effects models (LMM) similar to those applied in the main SPARKLE trial analysis were fitted to identify moderators at T2 and T3. The dependent variables were repeated 1-month and 2-month outcome measures (ie, child conduct and emotional problems in separate models), with a random intercept at the participant level to account for the repeated measures. Regardless of observed significance, all models included the main RCT analysis clinical outcome model covariates (the intervention arm, time, the intervention arm by time interaction allowing for different effects at the 2 outcome time points, and baseline outcome measure) and prespecified covariates (child age and gender), as fixed effects [15]. Baseline covariates that predicted missing outcome data, including household income and the overcrowding index for both clinical outcomes, were also incorporated in the analysis, as fixed effects, to be consistent with the main analysis and to make the missing at random assumption of the maximum likelihood estimation algorithm more plausible.

There were several differences between the main trial analysis and the current analysis. In contrast to the main trial analysis, which used household income and the number of adults in the household as separate covariates [15], we used only the overcrowding index. This was because the overcrowding index—which incorporates the number of adults as part of its calculation—was of interest in this study, so we used it rather than number of adults to avoid collinearity. Employment status at baseline predicted missing outcome data of emotional problems and was also incorporated as a fixed-effect covariate in models for emotional problems. In the main analysis, mean imputation [40] was applied to address missing baseline data (including “prefer not to say” responses) for child gender, family conflict, overcrowding index, and physical school attendance (used in the construction of the pandemic-related disruption index). In addition, categorical income was imputed using the mode.

Textbox 1 presents a list of steps and regression equations for the models used in the analysis of child conduct problems. A corresponding list for the analysis of child emotional problems, which includes employment status as a covariate, may be found in the Multimedia Appendix 1.

Textbox 1. A list of steps and regression equations in the analysis of child conduct problems.

1. Base model (linear mixed-effects models [LMM]):
    - The base model can be represented by the following equation:

      $$Y = \beta0 + \beta1\text{ Intervention arm} + \beta2\text{ Time} + \beta3\text{ (Intervention arm} \times \text{Time)} + \beta4\text{ Baseline child conduct problems} + \beta5\text{ Child age} + \beta6\text{ Child gender} + \beta7\text{ Household income} + \beta8\text{ Overcrowding index} + \varepsilon$$
2. Univariate LMM:
    - Fit LMM for each baseline moderator variable of interest as an independent variable in the base model background. Note that we do not know whether a variable is a moderator unless the interaction term in the second equation is significant, but we use that term for consistency. The regression equation example is as follows:

      $$Y = \beta0 + \beta1\text{ Intervention arm} + \beta2\text{ Time} + \beta3\text{ (Intervention arm} \times \text{Time)} + \beta4\text{ Baseline child conduct problems} + \beta5\text{ Child age} + \beta6\text{ Child gender} + \beta7\text{ Household income} + \beta8\text{ Overcrowding index} + \beta9\text{ Moderator} + \varepsilon$$
    - Fit LMM models for each baseline variable of interest as an independent moderator to the model background. The regression equation example is as follows:

      $$Y = \beta0 + \beta1\text{ Intervention arm} + \beta2\text{ Time} + \beta3\text{ (Intervention arm} \times \text{Time)} + \beta4\text{ Baseline child conduct problems} + \beta5\text{ Child age} + \beta6\text{ Child gender} + \beta7\text{ Household income} + \beta8\text{ Overcrowding index} + \beta9\text{ Moderator} + \beta10\text{ (Intervention arm} \times \text{Time} \times \text{Moderator)} + \varepsilon$$
3. Multivariate LMM:
    - Fit forward stepwise LMM with identified main effects from univariate models.
    - Add main effects and 3-way interaction terms in a stepwise manner. The regression equation example is as follows:

      $$Y = \beta0 + \beta1\text{ Intervention arm} + \beta2\text{ Time} + \beta3\text{ (Intervention arm} \times \text{Time)} + \beta4\text{ Baseline child conduct problems} + \beta5\text{ Child age} + \beta6\text{ Child gender} + \beta7\text{ Household income} + \beta8\text{ Overcrowding index} + \beta9\text{ Moderator } a + \beta10\text{ (Intervention arm} \times \text{Time} \times \text{Moderator } a) + \beta11\text{ Moderator } b + \beta12\text{ (Intervention arm} \times \text{Time} \times \text{Moderator } b) + \ldots + \varepsilon$$

Univariate Predictor Mixed-Effects Models

Initially, LMMs were fitted. Each baseline variable of interest, as listed in the objectives section, was included as an independent predictor in the base model described in the previous section. This step allowed for the assessment of the strength of association of each candidate factor individually, determined by likelihood ratio tests and the significance (*P* value) of each variable in turn. Given that the moderating effect of background and pandemic-related factors on intervention effects was the primary focus of this paper [15], the univariate models (ie, adding 1 potential moderator as an independent variable within the base model background) were fitted with intervention arm by time by potential moderator variable interaction terms. Any variable with either a main effect or a main effect and interaction term test *P* value of <.2 in the univariate model was taken forward into consideration in the multivariate models described in the following section. In the analysis of a 3-level categorical variable, pandemic-related disruption index, omnibus tests of significance for the interaction terms were conducted. This methodology involved using a specific test called "testparm" within the Stata software which executed a Wald test.

Multivariate Predictor Mixed-Effects Models

Following the univariate analyses, forward stepwise LMMs were fitted to build multivariate independent variable models (ie, might include more than 1 potential moderator as independent variables) in terms of the candidate moderators. Each of the identified main effects (*P*<.2) from the univariate model was manually added one at a time in a descending order with the strongest effect first, as assessed by the largest likelihood ratio test statistic. This enabled us to examine the influence of a range of possible factors simultaneously and assess the contribution of each factor. For each main effect added to the multivariate model, either due to indicating potential 3-way moderation in the univariate model (*P*<.2) or being included as a prespecified covariate, the corresponding 3-way interaction term was added to the model. If no 3-way interaction term was identified in the univariate model (*P*<.2), the factor was included only on its own as a main effect. Main effects and 3-way interaction terms were added in a stepwise manner until no further main effects and interactions terms were found to be statistically significant (*P*<.05). Robust standard errors were used in all final models to account for slight heteroscedasticity of residuals.

Results

Sample and Clinical Characteristics

The identical sample was used in this secondary analysis as in the main paper [15]—consisting of 646 parents with eligible children (mean age 7.45, SD 1.67 years; 51.1%, 330/646 male). Given that most variables used were previously described in the main paper, comprehensive information on sample characteristics at baseline is shown in Table S1 in Multimedia Appendix 1 and the 2 clinical outcomes (child conduct and emotional problems) at all time points are shown in Table S2 in Multimedia Appendix 1. Two baseline variables, namely, employment status and pandemic-related disruption index, were not previously reported and can be seen in Table 1. Both variables appear to be balanced across the trial arms. Most parents of children were in paid employment and reported some level of COVID-19 pandemic–related disruption.

Table 1. Previously unreported baseline variables for randomized arms and overall.

Baseline variable	FAU[a] arm (n=326)	Parent Positive arm (n=320)	Overall (N=646)
Employment status[b], n (%)			
In paid employment	251 (77.0)	256 (80.0)	507 (78.5)
Not in paid employment	75 (23.0)	64 (20.0)	139 (22.5)
Pandemic-related disruption index[c], n (%)			
0	50 (15.3)	53 (16.6)	103 (15.9)
1	164 (50.3)	163 (50.9)	327 (50.6)
2 and 3[d]	112 (34.4)	104 (32.5)	216 (33.5)

[a] FAU: follow-up as usual.

[b] Employment status was recoded into not in paid employment (at university, unable to work due to disability, homemaker or full-time parent, unemployed and seeking work, retired), and in paid employment (self-employed, part-time, full-time).

[c] Higher pandemic-related disruption index (a 3-level categorical variable) indicates more pandemic-related disruption.

[d] The 2 highest scores (2 and 3) in the pandemic-related disruption index were collapsed into 1 category.

Moderation of Parent Positive Versus FAU Results on Clinical Outcomes

All results from univariate LMM are shown in Table S3 in Multimedia Appendix 1. Child gender, age, and ADHD symptoms, parental psychological distress, family conflict, household income, employment status, household overcrowding index, and pandemic-related disruption index did not significantly moderate the effects of Parent Positive on child conduct problems at T2 and T3 (Table S3 in Multimedia Appendix 1).

For child emotional problems, when accounting for other variables in the multivariate model, gender was a significant moderator of the Parent Positive versus FAU intervention effect at T2 and T3 (Table 2). Specifically, the Parent Positive versus FAU lower emotional problems effects were close to or significant in males only (T2: *B*=–0.41, 95% CI –0.82 to 0.0004; T3: *B*=–0.76, 95% CI –1.22 to –0.30), with this effect being significantly different in males as compared with females at T3, who did not show a significant reduction in emotional problems in the Parent Positive group (*B*=0.12, 95% CI –0.30 to 0.54; see Figure 1 and Table S4 in Multimedia Appendix 1). This result was similar to the moderation effect of child gender found in the univariate model (Figure S1 in Multimedia Appendix 1). No other significant moderation effects on child emotional problems at 1 and 2 months of follow-up were found. Candidate moderators that showed only significant main but not interaction effects (ie, no moderation) from the multivariate LMM are further discussed in Multimedia Appendix 1.

Table 2. Multivariate linear mixed-effects models for child conduct and emotional problems.

Baseline variable	SDQ[a] Child conduct			SDQ Child emotion		
	B	2-Sided 95% CI	*P* value	*B*	2-Sided 95% CI	*P* value
Time[b]	0.01	–0.12 to 0.15	.82	0.52	–0.09 to 1.13	.10
Randomization arm[c]	–0.01	–0.24 to 0.22	.94	–0.57	–1.50 to 0.35	.23
Randomization arm ×[d] time	–0.17	–0.39 to 0.05	.13	–1.07	–2.03 to –0.11	.03
SDQ Child conduct	0.64	0.57 to 0.72	<.001	N/A[e]	N/A	N/A
SDQ Child emotion	N/A	N/A	N/A	0.72	0.67 to 0.78	<.001
Child age	–0.01	–0.07 to 0.05	.84	–0.01	–0.09 to 0.08	.90
Child gender[f]	–0.23	–0.43 to –0.03	.03	0.01	–0.37 to 0.38	.98
Child gender × time	N/A	N/A	N/A	–0.45	–0.85 to –0.06	.02
Child gender × randomization arm	N/A	N/A	N/A	0.16	–0.43 to 0.75	.60
Child gender × time × randomization arm	N/A	N/A	N/A	0.72	0.12 to 1.33	.02
Household income[g]	0.07	–0.18 to 0.32	.59	–0.30	–0.66 to 0.06	.10
Overcrowding index[h]	0.01	–0.26 to 0.29	.93	–0.03	–0.56 to 0.50	.90
Employment status[i]	N/A	N/A	N/A	0.07	–0.25 to 0.38	.68
Family conflict	0.18	0.11 to 0.26	<.001	N/A	N/A	N/A
SDQ Child ADHD[j] symptoms	0.09	0.05 to 0.13	<.001	0.09	0.04 to 0.14	<.001

[a] SDQ: Strengths and Difficulties Questionnaire.

[b] Reference category: time 2.

[c] Reference category: follow-up as usual arm.

[d] ×: Interaction effect.

[e] N/A: not applicable (indicates absence of the covariate for the given model).

[f] Child gender (1: male, 2: female) was treated as continuous due to mean imputation (mean 1.49) conducted for 3 participants.

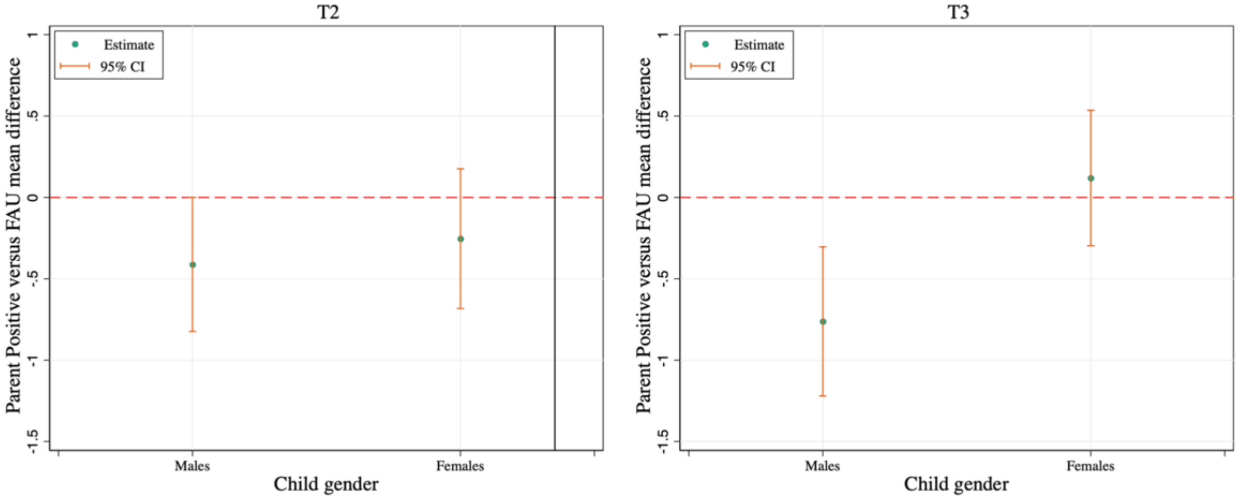
[g] Reference category: household income less than £29,999 (US $38,600.66) a year.

[h] Higher overcrowding index indicates more overcrowding at home.

[i] Reference category: not in paid employment.

[j] ADHD: attention-deficit/hyperactivity disorder.

Figure 1. Moderation of intervention effects on Strengths and Difficulties Questionnaire child emotional problems by child gender at time points 2 (1-month) and 3 (2 -months). Lower scores on the y-axis indicate a positive difference (ie, lower severity of child emotional problems). FAU: follow-up as usual.



Discussion

Principal Findings

Although research suggests that participant characteristics may impact the outcomes of parenting interventions, only a few studies have examined their moderating effects on child outcomes. Furthermore, the existing findings are often inconsistent and appear to depend on the specific intervention being studied [19,27]. As the Parent Positive app was developed to reverse children's increases in conduct and emotional problems experienced during the COVID-19 pandemic, moderating effects within this context have not yet been examined. This study aimed to identify child, family, socioeconomic, and pandemic-related disruption factors at baseline that may significantly moderate Parent Positive effects on children's conduct and emotional problems. The results showed that child gender was a significant moderator of the Parent Positive versus FAU effect on child emotional problems. None of the other investigated baseline factors played a moderating role in emotional problems, and no examined baseline factors were found to moderate effects on conduct problems.

This observed pattern of results in child conduct problems is similar to some previous research on face-to-face parenting interventions looking at child, family, and socioeconomic factors, indicating a lack of moderation effects [19,23,27]. However, it conflicts with some other studies suggesting significant moderation effects in the context of socioeconomic status [21], ADHD symptoms [41], and maternal depression [26]. Despite the growing emphasis on digital parenting interventions [12,13], the exploration of moderators in parenting interventions has predominantly centered on longer, face-to-face interventions guided by therapists [20]. This makes comparisons to most moderator studies challenging, considering the distinctive nature of Parent Positive as a short, smartphone app–based, and self-directed intervention, with an emphasis on fostering positive environments and experiences for both parents and children. Overall, these findings suggest that the Parent Positive effects on child conduct problems did not differ by the available participant characteristics. It should also be noted that a significant effect of Parent Positive versus FAU was not observed at 1- or 2-month follow-up on child conduct problems [15]. However, levels of conduct problems seemed to be decreasing at the 2-month follow-up after Parent Positive, possibly indicating that longer follow-ups may be necessary to see effects of the intervention on this particular outcome [42]. Subsequently, we might also see factors that moderate intervention effects.

After controlling for baseline emotional problems and other covariates, child gender was found to significantly moderate the effects of Parent Positive on child emotional problems at 1- and 2-month follow-up. While Parent Positive did not appear to be effective for females in terms of emotional problems, the intervention was effective for males. This reduction in emotional problem levels became more evident at the 2-month follow-up assessment. A similar effect was also found when examining moderation by child gender in the univariate model, enhancing reliability and robustness of this finding.

The finding of a moderation effect by child gender is similar to the finding of meta-analysis that looked at moderation of parenting interventions on child disruptive behaviors [20] but differs from findings in 2 RCTs [23,24]. This could be due to earlier studies predominantly involving males [43], whereas our sample had a more balanced representation of parents with male and female children. However, these prior studies examined the conduct problem outcome only, which might limit the comparability of the moderation effect on child emotional problems observed in our study. Notably, the emotional subscale of the SDQ used in this study encompasses dimensions such as anxiety and strongly aligns with anxiety measures across childhood [44], possibly allowing for meaningful comparisons with anxiety-focused treatments (eg, cognitive behavioral therapy). However, most studies in this domain have indicated that child gender does not moderate outcomes of treatments focusing on anxiety in children [45].

There are several other explanations. Parent Positive aimed to reduce child worry and enhance mood through positive parenting strategies while reducing harsh practices, aligning with evidence of parent training's impact on child internalizing problems [46]. Notably, parents frequently accessed booster components of Parent Positive that focused on family-related processes, potentially improving the overall emotional atmosphere in families using Parent Positive [15]. The observed gender moderation may be explained by these boosters having a more significant impact on males. Existing research shows that parents are more likely to use positive parenting strategies for females [47,48] while harsh parenting practices for males [49]. Consequently, it is possible that male children, who may exhibit more externalizing emotions such as anger [50], might have responded more robustly than females to the positive changes in parenting introduced by the boosters. The potential for a greater shift in parenting practices toward males may have contributed to the enhanced effectiveness of Parent Positive for male children in addressing emotional problems.

However, the lack of a more consistent gender effect across previous studies prompts considering additional factors that might contribute to this variability. Variations in study methodologies, sample characteristics, and cultural contexts across different studies could account for the inconsistent findings [19]. In addition, while changes in parenting practices may influence emotional outcomes in male children, the relationship with conduct problems in males might be more complex and multifaceted. Exploring this variability in future research, along with the interplay between child gender, parenting changes, and conduct problems, could provide a more comprehensive understanding of the observed patterns.

Another possibility is that societal gender expectations of emotion expression may have influenced our findings. Brody's theory [51] proposes that females are more likely to display internalizing emotions (eg, anxiety, sadness) while males tend to externalize emotions (eg, anger), which may contribute to the development of conduct problems [50]. These gender differences in emotional expression were supported by a meta-analytic review encompassing facial, behavioral, and vocal emotion expressions in children [52]. Given that our outcomes were parent-reported, and males are less likely to display internalizing emotions, it is important to consider the potential bias introduced by parents in accurately identifying and reporting emotions in males. Social expectations may also lead parents to anticipate and encourage less emotional expression in males than in females [51], possibly resulting in underreporting of emotional problems for male children [53]. To enhance the robustness of these findings, future research should consider incorporating additional measures of child emotional problems [53] from a range of informants (eg, teachers) and various technologies (eg, wearables that track heart rate variability as an indicator of anxiety).

Strengths and Limitations

Participant and pandemic-related disruption factors were explored in this study as potential moderators of Parent Positive in a large general population sample within a cohort. Unlike previous research on moderators of parenting interventions, child outcomes of both conduct and emotional problems were examined, with the latter essential given the pandemic-related increase.

A few limitations should be noted. First, child outcomes were parent-reported. Despite their importance, bias may have occurred because parents were unblinded [54]. While blinding of participants was not possible due to the research design, results should be replicated using more objective approaches such as observational measures of child behavior conducted by a blinded researcher [55]. Second, the relatively short follow-up times, chosen for practical reasons, could potentially mask the emergence of moderation effects that may require a longer duration to manifest. In addition, the low sociodemographic variability may have decreased statistical power and diminished chances to detect moderation effects by sociodemographic characteristics. Furthermore, because of the lack of variability in some of the sociodemographic characteristics (eg, household income and employment status), moderation of effects was examined in a binary way, and it is important to acknowledge that reducing this range into 2 categories may pose a limitation, as the distinct experiences within each category might vary considerably. Overall, replications with longer follow-up times are necessary, including with more families from low socioeconomic backgrounds, and racially and ethnically minoritized families to improve generalizability.

Finally, SPARKLE used a Trial within a Cohort design and participants were recruited from the Co-SPACE cohort, which allowed for rapid recruitment but had some limitations, as it likely attracted families with interest and internet access [56]. The sample also had higher levels of child conduct and emotional problems and ADHD symptoms than both the UK national survey [55] and the wider Co-SPACE study sample [29]. While levels of parental psychological distress were also higher than expected in the general population [36], they did not differ from levels reported in the wider Co-SPACE sample [37]. In addition, not all relevant moderators of interest from prior research were included (eg, young parent age and initial parenting confidence), as we relied on the available variables within the Co-SPACE data set. Future research incorporating a wider array of moderators in future studies could provide a more comprehensive understanding of intervention outcomes.

Conclusions

This study has demonstrated that Parent Positive has the potential to improve primary school-aged male children's emotional problems in a wide range of families. The findings suggest that the effects of Parent Positive on emotional problems do not differ for children with different levels of ADHD symptoms, socioeconomic status and household crowding, family conflict, and parental psychological distress. Pandemic-related disruption was also not found to influence the effectiveness of the app on child emotional problems. There were no differential effects of Parent Positive on conduct problems by any of the participant characteristics and pandemic-related disruption circumstances, noting that overall, the app was not found to be effective in addressing child conduct problems in the main SPARKLE trial analysis [15]. While our findings suggest positive emotional outcomes for male children, the exploratory nature of this study, along with potential limitations in statistical power to detect moderated effects and limited variability in some potential moderating variables, warrants caution in drawing definitive conclusions. However, if the male sex advantage in effectiveness turns out to be replicated, the reasons for this need to be identified and steps taken to adapt Parent Positive to increase its value for females. This could involve explorations of differences in the way that parents think about and react to emotional problems in their male and female children and subsequent change to the app to take account of these differences. Additional future research should focus on multivariate moderation analyses and replicate these findings in larger and diverse samples, with longer follow-up times, and across different contexts and settings, to better understand the app's effectiveness. In sum, while this study underscores the promising role of Parent Positive in fostering emotional well-being among male children, these findings are preliminary and continued research endeavors are essential to optimize its effectiveness and applicability in practice, especially in diverse familial contexts.

Conflicts of Interest

CC receives royalties from the sale of books for parents and clinicians on managing child anxiety problems from LittleBrown and Guilford Press. CD is the lead developer and has a nonfinancial interest in a number of parenting programs including Empowering Parents Empowering Communities, Helping Families Programme, Family Partnership Model, and BabyCHAT. EJSSB was involved in the development of the New Forest Parent Programme, Families Under Pressure and Parent Positive.

Receiving royalties for a book on the former. PW receives royalties from the sale of books for parents on helping their children overcome common psychological and emotional problems from LittleBrown. All other authors declare no conflicts of interest.

Multimedia Appendix 1
Additional details on statistical analysis, sample, clinical outcomes, and model results.
[DOCX File , 418 KB - pediatrics_v7i1e53864_app1.docx]

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Abbreviations

ADHD: attention-deficit/hyperactivity disorder
Co-SPACE: COVID-19: Supporting Parents, Adolescents, and Children During Epidemics
CONSORT: Consolidated Standards of Reporting Trials
DASS: Depression, Anxiety, and Stress Scale
FAU: follow-up as usual
LMM: linear mixed-effects models
RCT: randomized controlled trial
SDQ: Strengths and Difficulties Questionnaire
SPARKLE: Supporting Parents and Kids Through Lockdown Experiences
T1: baseline before randomization
T2: 1 month after randomization
T3: 2 months after randomization

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Original Paper

Development and Refinement of a Chatbot for Birthing Individuals and Newborn Caregivers: Mixed Methods Study

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Abstract

Background: The 42 days after delivery ("fourth trimester") are a high-risk period for birthing individuals and newborns, especially those who are racially and ethnically marginalized due to structural racism.

Objective: To fill a gap in the critical "fourth trimester," we developed 2 ruled-based chatbots—one for birthing individuals and one for newborn caregivers—that provided trusted information about postbirth warning signs and newborn care and connected patients with health care providers.

Methods: A total of 4370 individuals received the newborn chatbot outreach between September 1, 2022, and December 31, 2023, and 3497 individuals received the postpartum chatbot outreach between November 16, 2022, and December 31, 2023. We conducted surveys and interviews in English and Spanish to understand the acceptability and usability of the chatbot and identify areas for improvement. We sampled from hospital discharge lists that distributed the chatbot, stratified by prenatal care location, age, type of insurance, and racial and ethnic group. We analyzed quantitative results using descriptive analyses in SPSS (IBM Corp) and qualitative results using deductive coding in Dedoose (SocioCultural Research Consultants).

Results: Overall, 2748 (63%) individuals opened the newborn chatbot messaging, and 2244 (64%) individuals opened the postpartum chatbot messaging. A total of 100 patients engaged with the chatbot and provided survey feedback; of those, 40% (n=40) identified as Black, 27% (n=27) identified as Hispanic/Latina, and 18% (n=18) completed the survey in Spanish. Payer distribution was 55% (n=55) for individuals with public insurance, 39% (n=39) for those with commercial insurance, and 2% (n=2) for uninsured individuals. The majority of surveyed participants indicated that chatbot messaging was timely and easy to use (n=80, 80%) and found the reminders to schedule the newborn visit (n=59, 59%) and postpartum visit (n=66, 66%) useful. Across 23 interviews (n=14, 61% Black; n=4, 17% Hispanic/Latina; n=2, 9% in Spanish; n=11, 48% public insurance), 78% (n=18) of interviewees engaged with the chatbot. Interviewees provided positive feedback on usability and content and recommendations for improving the outreach messages.

Conclusions: Chatbots are a promising strategy to reach birthing individuals and newborn caregivers with information about postpartum recovery and newborn care, but intentional outreach and engagement strategies are needed to optimize interaction. Future work should measure the chatbot's impact on health outcomes and reduce disparities.

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KEYWORDS

postpartum care; newborn care; health education; chatbot; mHealth; mobile health; feedback; health equity

Introduction

Maternal mortality rates in the United States are increasing; in 2018, the maternal mortality rate was 17.4 per 100,000 live births, nearly doubling by 2021 to 32.9 per 100,000 live births [1]. Furthermore, there are stark inequities for Black women, who in 2021 suffered 69.9 deaths per 100,000 live births compared to 26.6 for non-Hispanic White and 28 for Hispanic women [1]. While about half of all deliveries in Washington, DC are among non-Hispanic Black women, data from 2014 to 2018 indicate that 92% of all maternal deaths occurred among non-Hispanic Black women [2]. Infant deaths in the United States are also unacceptably high, at a rate of 5.4 deaths per 1000 births, but even higher in Washington, DC, at 6.8 per 1000 births [3,4]. Non-Hispanic Black women and infants bear the primary burden of these mortality inequities. Racially and ethnically minoritized individuals experiencing the highest risk of maternal and infant mortality may have lower access to care due to structural discrimination [5,6].

In the "fourth trimester" (first 42 days after birth), there are significant caregiving demands, physical recovery from childbirth, and emotional challenges [7]. Despite the high-risk nature of this period, birthing individuals in the United States experience little support for postpartum health, and some have challenges accessing a visit 6 weeks after delivery [7]. Missing postpartum care has devastating health consequences: 65% of pregnancy-related deaths occur in the first year after delivery, 35% of which occur in the first 42 days after delivery [8]. An estimated 60% to 84% of pregnancy-related deaths are preventable [8,9], and insufficient knowledge regarding warning signs of complications is identified as the most common factor contributing to pregnancy-related death [9]. In relation to infant mortality, 64% of infant deaths occur in the first 27 days, and about 14% of infant deaths are attributed to sudden infant death syndrome and unintentional injuries [3], some of which could be prevented with education [10]. Increased awareness of postnatal warning signs through universal education may empower birthing individuals to call their health care provider and to know when to seek immediate care [11,12]. For newborns, prompt follow-up care with a pediatrician and understanding warning signs to seek care may also decrease adverse events [13].

Digital technologies may help provide timely and trusted health information to patient populations [14] including birthing individuals [15]. Digital technology is often promised as an opportunity to reduce some educational burden on providers and increase patient knowledge [16]. Chatbots are one type of digital tool for delivering health information on a variety of topics, which allow for patient interactivity through mimicked conversation [16,17]. Chatbots are defined as any software programs simulating human conversation, which vary from rule-based, decision tree-style menus of options to advanced technologies relying on artificial intelligence (AI) [18,19]. Overall, chatbots have demonstrated a high acceptability rate among birthing individuals and newborn caregivers [20-22] and are effective at delivering interventions targeting birthing individuals' depression [23] and anxiety [24], as well as helping parents identify newborn developmental delays [25]. While these studies provide promise for health information delivery via chatbot, there is a need to further understand how chatbot outreach is received in real-world settings, particularly among historically marginalized birthing individuals.

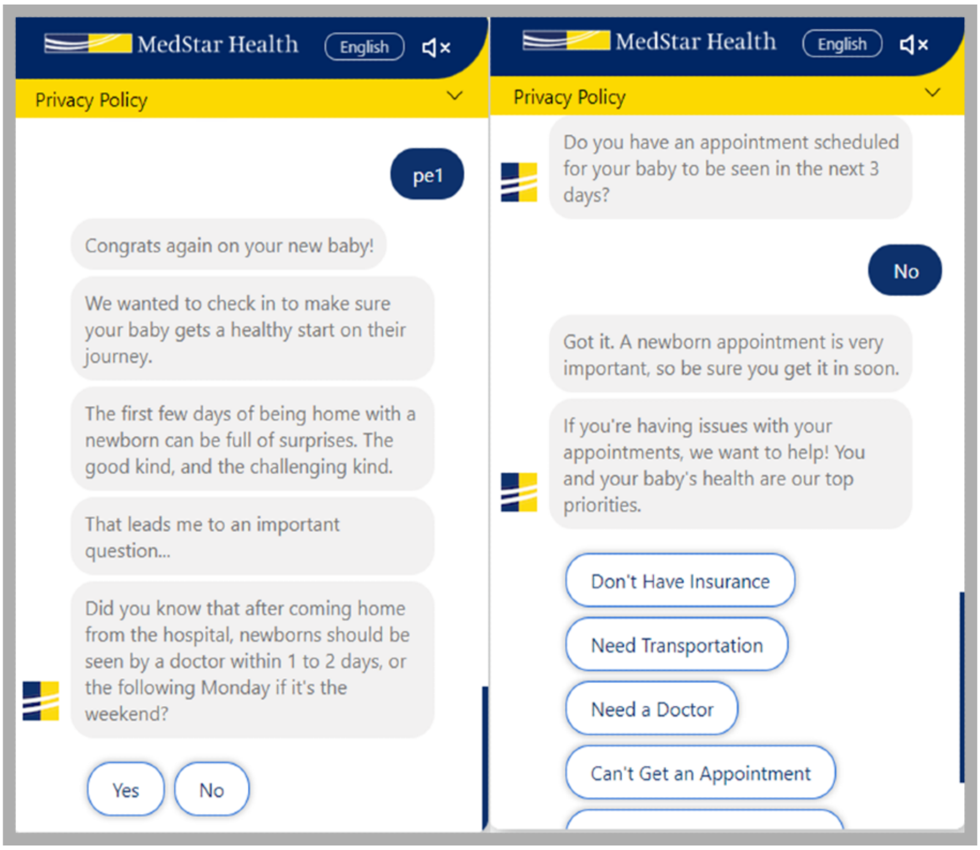
The goal of this study is to describe the development and refinement of chatbot outreach and content for postpartum individuals and newborn caregivers delivered as part of the standard of care. Postimplementation, we surveyed and interviewed socioeconomically, racially, and ethnically diverse patients who received chatbot messaging to improve the chatbot outreach and content.

Methods

Chatbot Development

We followed a person-centered approach to develop and refine a chatbot for postpartum individuals and newborn caregivers, with an emphasis on incorporating the perspectives and unique needs of our socioeconomically and racially diverse patient population [26]. The chatbot content was developed by a multidisciplinary team of experts in obstetrics, pediatrics, social work, psychiatry, mobile health, and health equity. The chatbot is intended to promote connection to care teams, provide education about warning signs, and deliver other postpartum and newborn information and resources (Figures 1 and 2). Two separate messaging streams (postpartum and newborn) were created because (1) newborns and postpartum patients are not always discharged together, and (2) some individuals may only need postpartum or just newborn content (eg, if there is a stillbirth, adoption, etc). We obtained a HIPAA (Health Insurance Portability and Accountability Act) waiver to use electronic health record (EHR) data to examine whether there was equitable chatbot engagement (defined as opening the chatbot link from the outreach message) by various patient characteristics.

Figure 1. Newborn chatbot examples.



pe1

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?

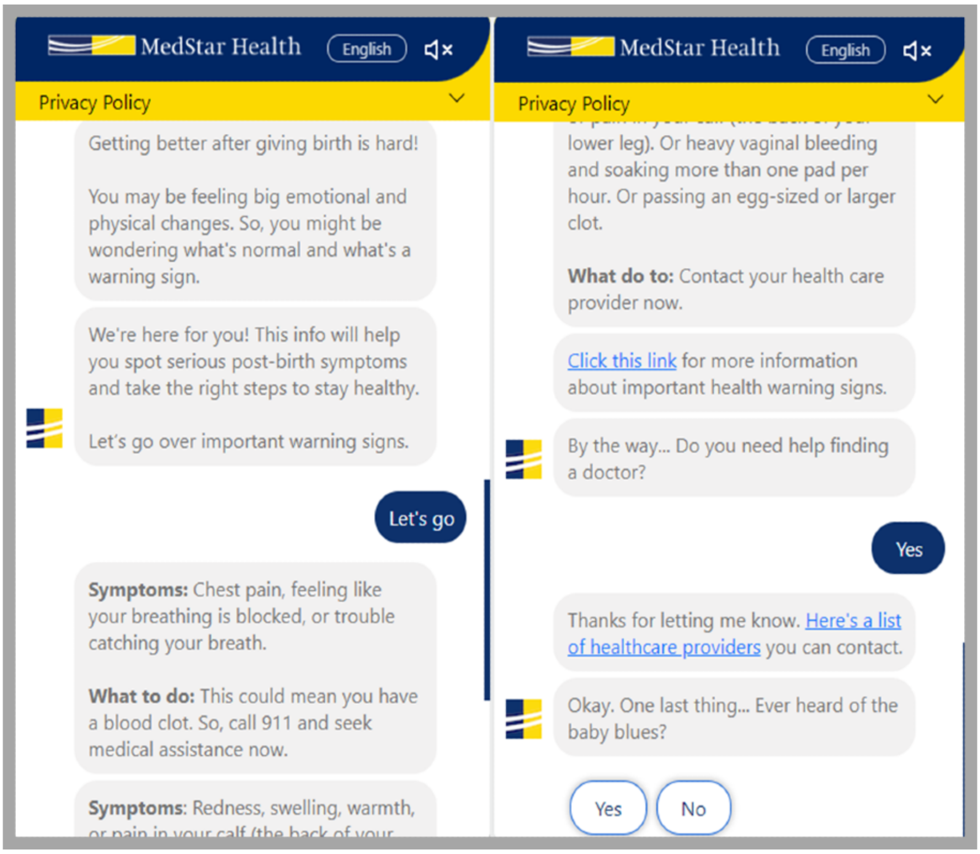
Do you have an appointment scheduled for your baby to be seen in the next 3 days?

No

Got it. A newborn appointment is very important, so be sure you get it in soon.

If you're having issues with your appointments, we want to help! You and your baby's health are our top priorities.

Figure 2. Postpartum chatbot examples.



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.

Let's go

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, or pain in your calf (the back of your

lower leg). Or heavy vaginal bleeding and soaking more than one pad per hour. Or passing an egg-sized or larger clot.

What do to: Contact your health care provider now.

Click this link for more information about important health warning signs.

By the way... Do you need help finding a doctor?

Yes

Thanks for letting me know. Here's a list of healthcare providers you can contact.

Okay. One last thing... Ever heard of the baby blues?

Survey and Interview Recruitment

We recruited English- and Spanish-speaking birthing individuals and newborn caregivers from a diverse, mid-Atlantic urban hospital. We generated a list of potential participants from the EHR, purposively selected by age, racial or ethnic group, insurance type, and prenatal care location. Individuals were contacted via email and phone to invite them to complete either (1) a brief web-based survey that was conducted via REDCap (Research Electronic Data Capture; Vanderbilt University) or (2) a semistructured interview that was conducted by phone or video call using Teams (Microsoft Corp).

For web-based surveys, we invited a distinct list of respondents balanced across those who did and did not engage with the chatbot. Of the 410 individuals contacted for the survey completion, 104 (25%) individuals completed the informed consent, and 100 (24%) individuals completed the survey between May 15, 2023, and August 8, 2023. For interviews, we invited individuals who opened the chatbot. Of the 110 individuals contacted, 28 (25%) individuals agreed to participate, and 23 (21%) individuals completed a semistructured interview between March 13, 2023, and June 1, 2023; the remainder missed the scheduled interview time and were not interested in rescheduling.

Ethical Considerations

The study protocol was approved by the institutional review board from MedStar Health Research Institute (IRB #5741). All participants provided informed consent, and data were anonymized for analysis. Individuals were compensated US $10 and US $50 for their participation in the survey and interview, respectively.

Demographic Data Collection

Demographic data related to the study was obtained by directly querying the integrated enterprise EHR system’s database to describe patients’ general chatbot engagement. We included race (Back or African American, White, other, or unknown), age, and insurance type (private or commercial, Medicare or Medicaid, other, uninsured, or unknown) of the birthing individual. For the survey and interviews, we collected self-reported sociodemographic characteristics of gender identity (woman, man, nonbinary, transgender, or other), race (American Indian or Alaska Native, Asian, Back or African American, Native Hawaiian or Other Pacific Island, White, or Other), and ethnicity (Hispanic vs non-Hispanic). For the survey, participants reported their age, sexual orientation, highest level of education completed, English literacy level, employment status, living arrangement, and type of health insurance. Age and insurance type were obtained from the medical records of interview participants. Participants of both the survey and interview also reported the number of times they gave birth, the number of children they cared for, prenatal and postpartum care locations, newborn care, and if they had support at home recovering from childbirth and with newborn care.

Survey Measures

Survey questions about the chatbot experience covered three domains: outreach strategies, usefulness of content, and usability. Outreach questions included, “How often did you open the links provided in the emails and SMS text messages?” and “Would you say the timing of the messages was: too frequent, just right, or not enough?” (response options: never, rarely, sometimes, often, or always). Regarding content, participants rated their level of agreement to a set of statements regarding the usefulness of the topics included in the chatbot experience (strongly disagree=1 to strongly agree=5). Regarding usability, participants rated their level of agreement with the statement “The chatbot was easy to use” (strongly disagree=1 to strongly agree=5) [27]. Participants also rated their level of agreement for the following statement “I would recommend the chatbot to other people” (strongly disagree=1 to strongly agree=5).

Interview Process

We approached the interviews from a pragmatic qualitative framework [28], which emphasizes discovering problems, information gaps, and real-world solutions to the problem. Thus, we developed a standardized semistructured interview guide with a focus on the pragmatic understanding of postpartum and newborn concerns, how to improve chatbot engagement, and increasing engagement with chatbot content (Table 1). The interview guide was tailored by engagement; for example, if a participant did not remember receiving the outreach messages, they were asked to describe factors that typically influenced whether they opened SMS text messages and emails from their health care provider. Prior to and during the interview, participants received and were shown screenshots of outreach emails and SMS text messages, the chatbot interface, and the lists of topics included in both chatbots.

Table 1. Interview guide sample questions.

Domains	Example questions
Health concerns	• What were your biggest health concerns for you or your baby after discharge from the hospital?
Chatbot outreach strategies	• Can you tell me your impressions of the SMS text messages and emails you received after your hospital discharge? • What did you think of the timing when the messages arrived?
Chatbot content	• What are your thoughts about the topics that we included in the birthing recovery or postpartum chatbot? • What are your thoughts about the topics that we included in the newborn chatbot? • What could we do to better support birthing individuals or caregivers in accessing these resources?
Chatbot usability	• What aspects of the chatbot were most helpful? • What aspects of the chatbot were least helpful? • How hard was it to use the chatbot?

Data Analysis

Audio recordings from the interviews were transcribed and reviewed for quality control using Otter.ai and coded using Dedoose (SocioCultural Research Consultants). Three research team members (JNRR, CS, and MS) met to create the initial codebook with operational definitions for each code. The three team members then coded two randomly selected interviews individually and finalized the codebook together. The team members then triple-coded 3 additional interviews to meet an interrater reliability of 80% with JNRR. The team members independently coded the remaining interviews, with regular meetings to discuss inconsistencies and coding questions. We selected representative quotes and demonstrated theme salience by summarizing whether the sentiment was reported across most, around half, or a limited number of participants. Given the small number of interviews and the research team's interest in the depth of response rather than the quantity of responses, we did not present statistics on the number of individuals reporting a specific theme. Descriptive statistics were used to describe the quantitative data using SPSS Statistics (version 29; IBM Corp).

Results

Chatbot Strategy

The initial postpartum chatbot outreach message was sent the day after the birthing individual was discharged home from the hospital, and the first newborn chatbot message was sent to the newborn caregiver listed in the medical record the day after their newborn was discharged from the hospital. The postpartum chatbot outreach SMS text messages and emails were sent in the morning and the newborn messages were sent in the afternoon. In Table S1 in Multimedia Appendix 1, there is a full description of the original chatbot content by day of the outreach message. The content was rule-based and allowed for interaction using fixed logic; it did not permit open-ended questions from the user or responses from a care team. Both chatbots were sent approximately weekly during the first 42 days of posthospital discharge.

Overall Chatbot Engagement

In regard to the postpartum chatbot, a total of 2244 (64%) birthing individuals opened the chatbot (Table 2) between November 16, 2022, and December 31, 2023. When evaluated by racial group, 62% (n=969) of the Black users, 78% (n=384) of the White users, and 62% (n=891) of those classified as Other opened the postpartum chatbot. In addition, the proportion of patients who opened that chatbot increased by age; for example, 55% (n=183) of birthing individuals 21 years old and younger opened the chatbot compared to 68% (n=429) of birthing individuals aged 37 and older. By insurance type, 69% (n=971) of birthing individuals with private or commercial insurance and 63% (n=631) with Medicaid or Medicare insurance opened the chatbot.

A total of 2748 (63%) caregivers opened the newborn chatbot between September 1, 2022, and December 31, 2023. By racial group, 61% (n=1256) of the Black caregivers, 81% (n=449) of the White caregivers, and 61% (n=593) of those classified as Other opened the newborn chatbot. In addition, 58% (n=246) of caregivers 21 years old and younger and 69% (n=516) of caregivers aged 37 and older opened the chatbot. By insurance type, 71% (n=1185) of caregivers with private or commercial insurance and 61% (n=799) with Medicaid or Medicare insurance opened the newborn chatbot.

Table 2. Demographic characteristics of patients who received and opened the postpartum and newborn chatbot.

	Postpartum chatbot			Newborn chatbot		
	Total received (n=3497)	Total opened (n=2244)	Percentage opened (n=64.2)	Total received (n=4370)	Total opened (n=2748)	Percentage opened (62.9)
Race						
Black	1566	969	61.9	2069	1256	60.7
Unknown	0	0	0	768	450	58.6
White	491	384	78.2	553	449	81.2
Other	1440	891	61.9	980	593	60.5
Age (in years)						
≤18	93	49	52.2	113	58	51.3
19-21	242	134	55.4	308	188	61
22-26	561	341	60.8	747	421	56.4
27-31	963	611	63.4	1199	743	62
32-36	1003	680	67.8	1260	822	65.2
37-41	543	364	67.0	640	445	69.5
>41	92	65	70.7	103	71	68.9
Insurance						
Private or commercial	1404	971	69.2	1675	1185	70.7
Medicare or Medicaid	1008	631	62.6	1304	799	61.3
Other	666	394	59.2	852	458	53.8
Uninsured	201	120	59.7	223	121	54.3
Unknown	218	128	58.7	316	185	58.5

Demographics for Survey and Interview Participants

Participants’ average age was 32 (SD 5.38) years old in the surveys, and 31 (SD 7.05) years old in the interviews (Table 3). A total of 40% (n=40) of survey participants and 61% (n=14) of interview participants identified as Black, and 27% (n=27) of survey participants and 17% (n=4) of interview participants identified as Hispanic. Over half of the Hispanic participants (18/27, 67% in the surveys and 2/4, 50%) in the interviews) identified Spanish as their preferred language. One-third of the participants in both the surveys and interviews indicated that this was their first time giving birth. About half of the participants in the survey (n=55, 55%) and interviews (n=11, 48%) had public insurance. Most of the survey and interview participants reported that they had a postpartum provider (n=78, 78% and n=22, 96%, respectively) and primary care provider (n=73, 73% and n=18, 78%, respectively) and that their newborns were receiving care outside of the integrated health care system (n=84, 84% and n=20, 87%, respectively).

Table 3. Participants' demographic and clinical characteristics for survey and interviews.

Characteristics	Survey (n=100)	Interview (n=23)
Age (years)		
Mean (SD)	32 (5.38)	31 (7.05)
Range	19-42	19-43
Sex, n (%)		
Female	99 (99)	23 (100)
Male	1 (1)	0 (0)
Sexual orientation, n (%)		
Straight	83 (83)	—[a]
Other	11 (11)	—
Prefer not to say	6 (6)	—
Ethnicity, n (%)		
Hispanic	27 (27)	4 (17)
Non-Hispanic	67 (67)	19 (83)
Prefer not to say	6 (6)	0 (0)
Race, n (%)		
Black only	40 (40)	14 (61)
Black + another racial group	3 (3)	2 (9)
White only	23 (23)	4 (17)
Other only	24 (24)	3 (13)
Prefer not to say	10 (10)	0 (0)
Relationship status, n (%)		
Partnered or married	63 (63)	—
Single or separated or divorced or widowed	29 (29)	—
Other	3 (3)	—
Prefer not to say	5 (5)	—
Education level, n (%)		
< High school	9 (9)	—
High school degree or equivalent	39 (39)	—
≥College degree	49 (49)	—
Prefer not to say	3 (3)	—
Employment status, n (%)		
Employed	62 (62)	—
Other	34 (34)	—
Prefer not to say	4 (4)	—
Living arrangement, n (%)		
Owner	30 (30)	—
Renter	54 (54)	—
Other	11 (11)	—
Prefer not to say	5 (5)	—
Times given birth		
Mean (SD)	2 (1.02)	2 (1.52)
Range	1-5	1-7

Characteristics	Survey (n=100)	Interview (n=23)
Number of children		
Mean (SD)	2 (0.89)	2 (1.48)
Range	1-4	1-7
Insurance type, n (%)[b]		
Private or commercial	39 (39)	12 (52)
Medicare or Medicaid	55 (55)	11 (48)
Other	3 (3)	0 (0)
Uninsured	2 (2)	0 (0)
Prefer not to say	6 (6)	0 (0)
Prenatal location, n (%)		
Internal clinics	47 (47)	12 (52)
External clinics	52 (52)	11 (48)
Prefer not to say	1 (1)	0 (0)
Connected to postpartum care	78 (78)	22 (96)
Has a primary care provider	73 (73)	18 (78)
Newborn care, n (%)		
Within an integrated health care system	14 (14)	3 (13)
External to integrated health care system	84 (84)	20 (87)
Prefer not to say	2 (2)	0 (0)
Postpartum support, n (%)		
Yes or sometimes	87 (87)	20 (87)
No	9 (9)	3 (13)
Prefer not to say	4 (4)	0 (0)
Newborn support, n (%)		
Yes or sometimes	89 (89)	20 (87)
No	8 (8)	3 (13)
Prefer not to say	3 (3)	0 (0)
English literacy, n (%)		
Very well or well	83 (83)	—
Not well or not at all	14 (14)	—
Prefer not to say	3 (3)	—
Preferred language, n (%)		
English	82 (82)	21 (91)
Spanish	18 (18)	2 (9)

[a] Not applicable.

[b] Participants could select >1 option.

Outreach Strategies: Satisfaction and Recommendations

Most survey participants (n=83, 83%) reported that they understood why they were receiving the outreach messages (Table 4). However, many interview participants reported being surprised when they received the messages, as they did not expect them (Table 5). Still, participants in the interviews found the outreach messages to be helpful. Participants recommended that the chatbot should be introduced both in prenatal care and by the recovery care team prior to discharge.

Interview participants reported that they opened the outreach messages because the messages came from the hospital where they delivered. Most participants in the survey (n=70, 70%) and interview preferred receiving messages via text because it was more personal, easier to notice, and involved fewer steps than email. However, during the interviews, it was noted that those who preferred emails did so because they could open the chatbot on their computer, which provided additional confirmation that the outreach messages were legitimate and not spam or scam.

More than half of the survey participants (n=56, 56%) indicated they opened the weekly chatbot link often or always. In the interviews, some participants reported that their decision to open each of the weekly chatbot experiences was based on the information or topic in the outreach message, as they only opened the chatbot experiences that were relevant to them. The interview participants also identified barriers to chatbot engagement including feeling overwhelmed with information, multiple household responsibilities, and confusing the chatbot with a survey.

Participants reported that the outreach messages were useful reminders of self-care and feeling supported by the hospital. Participants liked that the outreach messages were short, straightforward, and could be opened at any time, as opposed to a phone call which would be missed if they were not available. Participants also liked when the messages indicated what information would be covered in the chatbot experience. They recommended that the initial outreach should provide more information about why they are receiving the messages, and that all the messages should indicate what will be covered in each of the chatbot experiences. Furthermore, participants recommended making the messages more inviting, personal, and targeted. Some participants expressed that the chatbot's wording should be appropriate to a diverse literacy level; for example, a few participants noted that the term "postpartum" could be confused with postpartum depression, and one participant suggested changing the term "chatbot" to something more friendly like "check-in messages." One participant talked about a previous experience with stillbirth and suggested the postpartum chatbot would have been useful as she recovered.

Table 4. Survey feedback on outreach strategies and usability (n=100).

	Value, n (%)
Outreach strategies	
Confused with chatbot message	
Yes	7 (7)
Somewhat	10 (10)
No	83 (83)
Preferred outreach strategy	
Email	30 (30)
SMS text messages	70 (70)
Frequency of opening the chatbot	
Never or rarely	11 (11)
Sometimes	33 (33)
Often or always	56 (56)
Timing of messages	
Too frequent	10 (10)
Just right	80 (80)
Not enough	10 (10)
Usability	
Easy to use	
Strongly agree or agree	81 (81)
Neutral	16 (16)
Strongly disagree or disagree	3 (3)
Would recommend the chatbot	
Strongly agree or agree	72 (72)
Neutral	22 (22)
Strongly disagree or disagree	2 (2)
Not applicable	4 (4)

Table 5. Example of participants' interview responses by themes.

Themes	Quotes
Outreach strategies and timing	• "At the beginning, when I received the first message, I wasn't sure what to do, if should read it or not, later I decided to read it and I found it to be good, because it was good information." [Hispanic/Latina, Other, 38 years, female, 2 children] • "In the past, I was a victim of identity theft. I'm very leery about getting messages from different places ... It was one time where I thought that it was a scam but when I saw it said [health care system], that was my indication that it was something real, something important, and informational." [Non-Hispanic, Black, 35 years, female, 6 children] • "So the text here is quick, easy, it's telling you to the point, we know you're busy, you got a lot going on ... And typically, that's what people need these days ... There's something about that quick." [Non-Hispanic, Black, 40 years, female, 2 children] • "It was really helpful to have both emails and text messages, just as a follow-up in case I miss one or the other. But I felt it was like perfect timing, because it checked up on me." [Non-Hispanic, White, 31 years, female, 1 child] • "So, I may have opted out a little early. Which I feel like even though I did opt out I wish there was like another option that you know, I can get back in it ... Because at one point in time, I wish I was receiving the messages again after I opted out." [Non-Hispanic, Black, 25 years, female, 1 child]
Knowledge and information-seeking	• "I just relied solely on my family, I didn't really have resources to reach out to anything ... I didn't really have health concerns for myself, but for my son, it was just more so how to care for a baby that just got out the NICU. I didn't really have ... much information on things like that. So it was kind of like I had to learn by myself. And figure things I don't know." [Non-Hispanic, Black, 25 years, female, 1 child] • "There's some weird things that happened with the babies. There's like, how do you care for their umbilical cord? Once that falls off ... what do you do with it? That was a question I definitely Googled. They have weird skin stuff. What is normal? What's concerning?" [Non-Hispanic, White, 30 years, female, 2 children]
Chatbot content	• "I learned how to take care of my son, I learned how to take care of myself, [I received them] just recently leaving the hospital, I learned a lot of stuff." [Hispanic/Latina, Other, 29 years, female, 3 children] • "I didn't know anything about postpartum until I had my baby. So, really understand because it's like postpartum depression, like what you're talking about." [Non-Hispanic, Black, 22 years, female, 2 children] • "The one thing I can say I really enjoyed receiving messages about were the developmental milestones, because I always wanted to know if my baby was on track, being as he was premature baby ... And as a first-time parent ... It can be really overwhelming ... So being as though [health care system] was giving you information like vaccines, and you know, what to expect with these vaccines and things like that. I feel like that was very helpful..." [Non-Hispanic, Black, 25 years, female, 1 child] • "I was glad that it was put together because usually that is the time that I go through the worst end of postpartum depression. But even though I didn't have the effects of postpartum depression, like I usually do, this time around, I was just glad that it was something I could read to give, I guess you could say, some sense of comfort or hope to get me through it." [Non-Hispanic, Black, 35 years, female, 6 children] • "I feel like breastfeeding was the one thing that I was shocked by how hard it was. So, getting more support and encouragement would have been nice ... Feel like it's not just newborn care. That's also postpartum. My body too." [Non-Hispanic, White, 30 years, female, 2 children]
Chatbot usability	• "I think moms are getting the most information from their phones, and kind of a digestible bite size thing when you can, like, occasionally glance at your phone for a few minutes is helpful." [Hispanic/Latina, Other, 23 years, female, 2 children] • "It was really easy. I don't have any real complaints about it. It was very simple to use, in my opinion." [Non-Hispanic, Black, 23 years, female, 2 children] • "I had the information through text and email, and just the resources were really helpful, and then just how quickly the chatbot worked. And just that it also felt like I was talking to a real person, it felt like a very sophisticated robot ... And I remember, like, sharing those resources with my husband, too. So it was nice, because it like also added a source of credibility." [Non-Hispanic, White, 31 years, female, 1 child] • "Overall, just very helpful. And I thought it was really amazing to see ... just considering the generation that we are in, tech is constantly evolving. And I feel like the world should start evolving more, especially medical wise, just with technology and adapting, certain people that are getting more into technology. So, I thought that was very refreshing. Like I said, it's a very nice experience. Honestly, took me by surprise, I'm like, 'Woah, hospitals are doing this now?' Like this is great. But yeah, I thought that was pretty cool, too." [Hispanic/Latina, Other, 19 years, female, 1 child]

Themes	Quotes
Chatbot suggestions	• "It comes in English and I have to put it in the translator, and it gets a bit more difficult." [Hispanic/Latina, Other, 29 years, female, 3 children] • "...If there's some sort of way you can write in a question ... And even if it's not something that the chatbot can respond to, it can say, we received your question and someone will reach out to you." [Non-Hispanic, White, 30 years, female, 1 child] • "So maybe an opportunity of like, send this to like your husband, or whoever, like they need support. I know I needed a lot of support in those first two weeks because you're not supposed to go up and down the stairs. Things like that and how they can be supportive to you and the baby." [Non-Hispanic, Black, 26 years, female, 1 child] • "It would be great if all information appeared in one site that I could refer back to later and also have a choice of selecting which topic I want to learn about at any given time rather than a pre-determined order." [Non-Hispanic, Asian, 37 years, female, 1 child—Survey] • "...There could be a 12-week one, just because that's when a lot of transitions and a lot of people are going back to work or things like that." [Non-Hispanic, White, 30 years, female, 2 children]

Most participants in the survey (n=80, 80%) and interview liked the timing and frequency of the outreach messages, although a few survey participants (n=10, 10%) indicated that the messages were too frequent. Participants in the interviews and survey also recommended extending messaging to at least 12 weeks to support longer-term recovery and life transitions such as going back to work. One participant reported that she felt that the chatbot messages ended abruptly and recommended including a final message indicating that the chatbot experience was complete. Of note, one interview participant who opted out from the chatbot indicated regretting it and recommended including a summary of all the topics that will be covered before someone can opt out.

Chatbot Content Usefulness and Recommendations

Most of the participants in the survey and interview found all topics included in the chatbots to be useful. Participants noted that the chatbot information complemented and reinforced the information provided by their providers and at discharge. Some of the participants spoke about how the content supported them through their journey in their recovery and caring for their newborn. Specifically, topics rated as useful by the greatest percentage of survey participants included appointment reminders (n=59, 59% for newborn appointments and n=66, 66% for postpartum appointments; full results in Table S2 in Multimedia Appendix 1), and nearly a quarter of participants (n=22, 22%) thought that the resources to schedule appointments were useful. Participants further highlighted the importance of receiving tailored information for postpartum recovery. One interviewee noted that the information was beneficial for sharing newborn recommendations with other caregivers.

For the newborn chatbot, 86% (n=86) of the participants found the warning sign information to be useful and 58% (n=58) of the participants found the parental leave information to be useful. For the postpartum chatbot, 88% (n=88) and 86% (n=86) of the participants found the warning signs and postpartum depression information to be useful, respectively (Multimedia Appendix 1). For both the newborn and postpartum chatbots, interview participants recommended more information about breastfeeding (eg, engorgement or mastitis, how to latch, access to a pump, resources for lactation consultants, and differences between breast milk vs formula) and parental leave. Most participants also recommended that the resources to schedule and attend medical appointments (eg, transportation, childcare, or insurance recommendations) should be offered to all participants regardless of whether they indicate a need. Participants also requested information on how to improve communication with providers and more resources for emotional and practical support.

For the postpartum chatbot, survey and interview participants recommended adding additional information about postpartum recovery including mental health warning signs and support, vaginal birth, pain management, pelvic floor issues, and monitoring blood pressure. For the newborn chatbot, participants noted that it was important to add additional information about what is normal versus concerning for a newborn (eg, number of wet diapers, bowel movement texture and color, baby acne, cradle cap, umbilical cord, and circumcision recovery). Some participants also recommended adding specific tips on newborn care, such as changing newborn diapers, newborn sleep recommendations (eg, number of recommended hours, wake windows, and establishing sleep routines), and activities to do with a newborn. Participants with specific needs recommended additional targeted information; for example, participants with a premature newborn recommended adding specific information about premature newborns (eg, expected weight gain and recommended room temperature), participants with twins recommended including practical recommendations on how to care for twins, and participants with older children suggested more information about how to care for a newborn with older siblings at home.

Perceived Ease of Use

The majority of survey (n=81, 81%; Table 4) and interview participants who engaged with the chatbot found the chatbot easy to use. During the interviews, participants described the chatbot as personable and practical. Participants also liked that they could use their smartphones to open the chatbot. Most of the participants in the survey (n=72, 72%) and interviews indicated that they would recommend the chatbot to other people. Participants in the survey and interviews provided different suggestions to improve the delivery of chatbot information, which included a video or voiceover option, an option for patients to provide immediate feedback after navigating each experience, an option to share the chatbot content with their partner or other caregiver, and an option to easily go back to information of interest. Several participants recommended adding the capability to interact with a provider via the chatbot to answer nonurgent questions. Finally, Spanish-speaking participants recommended having the chatbot available in Spanish.

Discussion

Principal Findings

We found that the chatbot is a promising strategy to deliver relevant and timely education and referral to resources for birthing and caregiving individuals. To our knowledge, this is the first report on perceptions of a postpartum or newborn chatbot delivered at scale as part of usual care upon hospital discharge.

Previous studies illustrated preliminary interest in chatbots as a modality to receive information about pregnancy and postpartum concerns. Researchers who developed an artificial intelligence-based, open-ended question-and-answer chatbot using a community-engaged approach with pregnant women and new mothers of color also conducted community demonstrations to solicit feedback. They queried participants on interest in using a chatbot to receive information and found that 109 participants were highly receptive [20]. Our findings further expanded on the previous study by evaluating outreach strategies on how to best reach and engage patients by email and SMS text message.

This study suggests that the chatbot provided useful and timely information during the postpartum period. This is particularly relevant, as in a study with Black new mothers, none of the participants were able to identify more than five of nine key postpartum warning signs [29]. While we were unable to conduct a pre-post knowledge test through the chatbot, interview participants reported limited knowledge of key topics prior to discharge and found the postpartum warning signs and mental health information to be useful. Similar outreach and chatbot strategies targeting postpartum mental health issues have improved birthing individuals' well-being [23,24,30]. One study targeting postpartum depression found that patients who engaged highly with an AI chatbot had lower symptoms of depression during the postpartum period compared to patients with low engagement [23]. Other studies found that engaging with an SMS text-messaging program can reduce postpartum anxiety [24], and web-based courses that provide information to birthing individuals can lower anxiety and result in fewer emergency visits compared to standard of care [30]. Nevertheless, additional research is needed to understand how chatbots can serve to fill knowledge gaps in postpartum health care and impact postpartum and newborn health outcomes.

Chatbots provide a potential opportunity to create a sense of support for new parents or birthing individuals, which is important since social support is identified as a protective factor for postpartum depression and anxiety [31]. Our finding that more than 10% of the participants in the surveys and interviews reported that they did not have support for themselves or taking care of their baby after hospital discharge suggests an avenue for at least informational support through consistent outreach. Content also included in-person and web-based support communities that might be able to fill some of the gaps in support after delivery.

This study also elucidated postpartum individuals' and newborn caregivers' health information needs about postpartum and newborn care after discharge from the hospital. In general, participants desired more information about breastfeeding, postpartum recovery, mental health, and newborn care among other content areas. Participants who were planning to go back to work wanted more information about parental leave. These findings are similar to a scoping review reporting that nurses prioritized safety and avoiding adverse events after discharge (eg, the prioritized topics in our chatbot) and patients prioritized self-care, pain management, infant care, and parenting (eg, the topics many participants wanted to hear more about) [32]. Thus, increasing engagement with the newborn and postpartum chatbots may require including more material desired by patients to also deliver information about warning signs.

Limitations and Future Directions

While this study had an adequate representation of individuals from historically ethnically or racially minoritized populations, the chatbot was delivered in English and data collection was completed in English and Spanish. Although we shared screenshots of the outreach messages, chatbots, and topics covered by the chatbots during the interviews, the survey and interview relied on participants' recall of their experiences with the chatbot, which may have gotten confused with other outreach strategies they received including messages related to apps from their prenatal providers such as Babyscripts. Similarly, study participants might have more positive experiences with the chatbot compared to those we did not survey or interview. We attempted to mitigate this by including both people who did and did not engage with the chatbot. Finally, though participants indicated that the information provided in the chatbot was useful, we did not evaluate the impact of the chatbot on participants' knowledge, access to care, and overall well-being. Future research to examine how chatbot engagement affects patient knowledge about warning signs, appointment attendance, and other patient health outcomes is needed.

Conclusions

The postpartum and newborn chatbots were identified as an acceptable and useful strategy to provide information and resources to birthing individuals and newborn caregivers about postpartum recovery and newborn care. Nevertheless, future work should measure the impact of chatbots on specific postpartum and newborn health outcomes including health disparities.

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Data Availability

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

Authors' Contributions

JNRR wrote the results with input from HA. KEA wrote the first draft of the introduction and discussion, and MS wrote the first draft of the methods, all with significant input from JNRR and HA. JNRR, MS, and CS engaged in data collection, data curation, and analysis. HJB managed the population chatbot data and assisted in data selection. ADT conceptualized the study and was responsible for funding acquisition. JNRR and HA were responsible for study methodology, project administration, and supervision of the study team. CS, KGG, ADT, LP, JAR, HJB, and ADT contributed to the development of the chatbot and to reviewing and editing the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional tables.
[DOCX File , 22 KB - pediatrics_v7i1e56807_app1.docx]

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Abbreviations

AI: Artificial Intelligence
EHR: electronic health record
HIPAA: Health Insurance Portability and Accountability Act
REDCap: Research Electronic Data Capture

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Effectiveness of an e-Book on Bone Health as Educational Material for Adolescents: Single-Group Experimental Study

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Abstract

Background: Improved bone health during adolescence can have lifelong implications, reducing the risk of bone fragility.

Objective: This study aims to evaluate the effectiveness of an e-book in increasing knowledge about and promoting healthy practices related to bone health among Malay adolescents in Kuala Lumpur, Malaysia.

Methods: A total of 72 adolescents (female: n=51, 71%; age: mean 15, SD 0.74 y) were recruited from selected secondary schools. The participants answered a pretest web-based questionnaire on sociodemographic data, knowledge about osteoporosis, and physical activity. A video call was conducted to assess dietary calcium intake. Participants were provided with a link to an e-book on bone health and instructed to read it within 2 weeks. Postintervention assessments included those for knowledge, physical activity, dietary calcium intake, and acceptance of the e-book.

Results: There was a significant increase in the median knowledge score, which was 40.6% (IQR 31.3%-46.9%) during the pretest and 71.9% (IQR 53.9%-81.3%) during the posttest ($P<.001$). However, no changes were observed in dietary calcium intake or physical activity levels. Most participants did not meet the recommended calcium requirements (61/62, 98%) and exhibited sedentary behavior (pretest: 51/62, 82%; posttest: 48/62, 77%). The e-book, however, was well accepted, with the majority reporting that they understood the contents (70/72, 97%), liked the graphics (71/72, 99%), and approved of the layout (60/72, 83%) and font size (66/72, 92%) used.

Conclusions: The developed e-book effectively increases knowledge levels related to bone health and is well accepted among participants. However, this educational material did not improve bone health practices. Additional strategies are necessary to bridge the gap between knowledge and behavior change.

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KEYWORDS

osteoporosis; bone health; adolescent; knowledge; calcium; physical activity; e-book; effectiveness; educational; teens; youth; bone fragility; bone; Malaysia; online questionnaire; sociodemographic; calcium intake; diet; behavior change

Introduction

Throughout the human life span, bone modelling and remodelling are continuous and vital processes that shape bone architecture, crucially contributing to peak bone mass attainment [1]. Childhood and adolescence mark crucial periods for rapid bone growth and peak bone mass—the highest bone mineral density (BMD) attained in one’s lifetime [2]. Improving bone health during these phases yields long-term benefits, reducing the risk of bone fragility and fractures later in life [3]. Since BMD typically declines with age, achieving peak bone mass by 30 years of age and maintaining bone density into middle age are pivotal for mitigating osteoporosis risk [4]. Notably, a 10% increase in peak bone mass can delay the onset of osteoporosis by up to 13 years [5]. Factors that influence peak bone mass include genetics, calcium and vitamin D intake, and physical activity [6].

Osteoporosis is a systemic bone disease characterized by reduced bone mass and microstructural deterioration, heightening bone fragility and fracture susceptibility [7]. The disease results from an imbalance between bone formation and resorption, with the latter predominating. Osteoporosis prevalence generally increases with age [8], affecting approximately 1 in 3 women and 1 in 5 men aged older than 50 years [7]. A systematic review and meta-analysis estimated the global prevalence of osteoporosis to be 18.3%, based on a cohort of 103,334,579 individuals [9]. The analysis encompassed 86 studies that involved participants aged 15 to 105 years [9]. In Kuala Lumpur, Malaysia, a cross-sectional study reported a prevalence of 12.3% among 786 adults aged 40 years and older

[10]. By 2050, the hip fracture incidence in Malaysia is projected to increase to 3.55 times that in 2018 [11]. In China, a study involving 9826 women aged 40 years and older reported a slightly higher osteoporosis prevalence of 20.6% [12], while Korea showed a prevalence of 38% among women aged 50 years and older in a sample of 4011 individuals [13]. Preventive measures against osteoporosis include optimizing peak bone mass during adolescence, maintaining bone density in adulthood, and mitigating age-related bone loss [14,15].

Lifestyle factors, such as dietary calcium intake, vitamin D status, and weight-bearing exercise, significantly influence bone health. Calcium plays a crucial role in maximizing bone density and strength during growth and development [6]. Adequate calcium intake is important for achieving optimal peak bone mass and promoting bone health, whereas insufficient intake increases the risk of low BMD [16]. Vitamin D, which is synthesized through skin exposure to UV-B rays and obtained from dietary sources, is essential for calcium homeostasis and absorption [17,18]. Insufficient vitamin D status is a global concern and is exacerbated by environmental factors, clothing practices, sunscreen use, and weather variations [19]. High-impact and weight-bearing exercises, such as running and jumping, enhance bone strength [20]. However, studies in Malaysia have identified suboptimal dietary calcium intakes [21,22], insufficient vitamin D status [21-25], and low physical activity levels among adolescents [26].

Raising osteoporosis awareness among adolescents is important for reducing the risk of the disease later in life [27]. Despite its significance, research on osteoporosis knowledge among adolescents in Malaysia is limited, with such research predominantly focusing on adults and older populations [10,28]. One study highlighted deficiencies in osteoporosis knowledge and engagement in bone health practices among adolescents [29]. Specifically, adolescents and young adults often perceive other diseases as more serious than osteoporosis [29]. This underscores the need to increase awareness of bone health and osteoporosis among adolescents.

Educational programs targeting osteoporosis prevention hold significant potential for improving adolescent bone health [30]. A systematic review and meta-analysis conducted by Abdolalipour and Mirghafourvand [30] demonstrated that such programs positively influence adolescent osteoporosis prevention by improving dietary calcium intake, promoting preventive practices, and enhancing knowledge about and attitudes toward osteoporosis. Therefore, implementing initiatives that focus on adolescent osteoporosis prevention is paramount for fostering healthy lifestyles. Research consistently demonstrates that these educational interventions enhance knowledge, shape attitudes, and encourage dietary practices conducive to bone health [30]. In-depth individual and semistructured interviews with 60 young adults aged 17 to 30 years highlighted that while most seek bone health information on the internet, traditional sources such as parents, doctors, educators, and peers remain valuable [31]. Importantly, participants preferred educational programs that deliver concise and relatable messages and promote gradual lifestyle changes [31].

e-Books use computer technology to deliver information dynamically through sounds, graphics, images, animations, and videos, offering enriched content when compared to conventional books [32]. A literature review that assessed the effectiveness of e-books in student learning reported high effectiveness scores, which ranged from 80% to over 95% across multiple studies [32]. Furthermore, a study that compared e-books to traditional PowerPoint (Microsoft Corporation) methods in clinical teaching found that e-books enhance student satisfaction, improve teaching quality and methods, and increase student engagement [33]. This study aims to assess the effectiveness of an e-book with interactive multimedia features in increasing knowledge about and promoting healthy practices related to bone health among Malay adolescents in Kuala Lumpur, Malaysia.

Methods

Study Design and Participants

This study used an experimental design with purposive sampling to gather data from Malay adolescents aged 14 to 16 years who attended selected secondary schools in Kuala Lumpur, Malaysia. Without a control group, the chosen single-group experimental approach ensured uniform access to the educational material among all participants, aligning with ethical and practical considerations in academic research. Practical constraints within the school settings, such as challenges in recruiting a comparable control group and ensuring their nonexposure to the e-book, further supported the selection of this design. Despite inherent limitations in terms of internal validity, particularly threats related to the absence of a control group, this study represents an initial exploration of e-books as educational tools for adolescents.

Initially, invitations were extended to 14 schools, with 6 granting permission for participation following the dissemination of relevant information to homeroom teachers. Eligible participants were required to have access to electronic devices, such as mobile phones, tablets, or computers, with internet connectivity. Adolescents with health conditions, including visual or hearing impairments, autism spectrum disorder, attention-deficit/hyperactivity disorder, Down syndrome, cerebral palsy, dyslexia, aphasia, or physical disabilities, were excluded from this study.

Ethical Considerations

Ethical approval was obtained from the Universiti Kebangsaan Malaysia’s research ethics committee (reference code: UKM PPI/111/8/JEP-2022 - 139). The data collected in this study were anonymized by using a study-specific identification number. Further, participants were given a notebook worth RM 5 (US $1.12) as a token of appreciation.

Data Collection

The research information sheet and an informed consent and screening form were disseminated through a web-based platform (WhatsApp [Meta Platforms] messages with a document link) by homeroom teachers. Interested participants who met the eligibility criteria and obtained parental or guardian consent were contacted and provided with a link to access the pretest questionnaire via Google Forms. This questionnaire gathered sociodemographic information, assessed knowledge about osteoporosis, and collected data on physical activity levels.

After completing the pretest questionnaire, a video call session via Google Meet was scheduled to assess habitual dietary calcium intake. Participants were subsequently given access to an e-book on bone health and instructed to read it within 2 weeks. At the end of this period, participants completed a posttest questionnaire, which was almost identical to the pretest questionnaire but excluded sociodemographic information. Additionally, the posttest questionnaire included a section to assess participants' acceptance of the e-book. A second video call session via Google Meet was conducted to reassess participants' dietary calcium intake. The entire data collection process was conducted via the internet to minimize interference with school schedules.

Research Instruments

e-Book

The e-book, which consisted of 58 pages, was previously developed and validated by an expert panel [34]. It featured vibrant infographics and illustrations that covered the following seven subtopics: (1) "Let's Know Our Bones," (2) "Osteoporosis," (3) "Adolescents' Bone Health," (4) "Calcium," (5) "Vitamin D," (6) "Physical Activity & Exercise for Bone Strength," and (7) "7 Healthy Lifestyles for Bone Health." In addition, the e-book included a 5-minute summary video and a link to a short quiz.

Sociodemographic Profiles

The sociodemographic data collected included sex, date of birth, household income, and prior participation in a bone health or osteoporosis education program. Participants self-reported their body weight and height, and the BMI was calculated by dividing weight by the square of height. BMI-for-age was analyzed by using WHO (World Health Organization) AnthroPlus version 1.0.4 (WHO), with classifications based on WHO cutoff points [35].

Osteoporosis Knowledge

Participants' knowledge about bone health and osteoporosis was assessed by using the Revised Osteoporosis Knowledge Test Questionnaire, which has demonstrated high internal consistency (Kuder-Richardson-20 values of 0.85 overall, 0.83 for the nutrition subscale, and 0.81 for the exercise subscale) and test-retest reliability (*r*=0.87) [36]. The questionnaire was confirmed through content validity, establishing it as a comprehensive instrument that reflects current research and assesses osteoporosis knowledge in adults [36]. We adapted this questionnaire to assess osteoporosis knowledge in adolescents. A previous study used this questionnaire to determine osteoporosis knowledge in Iranian adolescents [37].

The 32-item questionnaire was translated into Malay by using a back-translation method. Some questions (eg, those concerning the recommended amount of calcium and vitamin D intake) were modified to align with Malaysian dietary guidelines for adolescents [16]. One point was given for each correct answer, and 0 points were given for incorrect or "Do not know" responses. Each participant's total score was then converted into a percentage and classified as a high (>80%), medium (60% - 80%), or low (<60%) knowledge level based on previous osteoporosis research [38].

Practices Related to Bone Health

Dietary calcium intake was assessed by using a food frequency questionnaire (FFQ) adapted from a previous study on postmenopausal women in Malaysia [39]. Notably, there was limited availability of FFQs tailored for adolescents in Malaysia. This FFQ, which moderately correlated with a 3-day food record (*r*=0.563) [39], encompassed 78 food items. Administration of the FFQ was conducted through web-based video call interviews. Participants reported their frequency of consumption (daily, weekly, or monthly) and estimated portion sizes for each food item. The total calcium intake for each participant was calculated by multiplying frequency of consumption; portion sizes (g); and calcium content per 100 g, which was derived from the Malaysian food database [40].

Physical activity levels were assessed by using the Physical Activity Questionnaire for Adolescents (PAQ-A) [41]. The questionnaire was previously translated into Malay and demonstrated a low correlation (*r*=0.23; *P*=.08) but high reliability (*r*=0.72; *P*<.001) when compared to pedometer data [42]. A study conducted in Poland demonstrated a strong correlation between PAQ-A scores and accelerometer data (*r*=0.94; *P*<.01) [43].

The PAQ-A consists of 9 items that evaluate the participants' physical activity involvement over the past 7 days. Each item is rated on a 5-point scale, ranging from 1 (indicating a low level of physical activity) to 5 (indicating a high level of physical activity).

Acceptance of the e-Book

Acceptance of the e-book was evaluated by using a questionnaire adapted from a study that assessed physical information leaflets for pregnant women [44]. The assessment focused on the following three domains: content, graphics, and design. The level of acceptance was determined based on the percentage of responses within each domain. Although the instrument was initially developed for evaluating physical information leaflets (ie, it may not directly align with e-books), the assessed domains (content, graphics, and design) remain pertinent for evaluating educational materials. In this study, acceptance of the e-book served as a secondary outcome.

Statistical Analysis

Data were analyzed by using IBM SPSS Statistics software (version 26.0; IBM Corp). The normality of continuous data was assessed by using the Shapiro-Wilk test. Descriptive statistics were reported as means and SDs for normally distributed data or medians and IQRs for nonnormally distributed data. Categorical variables were summarized as frequencies and percentages. The Wilcoxon signed rank test was used to compare pre- and postintervention scores of knowledge, physical activity, and calcium intake, due to the nonnormal distribution of the data. For categorical variables, associations and comparisons were assessed by using the chi-square test or McNemar test. A *P* value of <.05 was considered statistically significant.

Results

Sociodemographic Profiles

A total of 72 participants (age: mean 15, SD 0.74 y) were enrolled in this study, and no dropouts were recorded (Table 1). The majority of the participants were female (n=51, 71%). The household income distribution was nearly evenly split among the low-income (n=23, 32%), middle-income (n=23, 32%), and high-income (n=26, 36%) categories. Most participants (n=51, 71%) were within the normal weight range, with a mean BMI of 20.9 (SD 4.5) kg/m^2. Only 1 participant reported prior education on bone health.

Table . Sociodemographic profiles and physical characteristics of participants (N=72).

Parameter		Value
Age (y), mean (SD)		15.0 (0.74)
Sex, n (%)		
	Male	21 (29)
	Female	51 (71)
Household income (RM[a]), n (%)		
	Low (<4850)	23 (32)
	Middle (4850 - 10,959)	23 (32)
	High (>10,959)	26 (36)
Weight (kg), mean (SD)		53.2 (13.3)
Height (m), mean (SD)		1.59 (0.07)
BMI (kg/m^2), mean (SD)		20.9 (4.5)
BMI category, n (%)		
	Thinness (<−2 SDs)	6 (8)
	Normal (≥−2 SDs)	51 (71)
	Overweight (>+1 SD)	9 (13)
	Obese (>+2 SDs)	6 (8)
Attending bone health education program, n (%)		1 (1)

[a] A currency exchange rate of RM 1=US $0.22 is applicable.

Osteoporosis Knowledge

The educational intervention significantly improved participants' knowledge of osteoporosis; the median knowledge score increased from 40.6% (IQR 31.3%-46.9%) in the pretest to 71.9% (IQR 53.9%-81.3%) in the posttest (*P*<.001; Table 2). Before the intervention, the majority of the participants demonstrated low levels of knowledge (69/72, 96%). There was a notable improvement after the intervention, with 38% (27/72) achieving moderate knowledge and 32% (23/72) reaching a high level of knowledge.

Table 3 presents the percentages of correct and incorrect responses ("False" or "Do not know") before and after exposure to the educational materials. Significant improvements were observed across all knowledge domains. Notably, 36% (26/72) of participants remained unaware that aging increases the risk of osteoporosis. Similarly, a small proportion of participants did not recognize the benefits of aerobic dancing for bone health (8/72, 11%), the fact that cheese is a good source of calcium (8/72, 11%), and that adolescence is a critical period for building strong bones (2/72, 3%).

Table . Osteoporosis knowledge before and after the educational intervention (N=72).

Osteoporosis knowledge		Pretest	Posttest	*P* value
Score (%), median (IQR)		40.6 (31.3-46.9)	71.9 (53.9-81.3)	<.001[a]
Knowledge classification, n (%)				.34[b]
	High (score: >80%)	0 (0)	23 (32)	
	Moderate (score: 60% - 80%)	3 (4)	27 (38)	
	Low (score: <60%)	69 (96)	22 (31)	

[a] Wilcoxon signed rank test.

[b] Chi-square test.

Table . Analysis of osteoporosis knowledge questions before and after the educational intervention (N=72).

Questions		Pretest (correct), n (%)	Posttest (correct), n (%)	Pretest (incorrect), n (%)	Posttest (incorrect), n (%)	*P* value
Domain: risk factors of osteoporosis						
	1. Eating a diet low in dairy products	40 (56)	54 (75)	32 (44)	18 (25)	.01
	2. Being menopausal; "change of life"	26 (36)	50 (69)	46 (64)	22 (31)	<.001[a]
	3. Having a parent or grandparent who has osteoporosis	29 (40)	56 (78)	43 (60)	16 (22)	<.001[a]
	4. Being a White or Asian woman	5 (7)	28 (39)	67 (93)	44 (61)	<.001[a]
	5. Being an elderly	43 (60)	46 (64)	29 (40)	26 (36)	.73
	6. Having ovaries surgically removed	10 (14)	41 (57)	62 (86)	31 (43)	<.001[a]
	7. Taking cortisone (steroids; eg, prednisone) for a long time	25 (35)	43 (60)	47 (65)	29 (40)	.001
	8. Being overweight	33 (46)	53 (74)	39 (54)	19 (26)	.001
	9. Having an eating disorder	34 (47)	53 (74)	38 (53)	19 (26)	.003
	10. Consuming more than 2 alcoholic drinks per day	37 (51)	62 (86)	35 (49)	10 (14)	<.001[a]
	11. Smoking on a daily basis	38 (53)	55 (76)	34 (47)	17 (24)	.003
Domain: exercise						
	12. To strengthen bones, it is recommended that a person exercises at a moderately intense level for 30 min a day at least.... (answer: 7 days a week)	3 (4)	26 (36)	69 (96)	46 (64)	<.001[a]
	13. Exercise makes bones strong, but it must be hard enough to make breathing.... (answer: much faster, but talking is possible)	35 (49)	54 (75)	37 (51)	18 (25)	.001
	14. Which of the following activities is the best way to reduce a person's chance of getting osteoporosis? (answer: walking briskly)	6 (8)	25 (35)	66 (92)	47 (65)	<.001[a]

Questions		Pretest (correct), n (%)	Posttest (correct), n (%)	Pretest (incorrect), n (%)	Posttest (incorrect), n (%)	*P* value
	15. Which of the following activities is the best way to reduce a person’s chance of getting osteoporosis? (answer: lifting weights)	8 (11)	28 (39)	64 (89)	44 (61)	<.001[a]
	16. Which of the following activities is the best way to reduce a person’s chance of getting osteoporosis? (answer: jogging or running)	58 (81)	70 (97)	14 (19)	2 (3)	.004
	17. Which of the following activities is the best way to reduce a person’s chance of getting osteoporosis? (answer: aerobic dancing)	59 (82)	64 (89)	13 (18)	8 (11)	.38
Domain: calcium & vitamin D						
	18. Which of these is the best source of calcium? (answer: cheese)	52 (72)	64 (89)	20 (28)	8 (11)	.12
	19. Which of these is the best source of calcium? (answer: canned sardines)	14 (19)	44 (61)	58 (81)	28 (39)	<.001[a]
	20. Which of these is the best source of calcium? (answer: broccoli)	37 (51)	53 (74)	35 (49)	19 (26)	.005
	21. Which of these is the best source of calcium? (answer: yogurt)	56 (78)	67 (93)	16 (22)	5 (7)	.003
	22. Which of these is the best source of calcium? (answer: ice cream)	6 (8)	35 (49)	66 (92)	37 (51)	<.001[a]
	23. Which of these is the best source of calcium? (answer: almonds)	19 (26)	39 (54)	53 (74)	33 (46)	.001
	24. Which of the following is the recommended amount of calcium intake for an adolescent? (answer: 1300 mg daily)	16 (22)	54 (75)	56 (78)	18 (25)	<.001[a]

Questions	Pretest (correct), n (%)	Posttest (correct), n (%)	Pretest (incorrect), n (%)	Posttest (incorrect), n (%)	*P* value
25. How much milk must an adolescent drink to meet the recommended amount of calcium? (answer: 3 or more glasses daily)	18 (25)	47 (65)	54 (75)	25 (35)	<.001[a]
26. Which vitamin is required for absorption of calcium? (answer: vitamin D)	37 (51)	55 (76)	35 (49)	17 (24)	.003
27. Which is the best source of the vitamin required for the absorption of calcium? (answer: sunlight)	25 (35)	51 (71)	47 (65)	21 (29)	<.001[a]
28. Which is the best food source of the vitamin required for the absorption of calcium? (answer: salmon)	15 (21)	42 (58)	57 (79)	30 (42)	<.001[a]
29. Which of the following is the recommended amount of the vitamin required for the absorption of calcium for an adolescent? (answer: 15 µg daily)	18 (25)	47 (65)	54 (75)	25 (35)	<.001[a]
Domain: general knowledge on bone health					
30. When is the best time to build strong bones? (answer: adolescence)	67 (93)	70 (97)	5 (7)	2 (3)	.45
31. Osteoporosis can be diagnosed by.... (answer: DXA[b] scan)	42 (58)	58 (81)	30 (42)	14 (19)	.002
32. Once you have osteoporosis.... (answer: you can take medication to treat it)	19 (26)	42 (58)	53 (74)	30 (42)	<.001[a]

[a] McNemar test.

[b] DXA: dual-energy x-ray absorptiometry.

Practices Related to Bone Health

No significant differences were observed in dietary calcium intake (*P*=.31) and physical activity levels (*P*=.09) among adolescents following the intervention. Most participants exhibited inadequate calcium intake before (61/62, 98%) and after (61/62, 98%) the intervention. Similarly, a high proportion of participants maintained low levels of physical activity before (51/62, 82%) and after (48/62, 77%) the education intervention (Table 4).

Table . Practices related to bone health among participants (n=62).

Practices		Pretest	Posttest	*P* value
Calcium intake (mg), median (IQR)		575.8 (472.5-688.0)	585.9 (490.9-754.7)	.31[a]
Physical activity level (score), median (IQR)		2.2 (1.9-2.6)	2.3 (1.9-2.9)	.09[a]
Calcium intake classification, n (%)				>.99[b]
	Adequate (>1300 mg)	1 (2)	1 (2)	
	Inadequate (<1300 mg)	61 (98)	61 (98)	
Physical activity level classification, n (%)				.53[b]
	High (score: 4 - 5)	2 (3)	2 (3)	
	Moderate (score: 3)	9 (15)	12 (19)	
	Low (score: 1 - 2)	51 (82)	48 (77)	

[a] Wilcoxon signed rank test.

[b] McNemar test.

Acceptance of the e-Book

Table 5 shows participants’ feedback on the e-book. Overall, 97% (70/72) reported understanding the e-book content, with 71% (63/89) of responses (for the “Reasons for good understanding” question, participants could choose multiple responses) indicating that simple and easy-to-understand language facilitated comprehension. Furthermore, 93% (67/72) of participants emphasized the importance of graphics in the e-book, and nearly all participants (71/72, 99%) found the visuals attractive. Additionally, 78% (56/72) agreed that the color combination enhanced their reading experience, while most adolescents considered the layout of the pictures (60/72, 83%) and the font size (66/72, 92%) to be appropriate.

Table . Acceptance of the e-book on bone health among participants (N=72).

Evaluation aspects		Participants, n (%)
Understanding		
	Good understanding	70 (97)
Reasons for good understanding[a]		
	Simple and easy-to-understand sentence	63 (71)
	Appropriate words/terms used	17 (19)
	Attractive e-book	4 (5)
	Concise and precise	3 (3)
	Many photos/diagrams	2 (2)
Graphics importance		
	Yes	67 (93)
Attractiveness of graphic		
	Attractive	71 (99)
Color influenced reading		
	Yes	56 (78)
Appropriate picture layout		
	Yes	60 (83)
Appropriate font size		
	Yes	66 (92)

[a] Participants could choose multiple responses for this particular question. As such, the n values here refer to the number of responses, and the percentages were calculated by using the total number of these responses as the denominator (N=89).

Discussion

Osteoporosis Knowledge

This study demonstrates the effectiveness of an e-book–based educational intervention in enhancing adolescents' knowledge of bone health and osteoporosis. Our findings align with a meta-analysis of 18 studies, which reported significant differences in osteoporosis knowledge among adolescents between educational intervention groups and control groups [30]. Similar improvements have been observed across various populations, including adolescents [45], health care professionals [46], university students and academicians [47,48], and patients with osteoporosis [49]. Given the critical importance of maximizing peak bone mass during adolescence, implementing educational programs is highly justified [31].

Educational initiatives using diverse approaches and methods have consistently proven effective in increasing knowledge [45]. Web-based learning platforms offer flexible and accessible avenues for knowledge acquisition. Furthermore, leveraging technological advancements, such as those related to text, audio, and visuals, enhances information dissemination. This facilitates the development of interactive learning tools, such as images and videos, which effectively convey critical aspects of osteoporosis, such as nutrition and weight-bearing exercises [50].

Practices Related to Bone Health

Despite significant gains in knowledge, this study did not observe notable improvements in dietary calcium intake and physical activity among adolescents after the intervention. Most adolescents (61/62, 98%) exhibited inadequate dietary calcium intake, with the median daily intakes before (median 576, IQR 473-688 mg/d) and after (median 586, IQR 491-755 mg/d) this study being below the recommended 1300 mg/d [16]. This trend aligns with findings from a previous study of Malaysian adolescents, in which all participants (N=794) had inadequate calcium intakes (calcium intake: mean 377.4, 95% CI 365.1-389.7 mg/d) [22]. Similar inadequate calcium intakes among adolescents have been reported globally, including in Morocco (calcium intake: mean 522, SD 297 mg/d) [51], Brazil (calcium intake: mean 618.2, 95% CI 570.8-665.5 mg/d) [52], and the United States (calcium intake: mean 962, SD 478 mg/d) [53], indicating a widespread issue of low dietary calcium intake among adolescents. Adolescents appear to consume limited amounts of calcium-rich foods, particularly dairy products [51].

This study also highlighted low physical activity levels among participants, with median scores of 2.2 (IQR 1.9-2.6) during the pretest and 2.3 (IQR 1.9-2.9) during the posttest. This finding is consistent with a previous study of 13-year-old adolescents (n=289) in Malaysia, where low physical activity levels were reported (mean 2.01, SD 0.03) [21]. Again, our findings align with global trends, showing that many adolescents do not meet recommended physical activity levels. For instance, the WHO reported that globally, 81% of adolescents aged 11 to 17 years are insufficiently physically active [54]. Similar trends were noted in Portugal [55], Sweden [56], China [57], and Korea [58], of which all indicated low physical activity levels among adolescents. For instance, Marques et al [55] reported that in a sample of 520,533 participants, less than 20% of adolescents in Portugal participated in physical activity every day, and nearly 20% never engaged in any form of physical activity. Sedentary behaviors and insufficient physical activity negatively impact bone health and overall well-being.

Integrating Knowledge Into Behavior Changes

The gap between increased knowledge and unchanged health behaviors suggests that knowledge alone may not suffice to promote positive practices. Addressing both knowledge and bone health practices simultaneously is essential. This underscores the need for a comprehensive approach that integrates knowledge acquisition and behavior change techniques to foster optimal adolescent bone health practices. Our findings contrast with previous studies that demonstrated favorable impacts of educational interventions on behaviors such as calcium intake and physical activity among adolescents [59-61]. These disparities could be due to variations in the educational methodologies, particularly in facilitating behavior changes [59]. Direct educational approaches, such as interactive sessions that promote engagement and motivation, have shown promising results in improving adolescents' nutritional practices and physical activity levels [49,60,62].

It is worth noting that our intervention lasted for only 2 weeks, whereas previous studies implemented interventions over 2 to 3 months [60-62]. Behavior changes often require an extended period to be effectively integrated into daily routines [63]. The transtheoretical model of behavioral change suggests that behavior modification is a dynamic and individualized process involving various stages, including precontemplation, contemplation, preparation, action, and maintenance [64]. Therefore, extending the intervention period is essential to fully observe and understand the intervention's effects and assess its sustainability.

Nevertheless, a longer intervention alone does not guarantee sustainable behavior change. Incorporating behavior change theories and techniques, such as goal setting, self-monitoring, and feedback, may enhance the intervention's effectiveness. These techniques could facilitate the translation of knowledge into sustained behavior changes by actively engaging adolescents in their lifestyle practices. Additionally, using interactive elements, such as videos, quizzes, and simulations within e-books, can enhance the learning experience and support effective behavior change [65]. To ensure the long-term sustainability of the intervention, future studies should include systematic follow-up assessments to measure the retention of bone health–related knowledge and behaviors. Identifying barriers and facilitators to the ongoing use of the e-book, such as user engagement and perceived relevance, is also essential.

Acceptance Toward the e-Book

The e-book used in this study received positive feedback from adolescents, as they found it understandable, visually attractive, and well designed in terms of graphics and text size. Effective e-books should incorporate structured content and multimedia elements, such as sounds, graphics, images, text, and animations, to create an engaging and interactive learning experience [32]. e-Books can enhance adolescents' understanding by using visual elements, including animated images, to convey the information more engagingly [66]. Incorporating interactive multimedia elements in e-books makes learning exciting, meaningful, and inspiring for adolescents [67]. Special animations and effects, such as graphics and sounds, effectively capture adolescents' attention in educational settings.

Strengths and Limitations

This study is the first to assess Malay adolescents' knowledge and practices related to bone health following an educational intervention in Malaysia. The findings suggest that the e-book is effective for health promotion among adolescents. These results provide valuable insights for planning strategies to promote bone health among adolescents and the wider community, such as through the use of e-books.

Study limitations include the absence of a control group and uneven proportions of male and female respondents, which could have introduced bias. Additionally, the osteoporosis knowledge questionnaire and dietary calcium intake assessment evaluation tools have yet to be validated in the studied population. Furthermore, this study focused solely on calcium intake and physical activity, excluding other essential factors, such as vitamin D intake. The short intervention period also limited the ability to evaluate long-term behavior changes. Future studies should extend the intervention duration and include a broader range of bone health practices to provide a more comprehensive assessment.

Recommendations for Future Studies

Future research should focus on enhancing the e-book's content by incorporating more practical elements, such as easy-to-prepare recipes for calcium-rich foods and information on simple bone-health exercises. Integrating diversified and interactive educational content, including videos, quizzes, and simulations, can make learning more engaging and impactful. Such content can aim to engage adolescents and effectively promote the practical application of knowledge. To better foster sustained behavior changes, future studies should also consider extending the duration of the intervention period. Further, translating the e-book into other languages would increase its accessibility and cater to Malaysia's diverse population. Moreover, conducting similar studies among non-Malay adolescents would offer a broader understanding of bone health practices across different ethnic groups in Malaysia.

Conclusions

The developed e-book on bone health effectively increased knowledge related to bone health and was well received by Malay adolescents within our sample. However, the intervention did not significantly influence bone health practices, including dietary calcium intake (P=.31) and physical activity levels (P=.09). Additional strategies that integrate knowledge enhancement with practical demonstrations, interactive activities, and targeted approaches are necessary to promote the adoption of healthy behaviors for optimal bone health.

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Conflicts of Interest

None declared.

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Abbreviations

BMD: bone mineral density
FFQ: food frequency questionnaire
PAQ-A: Physical Activity Questionnaire for Adolescents
WHO: World Health Organization

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Corrigenda and Addenda

Correction: Assessing the Racial and Socioeconomic Disparities in Postpartum Depression Using Population-Level Hospital Discharge Data: Longitudinal Retrospective Study

Star Liu[1], BSc; Xiyu Ding[1], MSc; Anas Belouali[1], MEng, MSc; Haibin Bai[1], MSc; Kanimozhi Raja[1], MSc, MD; Hadi Kharrazi[2], MD, PhD

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In “Assessing the Racial and Socioeconomic Disparities in Postpartum Depression Using Population-Level Hospital Discharge Data: Longitudinal Retrospective Study” JMIR Pediatr Parent 2022;5(4):e38879 the authors noted 4 errors.

In “Results”, first paragraph, the numbers in parentheses “(66,939/160,066)” have been revised to “(65,028/160,066)”, as follows:

> *Of the study population, 40.63% (65,028/160,066) were White,...*

In “Results”, first paragraph, the numbers in parentheses “(26,360/160,066, 16.47%)” have been revised to “(12,658/48,953, 25.86%)”, as follows:

> *Among all racial groups, the Black population had the highest proportion of individuals living in areas with <US $59,000 median household income (12,658/48,953, 25.86%).*

Under Results, third paragraph, the word “higher” has been revised to “lower”, as follows:

> *Married women have significantly lower odds of PPD than women who were divorced (OR 1.99, 95% CI 1.71-2.31), legally separated (OR 1.97, 95% CI 1.60-2.41), single (OR 1.45, 95% CI 1.38-1.51), or widowed (OR 2.96, 95% CI 1.82-4.64).*

Under Results, third paragraph, the word “lower” has been replaced by “higher” in the sentence:

> *Women living in areas with a median household income <US $46,000 have higher odds of PPD than women living in areas with median household income >US $59,000 (OR 0.79, 95% CI 0.73-0.85).*

The correction will appear in the online version of the paper on the JMIR Publications website on October 9, 2024, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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Correction: Caregivers' Perceptions, Needs, and Data Sharing Concerns in mHealth Research on Pediatric Asthma: Cross-Sectional Survey Study

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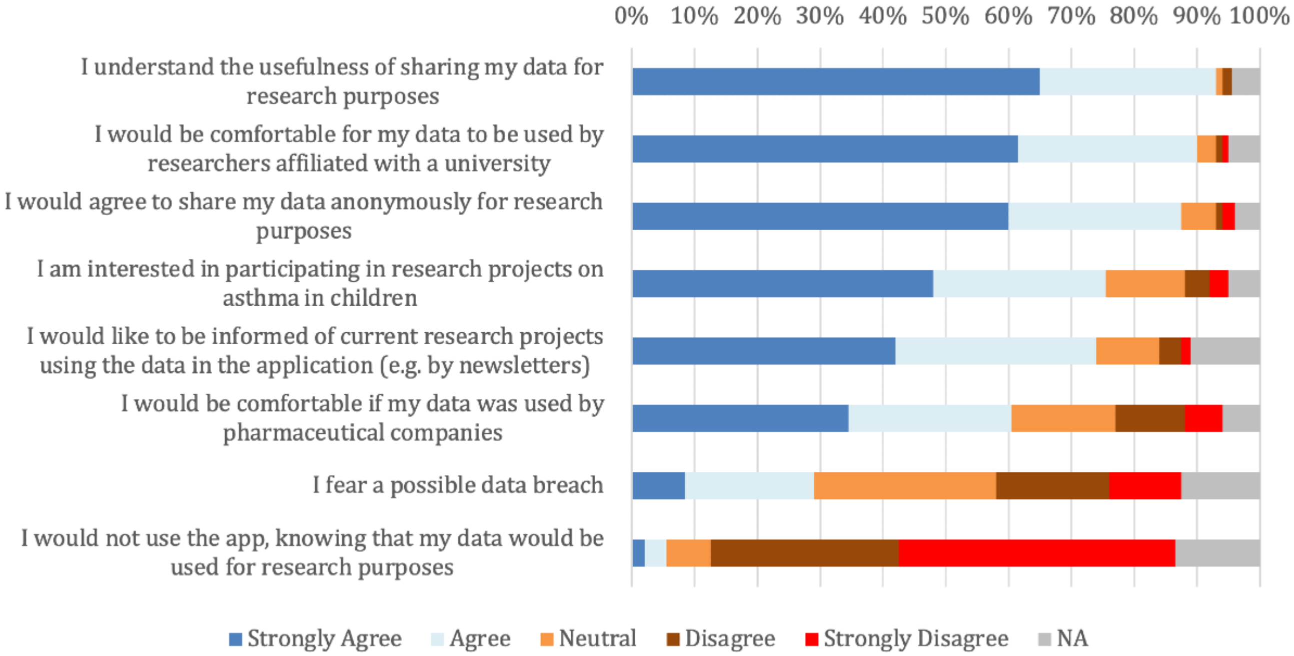
In "Caregivers' Perceptions, Needs, and Data Sharing Concerns in mHealth Research on Pediatric Asthma: Cross-Sectional Survey Study" (JMIR Pediatr Parent 2023;6:e49521) the authors noted one error.

In the original publication, Figure 2 included the correct caption but the image was a reproduction of Figure 1. This has been corrected, and Figure 2 will appear as attached.

Figure 1. Caregivers' perceptions on the use of data through mHealth for research. N/A: not applicable.



The correction will appear in the online version of the paper on the JMIR Publications website on January 12, 2024 together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

Conflicts of Interest

None declared.

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Social Media Use and Serious Psychological Distress Among Adolescents

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Abstract

This Research Letter describes the increasing trend of almost-constant social media use among California adolescents and the association with serious psychological distress, focusing on the influence of familial and experiential factors.

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KEYWORDS

social media; socials; youth; adolescents; teens; teenager; mental health; mental illness; mental disease; mental illnesses; psychological distress; psychological; psychology

Introduction

Increasing recognition of the potential dangers of excessive social media use on mental health has led to numerous calls for restraint and associated legal cases, as highlighted by the recent advisory issued by the US Surgeon General [1-3]; however, these dangers remain understudied. We examined social media use trends between 2019 and 2021 among adolescents in California. We further examined the association between almost-constant social media use and psychological distress using 2021 data, controlling for familial dynamics and adverse childhood experiences (ACEs), which are predictors of mental health [4] but have largely been overlooked in previous studies.

Methods

Survey and Data Collection

We used the California Health Interview Survey (CHIS) 2019-2021 data sets [5] for adolescents aged 12-17 years to examine trends in social media use. For a regression analysis examining the association between almost-constant social media use and psychological distress among adolescents, we used the 2021 data set with responses from 24,453 households, including 1169 participating adolescents. The CHIS randomly selects one adult to interview in each randomly sampled household, wherein households are selected using a geographically stratified address-based sample design. Following parental permission, surveys are conducted directly with a randomly sampled adolescent in the household. The survey, conducted either on the web or by telephone, includes a comprehensive set of health-related questions. Respondents are asked to report on typical daily use of social media on the following scale: less than a few times a day, a few times a day, many times a day, and almost constantly or more. We categorized this scale into a two-category variable wherein the category “almost constantly or more” is referred to as almost-constant social media use. Psychological distress was measured using the Kessler 6 series [6]; for this analysis, we examined the category of likely having had serious psychological distress in the past year. Family connection was measured through a series of questions, including how often the adolescent felt they were able to talk to family about their feelings, how often they felt family stood by them during difficult times, how often they felt safe and protected by the adult at home, and how often they had at least two nonparent adults taking a genuine interest in them. Adolescents responding “little to never” to any of these questions were assigned to a group characterized by little to no family connection. Adolescents responding having had at least one ACE were assigned “yes” to the ACEs variable.

Statistical Analysis

Demographic variables, including age, gender, race and ethnicity, and socioeconomic status, were included in the analysis as covariates. The data were weighted to account for the complex survey design and to generate population-level estimates. We used multivariate logistic regression models to examine the association between almost-constant social media use and serious psychological distress, controlling for demographic characteristics, family factors, and ACEs. All analyses were conducted using STATA 16.1.

Ethical Considerations

This study used deidentified, publicly available data, which does not constitute human subjects research as defined by regulation 45 CFR 46.102 of the US Department of Health and Human Services [7], and thus does not require ethics board approval. All CHIS respondents receive an initial survey invitation letter with a US $2 preincentive. Participation is voluntary and all participants provide informed consent before participating in the survey.

Results

Almost-constant social media use for the youngest teens (aged 12-14 years) increased significantly between 2019 and 2021, whereas this increase was not noted for older teens (aged 15-17 years). Among 12-14–year-old females, the rate of almost-constant use was 18.1% (95% CI 11.2-25.0) in 2019, 22.2% (95% CI 15.4-29.1) in 2020, and 28.9% (95% CI 20.8-37.0) in 2021; among 15-17–year-old females, the rate of almost-constant use was 33.0% (95% CI 25.8-40.2) in 2019, 26.9% (95% CI 20.8-32.9) in 2020, and 29.1% (95% CI 20.8-37.3) in 2021. Among male adolescents, almost-constant social media use increased significantly between 2019 and 2021 for both age groups. Among 12-14–year-old males, the rates were 11.9% (95% CI 6.2-17.6) in 2019, 22.7% (95% CI 16.4-28.9) in 2020, and 23.7% (95% CI 18.4-29.0) in 2021; among 15-17–year-old males, the rates were 14.1% (95% CI 9.8-18.4) in 2019, 22.4% (95% CI 17.3-27.6) in 2020, and 28.9% (95% CI 22.9-34.9) in 2021. By 2021, there were no longer significant differences in almost-constant social media use according to age group.

The rates of almost-constant social media use were the highest for teens living in poverty, those who have experienced ACEs, those who reported little to no family connection, and those who reported serious psychological distress (Table 1).

Regression analyses suggested a significant positive association between almost-constant social media use and psychological distress controlling for ACEs, family connection, and demographics (Table 2).

Table . Association of characteristics of adolescents (12-17 years old) with almost-constant social media use from the California Health Interview Survey 2021 (N=1169).

Characteristic		Almost-constant social media use, % (95% CI)
Total (all adolescents)		27.62 (24.19-31.35)
Age (years)		
	12-14	26.23 (21.48-31.61)
	15-17	28.98 (24.30-34.16)
Gender[a]		
	Female	28.97 (23.61-35.00)
	Male	26.35 (22.40-30.72)
Federal Poverty Level (%)		
	<300	33.19 (27.65-39.23)
	≥300	22.61 (19.26-26.35)
Race [b]		
	Asian	28.66 (21.02-37.76)
	Latino	30.23 (24.95-36.09)
	Black, African American, and other	22.72 (12.81-37.04)
	Two or more	27.94 (17.60-41.31)
	White	23.17 (18.21-29.01)
Serious psychological distress		
	Yes	37.36 (31.09-44.09)
	No	22.63 (19.27-26.38)
Adverse childhood experiences		
	Yes	36.17 (30.72-42.01)
	No	20.95 (17.48-24.91)
Family connection		
	Little to none	34.02 (28.47-40.04)
	More than little	22.21 (18.42-26.52)

[a] While the California Health Interview Survey collects data on nonbinary gender, for sample size considerations, we report only male and female categories here.

[b] The sample size was too small to produce reliable estimates for the Black/African American population alone, American Indian or Alaska Native, and Native Hawaiian or Pacific Islander populations.

Table . Association between almost-constant social media use and serious psychological distress among adolescents (aged 12-17 years) from the California Health Interview Survey 2021 (N=1169).

Variable		Adjusted odds ratio (95% CI)	*P* value
Social media use per day			.003
	Almost constant	1.673 (1.204-2.323)	
	Less than almost constant	reference	
Age (years)			.003
	12-14	reference	
	15-17	1.710 (1.205-2.429)	
Gender[a]			.005
	Female	1.597 (1.155-2.209)	
	Male	reference	
Federal Poverty Level (%)			.92
	<300	1.017 (0.709-1.460)	
	≥300	reference	
Race [b]			
	Asian	0.641 (0.377-1.089)	.10
	Latino	0.674 (0.469-0.967)	.03
	Black, African American, and other	0.807 (0.357-1.824)	.60
	Two or more	1.133 (0.617-2.079)	.68
	White	reference	
Adverse childhood experiences			<.001
	Yes	2.403 (1.736-3.327)	
	No	reference	
Family connection			<.001
	Little to none	2.171 (1.502-3.139)	
	More than little	reference	

[a] While the California Health Interview Survey collects data on nonbinary gender, for sample size considerations, we report only male and female categories here.

[b] The sample size was too small to produce reliable estimates for the Black/African American population alone, American Indian or Alaska Native, and Native Hawaiian or Pacific Islander populations.

Discussion

Our work is the first to examine the association between social media use and psychological distress controlling for ACEs and the adolescent-reported level of family connection, both of which are significantly associated with psychological distress [4]. Even when controlling for these and other demographic variables, almost-constant social media use remained significantly associated with psychological distress. Our key limitation is the cross-sectional nature of the data. Other limitations include the analysis of self-reported data on social media use, which may be subject to recall or social desirability bias, and possible other confounders not included in the analysis. Our work is consistent with prior research that finds increasing trends in use of social media among the youngest teens [8] and potential adverse mental health impacts from high or almost-constant social media use [9-12].

Data Availability

The data sets analyzed for this study are publicly available from the UCLA Center for Health Policy Research's California Health Interview Survey Public Use Files (PUFs) website [5].

Conflicts of Interest

None declared.

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Abbreviations

ACE: adverse childhood experience
CHIS: California Health Interview Survey

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Digital Health Innovations for Screening and Mitigating Mental Health Impacts of Adverse Childhood Experiences: Narrative Review

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Abstract

Background: Exposures to both negative and positive experiences in childhood have proven to influence cardiovascular, immune, metabolic, and neurologic function throughout an individual’s life. As such, adverse childhood experiences (ACEs) could have severe consequences on health and well-being into adulthood.

Objective: This study presents a narrative review of the use of digital health technologies (DHTs) and artificial intelligence to screen and mitigate risks and mental health consequences associated with ACEs among children and youth.

Methods: Several databases were searched for studies published from August 2017 to August 2022. Selected studies (1) explored the relationship between digital health interventions and mitigation of negative health outcomes associated with mental health in childhood and adolescence and (2) examined prevention of ACE occurrence associated with mental illness in childhood and adolescence. A total of 18 search papers were selected, according to our inclusion and exclusion criteria, to evaluate and identify means by which existing digital solutions may be useful in mitigating the mental health consequences associated with the occurrence of ACEs in childhood and adolescence and preventing ACE occurrence due to mental health consequences. We also highlighted a few knowledge gaps or barriers to DHT implementation and usability.

Results: Findings from the search suggest that the incorporation of DHTs, if implemented successfully, has the potential to improve the quality of related care provisions for the management of mental health consequences of adverse or traumatic events in childhood, including posttraumatic stress disorder, suicidal behavior or ideation, anxiety or depression, and attention-deficit/hyperactivity disorder.

Conclusions: The use of DHTs, machine learning tools, natural learning processing, and artificial intelligence can positively help in mitigating ACEs and associated risk factors. Under proper legal regulations, security, privacy, and confidentiality assurances, digital technologies could also assist in promoting positive childhood experiences in children and young adults, bolstering resilience, and providing reliable public health resources to serve populations in need.

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KEYWORDS

digital health; digital technology; digital intervention; digital health technology; artificial intelligence; machine learning; adverse childhood experience; ACE; positive childhood experiences; children’s mental health; mental health; mental illness; mental disorder; pediatric mental health; disease surveillance

Introduction

Exposures to both negative and positive experiences in childhood have proven to influence cardiovascular, immune, metabolic, and neurologic function throughout an individual’s life [1,2]. As such, adverse childhood experiences (ACEs) could have severe consequences on health and well-being into adulthood [3,4]. ACEs are defined as traumatic childhood events, including abuse (physical, emotional, or sexual), neglect (physical or emotional), household dysfunction, caregiver or parental loss, and experiences of trauma around other social determinants of health [5]. Repeated exposure to a broad variety of traumas in early childhood places particular strain on mental health and is correlated with illicit substance use disorders, depression, obesity, and increases in suicidal ideation into adulthood [6]. Due to recurrent stress response activation before the age of 18 years, children and young people with a history of multiple ACEs are at higher risk of developing neuropsychiatric and emotional disorders, including posttraumatic stress disorder (PTSD), anxiety or depression, attention-deficit/hyperactivity disorder (ADHD), and schizophrenia [7]. However, the relationship between ACEs and behavioral problems is sometimes characterized as bidirectional, with a disorder diagnosis preceding the incidence of ACEs [8]. Regardless of the bidirectional potential, estimates show that more than 50% of children and young people in the United States have reported experiencing at least 1 ACE before their 18th birthday, emphasizing a growing need for intervention, including the continued exploration of the role of positive childhood experiences (PCEs) [9].

Pressing the issue, the global COVID-19 pandemic influenced a marked rise in reported ACEs. A recent Adolescent Behaviors and Experiences Survey conducted by the Centers for Disease Control and Prevention found that 73% of high school–aged students reported experiencing at least 1 adverse event during the pandemic period [10]. The study found that exposed students had a significantly higher prevalence of mental health complaints and an increase in suicidal ideation as compared to adolescents reporting no ACEs [10]. In the wake of this escalation, a national emergency in child and adolescent mental health was declared by the American Academy of Child and Adolescent Psychiatry, the American Academy of Pediatrics, and the Children’s Hospital Association in late 2021 [11]. The advisory sheds light on the severe mental health consequences of the pandemic, noting the extraordinary weight of children and young people being forced to socially isolate and distance themselves from peers, cope with unprecedented grief, and adapt to digital learning environments [11]. Additionally, more than 140,000 children and young people were reported to have experienced the death of a parent or caregiver due to COVID-19 infection in the first year of the pandemic alone [12]. While associated concerns preceded the COVID-19 pandemic, recent exacerbation highlights the occurrence and related effects of adverse events on the mental health of children and young people as a critical public health issue.

Recent research efforts have focused on understanding how PCEs may help to counter the risks of ACEs [6,13]. Emerging evidence suggests that early access to safe, stable, nurturing environments; positive attachments with caregivers, peers, and teachers; interpersonal connection; opportunities for emotional growth; school engagement; and connection to culture and community are among PCEs linked to strengthening childhood resilience and overall health and well-being across the life span [14,15]. Such experiences aid in the vital development of a sense of belonging and connectedness, which often serve as a helpful buffer to the negative effects of ACEs [16].

As digital use by children and adolescents has exponentially increased over the past decade [17], the potential for digital health interventions is promising. The application of digital health technologies (DHTs) has the potential to assist in screening and mitigation of the profound impacts of early life experiences and improve the well-being of children and young people [18]. DHTs have been emerging as transformative solutions to challenges in health care delivery since the early 2000s and are considered to promote equitable, affordable, and universal access to patients and health care providers [19]. The technologies, such as mobile health (mHealth), health information technologies, wearable smart devices, wireless medical devices, personalized medicine, and telemedicine platforms, offer innovative tools to enhance population health and public health responses [20].

When used to mitigate the profound and long-lasting effects of adverse experiences on children and young people, comprehensive, trauma- and evidence-informed digital tools can increase treatment accessibility, strengthen prevention and screening resources, and bolster available support for individuals most vulnerable to ACEs. Given the ever-increasing ubiquity of digital tools, the distribution of DHTs has the potential to reach children and young people and their families on a more intimate level. The innovative development of DHTs for ACE intervention could open new therapeutic pathways for children and adolescents, and such DHTs could also serve as knowledge reservoirs for parents and caregivers to aid in promoting positive experiences in childhood, bolstering resilience [21]. As research examining the role of PCEs continues to grow, increased development of DHTs could provide new opportunities for novel approaches to trauma-informed care in both the clinical setting and in the home. With the help of resources and recommendations on demand, families could readily access personalized messages in the form of texts and multimedia aimed at countering the negative health effects associated with ACEs outside of the traditional clinical setting. This could alleviate several barriers to care, including financial constraints (ie, insurance and copay challenges), geographical or physical inaccessibility (ie, health care access in rural settings, transportation), additional childcare for large families, or inadequate health care resources (ie, provider shortages), providing immediate treatment from a distance [22].

Ultimately, promoting the use of DHTs expands care access and strengthens patient and family engagement. Accordingly, the objective of this literature review was to evaluate and identify means by which existing digital solutions may be useful in mitigating the mental health risk factors and consequences associated with the occurrence of adverse experiences in childhood and adolescence and preventing ACE occurrence, including by highlighting knowledge gaps or barriers for DHT implementation for vulnerable populations. We argue that DHTs could help to prevent and mitigate the lasting effects of ACEs on children and young people, bolstering resilience, promoting PCEs, and alleviating the burden of ACE-associated impacts on health and well-being into adulthood.

Methods

Search Strategy

We performed a search of existing literature, incorporating peer-reviewed studies that were identified from 3 databases (PubMed, SSRN, and Google Scholar) and published between August 2017 and August 2022, to allow for evaluation of the most recent applications of DHTs. Our search terms were used based on the thesaurus and keywords, including “digital health,” “adverse childhood experiences,” “artificial intelligence,” “domestic violence,” “abuse,” “mental health,” “family environment,” “COVID-19,” “suicide,” “depression,” “anxiety,” “social determinants of health,” “personal health library,” “precision medicine,” “substance abuse,” “alcohol use,” and “post-traumatic stress disorder.” Terms and keywords were combined to comprise search phrases, allowing for a more sensitive search. Search phrases included “the application of AI and DH to prevent ACEs,” “role of DH and AI for mental health,” “knowledge gap in digital health,” “significance of DH in mental health,” “specific AI solutions for ACE risks,” “DH interventions in adolescence,” “children who need special care,” “machine learning application,” and “electronic health record.” Additionally, reference lists from selected papers were searched for possible matches and inclusion.

Inclusion and Exclusion Criteria

Studies were included for review if they met the following eligibility criteria: (1) published from August 2017 to August 2022, (2) explored the relationship between digital health interventions and mitigation of negative health outcomes associated with mental health in childhood and adolescence, (3) examined prevention of ACE occurrence associated with mental illness in childhood and adolescence, and (4) conducted in the United States. Studies were excluded if they were not original research or were not available in the English language.

Study Selection, Data Extraction, and Analysis

The initial electronic database search generated papers whose titles or abstracts were collectively screened by 2 reviewers (RP and BMW) to ensure fit to the specified eligibility criteria. The following data were extracted: title, lead author, publication year, study purpose, study design, ACE risk factor indicated, and author’s conclusion. Extracted data were collated and stored on a Microsoft Excel spreadsheet (Microsoft Corp) coding matrix.

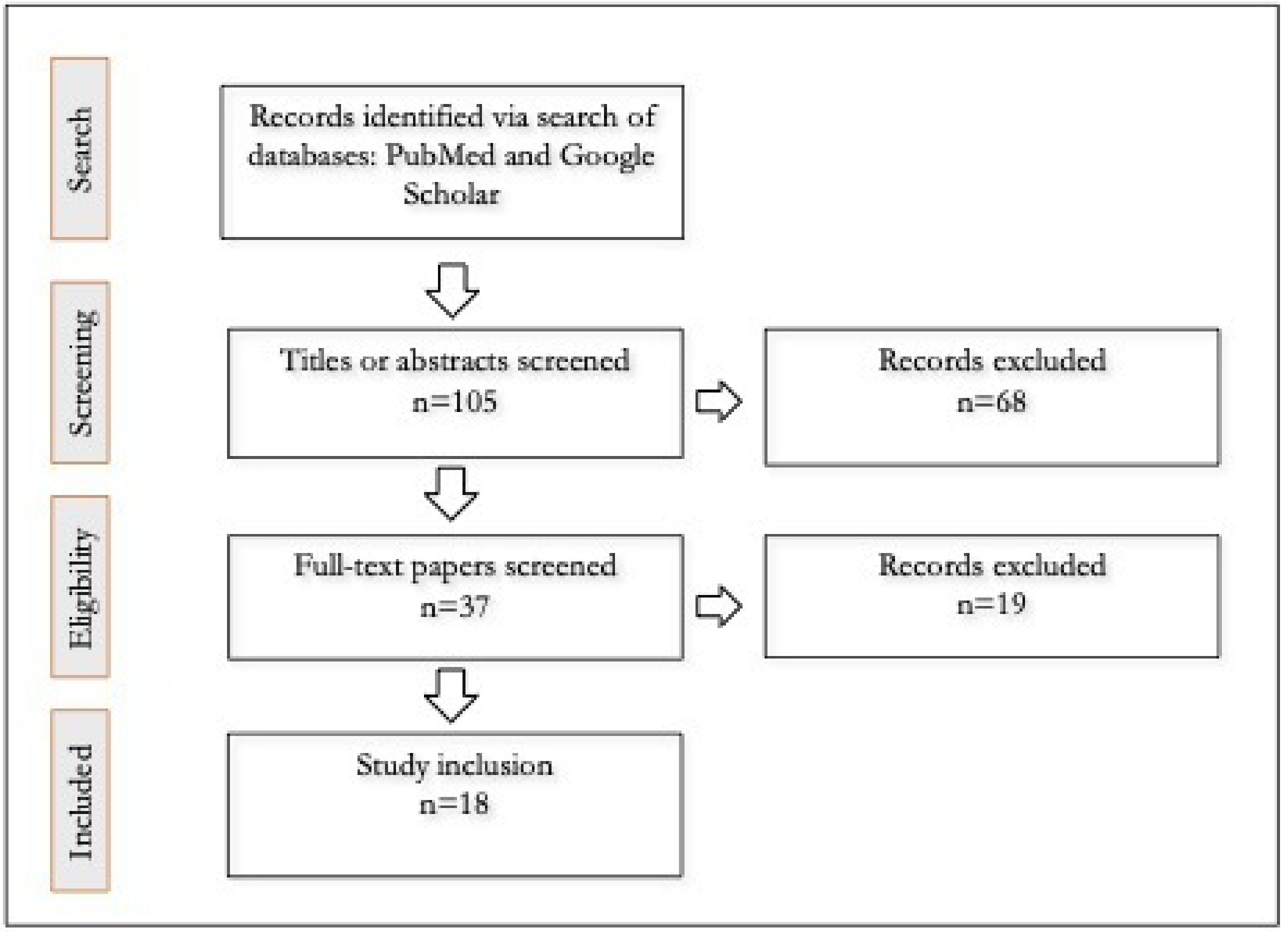
Results

Overview

The search of PubMed, SSRN, and Google Scholar and reference lists of each selected paper yielded a total of 105 results. In total, 87 studies were eliminated because they did not meet the inclusion criteria. After title or abstract screening and full-text review, a total of 18 studies were selected for data extraction and analysis, as demonstrated in Figure 1.

The oldest paper included in this study was published in August 2017, with others as recent as May 2022. Study characteristics and general information on papers selected for review are included and outlined in Multimedia Appendix 1. A total of 100% (18/18) of included papers positively reported the use of digital solutions for ACEs.

Figure 1. Paper selection process.



Use of DHTs for the Management of ACE-Related Mental Health Outcomes

Overall, 44% (8/18) of our examined papers reported the use of DHTs to identify indicators of mental illness and reduce the negative effects of such adverse experiences. Studies assessed the suitability, usability, and acceptability of digital health interventions for the management of mental health illness with findings in support of the effectiveness of computerized cognitive behavioral therapies [23-28]. Such tools are argued to help diagnose, predict, and prevent negative outcomes of mental health illness due to ACEs. Examined studies argue that digital solutions, such as educational mobile apps, directed at children and young people have the potential to be important assessment, management, and treatment tools to provide efficient access to health services and promote self-help in hours of need [23,25,28]. Similarly, another study found that children and young people responded well to structured digital peer-to-peer interactions and strength-based mHealth coaching [26]. Moreover, collective findings highlight the potential for the use of social media–based digital intervention for children and young people at risk of negative mental health outcomes associated with ACEs [27,28].

Posttraumatic Stress Disorder

Children exposed to traumatic ACEs are reported to have a higher incidence of PTSD compared to their peers without repeated stress [29,30]. One study from our search found promise in the use of artificial intelligence and longitudinal data to identify and treat children with PTSD as a result of childhood traumas [30]. Lekkas and Jacobson [30] found the use of geometric Global Positioning System data to measure daily minutes spent and the radius traveled away from home was an effective way to detect “avoidance symptoms” displayed by high-risk cohorts with a history of abuse and neglect. The study found that, without clinical predictors, the deployed passive monitoring tools successfully diagnosed PTSD more than 80% of the time [30].

Suicidal Behavior or Ideation

From our search, 22% (4/18) of selected studies characterized opportunities for DHTs, machine learning, and electronic health record restructuring to predict the suicidal risk in children and young people having experienced 1 or more ACEs.

Overwhelmingly, suicide rates are 30 times higher among adults with more than 4 ACEs, highlighting an urgent need for innovative solutions [31]. Findings from examined papers suggest that DHTs could play key roles in identifying predictors of suicidal behavior, violence, and unintentional injury. Chen and Chan [32] found that digital health interventions have great potential to reduce unintentional injury, violence, and suicide in children and young people who have witnessed or experienced 1 or more traumatic events. The study argues that future work should focus on intervention to increase access to comprehensive digital technologies for those who have experienced or witnessed abusive behaviors in childhood or adolescence [32]. Notably, conclusions from another investigation suggest that predictive models of suicide risk of children and adolescents, by using demographics, comorbidity diagnosis codes, laboratory test results, and medications from clinical records models, show good performances for estimation of short-term and long-term risks and identify significant predictors, which may assist in clinical practices [33].

Others found that DHTs can be used to successfully predict, and potentially prevent, suicide risk among adolescents [33-35]. One used machine learning to successfully detect 53% ‐ 62% of suicide-positive behavior with 90% specificity [34]. Findings support growing evidence that the innovative use of electronic health records can be useful in developing reliable predictive models for suicide risk among children and young people [34]. Similar findings were expressed by Walsh et al [35], whose findings further suggested that routinely collected clinical data can be leveraged to predict suicide risk in children and young people with a history of ACE with computational algorithms. However, it is important to note that these findings are not always generalizable on a global scale, as only a small proportion of existing digital platforms in low- and middle-income countries are evidence-based and frequently demonstrate low effectiveness due to factors such as societal mistrust [24]. As such, widespread adoption and scale-up of digital mental health interventions will require more rigor in research and study before widespread global implementation.

Anxiety or Depression

Anxiety is characterized by the reflection of internal feelings of discomfort expressed with uneasiness, and prolongation of these feelings can cause severe depression in children and young people [36]. Unfortunately, there are only a small number of studies available examining the correlation between ACEs and anxiety, with far fewer deciphering noticeable differences between anxiety and depression for children and young people having experienced 4 or more ACEs [36]. However, of the results from our search, 16% (3/18) indicated possible uses of digital health to support and care for children experiencing anxiety. Findings from one examined study suggest that digital interventions aimed at the improvement of anxiety symptoms in children and young people can be transformative in supplementing traditional treatment plans [37]. Khanna and Carper [37] found that digital mental health interventions, such as web- or cloud-based therapeutic programs, mobile apps, and virtual reality simulations, are reliable mitigation tools and should be used to supplement and maximize anxiety treatment completion.

This sentiment is echoed by both Williams and Fried et al [38,39], who also found a significant opportunity for the employment of digital interventions. Both argue that the development of mental health monitoring applications for anxiety and depression could allow for real-time recording of mental health symptoms, including perceived feelings and behaviors [38,39]. Conclusions suggest that population-wide use of such monitoring applications could reshape the clinical understanding and progression of mental health conditions, such as anxiety or depression, creating opportunities for targeted mitigation response [38,39].

Attention-Deficit/Hyperactivity Disorder

Children and young people experiencing the effects of ACEs are at heightened risk of developing behavioral disorders such as ADHD [40]. From our search, 16% (3/18) of examined studies highlight the use of digital therapeutic interventions for the improvement of ADHD. Studies found that game-based digital therapeutic devices, such as the Food and Drug Administration–approved EndeavorRx, support positive outcomes when used to treat ADHD among children aged 8 to 12 years without the need for pharmacological intervention [41]. Kollins et al [42] found that daily game-like interaction with a digital therapeutic program (AKL-T01) improved inattention in children and young people diagnosed with ADHD. Similarly, Fried et al [39] found that the use of a digital mindfulness application showed a marked reduction in inattentiveness and anxiety for children aged 6 to 12 years with a history of ADHD. Additionally, results from a survey administered during the 4-week pilot study found a correlation between sleep patterns and both stress levels and attention span [39]. These findings could help to inform appropriate management plans and highlight the potential for the continual development of game-like digital interventions designed to exercise memory training and neurofeedback [41,42]. These innovative applications not only provide clinicians with attention assessments by measuring key stimuli and response variabilities but also supply users with continual intervention by sharpening perseverance and self-efficacy skills [42].

Discussion

Principal Findings

Immense challenges exist in overcoming ACEs in children and young people. Physical, sexual, or emotional abuse in childhood can severely impact the health of children and young people. Children who have experienced or witnessed more than 3 related types of abuse are at high risk for self-destructive behaviors, including substance abuse, suicidal ideation, and overall poor resilience [43].

As screening can be time-consuming and difficult to implement on a broad-reaching scale, DHTs may provide a scalable approach to capturing vulnerability and resilience factors in real time. We argue findings from our review may suggest that incorporating DHTs for managing the mental health consequences of repeated exposure to childhood trauma shows promise for building childhood resilience.

Innovation

While arguably still in the early decades of meaningful implementation, there is pronounced potential for innovative digital technologies and interventions to identify indicators of mental illness and reduce the risk factors and negative effects of related adverse experiences. Mental illnesses related to ACEs are most commonly the result of enduring verbal, sexual, or physical abuse; neglect; parental separation or incarceration; familial substance abuse; domestic violence; poverty; peer rejection; and death or traumatic loss before age 18 years [44]. Additionally, many social determinants contribute to unfavorable familial conditions negatively affecting the health of children and young people, such as unemployment, food insecurity, single parenting, and unsafe neighborhood environments [44]. Support opportunities provided by DHTs supply health care providers with necessary mitigation tools for the extraction, processing, assessment, and analysis of patient-provided information for use in rapid response strategies [45-47]. Additionally, advancements in digital surveillance tools tasked with symptom-based geolocation could help pinpoint vulnerable communities for tailored mitigation, including comprehensive educational programs focused on the prevention of ACEs.

Perhaps harnessing the greatest potential are the innovation and scaling up of game-based therapeutic applications. As demonstrated in our results, these digital therapeutics have been shown to positively support the management and improvement of multiple mental health conditions (ie, PTSD, suicidal ideation, anxiety, depression, and ADHD) by engaging children and young people with unconventional treatment approaches [48]. For example, digital meditation and relaxation applications are therapeutic for children and young people with anxiety, depression, and sleeping problems, alleviating burdens related to increased stress factors and lack of adequate rest [39]. These technologies could also be used to facilitate resilience by promoting digital literacy and positive health information–seeking behavior and delivering precision health education or promotion. Digital interventions hold the potential to provide targeted resources to elevate PCEs, transforming early childhood experiences for those at the highest risk of facing adversity. DHTs may serve as a buffer against the effects of ACEs by broadening opportunities for exposure to positive experiences such as play, recognition, acceptance, praise, and other protective factors. Moreover, such digital technologies could prove to be advantageous in bolstering appointment and follow-up arrangements, patient screening and monitoring, and improvement of training and education for providers and decision makers. This bidirectional expansion could help bridge the gap between patient needs and care services.

Limitations

While this review highlights the strengths and successes of digital solutions for mitigating ACEs, it also helps uncover the need for further exploration of their actionability. Challenges related to addressing gaps in digital health literacy, high-speed internet access, confidentiality, reliability, and trust remain. Ethics and practice guidelines are needed, and questions remain regarding the level and quality of therapeutic involvement needed to maximize treatment to bolster resiliency and positive outcomes in youth. Moreover, underreporting of ACEs and subsequent lack of treatment of associated consequences remain barriers due to the sensitive, deeply personal nature of mental health illness [49]. The growing body of evidence supports and encourages the development of personalized patient-provider communications, the fostering of personal relationships, and the counteraction of misinformation as solutions to decrease uncertainty and bolster patient-provider trust [50-52]. Likewise, there is room for comprehensive DHTs tasked with the creation and amplification of tailored messaging to target populations who display hesitancy to openly discuss mental health concerns with care providers. These tools could offer comprehensive educational material during care visits, complementing the therapeutic relationship of interpersonal communication and treatment and helping to bridge the gap between patient and provider when discussing mental health.

Furthermore, training and ACE awareness or educational campaigns to bolster proficiency for health care professionals could be achieved through structured digital learning and mHealth technologies. With proper training, health care professionals would be adequately equipped to both assess and accurately report ACE-related findings and effectively communicate prevention and response strategies to patients at risk. Although DHTs harness the potential for the screening and prevention of ACEs, it is also imperative to facilitate equitable access to these digital tools for vulnerable, harder-to-reach communities. Special attention should be given to developing DHTs with the capability to navigate and transcend many social determinants of health. As previously mentioned, challenges related to high-speed internet access may prevent families from fully harnessing the potential of DHTs. With this in mind, a standard of DHT development should include the ability to access tools and resources offline. Moreover, contextual information should be made available at every literacy level to account for a range of understanding. Overall, vulnerable populations must be considered during policy development and decision-making before implementing any architecture.

There is also a growing need for transparency, explainability [53], and understanding of digital health infrastructure for children and young people, particularly for those with special needs. Technologies aimed at children and young people should be standardized, so that messaging is consistent across varying platforms and information systems, as standardization could aid in mitigating confusion among the public when navigating mental health illnesses and other health disparities. Adequate funding is needed for institutions of learning (ie, grade schools and universities) to offer courses on digital health literacy, health information–seeking behaviors, ACE risk factors or consequences, big data analytics, and artificial intelligence. Additionally, there is room for participation and infrastructure development from private sector stakeholders (eg, information and communication technology companies) to facilitate efficient operationalization and optimization of digital health initiatives. The progressive growth of DHTs, especially in preventing mental health issues, is warranted to make solutions more accessible to a broader range of those in need.

Conclusions

Successful development and deployment of digital solutions could reduce the consequences to mental health related to adverse childhood events; bolster childhood resilience; and influence future health policy, decision-making, and program implementation for ACE prevention and control [46,54].

From our findings, digital solutions, such as game-like mindfulness applications, have notably aided in the identification or treatment of PTSD, suicidal ideation, anxiety, depression, and ADHD in children at risk of or experiencing negative health effects associated with ACEs. While digital solutions should not be considered as a replacement for physical evaluation or treatment, the innovation of such tools could aid in identifying risk factors and preventing future complications and long-term illness or medical care dependence as a result of these conditions. We argue there is room for governmental and private sector stakeholder support of expansive, digital, open-source, modular DHTs with user-friendly graphical interfaces. Additionally, policy and data governance investments could support the tailored delivery of therapies and education efforts to ensure resource-limited populations have full access to these comprehensive technologies, preventing more severe negative outcomes.

Optimizing DHTs with the proper use of these technologies under regulatory control, screening, and prevention of the risks of ACEs can bolster public health response to mental health care for children and young people. Furthermore, consideration of the probable bidirectionality in the relationship between ACEs and mental health consequences when developing comprehensive digital tools could further help prevent associated impacts on well-being in adulthood, no matter the etiology of adversity. Regardless of origin or onset, prioritization of digital interventions targeting all underlying pathways could help to interrupt cycles of adversity and promote resilience for children experiencing mental illness. Future expansion of DHTs and their use could help bridge the gap between patients, providers, and researchers, increasing the number of PCEs and reducing associated morbidities and mortalities by enhancing screening and prevention of ACEs at earlier stages. Expanding and adopting such innovative, cost-effective digital solutions could have meaningful impacts on health care services for those affected by ACEs.

Authors' Contributions

BMW and RP conceptualized the study and drafted, reviewed, and edited the manuscript. NA and JAY reviewed and edited the manuscript. AS-N drafted, reviewed, and edited the manuscript; supervised the study; and acquired funding.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Summary table representing the characteristics of selected studies.
[DOCX File, 21 KB - pediatrics_v7i1e58403_app1.docx]

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Abbreviations

ACE: adverse childhood experience
ADHD: attention-deficit/hyperactivity disorder
DHT: digital health technology
mHealth: mobile health
PCE: positive childhood experience
PTSD: posttraumatic stress disorder

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Categorization of mHealth Coaching Technologies for Children or Adolescents With Type 1 Diabetes: Systematic Review

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Abstract

Background: Managing type 1 diabetes in children and adolescents can be difficult for parents, health care professionals, and even patients. However, over the last decades, the quality of services provided to patients with diabetes has increased due to advances in IT.

Objective: This study aims to comprehensively document the range of IT tools used in the management of diabetes among children and adolescents, with a focus on identifying the technologies most commonly used based on their frequency. In addition, the study aims to explore relevant methodologies for developing diabetes technology and provide valuable information to developers by delineating essential phases of the design process.

Methods: The literature search was focused on MEDLINE (PubMed), Web of Science, and Google Scholar for relevant studies. Keywords such as "type 1 diabetes," "adolescents," "kids," "mHealth," "children," and "coaching" were combined using Boolean operators. The inclusion criteria were open access, English-language papers published between 2012 and 2023 focusing on patients younger than 18 years and aligned with our research goal. The exclusion criteria included irrelevant topics and papers older than 18 years. By applying the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) method, 2080 studies were recognized, and after selection, 33 papers were agreed upon between the researchers.

Results: Four primary categories were defined: types of IT, methodology identification, purpose identification, and feature determination. Among these, mobile health (mHealth) apps emerged as the predominant type of information, garnering 27 mentions. In particular, user-centered design was identified as the most prevalent methodology, cited 22 times. The primary purpose of self-monitoring blood glucose values was mentioned 20 times, while patient education was the highest among common characteristics, with 23 mentions.

Conclusions: Based on our research, we advocate for developers to focus on creating an mHealth app that integrates gamification techniques to develop innovative diabetes management solutions. This app should include vital functionalities such as blood glucose monitoring, strategies to improve hemoglobin A_{1c} levels, carbohydrate tracking, and comprehensive educational materials for patients and caregivers. By prioritizing these features, developers can enhance the usability and effectiveness of the technology, thereby better supporting children or adolescents with diabetes in their daily management endeavors.

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KEYWORDS

type 1 diabetes; adolescents; children; parents; mHealth; information technology; PRISMA

Introduction

Background

A chronic condition of glucose metabolism known as "diabetes mellitus" is described by impaired insulin production and action. According to the etiopathology of diabetes, the 3 most common clinical classes are distinguished: type 1 diabetes (T1D), type 2 diabetes, and gestational diabetes mellitus [1,2]. T1D is the most common type of diabetes affecting children or adolescents, although it can occur in all age groups [3-6].

T1D is typically diagnosed at a young age. After a child is diagnosed with diabetes, the child and his caregiver or parents need a period of adaptation to the new situation. In addition, children or adolescents may struggle emotionally with their health conditions, especially those that are diagnosed early. Therefore, they need the support of their caregivers to manage their disease [6-8]. Caregivers are crucial supports for the ability of children or adolescents to self-manage T1D [6,7,9]. However, caregivers often report frustration, stress, and worry about their role [10]. This period after diagnosis can be challenging for both children and parents [8].

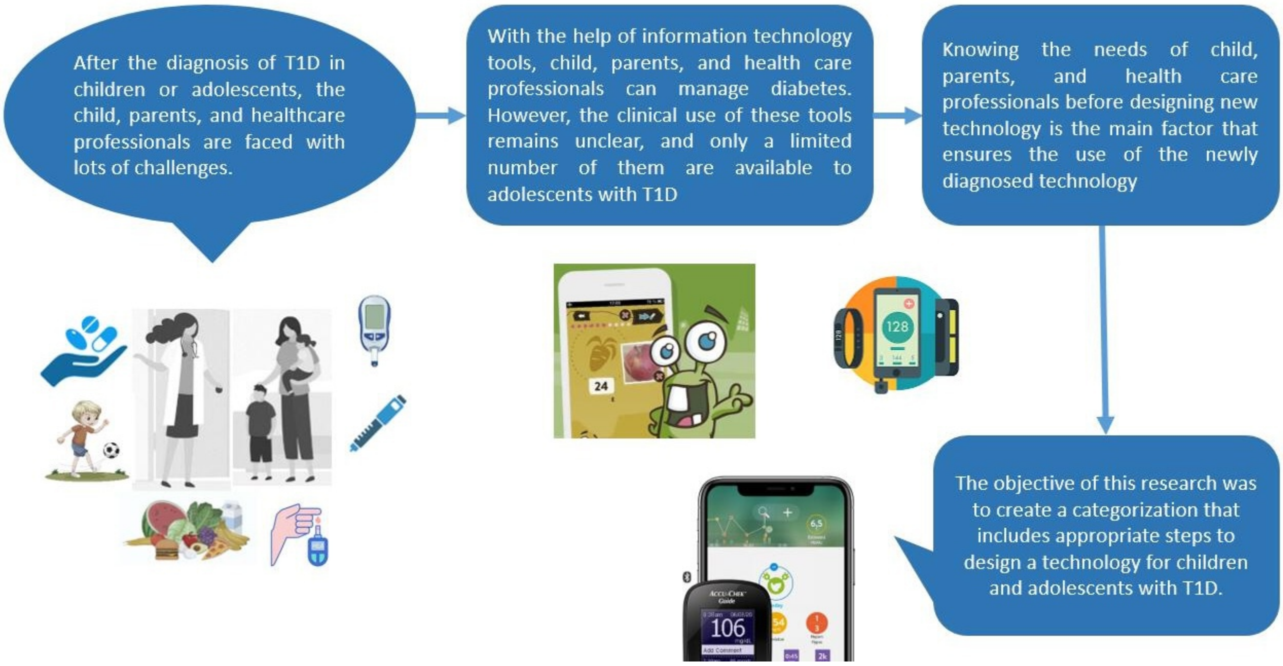
T1D requires a lifetime of self-management at home and in the community, which requires regular consultations with the health care team [11]. Intensive self-management is characterized by frequent self-monitoring of blood glucose (SMBG), physical activity, carbohydrate intake, and insulin doses by using multiple daily insulin injections or an insulin pump for basal and bolus insulin delivery [11,12]. Improved blood glucose control has been shown to reduce mortality and the incidence of serious and costly complications such as kidney and cardiovascular disease [11]. Achieving ideal blood glucose levels requires intensive self-management, which can be a challenge for young people [4]. Supporting adolescents and children in the self-management of T1D is an integral goal of health care. Health care professionals (HCPs) must guide insulin management and seek insight into the lived experiences of patients, such as social life, work, and school, to identify issues that influence self-management. In addition, adolescents or children with T1D often skip clinical visits, show a lack of adherence to monitor their hemoglobin A_{1C} (HbA_{1c}) trends, and endanger their current and future health [13-15].

The quality of services provided to patients with diabetes has increased due to advances in IT over the past few decades [16]. Numerous studies have investigated the efficiency of using websites, apps, and messaging systems as tools of IT to manage diabetes [4-7,13,17-23]. In this regard, along with various types of information technologies, the number of diabetes apps available for download on the iOS App Store and Google Play to improve diabetes self-management has proliferated recently [5,7,24]. The mobile health (mHealth) apps improve patient education and communication with HCPs and peers conveniently and interactively [13,25], especially among children or adolescents, an age group that easily adopts new technology [26].

Objective

This study aims to thoroughly catalog the variety of IT tools used in the management of diabetes among children or adolescents. The main goal is to identify the technologies that are most widely used by noting their frequency. The study also intends to investigate several approaches that are relevant to the creation of diabetes technology. It plans to provide developers in this industry with useful information by outlining the fundamental phases involved in the design process. Figure 1 shows the graphical abstract of the paper.

Figure 1. Graphical abstract. T1D: type 1 diabetes.



After the diagnosis of T1D in children or adolescents, the child, parents, and healthcare professionals are faced with lots of challenges.

With the help of information technology tools, child, parents, and health care professionals can manage diabetes. However, the clinical use of these tools remains unclear, and only a limited number of them are available to adolescents with T1D

Knowing the needs of child, parents, and health care professionals before designing new technology is the main factor that ensures the use of the newly diagnosed technology

The objective of this research was to create a categorization that includes appropriate steps to design a technology for children and adolescents with T1D.

Methods

The electronic databases used for the search were MEDLINE (PubMed), Web of Science, and Google Scholar. Keywords were “type 1 diabetes,” “adolescents,” “kids,” “mHealth,” “children,” and “coaching.” These were combined using the Boolean operator “AND” and included their respective synonyms with the operator “OR.” The inclusion criteria for the studies included open access, papers published in English from 2012 to 2023, patients with diabetes younger than 18 years, and consistent with the research goal. The criteria for exclusion were irrelevance to the major topic, older than 18 years, conference papers, reports, and theses. Our systematic database search identified 2080 studies from 3 databases. The study selection is using PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines [27].

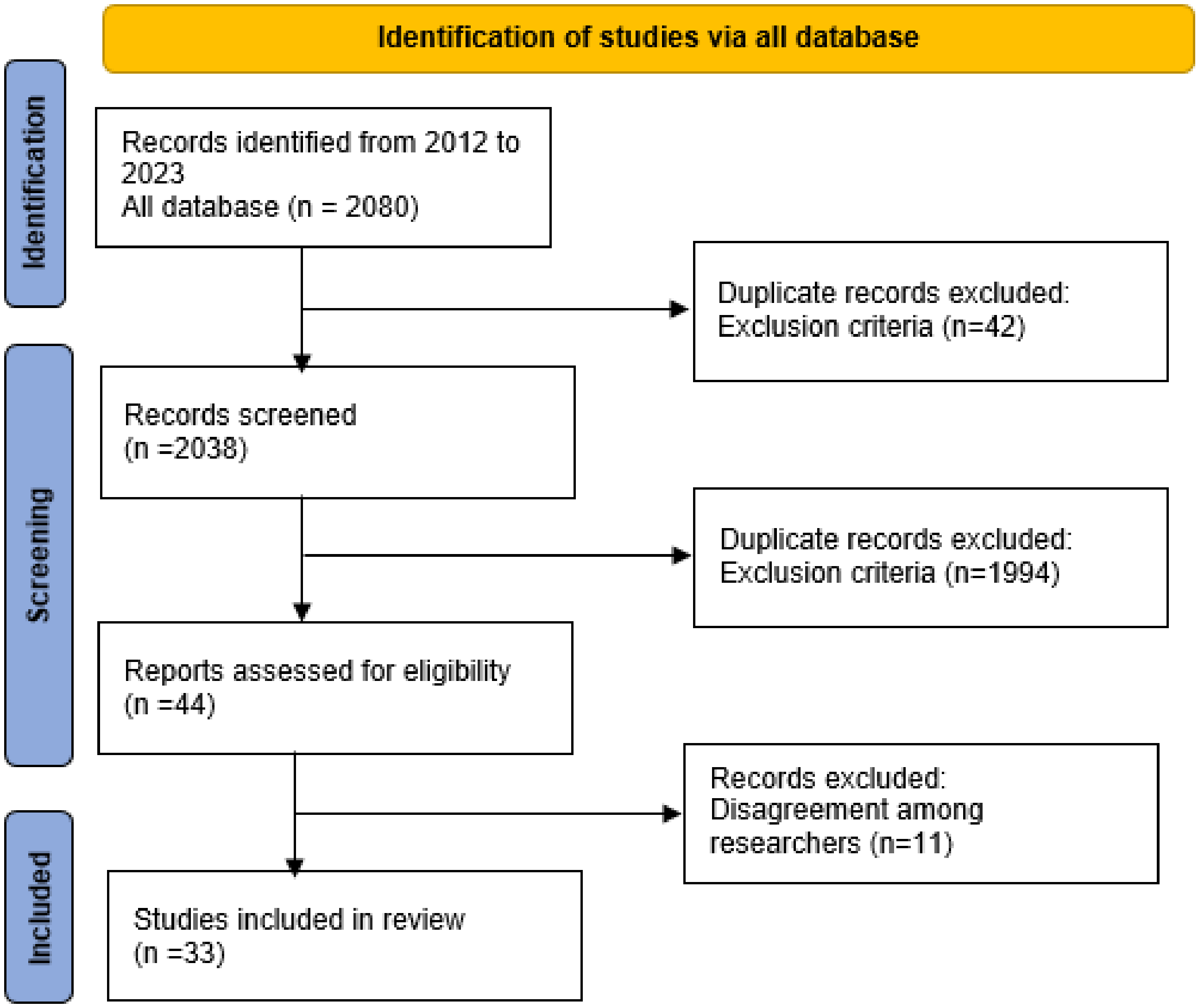
Results

Overview

Based on Figure 2, after filtering out publications based on duplication and exclusion criteria, only 44 remained. However, 11 of these were later excluded due to discrepancies among researchers. These papers did not achieve the consensus of researchers regarding their alignment with the objectives of the current research, leading to their exclusion. At the end of the selection process, 33 researchers fully agreed upon the papers. Of 33 research papers, 30 were in Google Scholar, 3 in PubMed, and nothing on Web of Science (after removing duplicates). Through exploration of the papers, it was initially found that the 3 main information technologies applied to the management of T1D among children or adolescents are the mHelath apps, the website, and the messaging system. Then, it became clear that the gamification, user-centered design (UCD), and text message systems were the 3 most popular methodologies to design new technology for diabetes. Finally, the procedures for creating a new technology for children or adolescents are as follows:

1. Types of IT
2. Methodological identification
3. Purpose identification
4. Feature determination

Figure 2. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart.



Types of IT

Through reviewing the papers, it becomes apparent that there are 3 main types of IT that are used in the management of T1D among children or adolescents, which are shown in Table 1.

Table . Types of IT.

Platforms	References
mHealth[a]	[4,5,7,8,11-13,15-23,28-37]
Websites	[6,16,17,35,38,39]
Messaging system	[21,40,41]

[a] mHealth: mobile health.

Methodology Identification

Three methods were recognized for designing an IT for the management of T1D in children or adolescents, which are summarized in Table 2.

A comprehensive overview of various information technologies and their respective features has been compiled in Table S1 in Multimedia Appendix 1 to maintain the study's brevity and avoid unnecessary complexity resulting from an excess of tables.

Table . Methodology identification.

Methods	References
Gamification	[6,8,22,23,32,37,38]
Text message system	[21,40,41]
UCD[a]	[4,5,7,8,11-13,15-21,28-31,33-36,39]

[a] UCD: user-centered design.

Purpose Identification

Upon reading the papers, it was concluded that recognizing the goal is a significant step in the development of a new technology. Table 3 presents the categorization of the goals extracted from the papers.

Table . Purpose identification.

Goal	References
Self-monitor blood glucose value	[4,6-8,11,12,16,17,22,28,29,32,33,35,37,38]
Improve HbA$_{1c}$[a]	[5,7,12,20,29-31,36,40]
Self-manage insulin adjustment	[6,18,22,23,28,38]
Improve the life quality	[6-8,12,15,38]
Improve the communication among parents, adolescents or children, and HCPs[b]	[4,7,11,12,32]
Promote parents' knowledge about diabetes	[16,17,32-34,36,42]
Enhance adolescents' or children's knowledge about diabetes	[6,7,12,18,19,21-23,30,33,38,41]
Track physical activity	[6,35,38]
Track food intake	[6,18,21,30,38]
Develop a device-agnostic cloud platform to host diabetes device data	[39]

[a] HbA$_{1c}$: hemoglobin A$_{1c}$.

[b] HCPs: health care professionals.

Feature Determination

Identification of stakeholders is necessary before determining the characteristics of the technology. Identified stakeholders are parents, caregivers, HCPs, and children or adolescents with diabetes. In Table S1 in Multimedia Appendix 2, the lists of questions asked of stakeholders are attached. In the following, the summaries of the questions are mentioned.

Parents were often asked the following questions:

> *What information should be included in the app; Do you like to see trends in a child's blood glucose, HbA$_{1c}$, and fasting blood glucose; How do you manage an adolescent's diabetes; What challenges come with having children with diabetes; How much could a child with diabetes benefit from an application made specifically for this purpose.* [8,12,18,42]

Furthermore, the questions about designing technology with the intention of gamification were as follows:

> *What is the most appropriate game design for a child with diabetes (taking care of a character, quizzes, runner game, storytelling); What is the most appropriate reward style that should be used in the game; What features would you like to have in the game.* [37]

Furthermore, questions such as, "If your HbA_{1c} is below the target range, what kind of information or message would you like to receive from the app?"; "What types of goals would you like to be able to set for yourself?"; "What was your experience and feelings about being diagnosed with diabetes?"; and "How do you deal with diabetes?" were frequently asked of adolescents [12,19]. Furthermore, "What thoughts and wishes are there regarding a virtual platform for children/adolescents?" [23]; this is a kind of question that was asked of HCPs.

Through the analysis of the responses of stakeholders to the questions, technological features emerge. Concise summaries of the features of the diabetes app are shown in Table 4.

Table . Feature determination.

Features	References
Reminders	[6,7,12,13,15,17,20,23,28,29,32-34,36-38,40]
Blood glucose tracking	[4,6-8,11,12,16,17,28,29,32,33,35-40]
Insulin administration	[5-8,12,17-19,23,28,29,31,32,36,38,40]
Carbohydrate counting	[5,7,8,12,13,15,17-21,23,29,30,32-34,37,39]
Patients' education	[4,6-8,11-13,15,17-21,28,30,32-34,37,38,40,41]
Communication among stakeholders	[5,8,13,15,20-22,28,30,32,35,36,40]
Track physical activity	[6,8,16,17,19,23,28,32,33,35,38,39]
Parental involvement	[4,7,11,12,29,33,34]
Chat with peers	[8,13,15,20]

Review of Current Technologies

Another point to consider when designing new technology is how successful the previously introduced technologies have been in achieving their goals. For the treatment of T1D in adolescents, Cafazzo et al [11] designed the Bant app using gamification incentives. They showed that the app improves the frequency of blood glucose monitoring in adolescents. Alsalman et al [23] proposed a gamification app in 2021; however, they have not provided any evidence of the app's usefulness. In addition, Schmidt et al [22] created the gamification app in 2022, but they have not yet shared any user evaluation data. In 2017, den Akker et al [38] described a platform, PERMAGON, that integrates gaming and coaching for adolescents with type I diabetes. The purpose of the platform was to support patients and their caregivers in self-management of diabetes through educational games, monitoring, and motivational feedback. In 2018, Klaassen et al [6] conducted a study to evaluate the efficacy of PERGAMON. They asked participants: "Do you expect that the PERGAMON platform will support you in your diabetes management?" Approximately 33.33% (33/100) of the participants answered "yes," which proved the effectiveness of the platform.

In 2017, Goyal et al [4] conducted a study on the Bant app to determine its impacts on HbA_{1c} and SMBG. They showed that the app has a positive impact on the use of SMBG data and glycemic control among youth. Klee et al [5] demonstrated that the Webdia app reduced HbA_{1c} levels in children who used it without increasing their prevalence of hypoglycemia. In 2017, Holtz et al [12] designed the MyT1DHero app using patient-centered methods to recognize their requirements. The participants confirmed that the new app would improve communication between parents and adolescents. The effectiveness of the MyT1DHero app in enhancing HbA_{1c} levels, adherence to diabetes care adherence, and quality of life was investigated in a new study by Holtz et al [7] in 2021. They showed that the app facilitates parent-adolescent communication, adherence to self-care, and improvement in quality of life. An Arabic-language application called Ana Alsukary was created in Saudi Arabia by Bitar et al [8]. This app consists of several features, one of which the users were interested in, namely, showing the location of stores that offer diabetes-friendly products. Caregivers of children with diabetes indicated that the app helps children understand their diabetes and adjust their lifestyle accordingly.

In 2017, Castensøe-Seidenfaden et al [13] designed a new app, Young with Diabetes (YWD), to support young people in the self-management of T1D. In 2018, Husted et al [15] examined the influence of YWD on young people's self-management for 12 months. Participants mentioned that peer support reduced feelings of loneliness and helped them acquire knowledge and skills to manage T1D. Another study was carried out by Castensøe-Seidenfaden et al. in 2018 [20] to investigate the effectiveness of YWD in improving HbA_{1c} levels. The results demonstrated that the value of the app could not improve HbA_{1c} but could be a useful addition to self-management. In another study by Ledderer et al [28], adolescents using the Diapplo app appreciated the design and user interface of the app as well as the functions to have an overview of blood glucose values. However, they stated that the content of the app only partially met their needs. They suggested integrating social networks into the app and providing more knowledge on how to deal with chronic diseases. Albanese-O'Neill et al [17] created an online DSMES website and a separate mobile subdomain for fathers, Mobile Diabetes Advice for Dads (mDAD). They evaluated a prototype of the site with fathers' participants. Information on mDAD was believed to be helpful by 55% (55/100) of fathers. Since many young adults with T1D struggle with the complex daily demands of adherence to their medical regimen and do not achieve glycemic control in the target range glycemic control, Stanger et al [36] provided a mobile app, SweetGoals, to study its ability to help young adults comply with their medical regimen. The results of their experiment will be published by December 2025.

Berndt et al [16] investigated the impact of Mobile Diab, a new mobile, website, and communication technology, to help the treatment and treatment of adolescents with T1D. They observed an improvement in the mean HbA_{1c} level. Frøisland et al [21] compared 2 types of technology, the Diamob application and diabetes message system, to determine which could have a better impact on diabetes management than others. The objectives of the Diamob app were communication between the patient and the health care team about carbohydrate consumption, insulin dosage, and types of physical activity. The diabetes message system has been used to send educational messages to patients and messages to HCPs when faced with obstacles in daily life. As a result, adolescents found both the Diamob and the diabetes message system practical as support for their diabetes self-management. They appreciated Diamob more than the text message app. In 2015, Frøisland and Årsand [30] developed and tested a new feature for Diamob that allowed one to take pictures of the food and then measure the carbohydrates in the food, the insulin dose needed, and the type and amount of physical activity. They concluded that adding this feature would go a long way toward helping young people understand the basics of diabetes. Hilliard et al [34] created and tested a new mHealth app for parents of teens with T1D, which is Type 1 Doing Well. Parents claimed that the app had high acceptance and the greatest suitability for providing information. The CanDIT (Canadian Diabetes Incentives and Technology) app was developed by Krmpotic et al [29]. The app was evaluated by a small number of youths. They stated that they use the app most often for SMBG. They reported that they liked the ability to set reminders and view their glucose history. They listed several suggestions for improving the app, such as the ability to personalize target blood glucose ranges, calculate insulin doses, enter blood glucose values, and track carbohydrate intake. Shetty et al [31] claimed that enabling young people with T1D to control their blood glucose levels during exercise is a complex challenge for HCPs. Therefore, they asked 10 young people with T1D to use the acT1ve mHealth app to help them exercise in real time. Participants indicated that the app improved their knowledge and boosted their confidence when exercising.

Zholdas et al [35] presented an information on technology–based mHealth monitoring system, including sensors, medical bracelets, and mobile devices with applications to calculate the probable change in a patient's blood glucose level after the end of physical activity. After a test, they demonstrated a drop in blood glucose levels after physical activity, which confirms their hypothesis that there is a link between physical activity and blood glucose levels. To host data from diabetic devices and develop an ecosystem of software innovation to treat T1D care, Neinstein et al [39] created a device-agnostic cloud platform, Tidepool, to host data from diabetic devices and catalyze an ecosystem of software innovation for T1D management. They concluded that the Tidepool platform can solve 2 current problems in the T1D device landscape: limited access to T1D device data and poor interoperability of data from different devices.

Text messaging is another type of platform used by researchers. Bin-Abbas et al [40] conducted a mobile phone messaging service for children or adolescents with T1D. Three types of mobile phone messages have been sent to children through their parents, including informational messages, interactive messages, and multimedia messages. The results showed that HbA_{1c} levels were significantly reduced, parents' knowledge of diabetes improved significantly, and text messages on mobile phones were a useful way of contacting each other between clinic visits. Zhang et al [41] conducted another study with the hypothesis that higher levels of participation in the intervention would yield better diabetes management and examined whether caregiver participation or other demographic factors were associated with the level of participation. They concluded that there was a good level of participation in a text messaging intervention for adolescents with T1D, and high participation was related to a greater improvement in caregiver-reported adherence. Race, ethnicity, and sex were the only demographic factors significantly related to the level of participation.

Discussion

Principal Findings

Management of diabetes can be difficult for children or adolescents, parents, and HCPs. To address this, technology plays a vital role in providing support. These modern technologies are characterized by significantly better cost-effectiveness, which is a stark contrast to traditional, more expensive alternatives. Unlike traditional systems, they eliminate typical total cost of ownership issues [43]. To better assist adolescents or children dealing with T1D, this study conducted a comprehensive assessment aimed at initially cataloging the range of IT tools used in diabetes management and pinpointing the most prevalent technologies used. Furthermore, the study delved into various methodologies relevant to the development of diabetes technology. Finally, it aims to provide developers in this field with valuable insights by delineating the fundamental phases inherent in the design process. Through a review of the literature, it became apparent that there are 4 key steps involved in designing a novel technology for the management of diabetes.

The initial step, as previously discussed, entails identifying the predominant IT used. In this regard, the mHealth apps emerged as the leader with 27 mentions, followed by websites with 5 mentions and text message systems with 3 mentions. This high frequency of mHealth apps is because children or adolescents have easy access to mobile phones, encouraging technology innovators to create more mHealth apps specifically for the management of diabetes. This finding corroborates previous research [13,25] indicating that mHealth apps effectively enhance patient education and communication with HCPs and children or adolescents conveniently and interactively.

The second step was to identify the main methodology for designing a new technology for children or adolescents with diabetes. It was evident that the most popular methodology is UCD, with 22 mentions. Gamification was referenced 8 times after UCD and messaging systems were cited 3 times. Gamification is the application of concepts of game design to the creation of settings that can encourage individuals to make healthier decisions [37]. Text message system is technique that uses a mobile phone to send messages to patients and their parents. UCD involved designing the app with the end user in mind, focusing on their needs, preferences, and behaviors throughout the design process. The age range of children or adolescents indicates that gamification may be the most successful strategy to motivate patients with diabetes to actively interact with the program, although UCD emerged as the most popular methodology. This can greatly support their attempts at self-management and encourage regular use, which will improve the management of their diabetes. Visualization plays a key role in captivating the interest of children and adolescents, making gamification an ideal avenue to incorporate various visually stimulating features. By creating a vibrant virtual world replete with colorful imagery, captivating stories, and charming characters, gamification provides the necessary motivation for patients with diabetes to use the app regularly. Through this engaging approach, the primary objective of helping patients manage their condition can be achieved in a lighthearted and enjoyable manner, particularly appealing to the younger demographic.

The third step involved identifying the core objectives that underlie the development of a new technology. Upon careful review of the literature, it became evident that SMBG values emerged as the primary purpose, cited 20 times. Following closely, the secondary objective was to improve HbA_{1c} levels, as mentioned 12 times. Finally, the objective of improving overall quality of life and increasing adolescents and children's knowledge about diabetes was highlighted 9 times. Among other goals, the frequency of SMBG highlights how crucial it is to build new technologies with the primary goal of helping patients monitor their blood glucose levels effectively. It is imperative to give priority to features that optimize blood glucose monitoring since they help patients reduce the risk of hypoglycemia and other related problems, improving their overall health.

The final step in technology design involves careful consideration of its features. Upon review, it became evident that patient education ranked highest with 23 mentions, followed closely by carbohydrate counting with 22 mentions and blood glucose tracking with 21 mentions. This underscores the importance of incorporating these key features into the design of a technology. It is clear that for children and adolescents, independent learning can be challenging, emphasizing the necessity of providing intuitive icons to support patients and caregivers in managing diabetes effectively. In addition, accurate carbohydrate counting is paramount, as any miscalculation can lead to incorrect insulin dosing, posing significant risks to the patient's well-being.

Based on our findings, we recommend that developers prioritize the creation of an mHealth app using a gamification methodology to design new diabetes management technologies. This approach should encompass essential characteristics such as blood glucose management, suggestions for improving HbA_{1c}, carbohydrate counting, and comprehensive educational resources for both patients and caregivers. By emphasizing these aspects, developers can ensure the effectiveness and user-friendliness of the technology, ultimately enhancing its use in supporting children or adolescents with diabetes in their daily management routines.

Limitations

The primary challenges encountered during this review stemmed from variations in the number of articles reviewed compared with the technologies identified. For instance, each group of papers (eg, [4,11], [7,12], [6,38], [21,30], and [13,15,20]) referenced a unique single app. In addition, article [8] mentioned 5 distinct apps; article [17] cited 2 separate apps; and article [37] included 3 apps, which add further complexity to the analysis. These differences make reviewing and analyzing the results more difficult and time-consuming.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Explanation of all information technologies and their features.
[DOCX File, 36 KB - pediatrics_v7i1e50370_app1.docx]

Multimedia Appendix 2
Explanation of stakholeders' questions.
[DOCX File, 18 KB - pediatrics_v7i1e50370_app2.docx]

Checklist 1
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist.
[DOCX File, 31 KB - pediatrics_v7i1e50370_app3.docx]

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Abbreviations

CanDIT: Canadian Diabetes Incentives and Technology
HbA_{1c}: hemoglobin A_{1c}
HCP: health care professional
mDAD: Mobile Diabetes Advice for Dads
mHealth: mobile health
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SMBG: self-monitoring of blood glucose
T1D: type 1 diabetes
UCD: user-centered design
YWD: Young with Diabetes

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Review

Internet-Based Interventions for Preventing Premature Birth Among Pregnant Women: Systematic Review

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Abstract

Background: Premature birth rates have slightly increased globally, making its prevention critical for both short-term and long-term health outcomes. Various interventions have been developed in response to the multifaceted risk factors for premature birth, including internet-based programs. These programs offer accessibility and enhanced engagement; however, their overall efficacy in preventing premature births requires thorough evaluation.

Objective: This systematic review aims to identify the study designs and assess the effectiveness of internet-based interventions in preventing premature birth among pregnant women.

Methods: A comprehensive search of the MEDLINE, Embase, CINAHL, and Cochrane Library databases was conducted to identify randomized trials and quasi-experimental studies evaluating internet-based interventions for premature birth prevention in pregnant women. The search was inclusive, with no restrictions based on language or geographical location, allowing for a comprehensive global perspective. The time frame for the inclusion of studies extended until February 2023. The risk of bias (RoB) in each study was independently assessed by 3 authors forming pairs, using the revised Cochrane RoB tool (RoB 2) for randomized trials, as per the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines. Owing to heterogeneity in populations, measurements, and interventions, a meta-analysis was not conducted.

Results: This review included 26 articles, comprising 12 intention-to-treat and 14 per-protocol studies. The overall RoB was high in most intention-to-treat studies and of some concern in most per-protocol studies. The target populations varied, including nonspecific pregnant women, those with gestational diabetes mellitus (GDM) or those at risk of GDM, individuals with anxiety or depression, and those experiencing preterm labor. Psychosocial, physiological, and wellness health outcomes were evaluated. Internet-based interventions effectively reduced stress/distress in nonspecific pregnant women but not in those experiencing preterm labor. Their effectiveness in reducing anxiety and depression varied, with inconsistent results among different groups. In women with GDM or those at risk of GDM, interventions successfully controlled fasting plasma glucose and 2-hour postprandial plasma glucose levels but did not consistently manage glycated hemoglobin levels. These interventions did not reduce the incidence of premature births across the various populations studied. The effectiveness of these internet-based interventions in addressing substance or alcohol abuse and insomnia also varied.

Conclusions: Internet-based interventions show promise in improving psychosocial health and managing blood sugar to prevent premature birth, highlighting variability in effectiveness across different risk factors. Further research, including clinical trials, is vital for developing, evaluating, and disseminating effective, safe internet-based interventions. Establishing standardized measurement tools and rigorous evaluation processes is crucial for enhancing these interventions' effectiveness and reliability in clinical practice, significantly contributing to preventing premature births and improving maternal health outcomes.

Trial Registration: PROSPERO CRD42021278847; https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021278847

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KEYWORDS

anxiety; body weight; depression; gestational diabetes mellitus; high-risk behavior; internet-based interventions; neonatal outcomes; pregnancy; premature birth; pregnancy outcomes; stress; systematic review

Introduction

Background

The estimated global premature birth rate per 100 live births increased slightly from 9.8% (13.8 million premature births) in 2010 to 9.9% (13.4 million premature births) in 2020 [1]. This indicates an average annual increase rate in premature birth prevalence of 0.14% [1]. Complications of premature birth are the leading cause of childhood mortality, which refers to the probability of dying between birth and exactly 5 years of age, expressed per 1000 live births. This encompasses 35% of neonatal deaths and 18% of deaths in children aged <5 years [2]. Compared with their term-born peers, premature babies are more likely to develop respiratory distress syndrome, sleep apnea, necrotizing enterocolitis, and intraventricular hemorrhage in the neonatal period [3] and have worse cognitive, language, and motor development and social-emotional competence as children aged <5 years [4,5]. In addition, young adults born preterm are more susceptible to psychological fragility (in terms of anxiety and insecurity) and tend to exhibit lower cognitive ability [6]. Therefore, reducing the incidence of premature births is of utmost importance for the short- and long-term health and development of children.

Sociodemographic, nutritional, medical, obstetric, and environmental factors can increase the risk of premature birth. Consequently, interventions have been developed to prevent or mitigate known modifiable risk factors for premature birth [7]. Primary and secondary prevention encompasses a wide range of interventions, including medication, surgical procedures, cervical devices, targeted diets, physical exercise, smoking cessation programs, nutritional supplementation, education, and various special tests or investigations [7,8]. For women to participate in preventive activities for primary health promotion; secondary activities; and tertiary activities, including lifestyle modification, health screening uptake, treatment compliance, and participation in rehabilitation programs, understanding and continuous motivation are required. Recently, internet-based interventions have been developed to provide health-related information to individuals who may not have direct access to medical facilities [9], offering accessibility and availability regardless of time and location [10]. In addition, internet-based interventions can enhance engagement with self-monitoring, promote health-related understanding, and increase knowledge and risk perception of disease as well as bolster self-efficacy in disease management [11].

Previous systematic reviews have thoroughly examined interventions aimed at preventing premature birth, evaluating the overall evidence for such interventions [7,8,12,13]. These reviews covered a range of specific interventions, including infection treatment [14], pharmacological methods [15-17], nutrient supplementation [18], cerclage [19], cervical devices [20], and social support [21]. However, to date, only 2 systematic reviews have explored internet-based interventions in this context, confirming the effectiveness of technology-supported lifestyle interventions [22] and telemedicine [23] specifically for pregnant women with gestational diabetes mellitus (GDM). Although the effectiveness of internet-based interventions for smoking cessation among pregnant women [24] and prenatal interventions for maternal health [25] has been established, their effectiveness in preventing premature birth remains unconfirmed.

Objectives

To address this gap, we conducted a systematic review of randomized controlled trials (RCTs) and quasi-experimental studies focusing on internet-based interventions for premature birth prevention. The objectives of this review were three-fold: (1) to describe the general characteristics of the studies included, (2) to identify the study designs of internet-based interventions pertinent to premature birth prevention, and (3) to evaluate the effectiveness of internet-based interventions in achieving outcomes related to premature birth prevention among the target population.

Methods

Design

This systematic review was conducted in accordance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines [26] and registered in PROSPERO (CRD42021278847). Our review focused on 2 specific research questions formulated using the Population, Intervention, Comparison, and Outcome strategy: (1) What is the efficacy of internet-based interventions in reducing the risk of premature birth among pregnant women compared to standard prenatal care? (2) How do internet-based interventions impact maternal health outcomes, such as stress, anxiety, and gestational diabetes, in pregnant women at risk of premature birth? These questions aimed to evaluate the effectiveness of internet-based interventions in both reducing premature births and improving crucial maternal health outcomes. Our systematic search targeted several electronic databases, including MEDLINE, Embase, CINAHL, and the Cochrane Library, focusing on studies published up to February 2023. To augment our database search, we manually reviewed the reference lists of the included publications.

Eligibility Criteria

Our inclusion criteria encompassed published RCTs, quasi-experimental studies, and experimental studies on the prevention of premature birth. We imposed no restrictions regarding the country or language of publication. The target population included all pregnant women, including those with normal or high-risk pregnancies, pregnancy complications, or at risk of premature birth. The interventions were internet-based and used various devices, such as computers and mobile phones. We excluded cross-sectional, case-control, retrospective, and prospective cohort studies; noncomparator experimental studies; animal experiments; reviews; qualitative studies; case reports; unpublished data; and gray literature, such as conference abstracts, letters, editorials, dissertations, and unavailable full texts. Studies targeting prepregnant women, women in the postpartum period, women outside childbearing age, and men were also excluded.

Search Strategy

Adapted search terms for each database included a combination of terms related to population (eg, “women”), pregnancy (eg, “premature birth” and “pregnancy”), information and communication technology (eg, “computer”), treatment (eg, “internet” and “online”), and study design (eg, “randomized controlled trial”). These terms were used to search titles, abstracts, keywords, or text words. The exact search terms are detailed in Multimedia Appendix 1.

Selection and Data Collection Processes

All identified studies were first imported into a reference manager for deduplication. The titles and abstracts were then independently screened by 2 of the 3 reviewers, working in rotating pairs (ie, A and B, B and C, and A and C). Following this initial screening, relevant studies underwent a full-text review. Disagreements at this stage were resolved through discussion or consultation with the third reviewer, ensuring a consensus on the inclusion of studies. Any studies found to be irrelevant after full-text review were excluded from further consideration. Simultaneously, a data extraction form was collaboratively developed and pretested by the reviewers to systematically collect review characteristics and outcome data from the selected studies. This process of data extraction was also conducted independently by 2 pairs of reviewers. In cases of discrepancies in the extracted data, the reviewers engaged in discussions to reach a consensus or consulted the third reviewer for an objective resolution.

Data Extraction

The extracted data included study characteristics (eg, authors, year, country of origin, research design, and sample size), study results (primary and secondary findings for outcome measures, including effect sizes), and intervention details (eg, name, method, timing, duration, and group type). Because of the variation in methodologies across studies, conducting a meta-analysis was considered unsuitable. Instead, information was synthesized narratively, categorizing outcomes into psychosocial, physiological, and wellness health outcomes. Effect sizes were calculated using means and SDs or frequencies and percentages depending on the study design.

RoB Assessment

Two pairs of reviewers independently assessed the methodological quality using the revised Cochrane RoB tool for randomized trials [27]. This tool evaluates 5 domains: randomization process, deviation from intended interventions, missing outcome data, outcome measurement, and reported result selection grouped into 3 levels of RoB (low risk, some concern, and high risk). Studies were categorized into 2 groups: intention-to-treat (ITT) and per-protocol (PP), with disagreements resolved through discussion or consultation with a third person.

Statistical Analysis

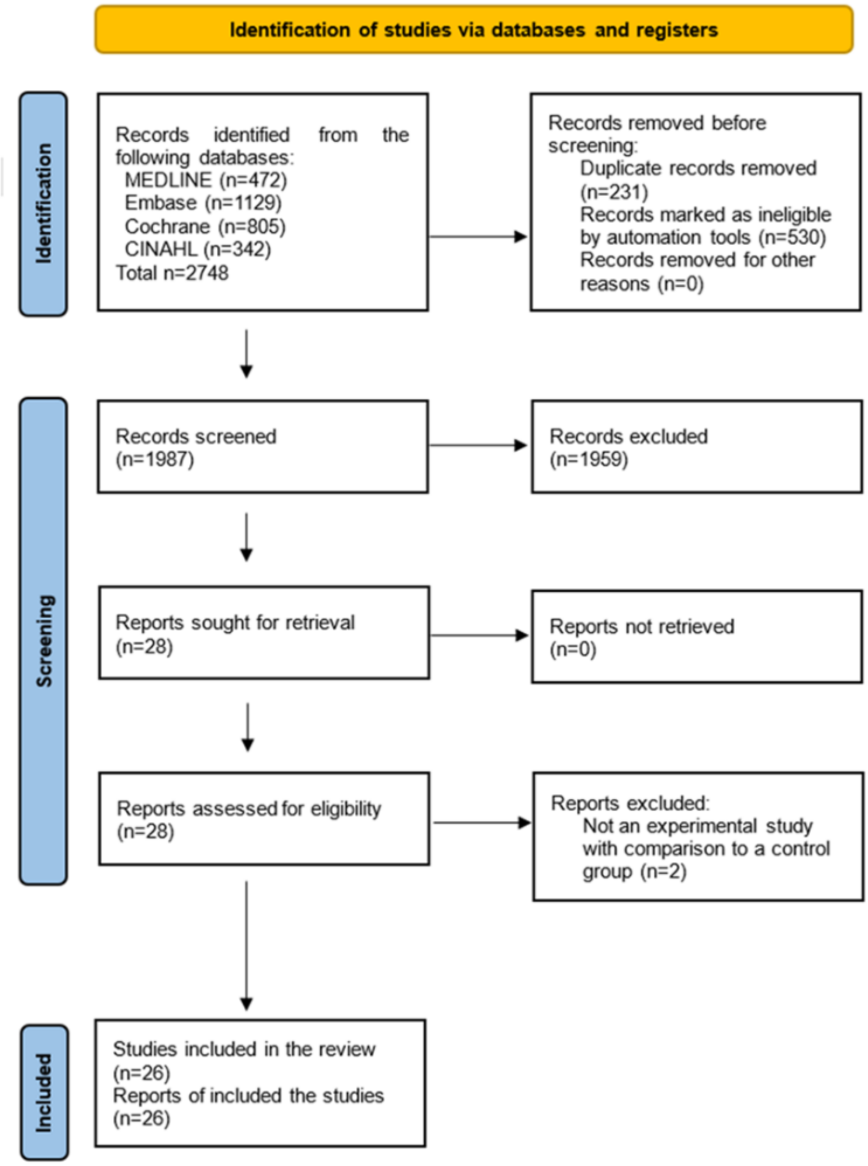
Owing to the heterogeneity in interventions and participant characteristics, we opted for a narrative synthesis instead of a meta-analysis. When available, effect sizes were calculated using data from the studies, using various metrics such as Cohen *d*, Cohen *f*, Morris *d*, Hedges *g*, Cohen *h*, odds ratio (*P* value and 95% CI), and relative risk (95% CI and *P* value) [28]. Of the 26 papers reviewed, 5 (19%) lacked sufficient statistical data to calculate the effect size of the intervention. We reached out to the authors of these papers for additional information. However, responses were not received for several of these inquiries, limiting our ability to calculate effect sizes for all studies. Consequently, effect sizes were calculated for 21 articles. In instances where additional data from the original authors were not obtained, our evaluations were based on the information available in the study. In cases where studies presented results solely in graphical form, we calculated effect sizes where possible, specifically if the graph provided measurable mean and SD. However, for graphics lacking detailed data, such as missing SDs, effect size calculation was not feasible.

Results

Overview

Initially, a total of 2748 articles were retrieved from the 4 databases. After excluding 761 duplicate articles, 1987 remained. During the initial screening stage, 1959 papers were excluded after reviewing the study title and abstract. The full texts of the remaining 28 studies were reviewed, and 2 studies that were not controlled comparative experimental studies—they were 1-group pre- and postintervention comparison studies—were excluded. Finally, 26 studies were selected for the systematic review. Figure 1 illustrates the study selection process.

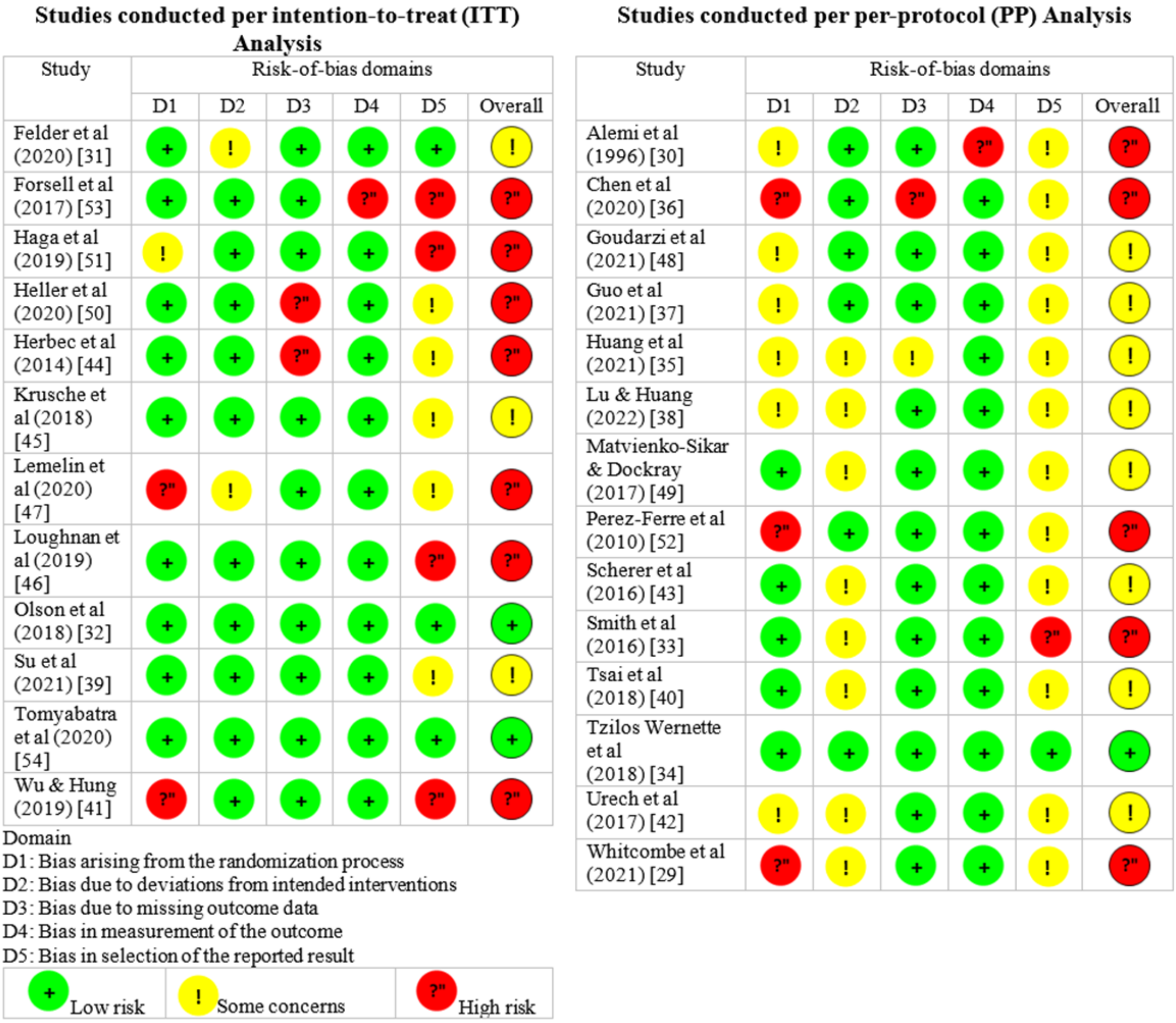
Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram showing the selection of included studies.



Quality of the Studies and RoB Assessment

In the subset of studies that used ITT analysis, the overall RoB was categorized as low for 17% (2/12) of the studies, exhibiting some concerns in 25% (3/12) of the studies, and high in 58% (7/12) of the studies. Among the studies using PP analysis, only 7% (1/14) of the studies were assessed as having a low RoB, whereas 57% (8/14) of the studies had some concerns, and 36% (5/14) of the studies were deemed to have a high risk. The detailed outcomes of the RoB assessment for the 12 ITT and 14 PP studies are shown in Figure 2.

Figure 2. Risk-of-bias (RoB) assessment using the revised Cochrane RoB tool for randomized trials [29-54].



Studies conducted per intention-to-treat (ITT) Analysis

Study	Risk-of-bias domains					
	D1	D2	D3	D4	D5	Overall
Felder et al (2020) [31]	+	!	+	+	+	!
Forsell et al (2017) [53]	+	+	+	?"	?"	?"
Haga et al (2019) [51]	!	+	+	+	?"	?"
Heller et al (2020) [50]	+	+	?"	+	!	?"
Herbec et al (2014) [44]	+	+	?"	+	!	?"
Krusche et al (2018) [45]	+	+	+	+	!	!
Lemelin et al (2020) [47]	?"	!	+	+	!	?"
Loughnan et al (2019) [46]	+	+	+	+	?"	?"
Olson et al (2018) [32]	+	+	+	+	+	+
Su et al (2021) [39]	+	+	+	+	!	!
Tomyabatra et al (2020) [54]	+	+	+	+	+	+
Wu & Hung (2019) [41]	?"	+	+	+	?"	?"

Domain
D1: Bias arising from the randomization process
D2: Bias due to deviations from intended interventions
D3: Bias due to missing outcome data
D4: Bias in measurement of the outcome
D5: Bias in selection of the reported result

+ Low risk	! Some concerns	?" High risk

Studies conducted per per-protocol (PP) Analysis

Study	Risk-of-bias domains					
	D1	D2	D3	D4	D5	Overall
Alemi et al (1996) [30]	!	+	+	?"	!	?"
Chen et al (2020) [36]	?"	+	?"	+	!	?"
Goudarzi et al (2021) [48]	!	+	+	+	!	!
Guo et al (2021) [37]	!	+	+	+	!	!
Huang et al (2021) [35]	!	!	!	+	!	!
Lu & Huang (2022) [38]	!	!	+	+	!	!
Matvienko-Sikar & Dockray (2017) [49]	+	!	+	+	!	!
Perez-Ferre et al (2010) [52]	?"	+	+	+	!	?"
Scherer et al (2016) [43]	+	!	+	+	!	!
Smith et al (2016) [33]	+	!	+	+	?"	?"
Tsai et al (2018) [40]	+	!	+	+	!	!
Tzilos Wernette et al (2018) [34]	+	+	+	+	+	+
Urech et al (2017) [42]	!	!	+	+	!	!
Whitcombe et al (2021) [29]	?"	!	+	+	!	?"

Study Characteristics

The 26 studies included in this review were conducted across various countries, with the largest number from the United States (6/26, 23% studies [29-34]), followed by China (4/26, 15% studies [35-38]), Taiwan (3/26, 11% studies [39-41]), Switzerland (2/26, 8% studies [42,43]), and the United Kingdom (2/26, 8% studies [44,45]). In addition, 1 study each was conducted in Australia [46], Canada [47], Iran [48], Ireland [49], the Netherlands [50], Norway [51], Spain [52], Sweden [53], and Thailand [54]. The publication years spanned from 1996 to 2022, with most studies (14/26, 54%) [32-34,40-46,49,51-53] published between 2010 and 2019, 42% (11/26) of the studies [29,31,35-39,47,48,50,54] published from 2020 to the time of the review, and 4% (1/26) of the studies [30] published before 2000. Among these, one study was published in Chinese [35] and another in Persian [48], with the remaining studies all written in English.

With regard to research design, 81% (21/26) of the studies used a randomized controlled experimental design [30-39,42-46,49-54], whereas 19% (5/26) of the studies used a quasi-experimental design [29,40,41,47,48]. The focus of these studies varied, with 8% (2/26) of the studies targeting pregnant women diagnosed with anxiety or depression [46,53], 27% (7/26) focusing on pregnant women with GDM or at risk of GDM [29,35,37-39,47,52], and 8% (2/26) involving women experiencing preterm labor [42,43]. Of the 26 studies, 1 (4%) was dedicated to pregnant smokers [44], 2 (8%) were dedicated to pregnant women using drugs or alcohol [30,34], and 1 (4%) was dedicated to those experiencing insomnia [31]. The remaining 42% (11/26) of the studies targeted nonspecific pregnant populations [32,33,36,40,41,45,48-51,54]. Detailed information on these studies is provided in Tables 1 and 2.

Table 1. Overview of the general characteristics of the studies (N=26).

Characteristics and category	Values, n (%)
Country	
Australia [46]	1 (4)
Canada [47]	1 (4)
China [31,37-39]	4 (15)
Iran [48]	1 (4)
Ireland [49]	1 (4)
Netherlands [50]	1 (4)
Norway [51]	1 (4)
Spain [52]	1 (4)
Sweden [53]	1 (4)
Switzerland [29,43]	2 (8)
Taiwan [40-42]	3 (11)
Thailand [54]	1 (4)
United Kingdom [44,45]	2 (8)
United States [30,32-36]	6 (23)
Publication year	
<2000 [32]	1 (4)
2000 to <2010	0 (0)
2010 to <2020 [29,34-36,41-46,49,51-53]	14 (54)
>2020 [30,31,33,37-40,47,48,50,54]	11 (42)
Publication language	
Chinese [35]	1 (4)
Persian [48]	1 (4)
English [29-34,36-47,49-54]	24 (92)
Research design	
RCT[a] [29,31-40,43-46,49-54]	21 (81)
Quasiexperimental trial [30,41,42,47,48]	5 (19)
Participants' characteristics	
Anxiety or depression [46,53]	2 (8)
GDM[b] or at risk of GDM [30,31,38-40,47,52]	7 (27)
Preterm labor [29,43]	2 (8)
Smoking [44]	1 (4)
Drug or alcohol use [32,36]	2 (8)
Insomnia [33]	1 (4)
Nonspecific [34,35,37,41,42,45,48-51,54]	11 (42)
Intervention type	
Website [29,30,34,35,41,43-47,49-51,53]	14 (54)
Computerizing intervention authoring system [36]	1 (4)
Website or mobile app [33]	1 (4)
Social network service [42]	1 (4)
Offline and instant messenger [38]	1 (4)

Characteristics and category	Values, n (%)
IoT[c] and instant messenger [39]	1 (4)
Only instant messenger [31,37,40,48,54]	5 (19)
Telemedicine system and SMS text messaging [52]	1 (4)
Electronic voice bulletin board by mobile [32]	1 (4)
Intervention delivery method	
Individual [29,30,33-36,38-41,43-47,49-53]	20 (77)
Group [31,32,37,42,48,54]	6 (23)
Intervention timing of pregnancy period	
≤First trimester	0 (0)
≤Second trimester [49]	1 (4)
≤Third trimester [29-39,41-48,50,52-54]	23 (89)
≤Post partum [40,51]	2 (8)
Intervention duration[d]	
Approximately 1 to 4 weeks [36,45,46,49]	4 (15)
Approximately 4 weeks and 1 day to 8 weeks [29,33,43,44,48,50]	6 (23)
Approximately 8 weeks and 1 day to 12 weeks [39,51,53]	3 (11)
Approximately 12 weeks and 1 day to 16 weeks [32]	1 (4)
Approximately 16 weeks and 1 day to 20 weeks [31,47,52]	3 (11)
Approximately 20 weeks and 1 day to 24 weeks [40,41]	2 (8)
Approximately 24 weeks and 1day to 28 weeks [35,38,42]	3 (11)
Approximately 28 weeks and 1 day to 32 weeks [34]	1 (4)
Approximately 32 weeks and 1 day to 36 weeks [54]	1 (4)
Not reported [30,37]	2 (8)
Comparator	
Usual antenatal care [31,39,40,42,51]	5 (19)
Usual antenatal health education [37,41,54]	3 (11)
Usual treatment [33,46,49]	3 (11)
Watching brief segments of popular television shows with subsequent questions [36]	1 (4)
One-page static, nonpersonalized website that provided brief standard advice [44]	1 (4)
None [29,30,32,34,35,38,43,45,47,50,52,53]	12 (46)
Not reported [48]	1 (4)

[a] RCT: randomized controlled trial.

[b] GDM: gestational diabetes mellitus.

[c] IoT: Internet of Things.

[d] Categorized based on maximum duration.

Table 2. Summary of the study designs for internet-based interventions in pregnant women (N=26).

Study, year; country	Study design (analysis sets)	Participants (intervention n/control n)	Experimental intervention	Intervention method and group type (I[a] or G[b])	Intervention timing and duration	Comparative intervention
Alemi et al [30], 1996; United States	2-armed RCT[c] (PP[d])	Pregnant drug-using participants from the previous study (28/25)	Talknet: a voice bulletin board for electronic self-help and group support	Communication via electronic bulletin boards: touch tone telephone (G)	Third trimester, intrapartum and 4 months	None
Chen et al [36], 2020; China	2-armed RCT (PP)	Pregnant women (83/85)	Health education on enhancing the compliance	Instant messenger by mobile phone	First, second, and third trimester and NR[e] (≥3 web-based courses)	Usual antenatal health education
Felder et al [31], 2020; United States	2-armed RCT (ITT[f])	<28 weeks' gestation with insomnia (105/103)	Sleepio (Big Health), digital cognitive behavioral therapy for insomnia	Website or mobile app (I)	First, second, and early third trimester (≤GA[g] 32 wks) and 6 wks	Usual treatment
Forsell et al [53], 2017; Sweden	2-armed RCT (PP)	10-28 weeks' gestation with depression (22/20)	ICBT[h] for antenatal depression	Website (I)	Late first, second, and third trimester and 10 wks	None
Goudarzi et al [48], 2021; Iran	2-armed quasi-experimental trial (PP)	<24 weeks' gestation (12/13)	Web-based unified transdiagnostic treatment on mental health problems	Instant messenger by mobile phone (G)	First, second, and early third trimester and 8 wks	NR
Guo et al [37], 2021; China	2-armed RCT (PP)	24-28 weeks' gestation; first-diagnosed GDM[i] (70/70)	Online-offline integrated medical care management	Offline and instant messenger by mobile phone (I)	Late second and third trimester and approximately 24-28 wks	None
Haga et al [51], 2019; Norway	2-armed RCT (ITT)	21-25 weeks' gestation (678/664)	Mamma Mia: a universal preventive intervention for perinatal depressive symptoms	Website (I)	Second and third trimester as well as post partum and 11.5 mo	Usual perinatal care
Heller et al [50], 2020; The Netherlands	2-armed RCT (ITT and PP)	<30 weeks' gestation (79/80)	MamaKits Online (internet-based problem-solving treatment) of depression and anxiety in pregnancy	Website (I)	First, second, and third trimester and 5 wks	None
Herbec et al [44], 2014; United Kingdom	2-armed RCT (ITT)	Pregnant smoking women (99/101)	MumsQuit: internet-based smoking cessation	Internet-based, access face-to-face, or telephone support (I)	First, second, and third trimester and 4 wks of prequit date support and up to 4 weeks of postquit date support (8 weeks)	One-page static, nonpersonalized website that provided brief standard advice
Huang et al [35], 2021; China	2-armed RCT (PP)	Pregnant women with GDM (144/151)	Mobile health management on GDM	Instant messenger by mobile phone (G)	Late second and third trimester and approximately 12-20 wks	Usual prenatal care
Krusche et al [45], 2018; United Kingdom	2-armed RCT (ITT)	12-34 weeks' gestation (107/78)	Be Mindful online	Website (I)	Late first, second, and third trimester and 4 wks	None
Lemelin et al [47], 2020; Canada	2-armed quasi-experimental trial (ITT)	21-30 weeks' gestation with newly diagnosed GDM (80/81)	Telehomecare (THCa) program for GDM management	Website (I)	Late second and third trimester and approximately 10-20 wks (until delivery)	None
Loughnan et al [46], 2019; Australia	2-armed RCT (ITT)	13-30 weeks' gestation with anxiety or depression (18/33)	MUMentum (unguided ICBT) for antenatal anxiety and depression	Website (I)	Second and third trimester and 4 wks	Usual treatment

Study, year; country	Study design (analysis sets)	Participants (intervention n/control n)	Experimental intervention	Intervention method and group type (I[a] or G[b])	Intervention timing and duration	Comparative intervention
Lu and Huang [38], 2022; China	2-armed RCT (PP)	Pregnant women with GDM (44/44)	Fetal monitoring using Internet of Things and GDM educational information	Instant messenger by mobile phone (I)	Late second and third trimester and 3 mo	Usual prenatal care
Matvienko-Sikar and Dockray [49], 2017; Ireland	3-armed RCT; 2-armed RCT for analysis (PP)	10-22 weeks' gestation (24/12)	Online mindfulness and gratitude intervention (body scan and reflection intervention)	Websites (I)	Second trimester and 3 wks	Usual treatment
Olson et al [32], 2018; United States	2-armed RCT (ITT and PP)	≤20 weeks' gestation (1126/563)	e-Mom, m-Mom: self-help, integrated mobile phone and web-based behavior change intervention in preventing excessive gestational weight gain	Website (I)	Late first, second, and third trimester and 28-30 wks	None
Perez-Ferre et al [52], 2010; Spain	2-armed RCT (PP)	24-28 weeks' gestation with GDM (49/48)	Telemedicine system	Telemedicine system based on internet and SMS text messaging (I)	Late second and third trimester and approximately 16-18 wks	None
Scherer et al [43], 2016; Switzerland	2-armed RCT (PP)	18-32 weeks' gestation with preterm labor (31/27)	Internet-based cognitive behavioral stress management	Website (I)	Late second and third trimester an 6 wks	None
Smith et al [33], 2016; United States	2-armed RCT (PP)	10-14 weeks' gestation (24/21)	Web-based behavioral intervention preventing excessive gestational weight gain	Website (I)	Late first, second, and third trimester, (3 weeks during GA approximately 10-36 wks) and approximately 20-26 wks	None
Su et al [39], 2021; Taiwan	2-armed RCT (ITT)	Pregnant women with GDM risk factors (56/56)	Web-based health management in preventing women at high risk of GDM from developing metabolic syndrome	Website, instant messenger by mobile phone (I)	Late second and third trimester as well as approximately 6-12 wks post partum and 6 mo	Usual prenatal care
Tomyabatra [54], 2020; Thailand	2-armed RCT (ITT)	Pregnant women (602/558)	Antenatal health education using audio-video social network about severe obstetric symptoms	Instant messenger: LINE app by mobile phone (G)	First, second, and third trimester and approximately 30-36 wks	Usual antenatal health education
Tsai et al [40], 2018; Taiwan	2-armed quasi-experimental trial (PP)	16-24 weeks' gestation (68/67)	Web-based antenatal care system and routine antenatal education	Website (I)	Second and third trimester and approximately 12-22 wks	Usual antenatal health education
Tzilos Wernette et al [34], 2018; United States	2-armed RCT (PP)	Unplanned pregnant women, condomless sex, and alcohol or drug use or at risk for prenatal alcohol/drug use (31/19)	Health Checkup for Expectant Moms of substance use and risky sex	Computerizing intervention authoring system (I)	First, second and third trimester and approximately 75 min	Watching brief segments of popular television shows with subsequent questions
Urech et al [42], 2017; Switzerland	2-armed RCT (PP)	18-32 weeks' gestation diagnosed preterm labor (50/43)	Internet-based cognitive behavioral stress management	Website (I)	Late second and third trimester and 6 wks	None
Whitcombe et al [29], 2021; United States	3-armed quasi-experimental trial (ITT)	21-30 weeks' gestation with newly diagnosed GDM (21/45/37)	Web-Based Instruction on Nutrition	Website (I)	Late second and third trimester and NR	None

Study, year; country	Study design (analysis sets)	Participants (intervention n/control n)	Experimental intervention	Intervention method and group type (I[a] or G[b])	Intervention timing and duration	Comparative intervention
Wu and Hung [41], 2019; Taiwan	2-armed quasi-experimental trial (ITT)	<12 week's gestation (66/55)	The Expectant Mother Club: Virtual Community	Closed social network community: closed community (G)	First, second, and third trimester and at least 24-26 wks	Usual prenatal care

[a] I: individual.

[b] G: group.

[c] RCT: randomized controlled trial.

[d] PP: per-protocol.

[e] NR: not reported.

[f] ITT: intention-to-treat.

[g] GA: gestational age.

[h] ICBT: internet-delivered cognitive behavioral therapy.

[i] GDM: gestational diabetes mellitus.

Intervention Characteristics

Targeted Health Issue

As shown in Table 2, the interventions in the reviewed studies varied widely. Of the 26 studies, 10 (38%) focused on mental health treatment: 2 (20%) studies focused on web-based mindfulness [45,49], 7 (70%) studies focused on various psychological treatments [42,43,46,48,50,51,53], and 1 (10%) study focused on insomnia [31]. Furthermore, 19% (5/26) of the studies examined antenatal care interventions: 1 (20%) for nonspecific pregnant women [40] and 4 (80%) for those with GDM [35,37,47,52]. Education was the focus of 11% (3/26) of the studies, with 1 (33%) study focusing on diabetes diet education [29] and 2 (33%) studies focusing on general pregnancy health education [36,54]. Five studies targeted health behavior interventions, including diabetes dietary intake and exercise management [38,39], prenatal weight management behavior [32,33], and health care for substance abuse and risky sexual behavior [34]. Three studies explored self-help groups, including a web-based community for nonspecific pregnant women [41], a group for pregnant women with substance abuse [30], and a support group for smoking cessation [44].

Intervention Method and Group Type

Overall, 54% (14/26) of the studies used websites for intervention delivery [29,32,33,40,42-47,49-51,53], whereas 19% (5/26) of the studies used instant messaging only [35,36,38,39,48,54]. Various other methods were used in individual studies, such as computerizing intervention authoring systems [34], a mix of websites or mobile apps [31], social network services [41], offline and instant messengers [37], Internet of Things and instant messengers [38], telemedicine systems and SMS text messaging [52], and electronic voice bulletin boards using mobile devices [30]. Six studies targeted groups [30,35,36,41,48,54], and the remaining 20 studies focused on individual interventions.

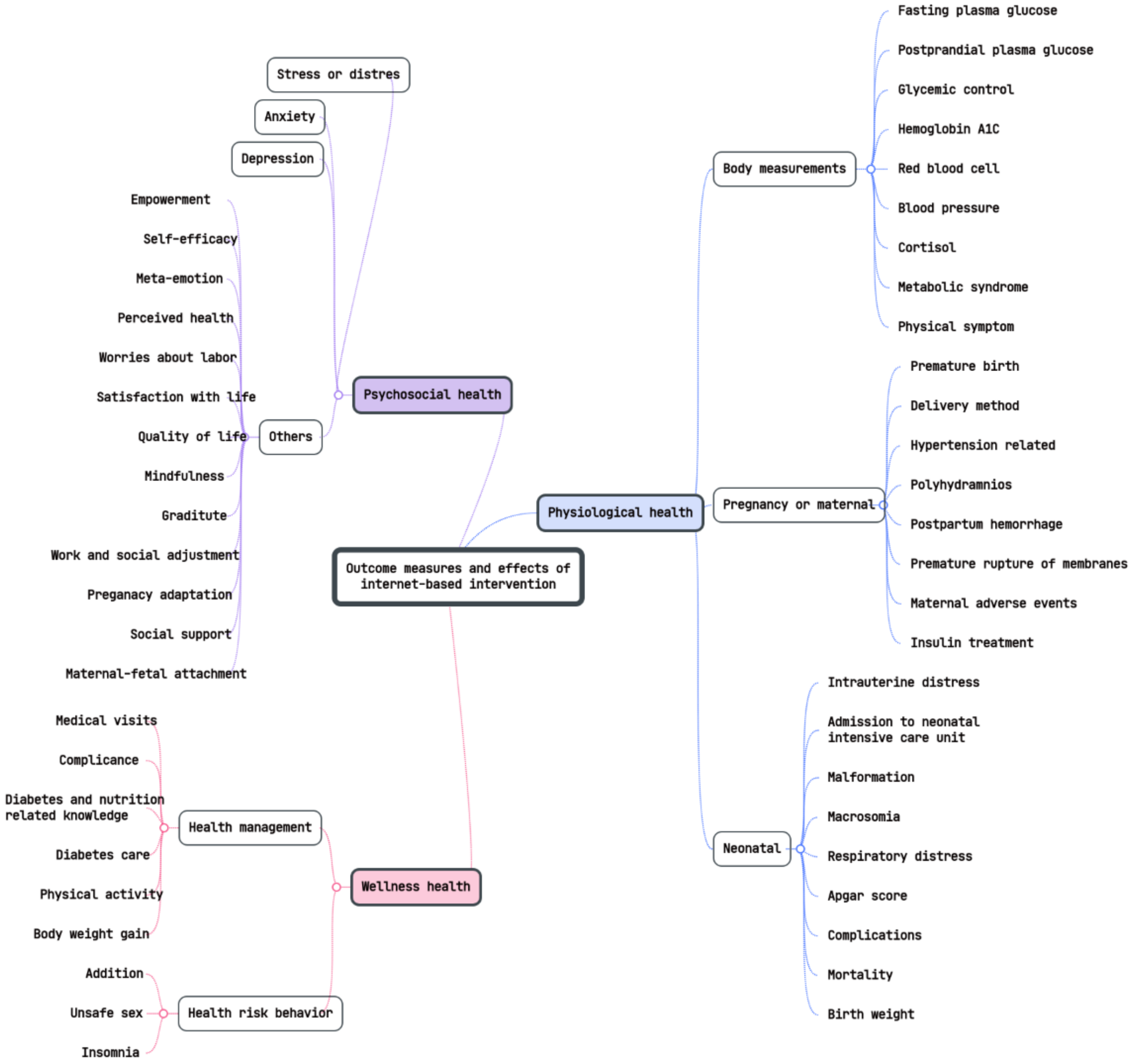
Intervention Timing, Duration, and Comparative Approaches

The timing and duration of the interventions varied across studies. Although no interventions were exclusively conducted during the first trimester, 4% (1/26) of the studies covered the first and second trimesters [49], 88% (23/26) of the studies spanned all trimesters [29-38,40-48,50,52-54], and 8% (2/26) of the studies extended into the postpartum period [39,51]. The duration ranged from ≤4 weeks in 15% (4/26) of the studies [34,45,46,49] to >32 weeks in 4% (1/26) of the studies [54], with 8% (2/26) of the studies not specifying the period [29,36]. With regard to comparative interventions, 50% (13/26) of the studies provided standard care or education to the control groups, such as usual antenatal care [35,38,39,41,51], health education [36,40,54], or typical treatments [31,46,49]. Unique approaches included watching brief television segments with questions [34] and accessing a basic, nonpersonalized website [44]. Of the 13 studies, 12 (92%) did not provide any intervention to control groups [29,30,32,33,37,42,43,45,47,50,52,53] and 1 (8%) did not report the intervention in the control group [48]. This variety in intervention timing, duration, and comparative approaches underscores the diversity in study methodologies and target populations (Table 2).

Outcomes and Effects of Interventions

The outcomes of the interventions, as detailed in Multimedia Appendix 2 [29-54], were divided into 3 main categories: psychosocial, physiological, and wellness health outcomes. Each category encompasses several subcategories, as shown in Figure 3.

Figure 3. Mind map of the outcomes and health impacts of internet-based interventions. BP: blood pressure; NICU: neonatal intensive care unit; RBC: red blood cell.



Psychosocial Health Outcomes

Within this domain, a total of 16 distinct outcomes were identified. These psychosocial health outcomes encompassed a range of factors, including stress or distress, anxiety, and depression, along with a variety of other elements related to mental, emotional, and social well-being.

Stress or Distress

Seven studies assessed stress or distress, with 4 (57%) targeting nonspecific pregnant women [40,45,48,49], 1 (14%) focusing on women with anxiety or depression [46], and 2 (29%) on those with preterm labor [42,43]. Stress or distress was the primary outcome in 6 (86%) of these 7 studies [40,42,43,45,48,49]. Among the 7 studies, 2 (28%) specifically addressed populations with stress issues [42,43], whereas 2 (28%) other studies involved nonspecific pregnant women without preexisting stress issues [45,49]. Significant reductions in stress or distress were observed in the intervention groups of the studies involving nonspecific pregnant women [40,45,48,49]. In a study targeting women with anxiety or depression, a significant reduction in distress was noted 1 week after the intervention, but this effect was not sustained at the 4-week mark [46]. Conversely, interventions in studies involving women with preterm labor did not yield significant effects [42,43].

Anxiety

Of the 9 studies examining anxiety, significant reductions were observed under certain conditions. One study targeting women with GDM reported immediate reductions in anxiety after the intervention [37]. Another study, focusing on individuals with anxiety or depression, noted a significant reduction in anxiety 9 weeks after the intervention [46], and a study targeting those with insomnia observed significant reductions after 10 and 18 weeks [31]. However, no significant changes in anxiety levels were observed in 4 studies involving nonspecific pregnant women [45,48,50,53] or in 2 studies involving women experiencing preterm labor [42,43]. Notably, anxiety was the primary outcome in only 1 of these studies [46].

Depression

In the 10 studies addressing depression, 3 (30%) reported significant reductions: 1 involving nonspecific pregnant women [45], 1 involving women diagnosed with GDM [37], and 1 focusing on individuals with insomnia [31]. A study targeting women with depression [53] found mixed results, with a decrease in 1 of the 2 assessments for depression. However, the interventions did not significantly impact depression in 4 studies with nonspecific pregnant women [41,49-51], 1 study with women having anxiety or depression [46], and 1 study involving preterm labor [42]. Only 3 of these studies measured depression as their primary outcome [50,51,53], and 1 study did not report its results [48].

Other Psychosocial Health Outcomes

This category encompasses various aspects of psychosocial health. Significant improvements were noted in empowerment [48], self-efficacy following meditation [40], and metaemotion [48]. In 4 studies assessing perceived health, no significant effects of the interventions were observed in 1 study involving nonspecific pregnant women [53], 1 study with individuals experiencing anxiety or depression [46], and 1 study with drug users [30]; however, a study involving women with GDM showed significant improvement in concise health status [37]. Individual studies measured labor-related worries [45], life satisfaction [49], and quality of life [46] but found no significant impact from the interventions. Mindfulness increased significantly in 1 of the 3 studies [45,48,49] targeting nonspecific pregnant women. These interventions did not yield significant effects on gratitude [49], work and social adjustment [53], pregnancy adaptation [41], or social support [41]. In studies involving pregnant women with anxiety or depression [46] and nonspecific pregnant women [41], maternal antenatal and maternal-fetal attachments were not significantly influenced by the interventions, respectively.

Physiological Outcomes

This section summarizes the physiological outcomes across 3 categories: body measurement, pregnancy or maternal, and neonatal.

Body Measurement

Nine studies focused on body measurement outcomes. Fasting plasma glucose (PG) levels, assessed in 3 studies, showed significant intervention effects in 2 studies on women with GDM [37,38] but not in women at GDM risk [39]. The 2-hour postprandial PG levels showed significant intervention effects in 2 studies [37,38]. One study reported significant intervention impacts on average glycemic control rates across fasting PG, 1-hour PG, 2-hour PG, and nighttime PG levels [35]. Glycated hemoglobin (HbA_{1c}) levels, measured in 2 studies [38,52], revealed significant intervention effects in 1 study [38]. One study noted significant intervention impacts on red blood cell and hemoglobin levels [38]. However, 2 studies found no significant intervention effects on systolic or diastolic blood pressure [39,52]. Waking and evening salivary cortisol levels showed significant changes [49], but the cortisol awakening reaction did not change significantly in a study targeting nonspecific pregnant women [49]. A study on women with preterm labor, however, showed significant effects [42]. Metabolic syndrome assessments in 1 study [39] revealed significant intervention effects on triglyceride and cholesterol levels, and metabolic syndrome changes, but not on high-density lipoprotein levels or waist circumference [39]. In addition, physical symptoms in nonspecific pregnant women showed no significant changes [41].

Pregnancy or Maternal

Eight studies reported on premature birth; no significant intervention effects were found, including 5 (63%) studies with women with GDM or GDM risk factors [35,37,39,47,52], 1 (13%) study on women with preterm labor [42], and 2 (25%) studies with nonspecific pregnant women [50,54]. In studies involving women with GDM, interventions showed no effect on assisted vaginal [47] or cesarean deliveries [35,39,47]. Three studies reported no impact on hypertension-related outcomes such as preeclampsia [39], gestational hypertension [47], or urine albumin-to-creatinine ratio [52]. There were also no significant effects on polyhydramnios [37], postpartum hemorrhage [35,37], or premature rupture of membranes [35,47]. However, 1 study reported a significant effect of interventions on maternal adverse events [38]. No significant effects were observed on the number of insulin-treated women in 1 study [52], but significant effects were noted on the total contact per insulin-treated woman (total hours) in another study [52].

Neonatal

Five studies involving women with GDM [35,37-39,54] reported on neonatal outcomes. Interventions showed no significant effects on intrauterine distress [37], admission to neonatal intensive care [35,39], malformations [35], macrosomia [35,37], or respiratory distress (neonatal asphyxia) in 2 studies [35,37], although 1 study reported a significant effect [54]. Significant effects were observed on the Apgar score in one study [38] and on the number of neonatal complications in another study [38]. The effect of interventions on low birth weight was not significant in one study [35], but the effect was significant in another study [39]. Two studies reported significant effects on birth weight [38,39].

Wellness Health Outcomes

This section describes 2 categories of wellness outcome measures used in the studies: health management and health risk behavior.

Health Management

The domain of health management included 6 outcomes. One study focusing on women with GDM reported a significant increase in the frequency of medical visits [47]. In another instance, the use of WeChat for health education and schedule reminders led to an increase in prenatal examinations [36]. Notable improvements in adherence to dietary standards were observed in a separate study [38], although another study found no significant impact of diabetes and nutrition-related knowledge [29]. The effectiveness of internet-based interventions was also evident in a study that focused on the diabetes care profile, demonstrating significant positive outcomes [37]. Furthermore, a web-based intervention aimed at enhancing physical activity resulted in significant increases in 20- and 30-minute sessions of moderate to vigorous activity per week [33]. Body weight gain, an important metric in maternal health, was assessed in 4 studies [32,33,39,52]. One study found no significant effects on several metrics, including the percentage of women exceeding the upper limit of the total gestational weight gain (GWG) guidelines at 28 weeks of gestation, the rate of GWG from 32 weeks until delivery, and the total GWG during this period [32]. Meanwhile, 2 other studies observed no significant changes in overall body weight [39,52], yet 1 study highlighted significantly lower BMI changes in the intervention group between 36 and 40 weeks of gestation and better weight recovery of 6 to 12 weeks post partum [39]. Another study, which found no significant effects on total GWG and the percentage gain according to the Institute of Medicine recommendations, reported significant improvements in adherence to these GWG guidelines [33].

Health Risk Behavior

Three outcomes were included under health risk behaviors. In the area of addiction, encompassing drug or alcohol use, one study found no significant differences between the intervention and control groups [30], whereas another study noted a significant difference over time [30]. A study on smoking cessation among pregnant women reported no significant effect on 4-week smoking abstinence [44]. Similarly, no significant differences were observed in a study examining condomless vaginal sex [34]. The severity of insomnia, a concern during pregnancy, showed inconsistent results in 2 studies [31,53]. While one study targeting pregnant women found no significant effect on insomnia severity [53], another study focusing on pregnant women with insomnia documented significant improvements in insomnia symptom severity, sleep efficiency, and sleep quality following the intervention [31].

Discussion

Principal Findings

This systematic review presents a comprehensive evaluation of web-based intervention studies focused on the prevention of premature birth in pregnant women. Various web-based interventions and diverse groups of pregnant women were included in the analysis; however, a significant gap was noted in studies that directly confirmed the effects of these interventions on premature birth. The measurement variables used to ascertain the direct effects of the interventions varied, and there were few well-designed interventional studies. These findings echo those of a meta-analysis of web-based educational interventions in 2022 [55]. Among the analyzed studies, only 12% (3/26) of the studies had an overall low RoB. Many of the included studies had moderate to high risk, primarily owing to nonblinding, adherence issues, and selection bias. This highlights the need for more high-quality intervention studies in this field. Blinding in internet-based intervention studies poses a challenge because of the active participation requirement and common attrition. Consequently, RCTs may not always unfold as intended. Thus, statistical analysis requires adjustment for participant bias, and participant characteristics should be carefully considered during interpretation.

This study found that most web-based interventions primarily used websites, followed by mobile instant messaging, aligning with common methods used in web-based health education interventions [56]. Only 1 intervention in this review used a mobile app [31], although it predominantly relied on mobile instant messengers for information delivery and encouraging participation. This approach is prevalent in countries such as China, Taiwan, Thailand, and Iran [35-39,48,54]. Recent studies, including 1 study using WhatsApp with a chatbot for health promotion messages, have shown higher uptake rates for interventions [57]. Mobile apps, being more accessible than websites, have shown greater effectiveness for glycemic control [11]. Further studies should thus compare the efficacy of websites and mobile apps and explore the use of mobile instant messengers and apps in more depth.

Premature births have many unexplained causes, with preeclampsia, eclampsia, intrauterine growth restriction, spontaneous preterm labor, and preterm premature rupture of membranes being the common causes [58]. Nonspecific pregnant women were the most common target group in the reviewed web-based interventions, followed by pregnant women with GDM, preterm labor, substance use, depression, and anxiety. However, experimental research on women with specific health issues is lacking. Although 7 experimental studies focused on pregnant women with GDM, highlighting the importance of blood glucose (BG) self-management, none targeted women with hypertensive disorders, which is crucial for early detection and management. Furthermore, despite spontaneous premature labor and preterm premature rupture of membranes being leading causes of premature birth [58], only 2 experimental studies [42,43] focused on these conditions. Hence, there is a critical need for further experimental studies targeting pregnant women with specific health conditions.

In most of the reviewed studies, interventions spanned the entire duration of pregnancy, likely because of the increasing risk of premature birth as pregnancy progresses. These web-based interventions typically lasted for 4 to 8 weeks, with a few studies using longer durations. This contrasts with web-based interventions for nonpregnant adults, where longer durations are more common [59]. Given the evolving physical conditions during pregnancy, there is a growing need for long-term interventions that cover the entire pregnancy period, aligning with the emphasis on a holistic approach to pregnancy health care [60]. This approach encompasses not only the pregnancy period itself but also the early and prepregnancy stages as well as the postpartum period. Web-based interventions offer the advantage of accessibility and flexibility, making them suitable for long-term implementation compared to in-person interventions. However, the conclusive impact of the intervention duration remains to be determined, indicating the need for further research.

Our research found that the interventions had varying effects on stress or distress among different groups of pregnant women. Studies involving nonspecific pregnant women [40,45,48,49] and those focusing on women diagnosed with anxiety or depression [46] reported significant reductions in stress or distress following the interventions. This success can partly be attributed to the interventions being tailored to the specific needs of these groups. For instance, the study by Loughnan et al [46], which applied self-guided cognitive behavioral therapy, was specifically designed to target anxiety and depression, closely aligning with participants' conditions. In contrast, interventions aimed at pregnant women with preterm labor did not achieve a similar reduction in stress or distress [42,43]. This disparity may be owing to the interventions in these studies, which were led by Scherer et al [43] and Urech et al [42], not being adequately customized to meet the unique needs of patients experiencing premature labor. Given that the condition of premature birth was not directly addressed [42], it is possible that the programs were less effective for these participants. In addition, as gestational age increased and fetal maturation progressed, the health risks for the newborn decreased [42], which might have influenced the perceived stress levels and the efficacy of the interventions.

The studies included in this research used various interventions, such as cognitive behavioral management [42,43,45,46,49], unified transdiagnostic treatment [48], and antenatal care system [40]. Each of these approaches has its own theoretical basis and methodological implications, which could affect the outcomes. Furthermore, the studies used different stress assessment tools, including the Perceived Stress Scale, Pregnancy Stress Rating Scale-36, and Prenatal Distress Scale. It is important to note that these are self-report screening questionnaires and not diagnostic assessment tools evaluated by trained professionals. This raises questions about the generalizability and applicability of the findings to individuals clinically diagnosed with stress or distress.

The interventions showed significant effects on anxiety in studies targeting women with anxiety [46], GDM [37], and insomnia [31]. However, no significant effects were noted in studies targeting women with preterm labor [42,43]. This aligns with the earlier findings regarding stress. The diversity of the interventions and measurement tools used across the studies, particularly as only 2 studies used the same tools [45,53], indicates the need for further research to reliably estimate these effects on anxiety. In addition, concerning depression, the cognitive behavioral interventions did not significantly impact pregnant women with anxiety or depression [46] or those with preterm labor [42] assessed by the Edinburgh Postnatal Depression Scale (EPDS). Similarly, women with depression [53] showed no significant changes when evaluated using the EPDS, though different results emerged from the Montgomery-Åsberg Depression Rating Scale. Furthermore, 2 studies targeting depression in general pregnant populations [50,51,53] used the EPDS but reported no significant effects [50,51]. The EPDS, although effective in detecting postpartum depression, might be less sensitive in identifying severe or prenatal depression [53]. Notably, in women with insomnia [31], depression significantly decreased when assessed with the EPDS and treated with cognitive behavioral methods. This raises questions about the validity of the EPDS during pregnancy, especially for those at a high risk for depression. Furthermore, most internet-based interventions for depression in pregnant women did not yield effective outcomes as measured by the EPDS. Ashford et al [61], however, claimed its effectiveness in perinatal depression. This discrepancy could be owing to differing methodological qualities; the studies in this review had a high overall RoB, whereas Ashford et al [61] included studies with average to high methodological quality.

This review underscores a notable inconsistency in the types of interventions, target audiences, and assessment tools used across the studies examined. Dennis [62] emphasized the importance of preventive interventions for mental health issues in pregnant women, particularly advocating for targeting women with identified risk factors [63]. In our analysis, the limited effects of interventions aimed at reducing anxiety or depression among nonspecific pregnant women [50,51] could be attributed to the absence of specific risk factors for these conditions. This observation suggests that the effectiveness of preventive psychosocial health interventions may be enhanced by tailoring them to the needs of women with identifiable risk factors.

Most studies in our review focused on verifying the effectiveness of BG control in women with GDM. The research demonstrated significant effects on both fasting BG and 2-hour BG levels in several studies [11,22,23,64], aligning with the findings from previous meta-analyses. However, variations were observed, such as in 1 study using a telemedicine system where HbA_{1c} levels were significantly lower in the experimental group [65]. Conversely, a study that provided educational information on GDM did not show a significant impact. These discrepancies might be because of factors such as the duration of the interventions, sensitivity of the indicators used, and the limited number of trials conducted. The physiological changes during pregnancy, such as iron deficiency and reduced life span of red blood cells, can affect the sensitivity of HbA_{1c} assays [65]. In contrast, glycated albumin, with a shorter half-life, may offer a more accurate measure of short-term glucose fluctuations. However, research on glycated albumin in pregnant women is still limited [11], suggesting an area that warrants further investigation in the future.

In terms of preventing premature birth, interventions targeting women with GDM or those at risk for GDM did not demonstrate a significant effect on this outcome [35,37,39,42,47,50,52,54]. These studies primarily assessed the role of internet-based intervention in addressing the causes of premature birth, analogous to managing diabetes for blood sugar control. The complexity of factors influencing premature birth makes it challenging to ascertain the direct preventive effects of these interventions. Hence, premature birth was not the primary outcome in any of the reviewed studies. Given the insufficient number of studies specifically examining each intervention type, it becomes necessary to continue evaluating premature birth as a secondary outcome in future research. This approach will further our understanding of how interventions can mitigate or eliminate the causes of premature birth, thereby enhancing maternal and neonatal outcomes.

Strengths and Limitations

This systematic review contributes to the literature by methodically analyzing internet-based interventions aimed at preventing premature birth. Its main strength lies in its extensive focus on a broad spectrum of outcomes, covering a wide range of maternal and neonatal health aspects. Another key strength is the inclusivity of the review, encompassing a diverse range of populations. The absence of geographical or language restrictions in the selection criteria enhances the comprehensiveness and global applicability of the review. This broad and inclusive approach not only illuminates the potential of internet-based interventions in the pregnancy context but also delineates their limitations, thereby laying a foundation for future research endeavors and informing clinical practice with a more global perspective.

However, the review has several limitations that need to be considered. Its reliance on studies from only 4 databases may have missed relevant research from other sources, potentially limiting the scope of the findings. The exclusion of specific types of publications, such as conference abstracts and dissertations, coupled with limited responses from original authors for additional data, could have introduced publication bias. In addition, 2 studies translated from non-English language using Google Translator may have inaccuracies in translation, affecting the interpretation of these studies. Although backward and forward citation tracking of the final included articles was initially planned, it was not conducted because of resource constraints and the comprehensive nature of the initial search. The underrepresentation of studies with a low RoB in this review suggests the need for caution in generalizing the results. Moreover, the focus on studies predominantly from countries with high internet use may limit the applicability of the findings to regions with different internet access levels and use patterns. Therefore, the results should be interpreted with an understanding of these contextual differences.

Conclusions

This systematic review uncovered a wide array of internet-based interventions that target risk factors associated with premature birth, with notable efficacy in the realms of psychosocial health and blood sugar management. However, interventions addressing other risk factors have shown a considerable diversity in measurement methods and a range of experimental effects. This variability points to an ongoing challenge in accumulating robust evidence. These findings underscore the critical necessity for future clinical trials to not only develop and test but also widely disseminate internet-based interventions that are both safe and effective. In addition, there is a pressing need for the creation of standardized measurement tools. Rigorous evaluation processes should be established to enhance the effectiveness and reliability of these interventions in clinical settings. Such efforts are essential for ensuring that these digital health solutions can effectively contribute to the prevention of premature births and improve maternal health outcomes on a broader scale.

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Authors' Contributions

SHK, SYJ, and JHP developed the research questions. SHK was responsible for the methodology design and leading the review process. The review process, including resolving discrepancies, screening and selecting studies, and extracting and coding data, was jointly conducted by SHK, SYJ, and JHP. Descriptive analyses and the preparation of tables and figures for the manuscript were conducted by SHK, JHP, and JCDG. All authors were involved in the interpretation of the findings. Initial drafting of the manuscript was done by SHK and JCDG. The manuscript was revised and the final version was approved by all authors.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy for the specific database.
[PDF File (Adobe PDF File), 222 KB - pediatrics_v7i1e54788_app1.pdf]

Multimedia Appendix 2
Outcome measures and effects of internet-based intervention on pregnant women.
[PDF File (Adobe PDF File), 360 KB - pediatrics_v7i1e54788_app2.pdf]

Multimedia Appendix 3
PRISMA 2020 Checklist.
[PDF File (Adobe PDF File), 54 KB - pediatrics_v7i1e54788_app3.pdf]

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Abbreviations

BG: blood glucose
EPDS: Edinburgh Postnatal Depression Scale
GDM: gestational diabetes mellitus
GWG: gestational weight gain
HbA1c: glycated hemoglobin
ITT: intention-to-treat
PG: plasma glucose
PP: per-protocol
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT: randomized controlled trial
RoB: risk of bias

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Review

Psychological Interventions and Those With Elements of Positive Psychology for Child and Youth Mental Health During the COVID-19 Pandemic: Literature Review, Lessons Learned, and Areas for Future Knowledge Dissemination

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Abstract

Background: There was a marked decline in child and teenage mental health worldwide during the pandemic, with increasing prevalence of depression, anxiety, and suicide. Research indicates that positive psychological interventions may be beneficial for mental health.

Objective: The aims of this review were to evaluate positive psychological interventions for child and youth mental health implemented during the COVID-19 pandemic and assess overall effectiveness for mental health and knowledge.

Methods: We undertook a literature search of PubMed, MEDLINE, and Google Scholar for all eligible studies on digital and hybrid in-person psychological interventions for youth mental health during the COVID-19 pandemic. A particular emphasis was placed on positive psychological interventions or interventions that had components of positive psychology, including gratitude, acceptance, positive emotions, or resilience building.

Results: A total of 41 interventions were included in this review. Most of the interventions were digital. Overall, most of the interventions assisted with one or more mental health or psychological indicators, such as depression, anxiety, posttraumatic stress disorder, stress, and resilience. However, findings were mixed when it came to targeting both depression and anxiety together. The interventions that promoted youth mental health most often had a range of diverse positive psychology components and were evidence based. Not all studies measured changes in mindfulness. Few studies examined knowledge acquired on mental health self-care, managing mental health problems, knowledge of positive psychological techniques, mindfulness knowledge, or mental health self-efficacy.

Conclusions: Diverse multicomponent interventions appear to assist with youth mental health overall, although their effects on both depression and anxiety are less clear. There is also a need for more research on knowledge gains to determine whether the interventions improved knowledge on mental health–supportive behaviors, which may be sustained beyond the intervention. Finally, more studies need to evaluate whether the interventions assisted with increasing self-efficacy for practicing positive psychological techniques as well as changes in mindfulness levels. Future studies should not only assess effectiveness for mental health outcomes but also assess knowledge translation, with valid measures of knowledge and self-efficacy for mental health–supportive behaviors and positive psychological skills acquired (eg, the ability to practice mindfulness).

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KEYWORDS

positive psychology; mindfulness; resilience; mental health; flourishing; knowledge translation; depression; anxiety; stress

Introduction

Background

Worldwide, there was an increase in mental health problems in children and teenagers, including increasing rates of depression, anxiety, and suicide, during the global COVID-19 pandemic [1]. Systematic reviews have estimated the global prevalence of childhood and teenage depression at 23% and anxiety at 28% [2], whereas the prevalence of suicidal ideation was estimated to be 29% to 33% in this age group [3]. A study in Australia found an increase in the use of helplines for kids to cope with mental health issues [4]. Higher levels of isolation were reported in children and teenagers resulting from the closure of schools and reduced socialization with peers, coupled with challenges stemming from reduced access to mental health services [1,5]. Moreover, data from the World Health Organization (WHO) indicate that there were barriers to accessing mental health care services, particularly among children and teenagers, who experienced a 72% disturbance in their mental health care, with counseling and psychotherapy being the leading services that were affected during the transition to digital care [6].

Given the serious consequences for child and youth mental and psychological health, there is a need to evaluate what strategies were effective for buffering against the deleterious impact of the pandemic. Without understanding what measures were effective for helping children and youth cope and adjust to the "new normal" gaps and barriers will remain when it comes to future pandemic preparedness in relation to mental health crises in this population.

A systematic review comparing the prepandemic and pandemic periods found that youth experienced higher levels of isolation, depression, and anxiety during the pandemic [7]. Data from the WHO suggest that children from economically-deprived backgrounds were impacted the most [8]. Research also suggests that certain personality and neurodevelopmental types were differentially affected during the pandemic. For example, research has found that children with neurodevelopmental disorders had higher anxiety during the pandemic [9] and that siblings often provided social support for distressed children with disabilities [10]. In addition, a systematic review found that some children experienced boredom during the pandemic [11], which was also found in other studies among neurotypical individuals [9,12,13].

The pandemic also created challenges for parents in terms of adjusting to learning from home [14]. Research from the All Our Families cohort in Calgary, Alberta, also found a rise in depression by 3.2 points and in anxiety by 2.39 points in mothers during this period when compared with the 3-year period before the pandemic [15]. They struggled with managing homeschooling, lack of daycare, and financial troubles [15].

Research from the WHO indicates that social support was a major buffer for promoting mental well-being in children and teenagers during the pandemic [8]. The prevailing literature also suggests that self-care, positive psychological states, and resilience have protective effects on well-being, stress management, and mental health [16-23]. Positive psychology is described as a state of flourishing and thriving even when experiencing health problems or hardship by living one's best life [19]. Individuals who have high levels of positive mental health and resilience [24] and who score high on resilience tend to have lower levels of depression [24] and anxiety [23]. Individuals with high levels of positive mental health are 27 times more likely to recover from mental health issues relative to their counterparts with low levels of positive mental health [25]. Furthermore, positive mental health has been found to be a buffer for suicide prevention in patients with depression [26].

Positive psychology is relevant to children and youth in relation to their mental health during the pandemic. Positive psychology can help youth by providing them with the necessary tools and resources to increase their resilience, well-being, and ability to cope during difficult times, which is especially relevant to the global youth mental health crisis during the pandemic [16-23]. Individuals can be struggling with mental health problems, yet they can demonstrate resilience and flourish. Flourishing focuses on thriving amidst hardship by living one's best life even when experiencing metal health problems or other difficulties [18,19] and is particularly relevant for youth, given the mental health crisis worldwide [18,19]. Flourishing has several essential elements, which include life satisfaction, meaning or purpose in life, character or virtues, and positive affect. It also includes happiness, social relationships, and mental health [27-29].

Resilience is a form of internal coping in one's given environment regardless of external stressors that one may encounter [30]. Resilience has also been found to be inversely related to mental health problems and a buffer against stress [21]. Building resilience and helping youth find ways to flourish include assisting youth in acquiring the skills and tools to cope during difficult life circumstances [20]. Considering the relevance of positive psychology and its components for youth mental health, more research is needed to better understand the types of positive psychological interventions that have been developed, including ones that aimed to increase flourishing and build resilience in youth during the COVID-19 pandemic and their overall effectiveness for mental health.

In addition to positive psychology, there are also psychological interventions that are closely connected to it and potentially of great importance for youth mental health during the pandemic. Research indicates that mindfulness, a form of present-moment awareness using formal and informal meditation, may help build resilience through greater self-awareness, acceptance, kindness, and gratitude [31]. Mindfulness also has elements that are of great importance to positive psychology, including self-acceptance, compassion, positive emotions, and gratitude [32,33]. Research also indicates that mindfulness practice may help with the development of compassion and reducing stress, anxiety [34], and depression [10-13]. Studies have further found that, when students are more mindful, they can learn more in the classroom and be more focused on given tasks and are more creative [14,15]. Mindfulness is of relevance to mental well-being in children and youth during the pandemic [34]. Cross-sectional research on mindfulness in children has found that higher levels of mindfulness (children who were more mindful) were linked to higher coping during the pandemic [34]. Even with the pandemic coming to an end, young people may still face hardship and personal crises, and there is a need to provide them with coping skills.

Finally, research has found that higher levels of social support, coupled with positive coping strategies, were protective for youth mental health during the pandemic [35]. Recommendations for helping children and adolescents have included developing coping strategies as well as receiving social support from family members [2]. Thus, investigating interventions that have assisted youth with positive coping and psychological and social support during the pandemic to promote youth mental health can inform strategies for future mitigation of mental health concerns in other crises.

Furthermore, to the best of our knowledge, there has not been a review that has evaluated what types of positive psychological interventions have been undertaken for youth mental health, including their fundamental components and whether they were effective for alleviating mental health and psychological indicators such as resilience, stress, and well-being during times of unprecedented crises, stemming from the pandemic.

In addition to traditional positive psychological interventions, there also has not been a review that has explored psychological interventions that have common elements that are related to traditional positive psychology, such as gratitude and resilience building [32,33]. Thus, it is also of interest to explore interventions that contain elements that are related to positive psychology, such as mindfulness, which focuses on self-acceptance, compassion, and gratitude, among other things [32,33]. Some experts also argue that cognitive behavioral therapy (CBT) has important elements that are of fundamental relevance to positive psychology, including its focus on positive emotions [36], hope, and strength building, highlighting that it is useful to include interventions that are informed by CBT as well. In recent times, there has also been a shift toward a "positive CBT" model of care whereby the core treatment focus is on positive aspects exclusively [37].

In addition, little is known about the uptake of mental health–promoting behaviors, such as mindfulness, from positive psychological interventions. For example, studies have examined whether mindfulness interventions assist with mental and psychological health but have not measured knowledge levels, and few have measured changes in mindfulness [38,39]. There is a need to investigate whether positive psychology interventions help youth with gaining important knowledge surrounding mental health as well as techniques derived from positive psychology, such as mindfulness for self-care. Mental health literacy has also been found to be an important determinant of help-seeking behaviors [40], and exploring it in relation to positive psychological interventions in youth during the pandemic is of research interest. Understanding whether the interventions effectively disseminated knowledge on self-care in relation to mindfulness and knowledge of positive psychological techniques to assist with coping is also important. Often, research is not translated into practice [41], and developing effective knowledge dissemination strategies enables evidence-based research findings to take shape in the community through increased awareness and greater adoption of these mental health–promoting resources and behaviors.

Objectives

This review had the following aims:

1. To better understand what positive health psychology interventions (including resilience and flourishing focused), as well as interventions that have common elements related to positive psychology (eg, mindfulness-based interventions or CBT-based interventions [36]), were developed during the pandemic and their overall effectiveness for youth mental health, including depression, anxiety, and well-being.
2. To better understand whether the psychological interventions increase levels of mindfulness and resilience in youth.
3. To better understand whether the psychological interventions increase knowledge of positive psychology practices, including knowledge levels of mindfulness in youth and knowledge of mental health self-care behaviors. In other words, did the interventions assist with knowledge translation (KT) on how to practice self-care and resilience coping skills?

Methods

Study Design

A literature search was undertaken in PubMed and MEDLINE for all relevant studies on traditional positive psychological interventions or psychological interventions with elements that are common to positive psychology for child and youth mental health during the pandemic, using the PRISMA-P (Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Protocols) guidelines [42]. Google Scholar and manual hand searches were also undertaken to identify any additional studies.

Inclusion and Exclusion Criteria

All positive psychological interventions studies on children (aged <10 years), preteenagers (aged 10-12 years), teenagers (aged 13-18 years), or youth and student mental health (ages of 18-24 years) were included if they were undertaken during the pandemic period (March 2020 to December 2022). The search was undertaken in December 2022 and recently updated in July 2024 to capture additional studies that were undertaken during the pandemic but published at a later date. Studies that were designed before the pandemic but evaluated the effects of the intervention during a period of the pandemic were also included. We included mindfulness-based interventions, CBT, flourishing, and resilience, among other interventions that fell under the positive psychology umbrella for youth mental health. Reviews were excluded, as well as articles that were not published in peer-reviewed journals. Studies must have been published in the English language to be included. Qualitative studies were excluded. Studies must have been interventional in design, such as randomized controlled trials (RCTs) or quasi-experimental 1-arm pretest-posttest designs. Pilot RCTs were included. Studies on program implementation or health care service delivery experiences or perspectives were excluded. Only studies that evaluated the effectiveness of positive psychological interventions were included.

Search

A medical librarian assisted with the search strategy. Keywords included word variations for “mindfulness” or “intervention” and “mental health” or “flourishing” or “resilience” or “stress” or “positive psychology” and “young adult” or “teenager” or “youth” and “knowledge” or “knowledge translation.” The population included young adults, children, and teenagers. The interventions included positive psychological interventions, mindfulness-based interventions, and CBT, among others. The outcomes included depression, anxiety, stress, and resilience, among others. The comparator included a control group (standard or usual care), but single-arm pretest-posttest studies did not have a comparator. Word variations for each outcome, intervention, and population were entered into the search. The search was rerun and updated again in July 2024 to ensure that all relevant studies were still included. An example of the search strategy is detailed in Textbox 1.

Textbox 1. PubMed search strategy example.

Search strategy

- (“Adolescent” [Medical Subject Heading (MeSH)] OR teen [ti] OR teens [ti] OR teenage* [ti] OR adolescen* [ti] OR youth [ti] OR youths [ti] OR “young people” [ti] OR “young adult” [ti] OR “young adults” [ti] OR “Child” [MeSH:NoExp] OR child* [ti] OR family [mh] OR caregiver [mh] OR parent [ti] OR parents [ti] OR parental [ti] OR familial [ti] OR family [ti] OR families [ti] OR mother* [ti] OR father* [ti] OR caregiver [ti]) (“mindfulness” [MeSH] OR “mindfulness” [all fields] OR mbct [tiab] OR mbsr [tiab] OR “Mindfulness-Based Cognitive Therapy” [tiab] OR “Mindfulness Based Stress Reduction” [tiab] OR “MBI” [tiab] OR “mindfulness-based interventions” [tiab] OR meditation [tiab] OR “Mental Disorders/therapy” [MAJR] OR ((“Mental Health” [MeSH:NoExp]) AND “First Aid” [MeSH:NoExp]) OR “Psychological First Aid” [MeSH] OR “mental health first aid” OR “psychological first aid” OR “resilience, psychological” [mh] OR “resilience” [tiab] OR “hardiness” [tiab] OR “posttraumatic growth” [tiab] OR “post-traumatic growth”[tiab] OR “personal growth” [tiab] OR “psychological well-being” [tiab] OR “stress related growth” [tiab] OR “coping behavior” [tiab] OR “emotional stress” [tiab] OR “mental health”[MeSH] OR “mental health” [tiab] OR “flourishing” OR “flourish” OR “Emotions” [MeSH] OR “positive psychology” OR “Psychological Recovery”) (“diffusion of innovation” [mh] OR “diffusion of innovat*” [Tiab] OR “information dissemination” [mh] OR “knowledge util*” [tiab] OR “knowledge uptake” [Tiab] OR “knowledge transfer*” [Tiab] OR “knowledge implement*” [Tiab] OR “knowledge disseminat*” [Tiab] OR “knowledge translat*” [Tiab] OR “research utiliz*” [Tiab] OR “research uptake” [Tiab] OR “research transfer*” [Tiab] OR “research implement*” [Tiab] OR “research disseminat*” [Tiab] OR “research translat*” [Tiab] OR “health services research” [tiab] OR (“utili*” [Ti] AND “review” [Ti]) OR implement* OR train*) (“covid 19” [tiab] OR “covid 19” [MeSH] OR “sars cov 2” [tiab] OR “sars cov 2” [MeSH] OR “severe acute respiratory syndrome coronavirus 2” [all fields] OR “ncov” [all fields] OR “2019 ncov” [all fields] OR “Pandemics” [MeSH])

Screening and Data Extraction

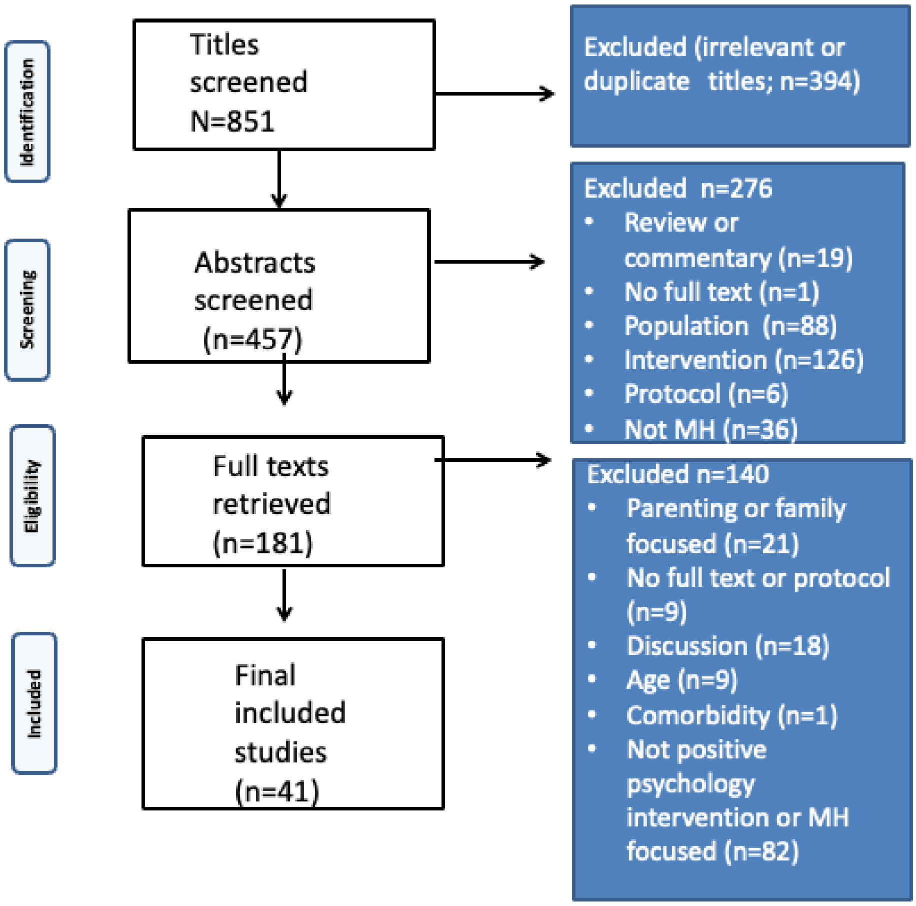
Titles were screened for relevance followed by screening of abstracts against the inclusion and exclusion criteria, followed by retrieval of full-text articles. Full texts meeting the inclusion criteria were included in the review. Data were extracted and summarized in tabular format. This included the study general characteristics, measures, outcomes (mental health), positive psychology intervention types, mindfulness attributes, behavior change techniques, intervention details, and knowledge.

Results

Overview

A total of 41 psychological interventions targeting youth during the pandemic met the inclusion criteria and were included in the review [43-83] that were either purely positive psychological interventions or had common elements that are of great relevance to positive psychology. The results are summarized in Multimedia Appendix 1 [43-55,57-74,76-78,80-83]. Most of the interventions were delivered digitally during the pandemic. The interventions included web-based interventions, mobile health apps, videos, web-based audios and lectures, and emails. In total, 3 were apps, of which 2 were chatbot apps [45,52,60]. A total of 5% (2/41) of the interventions were delivered over WeChat (Tencent) [54,66]. The studies spanned the United States, Canada, Australia, the United Kingdom, Italy, Portugal, Spain, China, Iran, Tunisia, and Vietnam. The search, including the screening process, is illustrated in Figure 1.

Figure 1. Primsa flow chart.



Intervention Content

Almost all of interventions were digital, with the majority being delivered through a web-based mobile health app-based platform [45-47,49-56,58-68,70-73,76,79-82]. Several studies were of mindfulness-based interventions or included mindfulness components [43,44,46,50-52,56,57,60,66-69]. Some of these interventions combined various elements of mindfulness, such as acts of gratitude, breathing, and meditation, whereas 5% (2/12) included mind-body movement with yoga [44,45]. In total, 7% (3/41) of the interventions included more formal mindfulness techniques derived from mindfulness-based stress reduction (MBSR) [43,56,66]. There were also several CBT based studies [54,55,58,59,61-65], as well as mixed hybrid CBD studies involving other techniques such as combined CBT with dialectical behavior therapy (DBT) [65] and combined mindfulness with CBT [62,64]. A few of the studies had a social support component, with one comparing CBT with social support informed by the social identity framework [48], another including social support with DBT and other positive psychology principles [65], and a third including social support with mindfulness [57]. One study had a spiritual element, focusing on prayer with a counselor along with meditation [49]. Additionally, a few of the studies combined several different positive psychological components, such as positivity, compassion, and meaningful engagement [53] or self-care, compassion, and meditation [47].

Positive Psychological Interventions for Youth Mental Health

Overview

Overall, almost all of the psychological interventions targeting youth mental health had positive results on one or more mental health outcomes, but a monitory of the studies did not find that the interventions were effective for any of the measured mental health outcomes [44,50,51,67]. The studies with negative findings often tended to not include a thoroughly described program and theoretical underpinning. For example, they did not describe the details of the mindfulness program [50] or vaguely described informal mindful photography practice with acts of kindness [51] or mind-body movement with breathing [44] rather than relying on evidence-based structured programs with mindfulness techniques that were described in greater detail.

Effects on Depression

Many of the studies that measured depression found that the interventions improved depression [43,45,53,54,58,59,61,65,66,68,71,73,74,77,80], but a minority not find that the interventions assisted with depression [62,64]. Of these studies, some were on mindfulness-based interventions [43,66,68], while others were predominantly CBT interventions [54,59,61,65], with one combining resilience with CBT training [61] and another combining CBT with DBT [65]. In addition, one was a multicomponent positive psychological intervention [53], whereas another was a yoga intervention [45]. Social support was found to be superior to CBT in one study for depression [48], whereas another study found that social support was as effective as mindfulness for alleviating depression even though mindfulness was helpful [66]. A web-based intervention involving Ipsha yoga with audios, found that depression was alleviated in the intervention arm but only at week 2 [45].

Effects on Anxiety

Several of the studies that measured changes in anxiety found that the positive psychology interventions assisted with anxiety. Of the studies that demonstrated effectiveness, one was a multicomponent positive psychological intervention [53], several were mindfulness-based interventions [43,52,64,66,70,72,82] as well as CBT based [54,55,58,59,63,64,73,74,77].

Effects on Both Anxiety and Depression

Although several studies found independent effects of the interventions on improving either depression or anxiety, some studies had mixed findings with regard to the effects of the interventions on effectively targeting both depression and anxiety. In other words, some studies found that the interventions assisted with both depression and anxiety together, whereas others did not. Several studies found that the interventions were effective for decreasing both depression and anxiety [43,53,54,58,59,66,73,74,77]. For example, the 8-week MBSR randomized pilot study in 49 participants by An et al [43] found that the intervention reduced depression and anxiety by 40% and was associated with changes in the brain on electroencephalogram readings. In addition, one study was a multicomponent 8-week positive psychology RCT involving 366 participants and found reductions in depression and anxiety [53].

A few studies did not find that the interventions reduced both anxiety and depression together [45,61,64,70,80,81]. For example, the 4-week MBSR with mindfulness-based cognitive therapy (MBCT) RCT (N=144) by Sun et al [66] found reductions in anxiety but not depression in the intervention arm relative to the control arms. Furthermore, while the 4-week CBT RCT (N=585) by Rackoff et al [61] found that the intervention reduced depression, there were no substantial changes in anxiety. In contrast, the 8-week CBT RCT (N=177) by Simonsson et al [64] found reductions in anxiety but not depression in youth. Both studies had some elements of mindfulness. In addition to this, the 8-week web-based CBT plus mindfulness intervention by Ritvo et al [62] did not have any significant effects on depression or anxiety. This contrasts with a CBT chatbot app that reduced depression and anxiety levels in youth [54].

Effects on Posttraumatic Stress Disorder

A total of 4% (2/41) of the studies evaluated the effects of the positive psychology interventions on posttraumatic stress disorder (PTSD) in youth during the pandemic and found significantly lower levels of PTSD in intervention participants relative to controls [57,59].

Positive Psychological and Derived Interventions for Youth Psychological Stress and Well-Being

Most of the studies that evaluated stress found that stress was reduced in youth after the psychological interventions [43,45,46,49,52,53,61,62,68], but it should be noted that one of these studies found only marginal effects [52]. Well-being was also higher in the intervention arms relative to the control groups in a few studies that assessed it [45,46,53]. Youth also scored higher on various emotional facets and character traits, including positive affect [45], hope, optimism, emotional regulation [53], forgiveness [60], and life satisfaction [60].

Flourishing and Its Core Elements: Affect, Life Satisfaction, Character, Meaning, and Relationships

We did not find any positive psychology interventions that measured and evaluated human flourishing in youth at baseline and follow-up during the pandemic. However, a minority of the positive psychology interventions included fundamental elements of human flourishing from its core definition [27,29]. This included character, positive emotions, meaning, happiness, purpose, life satisfaction, social relationships, affect, and mental health [28,52,53,61,62].

The study by Krifa et al [53] found that multiple positive psychological interventions may be superior for youth mental health by combining compassion, positivity, and meaningful engagement in a digital intervention. Although they did not directly measure flourishing, these elements are fundamental complements of flourishing [53]. The 2-week RCT (N=250) by Dupont et al [51] focused on small acts of kindness, gratitude, and mindful photography, although the study did not have significant effects on any mental health outcomes of interest. The 2-week RCT (N=164) by Pizarro-Ruiz et al [60] involved an app that promoted positive affect, life satisfaction, and forgiveness. Similarly, the study by Rackoff et al [61] targeted positive affect but also included elements that focused on building healthy relationships and coping skills and finding a greater meaning in life. The 8-week RCT (N=154) by Ritvo et al [62] combined mindfulness with other positive psychological elements linked to flourishing, including life satisfaction, healthy relationships, coping skills, and a healthy lifestyle. Similarly, the 4-week pretest-posttest study by Gabrielli et al [52] (N=71) combined mindfulness with behavioral coping strategies that assisted with emotional regulation. The 4-week RCT (N=190) by Dorais and Gutierrez [49] focused on meaning and purpose in life through prayer.

Knowledge Uptake

Almost none of the studies evaluated knowledge dissemination and uptake levels for mental health knowledge and self-care knowledge, among other key knowledge-related domains relevant to the positive psychology interventions. Only one of the studies, the study by Sun et al [66], evaluated knowledge in relation to self-care, regulating emotions, the mind and body, and coping with stress. The study by Sun et al [66] found that knowledge of self-care behaviors, emotional regulation, and stress coping improved after the intervention. Although one study found that participants had higher levels of emotional regulation, it did not assess knowledge levels [53]. In addition, only one study evaluated motivation to learn and found that participants were motivated to continue to learn about self-care in a compassion, self-care, and meditative intervention [47].

In addition to knowledge gained and motivation to learn, 4% (2/41) of the studies considered self-efficacy for managing mental health. One study assessed changes in mental health self-efficacy and management but did not find that the intervention increased overall levels [65], whereas another found that mental health self-efficacy increased [58].

Furthermore, none of the studies evaluated self-efficacy to practice mindfulness or other positive psychology techniques, including CBT. Only one study, the study by Sun et al [66], reported that participants had learned how to practice mindfulness, including self-regulation of the mind and body, whereas another study found that participants enjoyed learning the mindfulness modules [52]. This suggests that only a minority of studies considered knowledge and skill acquisition in relation to positive psychological techniques, whereas none considered self-efficacy.

Study Quality

Overall, the studies were of average quality when considering several factors, including those listed by the Cochrane Risk of Bias grading tool [50]. The study duration ranged from 2 weeks to 1 year. Mindfulness-based interventions are traditionally 8 weeks in duration; hence, studies shorter than this were graded as weak [84]. Most of the studies were RCTs. Blinding was usually not undertaken except in a few studies in which the assessors or participants were blinded, but not both [49,50,60,61]. Most studies had good overall retention levels. Several studies also undertook a priori power calculations, ensuring that they were sufficiently powered with adequate sample sizes to detect a difference if one existed between the intervention and control arms [44,45,49-51,53,54,61,62,66]. In addition, the studies used data collection methods that were valid and reliable, or the questionnaires had been previously used and validated.

Discussion

Principal Findings

We aimed to better understand what positive psychology or positive psychology–derived or related interventions (including ones that had common elements from positive psychology) were implemented to address mental health concerns among youth during the pandemic.

First, we aimed to better understand what types of interventions were implemented and the types of media and techniques that were used. Overall, the interventions that targeted more than one element were more likely to have significant effects on one or more mental health outcomes [53]. The interventions were diverse, often combining various facets of positive psychology along with mindfulness or CBT. Among the interventions, almost all had a CBT or mindfulness component (including informal practice or movement). However, only a minority had a formal mindfulness program derived from MBSR or MBCT, with the rest providing fewer details. The studies in this review included combinations of CBT with mindfulness, combined CBT with resilience training, combined either mindfulness or CBT with social support, as well as combined CBT with DBT. In addition, there was a multicomponent + psychology intervention, informal mind-body movement with yoga interventions, and combined positive psychology with informal mindfulness (eg, gratitude and compassion), and 1 (1/41, 2%) was based on meditative counseling with prayer. We also found that some elements of flourishing, namely, life satisfaction; positive emotions; purpose; and certain qualities, including gratitude, were targeted in the studies. However, none of the studies evaluated flourishing as an entire construct, which could be useful in future positive psychological interventions to determine whether they assist with flourishing.

Second, we further aimed to determine whether the interventions were effective for improving mental health. Overall, the interventions demonstrated effectiveness for improving mental health in youth. Almost all of the interventions helped with one or more mental health outcomes, including depression, anxiety, stress, PTSD, and resilience among youth. Many of the mindfulness-based interventions assisted with depression and anxiety. Previous research has found that mindfulness and CBT are effective for anxiety and depression [85-88], confirming our findings. The prevailing literature on positive psychology also indicates that it helps with resilience and improving positive affect [89,90], which was also found in this review.

Furthermore, the studies were heterogenous in terms of program content, with the interventions that implemented comprehensive media with evidence-based MBSR or MBCT usually showing positive effects compared with interventions that did not elaborate on their programs. Thus, it appears that multicomponent interventions that used diverse media and had greater intervention complexity were more likely to have positive results for mental health in general. For example, only the chatbot study showed significant effects compared with the web-based mindfulness one [52,62]. It could perhaps be that mobile apps for mindfulness combined with other positive psychology elements can best support youth during global crisis times, such as during a pandemic. Previous research has also found that evidence-based mindfulness interventions were effective for depression and anxiety during the pandemic [91].

Although most of the included studies found improvements in depression and anxiety, not all studies in this review helped with alleviating both anxiety and depression together in a single intervention. However, it is important to stress that it is not unusual for interventions to not work simultaneously for both depression and anxiety given their heterogeneity and the fact that there are fundamental differences in the conditions that may require different therapeutic approaches [92]. A few studies did not find that the interventions reduced both anxiety and depression together [45,61,64,70,80,81]. For example, the 4-week MBSR with MBCT RCT (N=144) by Sun et al [66] found reductions in anxiety but not depression in the intervention relative to the control arms. Furthermore, while the 4-week CBT RCT (N=585) by Rackoff et al [61] found that the intervention reduced depression, there were no significant changes in anxiety. In contrast, the 8-week CBT RCT (N=177) by Simonsson et al [64] found reductions in anxiety but not depression in youth. Both studies had some elements of mindfulness. In addition to this, the 8-week web-based CBT plus mindfulness intervention by Ritvo et al [62] did not have any significant effects on depression or anxiety. This contrasts with a CBT chatbot app that reduced depression and anxiety levels in youth [54].

In addition, deciphering why a minority of the studies did not help for either depression or anxiety is challenging as some studies had common interventional content and duration with others that were effective for the same mental health outcomes. For instance, It could be argued that the 4-week CBT intervention that only found improvements in depression needed a longer duration for it to ameliorate anxiety [66], but a similar study of 4 weeks with a comparable sample size found the opposite [61]. It should be noted that this study combined both MBSR with MBCT, which could theoretically indicate that a shorter study requires a more rigorous combined approach, although more research on this topic is needed. It is also worthwhile to consider the intervention media and specific content. The study that only found improvements in anxiety but not depression integrated mindfulness over WeChat and Zoom (Zoom Video Communications) [66], whereas the study that found the opposite used web-based CBT learning modules [61]. From a technology standpoint, one used video-based communication and chat, whereas the other used a web-based medium with courses. It is interesting to note that the intervention that did not find any improvements in depression or anxiety delivered CBT on the web and also offered peer support. Thus, there is insufficient evidence to be able to discern whether specific interventional content, such as the media through which the interventions were delivered, impacted outcomes.

Our review also found that the effects on stress are consistent with the literature on mindfulness and CBT showing a positive effect on stress [88,93]. The reasons for the lack of consistency in studies during the pandemic are unclear. However, the pandemic was an unprecedented time; hence, the global economic, physical health, and psychological health effects of the pandemic could have impacted the delivery and effectiveness of the interventions. Psychological stress was higher during this time [94]; hence, reducing it to “normal prepandemic times” levels was perhaps more challenging, especially in populations who already had high stress before the pandemic, which further compounded it.

It would be of research interest for future studies to undertake functional magnetic resonance imaging scans to evaluate whether the mindfulness-based interventions lead to actual changes in the brain [95], which could complement subjective self-report measures of changes in mindfulness.

Third, we aimed to determine what KT strategies were used and whether the interventions improved knowledge regarding self-care, mental health, and resilience. We found that there is a gap in the literature when it comes to KT and knowledge dissemination in positive psychology interventions for mental health to youth. Only 7% (3/41) of the studies actually assessed either knowledge (1/41, 2%) or self-efficacy for managing mental health in youth. To understand whether participants actually acquired new knowledge and whether it was disseminated properly, future studies need to measure knowledge levels of positive psychological techniques, including mindfulness, and overall knowledge of mental health care and self-care. It is also important to evaluate self-efficacy for mental health care, and only 4% (2/41) studies examined this. Without understanding whether participants gained knowledge and have perceptions of being capable of taking care of their mental health, the outcomes of these studies are difficult to interpret. Self-efficacy has been previously linked to behavior change [96], highlighting its pertinence to self-care behaviors regarding mental health. Knowledge has been previously found to increase self-help behaviors and awareness of mental health problems in young adults [40]. In addition, by measuring improved knowledge, clinicians can be reassured that knowledge acquisition of new mental health techniques and self-care behaviors assists patients.

Finally, few studies examined knowledge acquired in relation to mental health self-care of mental health literacy. However, it is important to note that a recent systematic review and meta-analysis found that higher levels of mental health self-efficacy specifically do not always lead to behavior change involving help-seeking behavior, and barriers regarding stigma remain [97].

In addition to positive psychology for coping during the pandemic, there are other self-care lifestyle behavioral factors that children and teenagers may modify to improve their mental health. For example, research from the All Our Families cohort in Canada found that improved sleep and reduced screen time were both protective for depression and anxiety in children [98-100]. Research has also found that physical activity is protective of mental health in youth [101]. Thus, interventions and knowledge dissemination efforts may benefit from combined behavioral lifestyle and resilience coping strategies to target child and youth mental health.

Recommendations and Future Areas of Research and Pandemic Preparedness

We recommend integrating the concept of flourishing, positive psychology, and evidence-based mindfulness programs (eg, MBSR) into existing KT programs. This would involve a unified model of knowledge dissemination and implementation, catered to key stakeholders and mental health first aid training providers. Future studies should also measure knowledge levels of self-care behaviors, including mindfulness or general meditative practice, resilience coping skills, mental health self-care knowledge, knowledge of mental health management, and self-efficacy. Ideally, they should combine resilience-building skills with lifestyle behavioral factors (eg, sleep, physical activity, and screen time modifications). Future studies could consider developing a KT tool that will provide children, teenagers, and their families with useful resources on how to build resilience, meditate, and change their lifestyle behaviors to promote mental health.

Finally, future research should further examine the specific barriers related to implementing these interventions during the pandemic to better prepare for a future pandemic. Nevertheless, it is encouraging to note that most studies successfully implemented their interventions using digital media, something that is more accessible during pandemic-related restrictions and lockdowns. Qualitative research with stakeholders, including the young adult participants, could provide a deeper insight into specific facilitators and barriers experienced during the pandemic, which could help with improving the interventions and future pandemic preparedness.

Limitations

A limitation of this review is that only 1 reviewer screened the articles due to resource limitations. Ideally, there should be 2 reviewers who screen articles in scoping reviews, reducing bias in selection and in correctly identifying all sources, which makes this more of a narrative literature review. This study is also limited by resources, whereby we accessed free, publicly available articles, which limited the number of databases that were accessed to 3. There is always a possibility that there were more studies that were not included. However, one reviewer redid the search in July 2024 to make sure that no additional studies were missed in the existing databases that were searched.

In addition, we included pretest-posttest 1-arm study designs and did not restrict the inclusion to only RCTs. However, our goal was not to undertake a meta-analysis but to broadly understand what types of interventions were undertaken during the pandemic, considering that randomization was not always possible during the youth mental health crisis throughout the pandemic.

Nevertheless, there are several strengths to this review, including the fact that it comprehensively captured a diverse range of psychological interventions during the pandemic period. There is a possibility that there are more articles that were overlooked given the resource limitations, but this review shows a comprehensive overview of the patterns and types of studies with their common findings during the global COVID-19 pandemic.

Conclusions

We aimed to review what types of positive psychological interventions or positive psychology–related (with derivatives of positive psychology, such as gratitude, positive emotions, and acceptance) interventions were developed during the global youth mental health crisis of the COVID-19 pandemic to meet the mental health needs of youth during this time. We identified 41 psychological interventions that were undertaken in youth during the pandemic. The studies had mixed findings, but overall, the ones that targeted several positive psychology elements, had clearly defined intervention content, or used evidence-based mindfulness programs had greater effectiveness. The reasons why some mindfulness-based interventions had mixed results during the pandemic are not entirely clear. Finally, there is a gap in the knowledge dissemination and uptake literature, whereby most studies did not assess mental health knowledge; mental health management knowledge; self-efficacy for managing mental health problems; or knowledge levels and self-efficacy for practicing positive psychological techniques, including mindfulness. Future studies should measure knowledge and self-efficacy as part of a KT strategy to promote youth mental health, but they should also consider barriers.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Table 1.
[PDF File (Adobe PDF File), 168 KB - pediatrics_v7i1e59171_app1.pdf]

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Abbreviations

CBT: cognitive behavioral therapy
DBT: dialectical behavior therapy
KT: knowledge translation
MBCT: mindfulness-based cognitive therapy
MBSR: mindfulness-based stress reduction
PRISMA-P: Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Protocols
RCT: randomized controlled trial
WHO: World Health Organization

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Review

The Feasibility and Acceptability of Using a Digital Conversational Agent (Chatbot) for Delivering Parenting Interventions: Systematic Review

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Abstract

Background: Parenting interventions are crucial for promoting family well-being, reducing violence against children, and improving child development outcomes; however, scaling these programs remains a challenge. Prior reviews have characterized the feasibility, acceptability, and effectiveness of other more robust forms of digital parenting interventions (eg, via the web, mobile apps, and videoconferencing). Recently, chatbot technology has emerged as a possible mode for adapting and delivering parenting programs to larger populations (eg, Parenting for Lifelong Health, Incredible Years, and Triple P Parenting).

Objective: This study aims to review the evidence of using chatbots to deliver parenting interventions and assess the feasibility of implementation, acceptability of these interventions, and preliminary outcomes.

Methods: This review conducted a comprehensive search of databases, including Web of Science, MEDLINE, Scopus, ProQuest, and Cochrane Central Register of Controlled Trials. Cochrane Handbook for Systematic Review of Interventions and PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines were used to conduct the search. Eligible studies targeted parents of children aged 0 to 18 years; used chatbots via digital platforms, such as the internet, mobile apps, or SMS text messaging; and targeted improving family well-being through parenting. Implementation measures, acceptability, and any reported preliminary measures of effectiveness were included.

Results: Of the 1766 initial results, 10 studies met the inclusion criteria. The included studies, primarily conducted in high-income countries (8/10, 80%), demonstrated a high mean retention rate (72.8%) and reported high acceptability (10/10, 100%). However, significant heterogeneity in interventions, measurement methods, and study quality necessitate cautious interpretation. Reporting bias, lack of clarity in the operationalization of engagement measures, and platform limitations were identified as limiting factors in interpreting findings.

Conclusions: This is the first study to review the implementation feasibility and acceptability of chatbots for delivering parenting programs. While preliminary evidence suggests that chatbots can be used to deliver parenting programs, further research, standardization of reporting, and scaling up of effectiveness testing are critical to harness the full benefits of chatbots for promoting family well-being.

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KEYWORDS

chatbot; parenting intervention; feasibility; acceptability; systematic review; implementation

Introduction

Background

Parenting, even in ideal conditions, is a stressful and challenging experience that can manifest in a variety of ways, such as emotional distance from the child, exhaustion in the parental role, decrease in self-efficacy, and loss of a sense of accomplishment as a parent [1]. Parental mental health issues can significantly impact the behavioral outcomes of children, particularly depression and anxiety [2,3]. Thus, finding cost-efficient and scalable approaches to improve parenting skills, reduce parental stress, and support healthy child development is critical to promoting family well-being. In low- and middle-income countries (LMICs), the effects of poverty are exacerbated by existing public health emergencies such as humanitarian crises, displacement, and poor mental health care [4]. These emergencies are associated with increases in violence against children which, in turn, is associated with poor outcomes such as behavioral problems, intimate partner violence, and low cognitive stimulation [4]. Preventing and reducing child maltreatment and its negative developmental outcomes are also linked to the United Nations Sustainable Development Goals (eg, 16.2: “End abuse, exploitation, trafficking and all forms of violence against and torture of children” and 1.3: “Implement nationally appropriate social protection systems and measures for all, including floors, and by 2030 achieve substantial coverage of the poor and the vulnerable”) [5]. Global emergencies such as pandemics, climate change–related natural disasters, and conflict-related displacement have only further highlighted the increasing need to provide support to families coping with stress and promoting a positive child-parent relationship.

Parenting Programs

Parenting programs (also “parenting skills training”) are interventions that aim to improve parenting skills and support parents in acquiring knowledge and or skills to improve the health and well-being of children, including improving the parent-child relationship [6]. These programs, often conducted in group settings, can have a range of theoretical underpinnings and are typically manualized. They are flexible in length, typically ranging 8 to 12 weeks, and can be delivered in a variety of community settings by trained facilitators or subject matter experts [7]. Delivery components typically include (1) presentation of new information (eg, a framework for communicating with the child during an argument), (2) introduction of exercises and opportunities for guided practice (eg, structured scenarios with role-playing), (3) facilitated group discussion, (4) home assignments to apply learned skills with children, and (5) opportunities to provide feedback and discuss home assignments [8].

Programs can be designed for parents individually, as couples (if applicable), with children or adolescents present, or without. Typically, these programs aim to achieve a combination of (1) *educating* parents by providing new information, (2) shifting *attitudes* about parenting practices, and (3) changing the *behavior* of parents [9].

There is extensive evidence to suggest that parenting programs can increase positive parenting skills, improve the parent-child relationship, reduce the use of harsh discipline, and improve child behavioral problems [5]. Programs have been specifically designed for resource-limited settings [10,11], and some can be effectively integrated with other public initiatives such as cash transfer programs [12]. Programs such as Incredible Years, Triple P, Parent-Child Interaction Therapy, Parent Management Training Oregon, Strengthening Families, and Parenting for Lifelong Health have demonstrated to have shown positive outcomes and, in some cases, long-lasting effects [5]. The effectiveness of parenting programs has led to international promotion and scale-up with the support of organizations such as the United Nations International Children’s Emergency Fund and the World Health Organization [13]. Effective scale-up of parenting programs may also thus create a delivery pipeline for other related interventions, such as parental or child-specific mental health interventions, gender-based violence reduction interventions, or integration with other public health initiatives.

Digital Behavior Change Interventions

Digital behavior change interventions (DBCIs), also referred to as behavioral intervention technology-based interventions, are interventions that use technology to support and promote healthy behaviors [14]. These may include interventions supported or delivered via a range of technologies such as websites, mobile apps, software, sensors, or hardware devices to change emotions, behaviors, or cognitions [15,16]. DBCIs can be used to increase the reach of in-person social interventions, particularly to populations that lack access to in-person programs or where in-person services are unavailable. DBCIs can be *guided*, which includes a significant in-person, synchronous component to support implementation, such as an internet-based program for reducing anxiety, which also includes regular low-touch support from a therapist or peer support [17]. They can also be *self-guided*, in which the intervention is administered completely digitally and can be completed asynchronously, similar to a manualized workbook-driven intervention [18,19]. DBCIs are often used in health settings [20-22].

Chatbots

Digital conversational agents, or “chatbots,” are a type of self-guided DBCI. Chatbots respond to written and spoken language with text or spoken language, which can be prewritten or generated by artificial intelligence. Their capability is far-ranging; the simplest implementation of chatbots uses predefined algorithms where specific outputs are triggered by specific inputs from the user, while a highly sophisticated chatbot may use an artificial intelligence model to generate novel responses and learn from a user’s behavior to personalize responses over time [23]. Chatbots can be particularly useful for emulating human interaction and have been used successfully in physical health care, mental health care, and educational settings. In some cases, chatbots have demonstrated levels of trust with study participants similar to in-person interventions with physicians, therapists, or educators [19,24,25]. Chatbots can also be combined with other intervention modalities to support sustained engagement or on-demand, interactive access to intervention content [26,27].

Chatbot-based implementations of parenting programs can be delivered via internet-based messaging platforms (eg, Facebook Messenger, WhatsApp, and Signal); mobile apps that embed the chatbot within; and SMS text messaging, which does not require a mobile internet connection, is capable of sending multimedia content, and can be accessed at any time. SMS text messaging–based support messages have already been used to support in-person parenting programs in LMICs [28]. Their automated and highly customizable design makes the mode of delivery potentially useful for intervention settings that lack access to in-person services, require flexibility in participating in an intervention (such as a parenting program), or prefer a lower-intensity form of intervention. SMS text messaging delivery also has cost implications for providers, making them less feasible for wide-scale use in low-resource settings without government or telecom provider partnerships. With the introduction of powerful large language models capable of replicating highly accurate syntax and tone, there is a newfound need to understand the extent to which chatbot technology can be a suitable method for delivering interventions to populations experiencing barriers to in-person implementations.

Past reviews have examined the feasibility, acceptability, intervention characteristics, and effectiveness of digital parenting interventions, particularly for infants and young children [29,30]. These reviews have focused primarily on more complex digital modalities that include internet-based multimedia content, digitally supported interventions with primary in-person components, and technology that connects parents with in-person support [31,32]. Little work has focused on self-guided digital interventions such as chatbots. Preliminary pilots and trials of parenting programs delivered via chatbots have begun to be published, though, to the best of our knowledge, no synthesis has examined whether the evidence indicates that chatbots are a feasible and acceptable method for delivering parenting programs. Answering this question is critical for guiding future research in scaling up chatbot-based parenting programs. It is essential to evaluate the feasibility and acceptability of chatbot-based parenting programs as a whole, rather than focusing solely on individual studies. Understanding these aspects is crucial for determining the viability of this technology as a route for intervention delivery as well as developing it further. The aim of this study is to systematically review the existing studies reporting on the feasibility and acceptability of chatbot-delivered parenting interventions. We aim to describe the various types of parenting chatbots, explore the methods used to assess the feasibility and acceptability of chatbot-based parenting interventions, and evaluate the quality of evidence supporting this technology.

Methods

Reporting Guidelines

The design of this study followed the *Cochrane Handbook for Systematic Review of Interventions* [33] and the updated 2020 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines for conducting and reporting systematic reviews [34].

Inclusion Criteria

Studies were included if they targeted parents of children aged 0 to 18 years. The intervention needed to report an explicit focus on improving overall psychosocial well-being of family via advances in parenting, including reducing negative phenomena such as violence against children, abuse of children, and harsh parenting practices. The intervention needed to be delivered in the form an interactive conversational agent ("chatbot") but could do so through any digital modality (internet based, mobile app, or SMS text messaging). For example, a website delivering a parenting skills training program to reduce child behavior problems and improve the parent-child relationship would only be included if the content was delivered via an identifiable, automated conversational agent within the website. Chatbots with and without artificial intelligence models for generating responses were included. In addition, the chatbot needed to be the primary component of intervention delivery, rather than as an add-on for monitoring or support purposes; studies with in-person components outside of onboarding were excluded. Intervention content could vary but needed to aim mainly and explicitly to improve parenting skills, including knowledge of or attitudes about parenting practices, self-care as it relates to parenting, the parent-child relationship, and preparing for parenting. Interventions that included lifestyle-related interventions were only included if the intervention content targeted changes in parental knowledge, attitudes, or behaviors. Studies in English and Spanish were included. No time restrictions were imposed on articles, though it was noted that studies before the 1990s would likely not meet the criteria, as this predated the internet. Data extracted from peer-reviewed published articles and gray literature, such as reports of ongoing studies, protocols, conference proceedings, and dissertations, were included to identify full reports of studies. Any study design meeting the abovementioned criteria was included to characterize this literature as broadly as possible.

Exclusion Criteria

Solely qualitative articles were excluded. Studies with in-person components outside of onboarding were excluded. Studies that did not explicitly focus on improving overall psychosocial well-being of family via advances in parenting, including reducing negative phenomena such as violence against children, abuse of children, and harsh parenting practices, were excluded. Articles that did not feature an interactive conversational agent ("chatbot") or were delivered via nondigital modalities were excluded. Studies where the chatbot was not the primary component of intervention delivery were also excluded. Articles in languages other than English and Spanish were excluded. Studies with no clear target on improving parenting skills, including knowledge of or attitudes about parenting practices, self-care as it relates to parenting, the parent-child relationship, and preparing for parenting, were not considered. Interventions that included lifestyle-related interventions but did not target changes in parental knowledge, attitudes, or behaviors were excluded.

Primary and Secondary Outcomes

Primary outcomes of this review were measures of implementation, acceptability, and secondary measures of family well-being as measured by changes in parental knowledge, attitudes, behaviors, and psychological well-being (including symptoms of anxiety or depression) as well as child outcomes, such as reduction of behavioral or emotional problems. If multiple measures of implementation and acceptability were reported, these were categorized into primary and secondary measures with respect to their reporting within the study.

Due to the nascency of the literature, criteria for inclusion were developed to maximize *sensitivity* across population and outcome descriptors, while also maximizing *specificity* with the type of intervention. Nonrandomized studies, including feasibility and acceptability studies, as well as quasi-experimental studies, were included alongside randomized trials. Further details regarding the inclusion and exclusion criteria can be found in Textbox 1.

Textbox 1. Intervention inclusion and exclusion criteria.

Inclusion criteria

- Intervention targets parents of children aged 0 to 18 years
- Intervention aims to improve the overall psychosocial well-being of family via changes in parenting, including reducing negative phenomena, such as violence against children
- Intervention is delivered via a digital, interactive conversational agent (“chatbot”)
- Intervention primarily and explicitly aims to improve parenting skills, including enhancing knowledge and attitudes

Exclusion criteria

- Intervention is delivered to children (but may have parental involvement)
- Intervention aims to improve outcomes tangentially related to well-being of family, including health reminders, disease prevention, weight management, and smoking cessation
- Intervention does not contain a digital, interactive conversational agent (websites, SMS text messages with no interactive component, and mobile apps with no interactive component)
- Intervention uses a digital chatbot as an add-on for monitoring or support purposes, rather than as a primary delivery mechanism
- Intervention delivers skills that are tangentially related to good parenting (child weight management, reducing unhealthy food intake, vaccine uptake, and health reminders) but are not parenting skills (mental health interventions)

Search Strategy

The search was conducted in August 2023. Web of Science (Science Citation Index, Social Sciences Citation Index, Conference Proceedings Citation Index, and Emerging Sources Citation Index), MEDLINE, Scopus, ProQuest (Social Sciences Collection), and Cochrane Central Register of Controlled Trials were searched. All database searches were exported to Covidence systematic review software [35] for deduplication and screening. The search string was developed using the PICO framework (Population, Intervention, Comparator, Outcomes), shown in Textbox 1. A full search string can be found in Multimedia Appendix 1.

Study Selection

All stages of the study process, including title and abstract screening, full-text review, data extraction, and quality assessment, were double-screened by MCK and AR. Screeners were blinded until the team met to resolve conflicts. Conflicts not resolved by consensus were advised on by the senior reviewer (FG). Study selection was conducted independently by the main coder (MCK) and a trained coder (AR) by title, abstract, and then full text. Intercoder reliability was maintained at each step of the screening process. The main coder opted to establish reliability at each stage independently to account for the range of considerations associated with each stage [36]. The main coder recruited and trained the second coder by jointly screening 25 (1.4%) of the 1766 included studies. Any questions about inclusion criteria were addressed before independent screening of titles and abstracts. Full-text screening involved joint training and screening of 10 studies. The main coder provided training on data extraction variables, and discussions followed independent coding of a small number of selected studies. Percent agreement was calculated at each stage by comparing agreements to selections. Successful training required ≥90% agreement, exceeding standard practice [36,37]. Any disagreements not resolved by discussion were settled by a third coder. Textbox 1 was used as a reference for screening, and the author and second coder met twice to resolve conflicts identified between screening. All excluded articles were labeled with a reason for exclusion.

Data Extraction

Before extraction, separate articles were selected from the study by Vissenberg et al [38], a different but topically relevant review to practice applying the data extraction template to a similar group of studies. Due to the heterogeneous nature of study design and interventions, a meta-analysis synthesis was not possible. Instead, the features of interest included variable measures of feasibility and acceptability, type of delivery, and income level of intervention setting, and any measures of effectiveness were narratively synthesized.

Primary feasibility outcomes were operationalized as the included study's main reported quantitative metric of engagement, which could vary between studies. Primary acceptability outcomes were operationalized as the included study's main reported quantitative metric of acceptability, and if multiple measures were reported, measures of participants' (1) overall appraisal of the intervention, (2) reported likelihood of using the intervention again, or (3) likelihood of recommending the intervention to someone else were considered primary measures. Secondary feasibility outcome measures were any additional quantitative measures of engagement. Secondary acceptability measures were any additional quantitative or qualitative variables related to participants' experience with the intervention, or (2) or (3), if (1) was reported. Any effectiveness measures reported by each study was also extracted. Reported barriers and facilitators to use, either through free-response items on end point surveys or through participant feedback, were also extracted.

Assessment of Study Quality and Risk of Bias

Studies that met the eligibility criteria were assessed for quality and relevance using the Weight of Evidence (WoE) framework [39]. Each study was scored across three criteria: (1) WoE A: general quality, (2) relevancy of study design to review question, and (3) relevancy of intervention design to review question, to produce (4) an overall WoE score. Each criterion was given a score of 1 ("Low"), 2 ("Moderate"), or 3 ("High"). Criteria (2) and (3) are prespecified in the study by Gough [39]. Full WoE assessment criteria can be found in Table 1. To assess study quality more objectively, the *Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields* (QualSyst) [40], which is designed for mixed methods, pre-post, and randomized designs, was used to score WoE A. Example items from QualSyst include the following: "Was the research question sufficiently described? (item 1)," "If interventional and blinding of subjects was possible, was it reported? (item 7)," and "Were the outcome measures well-defined and robust to measurement bias? (item 8)." A full list of items is provided in Multimedia Appendix 2.

Table 1. Weight of Evidence assessment rubric.

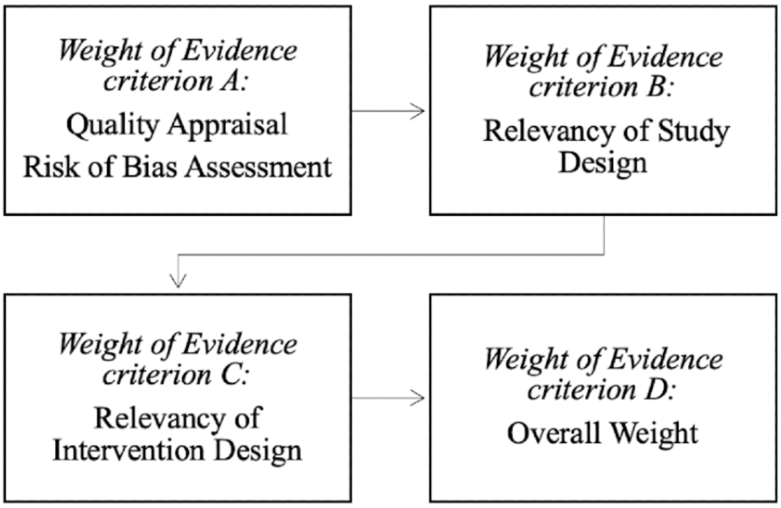
	Criterion A: QualSys[a] quality appraisal tool score	Criterion B: relevancy of study design	Criterion C: relevancy of intervention design	Criterion D: averaged weight (criteria A, B, and C)
Low (=1.00)	0-0.55	• Does not mention feasibility and/or acceptability AND/OR • Makes conclusions about feasibility and acceptability without a clear link to evidence	• <60% of the content delivered is parent skills training OR • Partially automated, but manual components OR • Has an equal number of components that are nondigital	1.00-1.75
Moderate (=2.00)	0.56-0.80	• Mentions feasibility and acceptability measures AND/OR • Measures are not adequate for assessing feasibility and acceptability; makes strong conclusions with mixed evidence	• >60% of content is parent skills training OR • Primarily automated but includes at least 1 manual component OR • Mostly digital, may have some nondigital components	1.76-2.65
High (=3.00)	0.81-1.00	• Explicitly reports feasibility and acceptability measures or effectiveness (if feasibility and acceptability has been established) AND/OR • Measures are adequate, and conclusions about feasibility and acceptability are in line with the evidence provided	• Only delivers parenting training (which may include parenting-specific stress management) AND • Fully automated OR • Fully interactive • Completely digital	2.66-3.00

[a] QualSys: Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields.

Cut points from QualSyst were used to harmonize scoring between the 2 tools, where a QualSyst score of 0 to 0.55 was translated to a WoE score of 1 ("low"), 0.56 to 0.80 to 2 ("moderate") and 0.81 to 1.00 to 3 ("high").

To assess risk of bias, domains from the Cochrane Risk of Bias in Nonrandomized Studies of Interventions and Risk of Bias Tool version 2 [41,42] were identified and assessed against the 14 criteria in the QualSyst tool. Descriptions of how to assess each domain in the Cochrane Risk of Bias in Nonrandomized Studies of Interventions were used to guide the review process. The quality and risk of bias assessment process is described in Figure 1.

Figure 1. Quality and risk of bias assessment.

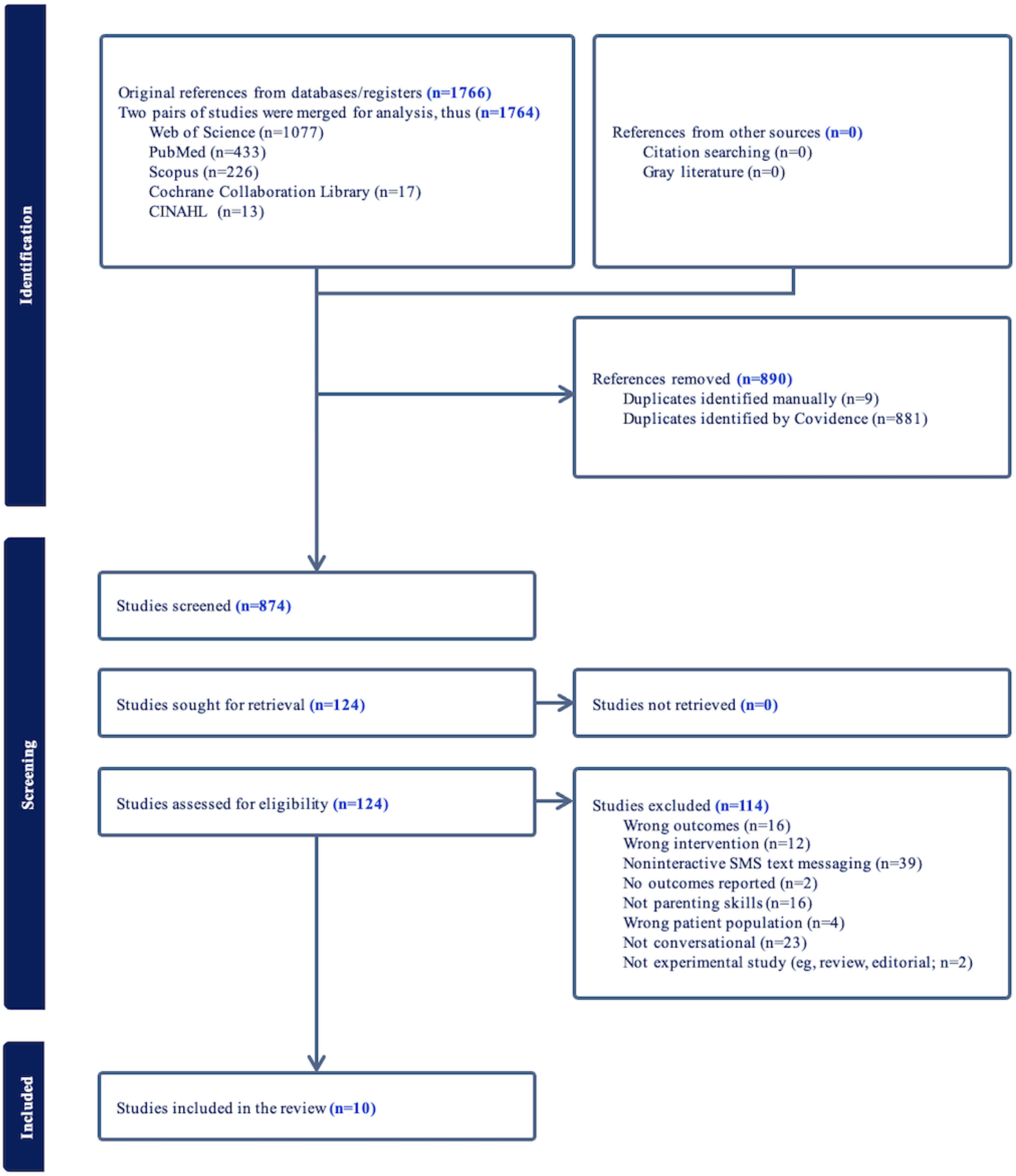


Results

Included Studies

The search yielded 1766 results, and 874 studies remained after deduplication (Figure 2). After title and abstract screening, full text of 124 studies were screened and 114 were excluded, leaving 10 included studies. The most common reasons for exclusion were the intervention being noninteractive (39/114, 34.2%); digital, but not in a conversational messaging format (23/114, 20.1%); did not include parenting-related outcomes (16/114, 14%); and did not deliver parenting skills as a primary component of the intervention (16/114, 14%). The complete list of exclusions can be seen in Figure 2. A total of 4 articles were merged into 2 studies: (1) the studies by Fletcher et al [43,44], due to the 2019 publication describing the development and intervention content and 2020 describing the feasibility study, and (2) the studies by Entenberg et al [45,46], as they report on different, relevant aspects of the same trial.

Figure 2. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) study flow diagram.



Among the 10 studies included, 8 (80%) were conducted in high-income countries—3 (30%) in Australia [43,44,47]; 2 (20%) in Argentina [46,48]; and 1 (10%) each in the United States [49], Taiwan [50], and Singapore [51]. A total of 2 studies were carried out in middle-income countries, with 1 in Brazil [52] and 1 in Peru [53]. The total participant pool across all studies (n=772) was drawn from diverse settings, including inpatient, outpatient, university, and community settings. The studies focused on parents with children spanning various age groups: 3 studies involved parents with infants aged 0 to 3 months [43,44,52], 4 studies targeted parents with children aged 2 to 11 years [46-48,50], 1 study addressed adolescents aged 13 to 18 years alongside the parenting intervention [49], another study included pregnant women and mothers with children aged 0 to 6 years [53], and 1 study focused on prospective parents, evaluating the intervention with men and women of childbearing age who mostly did not have children [51]. A full description of the characteristics of the included studies can be found in Table 2.

Table 2. Sample characteristics of the included studies.

Study, year	Country	Service setting	Income level	Study design	Population	Participant mean age	Method of recruitment	Total number of participants	Intervention length	Theoretical orientation (if stated)	Delivery type
Entenberg et al [45,46], 2023	Argentina	Not included	High-income setting	Randomized controlled trial	Parents in Argentina with at least 1 child aged 2 to 11 years	35.85 (SD 5.77)	Facebook posts and email list advertisements	170 (intervention group: 89; control group: 81)	15 minutes	Incredible Years Parenting Programme; behavior change techniques	Facebook Messenger
Fletcher et al [43], 2017	Australia	Not included	High-income setting	Pilot feasibility and acceptability study	Fathers expecting a child within 6 months or fathers with infants younger than 3 months	33.7 (range 21-59)	Advertisement posters in community centers, through Facebook forums, and at the hospital neonatal intensive care unit via trained staff	46	6 weeks	Psychoeducation, mood monitoring, and awareness	SMS text messaging
Fletcher et al [44], 2020	Australia	Not included	High-income setting	Pilot feasibility and acceptability study (no effectiveness)	Partners of mothers diagnosed with perinatal mental illness	29.3	Partners were invited after clinical interview at regional health centers	23	44 weeks	Psychoeducation, mood monitoring, and awareness	SMS text messaging
Mason et al [49], 2021	United States	Health care clinic	High-income setting	Randomized controlled trial	Parents of adolescents (aged 13 to 18 years) participating in the substance abuse prevention program	Parent mean age not reported	Community partner advertisement	52 (parents); 69 (adolescents)	4 weeks	Behavioral-skill framework (Dishion et al [54])	SMS text messaging
Entenberg et al [48], 2021	Argentina	Not included	High-income setting	Randomized controlled trial	Parents aged ≥18 with at least 1 child aged 2 to 10 years; not seeking psychological treatment	33.3% (n=11) of the participants were aged between 30 and 33 years, 30.3% (n=10) aged between 34 and 37 years, and 36.4% (n=12) were aged ≥38 years	Facebook posts	33	20 minutes	Incredible Years Parenting Programme	Facebook Messenger
Barreto et al [52], 2021	Brazil	Hospital	High-income setting	Intervention development and acceptability evaluation	New mothers aged >18 years with newborns of at least 24 hours old	24.4	Approached by research team in hospital and asked to participate	142	No time limit	Not stated	Within app

Study, year	Country	Service setting	Income level	Study design	Population	Participant mean age	Method of recruitment	Total number of participants	Intervention length	Theoretical orientation (if stated)	Delivery type
Downing et al [47], 2018	Australia	University (for initial onboarding)	High-income setting	Randomized controlled trial	Parents of children aged 2 to 4 years	Intervention group: 36.1 (3.9); control group: 34.1 (3.7)	Snowball method through community outreach and advertising	57 (Intervention group=30, control group =27)	6 weeks	Behavior change (CALO-RE)	Text messaging
Yu et al [50], 2023	Taiwan	Not reported	High-income setting	Intervention development and acceptability evaluation	Parents with childrearing difficulties	NR[a]	NR	58	12 weeks	Behavior change	Within app
Chua et al [51], 2023	Singapore	Tertiary public hospital	High-income setting	Intervention development and acceptability evaluation	Men and women of childbearing age; 10 with no children, single	26.7	Convenience sampling	11	28 weeks	Bandura self-efficacy theory, positive psychology, and psychoeducation	Within app
Jäggi et al [53], 2023	Peru	In home for onboarding and baseline interviews	Low-income setting	Pilot feasibility and acceptability study	Pregnant women and mothers with children aged 0 to 6 years	29	Convenience sampling	180	20 weeks	NR	Facebook Messenger

[a] NR: not reported.

Study Design and Intervention Structure

A total of 3 studies were randomized, 4 were nonrandomized evaluations of intervention feasibility and acceptability, and 3 were intervention development reports that included preliminary surveys of acceptability. A full description of the characteristics of included studies can be found in Table 2. Participants were recruited by diverse methods, with advertisements on social media in parent groups being the most common. Sample sizes ranged from 11 to 170 participants. The 10 studies evaluated 8 distinct interventions delivered via SMS text messaging (4/10, 40%), Facebook Messenger (3/10, 30%), and a mobile app (3/10, 30%). While all the intervention aims included improving parenting skills, specific content varied and included positive praise, improving the parent-infant relationship, reducing parental stress, improving communication skills, and improving parental confidence. Intervention duration ranged from 15 minutes to 11 months, with 1 intervention [52] allowing parents to use the chatbot as long as needed with a prespecified end time to the pilot or experimental period. Theoretical orientation was not clearly reported in most cases, but behavior change (4/10, 40%) and psychoeducation (3/10, 30%) were the most reported.

Factors Related to Implementation and Acceptability

Interactivity

Interactivity varied between interventions and was difficult to compare. One dimension of interactivity is the ability of the chatbot to respond realistically to queries or responses from participants. For example, the chatbot assessed by Entenberg et al [45,46,48] could be considered highly interactive, as they were supported by an artificial intelligence model that produced realistic speech-like text and could respond to participant messages that may have not been predicted by intervention developers. The other interventions were automated but used prewritten text message flows. As a result, intervention developers either predicted possible responses that the chatbot could respond to, or, more often, had specific response options embedded in messages to cue participants. Another dimension of interactivity is the extent to which content requires a response from participants. Generally, while some included studies gave examples of messages or templates, no studies had content flows accessible to independently assess the types of responses required from participants to interact with the content. Barreto et al [52], Entenberg et al [45,46,48], and Mason et al [49] delivered content that was both conversational and required complex textual responses to prompts from the chatbot, whereas Fletcher et al [43,44] and Downing et al [47] used templated messages that embedded cued responses to participants in messages and did not require complex textual inputs from the participant to continue. The latter studies also sent messages less frequently, and some messages did not require responses from participants. Considerable variation in both the degree of interactivity and the theoretical orientation of interventions, coupled with differences in their duration, poses a significant challenge in assessing the influence of interactivity on participant engagement.

Length of the Intervention

Intervention length also varied substantially, which can be attributed in part to variable approaches for the intended aim of the intervention for the participant. The studies by Barreto et al [52] and Fletcher et al [43], for example, were explicitly designed to serve as an on-demand source of information for parents to access or be prompted by over a long period, as evidenced by the substantially longer intervention period (note: the study by Barreto et al [52] does not specify a maximum length of intervention). In contrast, the intervention tested by Entenberg et al [45,46,48] was brief, lasting <30 minutes, and focused on a specific parenting skill. These interventions represent 2 extremes in terms of length within the review and demonstrate the relationship between purpose and duration. This relationship is also evident when examining the relative interactivity of the chatbot interventions. For instance, the intervention by Entenberg et al [45,46,48] involved a brief but highly detailed interactive exchange between the chatbot and the participant. In contrast, interventions by Mason et al [49] and Downing et al [47] were lighter touch, with messages requiring shorter responses that were often limited to “Yes,” “No,” or other affirmative responses.

Delivery Mode Informs Measurement Limitations

The considerable heterogeneity in measuring feasibility outcomes, such as retention, engagement, and completion, can in part be attributed to the platforms the chatbots were delivered on. For example, Barreto et al [52] delivered the chatbot in a downloadable mobile app, where it was possible to measure engagement characteristics such as mean length of engagement, which menus were accessed, and which information was accessed. Alternatively, interventions delivered via SMS text messaging, where that level of use data is not available, primarily measured engagement characteristics by number of responses or engagement with external links. Interventions delivered via Facebook Messenger reported less engagement-related data as via mobile app, but more than SMS text messaging–based interventions. Thus, a relationship between *how* the intervention is delivered and *what* engagement data can be collected exists and can affect feasibility reporting.

Quality Assessment

Overview

The 10 studies included in the review were evaluated across three criteria: (1) quality of study and risk of bias, (2) relevancy of study design to review question, (3) relevancy of intervention to review question, using a WoE framework (refer to Table 1 and Multimedia Appendix 2 for evaluation criteria). A full list of quality assessment ratings may be found in Multimedia Appendix 3.

Individual Quality and Risk of Bias

Less than of the included studies were rated as high quality with a low overall risk of bias (4/10, 40%) or moderate quality with a low-to-moderate overall risk of bias (1/10, 10%), and half were rated as low quality with a high potential risk of bias (5/10, 50%). The most common reasons for lower ratings included unclear outcome measures, a lack of control for potential confounding variables, or unclear or inadequate analysis.

Relevancy of the Study Design

Most studies had highly relevant study designs (6/10, 60%). The most common reasons for studies being rated as “low” in relevancy of study design was due to not primarily measuring feasibility and for making conclusions about feasibility or acceptability without clear links to reported evidence.

Relevancy of the Intervention

Most studies had moderate (6/10, 60%) or highly relevant interventions (3/10, 30%). The most common reason for lower ratings were additional content unrelated to parenting skills rather than core content being unrelated to parenting skills.

Overall WoE

In total, 30% (3/10) of the studies demonstrated “high” quality, indicating robust methodology and high relevance to the research question. Of the 10 studies, 3 (30%) were rated as “low” quality, indicating issues with reporting and measurement. For example, Barreto et al [52] measured participant engagement by the mean number of access events but failed to clarify how this was operationalized or how confounding factors such as repeated access within a short period were controlled in the study. Overall, the evidence was moderately weighted (mean 2.36, SD 0.65), with 3 (30%) of the 10 studies receiving a high-weighted evidence rating, 4 (40%) studies receiving a moderate-weighted evidence rating, and 3 (30%) studies receiving a low-weighted evidence rating. This indicates that the current evidence moderately supports the feasibility and acceptability of chatbot-delivered parenting programs, but substantial development in both the evidence and reporting of findings is needed.

Feasibility and Acceptability

Primary Implementation Measures

Retention was the most reported primary measure of implementation (8/10, 80%), though the operationalization of the measure varied between the 8 studies. A full description of the feasibility, acceptability, and preliminary outcomes can be found in Table 3. One study [52] reported the mean number of times the chatbot was accessed as a primary implementation measure, and 1 study [51] did not report any implementation measures. A total of 3 studies measured retention by participants fully completing the program, 2 studies [43,44] measured retention by participants who did not opt out of the intervention by the end of the evaluation period, 2 studies [47,50] measured retention by the number of participants who completed the postintervention survey, and 1 study measured retention by the number of active users at the end of the prespecified intervention evaluation period [53]. A weighted mean retention rate was calculated as 72.8% retention across studies, though this reflects retention rates reported by studies pooled together, without adjusting to compare similar measures to one another.

Table 3. Feasibility, acceptability, and effectiveness outcomes of the included studies.

Study, year	Total number of participants	Primary feasibility measure	Score (primary feasibility)	Secondary feasibility measure	Score (secondary feasibility)	Primary acceptability measure	Score (primary acceptability measure)	Secondary acceptability measures	Score (secondary acceptability)	Effectiveness outcome measure	Score (effectiveness)	Recommendation for use
Entenberg et al [45,46], 2023	170 (Intervention group: 89, control group: 81)	Retention	Dropout: 29% (26); completed intervention: 66% (59); completed follow-up: 28% (25)	Completion, dropout by skill and number of messages	Intervention group: 66.3% (59/81), skill 1: 17.98% (16), skill 2: 6.86% (5), skill 3: 7.35% (5), skill 4: 1.58% (1), and skill 5: 4.83% (3); number of messages: 49.8 (SD 1.53; range 20-80)	Satisfaction (1-5); Net Promoter Score (1-5)	Satisfaction: 4.19 (0.79); Net Promoter Score: 4.63 (0.66)	Survey (Likert 1-5): ease of use, comfort, absence of technical problems, interactivity, and usefulness in everyday life	Survey (Likert 1-5): ease of use: 4.66 (0.73) comfort: 4.76 (0.46) absence of technical problems: 4.69 (0.59) interactivity: 4.51 (0.77) usefulness in everyday life: 4.75 (0.54)	Self-efficacy, disruptive behavior	Mean 0.21 (SD 0.59); mean 0.37 (SD 0.96)	Recommended
Fletcher et al [43], 2017	46	Retention (*measured by number ofparticipants who did not explicitly exit the intervention*)	87%	Accessing embedded links	Embedded links: most frequently clicked= 14/65 (22%); mood tracker: 24 (52%) responded ≥1 times	Recommend to others (Likert 1-5)	4.6	Structured phone interview (11 Likert scale questions): usefulness of intervention	4.32 (0.58)	NR[a]	NR	Recommended
Fletcher et al [44], 2020	23	Retention (*measured by use of embedded links and responses to the mood tracker*)	95.6% (22/23)	Embedded links: most frequently clicked= 8/23 (34.8%); mood tracker link, no response: 6/23 (26.1%)	1 (4.3%)	Likert Survey: "The messages helped me to develop a strong relationship with my new child."	80%—agree or strongly agree	Likert survey: "The mood tracker messages, where I could respond to questions about how I was feeling, were useful for me"	43.8% (7)—agree or strongly agree	NR	NR	Recommended

Study, year	Total number of participants	Primary feasibility measure	Score (primary feasibility)	Secondary feasibility measure	Score (secondary feasibility)	Primary acceptability measure	Score (primary acceptability measure)	Secondary acceptability measures	Score (secondary acceptability)	Effectiveness outcome measure	Score (effectiveness)	Recommendation for use
Mason et al [49], 2021	52 (parents); 69 (adolescents)	Retention *(measured by number of participants who completed the intervention)*	98%	Response rate	93%	Helpfulness (measured at postintervention survey)	78%	Self-report: (1) satisfaction with no of texts and (2) use of skills	(1) 96% and (2) 91%	Parenting Practices Scale	0.34, SE 0.27, *P*=.21	Recommended
Entenberg et al [48], 2021	33	Retention *(measured by number of participants who completed the intervention)*	78.8% (26)	Number of messages sent	54.24 (SD 13.05)	Net Promoter Score (1-10)	7.44 (SD 2.31)	NR	NR	NR	NR	Recommended
Barreto et al [52], 2021	142	Mean number of times accessing chatbot	2	Length of conversation	27 seconds	Likert survey of experience and attitudes: "I liked using the GCBMB."	96.4% "Totally agree" (137)	NR	NR	NR	NR	Recommended
Downing et al [47], 2018	57 (intervention group: 30, control group: 27)	Retention *(measured by number of participants who completed the intervention)*	Intervention group: 63%, control group: 70%	Number of replies to goal monitoring messages	83.3% (145/173)	Self-report use	95% (19/20) report reading at least 9 of 12 messages	NR	NR	Children's sitting time (activPAL)	−30.6 minute/day	Recommended
Yu et al [50], 2023	58	Retention *(measured by the completion rate of the postintervention survey)*	51.7%	NR	NR	Chatbot usefulness for problem-solving *(Self-report questionnaire)*	>4.5/5 on all 6 items	NR	NR	NR	NR	Recommended
Chua et al [51], 2023	11	NR	NR	NR	NR	User acceptability testing survey, *(items 4-9; 1-7 Likert scale)*	Language appropriateness: mean=6.25; perceived friendliness: mean=5.9; enjoyability of use: mean=5.7	NR	NR	NR	NR	Recommended

Study, year	Total number of participants	Primary feasibility measure	Score (primary feasibility)	Secondary feasibility measure	Score (secondary feasibility)	Primary acceptability measure	Score (primary acceptability measure)	Secondary acceptability measures	Score (secondary acceptability)	Effectiveness outcome measure	Score (effectiveness)	Recommendation for use
Jäggi et al, [53], 2023	180	Retention *(measured by the number of active users at the end of the intervention period)*	41.7%	Intervention connectivity coverage	Urban (100%, 5/5), rural (22%, 10/44)	Chatbot usefulness (*Likert-like scale)*	87% rated "useful" to "very useful"; mean 4.37/5 (SD 1.00)	NR	NR	NR	NR	Recommended

[a] NR: not reported.

Secondary Implementation Measures

A total of 7 studies reported secondary measures of implementation. Fletcher et al [43,44] reported engagement as measured by the number of participants who accessed embedded links within the chatbot's mood tracker at least once (24/46, 52% and 8/23, 26%, respectively). In addition to overall retention, Entenberg et al [45,46] assessed retention by intervention component, reporting a 79% (26/33) retention rate after the first of 5 components, as well as the number of messages sent between the chatbot and participant (mean 49.8, SD 1.53). Entenberg et al [48] also reported the number of messages sent (mean 54.24, SD 13.05). Similarly, Barreto et al [52] measured mean duration of chatbot-participant interaction (27.0 seconds). Mason et al [49] measured engagement by the percentage of participants who responded to the 3-month follow-up survey (48/52, 92%). Jäggi et al [53] was the only study that reported a non–engagement-related secondary measure of implementation examining intervention connectivity coverage for the chatbot across 49 test sites (urban: 5/5, 100%; rural: 10/44, 22%).

Primary Acceptability Measures

All 10 studies used self-report data to assess acceptability. The most common measure was a Likert-like scale with an item asking participants to indicate their overall attitudes toward the chatbot. Items varied in focus. Fletcher et al [44] asked participants to indicate the extent to which they agreed that "The messages helped me to develop a strong relationship with my child," whereas Barreto et al [52] asked participants to rate the extent to which they agreed with the statement "I liked using the chatbot." A total of 2 studies [46,48] assessed the likelihood of recommending the chatbot to a friend, as measured by the Net Promoter Score [55]. The study by Downing et al [47] was the only study that reported self-reported use as secondary measure of acceptability, as indicated by the percentage of participants reported reading at least 9 (95%) of 12 messages. While a weighted mean was not calculated due to the considerable heterogeneity in survey items, all studies reported high acceptability across their chosen measures.

Secondary Acceptability Measures

A total of 5 studies reported secondary measures of acceptability. All 5 studies [43,44,46,48,49] used quantitative self-report surveys to identify participant attitudes about ease of use, perceived usefulness, and comfort with the chatbot. Similar to primary acceptability and primary feasibility measures, there was considerable heterogeneity, though all studies reported high acceptability across additional measures. Entenberg et al [45,46] reported high ease of use (mean 4.66/5.0, SD 0.73), Fletcher et al [43,44] found high perceived usefulness (mean 4.32/5.0, SD 0.58; approximately 43.8% of participants agreed that the mood tracking interactive component was helpful), and Mason et al [49] found that 91% of the participants reported using skills learned from the chatbot within 3 months after the program.

Preliminary Effectiveness

A total of 3 studies reported effectiveness outcomes. Entenberg et al [45,46] observed a small positive effect of the intervention on mean parental self-efficacy (Cohen d=0.36; mean 0.21, SD 0.59) and a moderate decrease in disruptive behavior (Cohen d=0.39; mean 0.37, SD 0.96), though neither reached statistical significance. Mason et al [49] also identified a small positive effect on parenting practices, measured by the Parenting Practices Scale (Gorman-Smith et al [56]; $F_{1,150}$=0.57), but it did not achieve statistical significance (P=.45). Downing et al [47] did not report effectiveness outcomes related to parenting but focused on child sedentary behavior, a primary outcome related to the intervention aim. They found a significant positive effect of the intervention, indicating a decrease in the average number of minutes children spent sedentary per day (adjusted mean –22.3 min/day; 95% CI –80.8 to 36.3), suggesting preliminary effectiveness.

Barriers and Facilitators to Use

A total of 5 studies reported on barriers and facilitators to use within the chatbot interventions [43,46-48,53]. All studies collected data through structured interviewing and Likert-like surveys. Parental busyness, impersonal and inflexible response from chatbots, technical problems, and repetitive or unengaging information were reported as barriers to use. Participants solely owning the device used for the intervention, technical support call buttons, encouraging messages, communication style and advice perceived as helpful, goal setting, and easy-to-understand messages were reported as facilitators for use. While other studies discussed potential barriers and facilitators, none reported formal methods for assessing these within the study.

Discussion

Principal Findings

This is the first study to review the implementation and acceptability characteristics of chatbot-delivered parenting interventions. Findings suggest that chatbots can be a feasible and acceptable method for delivery, but further research is required to assess whether engagement with the technology can be sustained as well as effectiveness compared to other digital parenting interventions. We identified an average retention rate of 72.8% across included studies. While all included studies individually conclude that chatbot interventions are implementable and acceptable, substantial development is needed in the standardization of definitions, measurements, and reporting. In addition, there is some evidence supporting moderate levels of implementation feasibility and acceptability of these interventions in high-income countries. However, there is limited evidence in middle-income countries and none in low-income countries. Implementation, primarily measured by retention, appeared to be high across included studies, as did retention as measured by program completion. Acceptability, primarily measured by self-report items about attitudes toward satisfaction and usefulness, was also considerably high in all included studies.

In addition, this review found that the delivery of parenting chatbots cited in included studies encountered external barriers such as parental busyness and internal barriers such as inflexible responses from the chatbots, technical problems, or repetitive information. Generally, chatbots were more acceptable when they used encouraging messages, easy-to-understand content, and content that was perceived as helpful or involved incremental goal setting. However, this review did not focus on identifying qualitatively reported barriers and facilitators to use, and no included studies looked specifically at these factors.

Measuring Implementation and Acceptability in Digital Health Interventions

The high rates of retention and program completion reported from included studies on parenting program chatbots was unexpected given that digital health and mental health interventions generally suffer from low retention rates. While completely digital parenting programs have not been widely studied (refer to the study by Hansen et al [57], which reports retention rates of >70% for in-person interventions that are assisted by technology), a reasonable comparison to a parenting chatbot may be self-guided mental health mobile apps, as they are asynchronous, primarily or totally digital, and interactive. By contrast, Baumel et al [58] reported in a review of 93 mental health mobile apps that the median retention rate after 15 days was 3.9%. In a meta-analysis of 10 randomized controlled trials (n=1090) of digital self-guided interventions for depression, Karyotaki et al [59], found that 40% of participants dropped out before completing 25% of the intervention, and only 17% of the participants completed all the intervention. By contrast, this review reported that, across included studies, 72.8% of participants completed the intervention, which is higher than past reviews of digital health interventions have reported.

There are a few possible explanations for the high retention rates reported in this review. First, implementation and acceptability studies are particularly prone to publication bias, where researchers tend to publish studies with favorable outcomes for publication [60]. Second, compared to other types of digital health interventions that report lower retention, these interventions engaged parents with content primarily about the child and parent-child relationship, rather than solely the parent. This could be more compelling and not provoke the stress and subsequent avoidance associated with self-guided digital health and mental health interventions, which require internal motivation. Third, these interventions took place in high-income settings with onboarding and support from research teams for technical challenges, which could reduce attrition related to difficulty of use, stress, and lack of digital literacy. Finally, these high retention rates could indicate a more fundamental issue with measurements of engagement in digital interventions. Measuring engagement often includes retention, but retention can be measured differently depending on the study design and type of intervention. This lack of standardization in reporting guidelines can promote reporting bias in favor of statistics that indicate greater engagement. Standard measures of engagement, such as response or completion rate, could reduce heterogeneity in reporting. In this review, retention was operationalized variably across studies and did not necessarily align with standard definitions, opting instead for constructs such as program completion or end-survey completion. In some cases, program completion was indicated by not opting out of the chatbot, which may be alternatively described as program enrollment, rather than completion.

Operationalization of engagement also varied, leaving it subject to reporting bias. Some studies measured factors such as the number of interactions, length of responses, or number of modules completed. In contrast, studies limited to SMS text messaging could only track whether participants clicked on embedded links or responded to interactive messages. SMS text messaging–based interventions are also limited in how they track engagement. Links are commonly used to direct participants to a web browser page where engagement can be measured, given that SMS text messaging services lack the same depth of user data collection as mobile as. This highlights how the variability in intervention and study design can impact engagement and, as a result, reporting of retention. The ability to capture engagement data varies by platform; for example, a chatbot embedded in a mobile app can track engagement throughout the digital environment, whereas integrations with existing messaging platforms such as WhatsApp and Facebook Messenger can only collect engagement data as moderated by the platforms themselves. Current literature suggests using multiple valid measures of engagement to build a more complex, multidimensional model of engagement, though this is not always possible with SMS text messaging–delivered interventions. By contrast, trials of in-person parenting programs typically report higher retention rates, though these vary considerably due to barriers associated with in-person delivery [28,61].

Limitations and Strengths

The review also had several limitations. First, the included studies were conducted exclusively in high-income settings, which severely limits the generalizability of these findings to LMICs. Digital literacy, access to consistent cellular service, access to private devices, and privacy concerns disproportionately affect populations in LMIC settings, which many of the included studies did not need to address. Second, the broad inclusion criteria contributed to the significant heterogeneity observed in the types of interventions studied, although some included interventions only marginally met the criteria. Third, the range in study quality may limit the generalizability of the study conclusions. Fourth, the heterogeneity of measurements and small sample size made conducting a meta-analysis impossible. The review also had several strengths. First, it is the first study to review chatbots as a mode for delivering programs that promote family well-being and searched a wide range of databases and gray literature comprehensively. Second, it uses a WoE approach to assess quality and risk of bias, which can more carefully account for study design, intervention design, and study quality when assessing the overall quality of evidence. Third, it compares studies' approaches to measurement to identify how observed heterogeneity might impact reporting and interpretation of findings.

Future Research

There are 3 primary areas of future research related to this study. First, future studies of chatbot-delivered parenting interventions should adopt and adhere to standardized reporting guidelines for digital health interventions such as the mobile health evidence reporting and assessment checklist [62]. Second, further development of guidelines that focus on standardized reporting of feasibility and acceptability measures will allow for between-study comparisons, which is critical for future reviews. Third, future studies should identify barriers to engagement more specifically within the digital environment through collecting additional use data as well as conducting qualitative interviews with participants.

Conclusions

Digital conversational agents as a delivery mechanism for parenting interventions are still in the nascent stages. Significant development is needed in the measurement and reporting of feasibility and acceptability outcomes, as well as in identifying the barriers to and facilitators of engagement with these interventions. This study reviewed the evidence for the feasibility and acceptability of using digital conversational agents to deliver parenting interventions. Given the limited available evidence and its relevancy to the research question, the included studies suggest that digital conversational agents can be a feasible and acceptable way to deliver parenting interventions. A more detailed analysis revealed that considerable heterogeneity in the design of interventions and the measurement of feasibility and acceptability outcomes make comparing findings between studies more challenging and uncertain. However, the overall quality of the findings was moderate, and most of the evidence was in favor of demonstrating feasibility and acceptability. Importantly, these conclusions are drawn from limited evidence. This review highlights the need for more rigorous standardization of reporting on digital interventions, additional research designing and testing new parenting chatbot interventions, and scaling up effectiveness testing of the studies included in this review.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Systematic review search string.
[DOCX File , 13 KB - pediatrics_v7i1e55726_app1.docx]

Multimedia Appendix 2
Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields template.
[DOCX File , 16 KB - pediatrics_v7i1e55726_app2.docx]

Multimedia Appendix 3
Weight of Evidence ratings.
[XLSX File (Microsoft Excel File), 11 KB - pediatrics_v7i1e55726_app3.xlsx]

Multimedia Appendix 4
PRISMA Checklist.

[PDF File (Adobe PDF File), 108 KB - pediatrics_v7i1e55726_app4.pdf]

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Abbreviations

DBCI: digital behavior change intervention
LMIC: low- and middle-income country
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

QualSyst: Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields
WoE: Weight of Evidence

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