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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

Kar Mun Chong[1], BSc; Airu Chia[2], BSc, PhD; Nur Syahirah Shah Budin[1], BSc, MSc; Bee Koon Poh[1], BSc, PhD; Nor Aini Jamil[1], BSc, MSc, PhD; Denise Koh[3], BSc, MSc, PhD; Mary Foong-Fong Chong[2], BSc, PhD; Jyh Eiin Wong[1], BSc, MSc, PhD

[1]Center for Community Health Studies (ReaCH), Faculty of Health Sciences, Universiti Kebangsaan Malaysia, Kuala Lumpur, Malaysia
[2]Saw Swee Hock School of Public Health, National University of Singapore, Singapore, Singapore
[3]Centre of Community Education & Wellbeing, Faculty of Education, Universiti Kebangsaan Malaysia, Selangor, Malaysia

Corresponding Author:
Jyh Eiin Wong, BSc, MSc, PhD
Center for Community Health Studies (ReaCH)
Faculty of Health Sciences
Universiti Kebangsaan Malaysia
Jalan Raja Muda Abdul Aziz,
Kuala Lumpur, 50300
Malaysia
Phone: 60 3 9289 7683
Email: wjeiin@ukm.edu.my

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

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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Original Paper

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

Nipuna Cooray[1], PhD; Catherine Ho[1], BSc; Amy Bestman[1], PhD; Susan Adams[1,2], MD, PhD; Natasha Nassar[3], PhD; Lisa Keay[1,4], PhD; Julie Brown[1], PhD

[1]The George Institute for Global Health, Faculty of Medicine and Health, University of New South Wales Sydney, Barangaroo, Australia
[2]Department of Paediatric Surgery, Sydney Children's Hospital, Randwick, Australia
[3]Children’s Hospital at Westmead Clinical School, Faculty of Medicine and Health, University of Sydney, Sydney, Australia
[4]School of Optometry and Vision Science, Faculty of Medicine and Health, University of New South Wales Sydney, Sydney, Australia

Corresponding Author:
Nipuna Cooray, PhD
The George Institute for Global Health
Faculty of Medicine and Health
University of New South Wales Sydney
Level 18, International Towers 3
300 Barangaroo Ave
Barangaroo, 2000
Australia
Phone: 61 468311723
Email: ncooray@georgeinstitute.org.au

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.

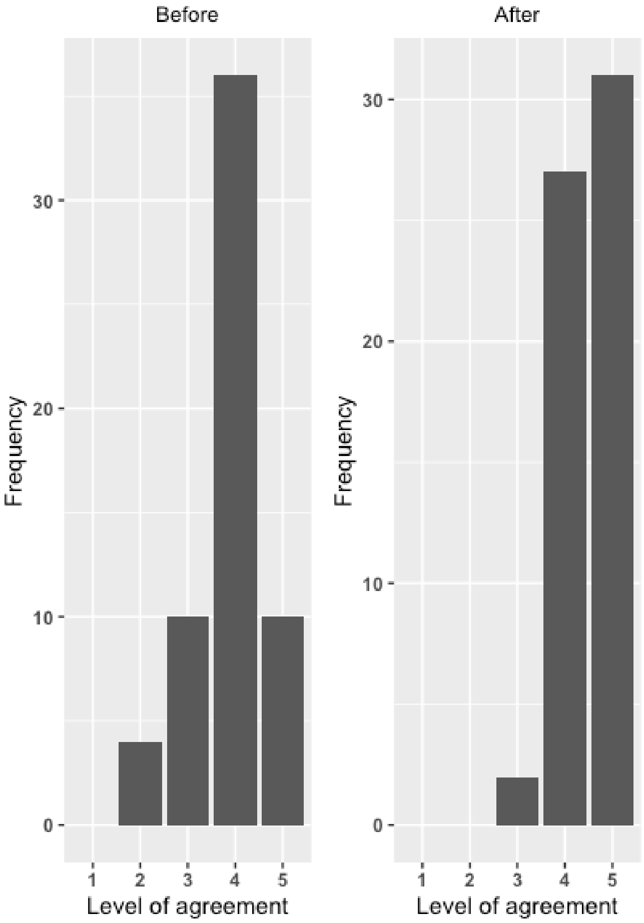


Figure 2. Level of agreement with “Falls in children under 1 can be prevented”: before versus after.

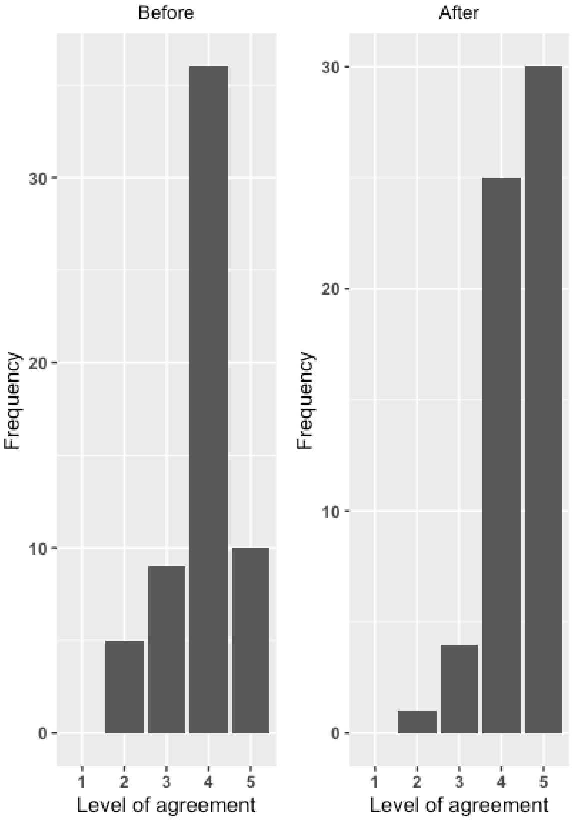


Figure 3. Level of agreement with “I am confident I can take actions to reduce the risk of my child falling”: before versus after.

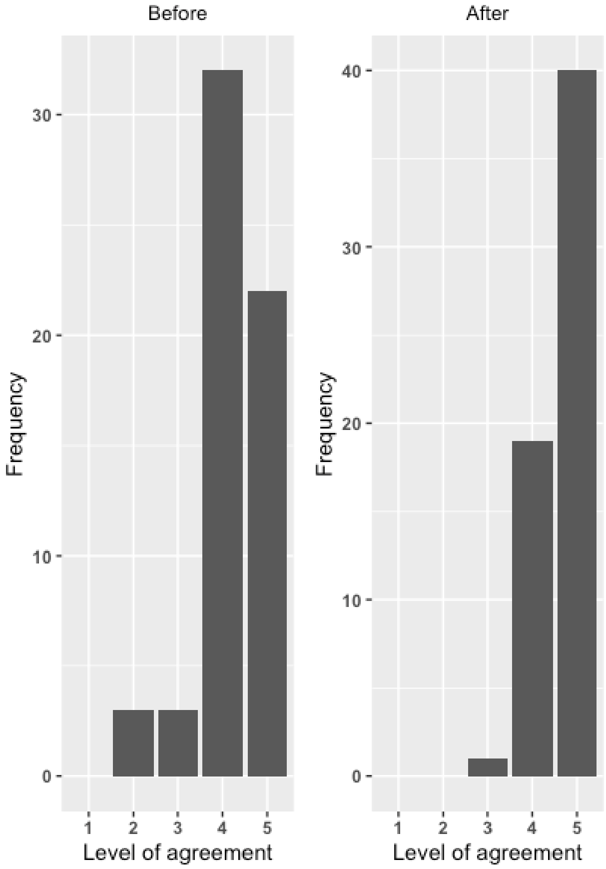
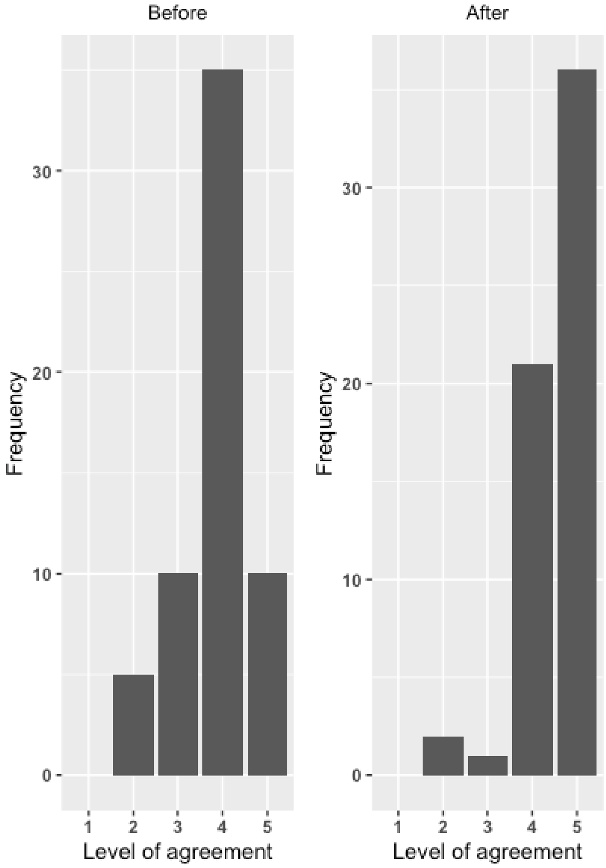


Figure 4. Level of agreement with “I have taken specific actions to reduce the risk of my child falling”: before versus after.



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

Sarah K Burns[1], MSW; Tamar Krishnamurti[2], PhD; Tran T Doan[1], MPH, PhD; Janel Hanmer[2], MD, PhD; Alejandro Hoberman[1], MD; Jeremy M Kahn[3,4], MD, MS; Kelsey Schweiberger[1], MD, MS; Kristin N Ray[1], MD, MS

[1]Department of Pediatrics, University of Pittsburgh School of Medicine, Pittsburgh, PA, United States

[2]Department of Medicine, University Pittsburgh School of Medicine, Pittsburgh, PA, United States

[3]Department of Health Policy & Management, University of Pittsburgh Graduate School of Public Health, Pittsburgh, PA, United States

[4]Department of Critical Care Medicine, University of Pittsburgh School of Medicine, Pittsburgh, PA, United States

Corresponding Author:
Kristin N Ray, MD, MS
Department of Pediatrics
University of Pittsburgh School of Medicine
CHOB 3rd Floor
3414 Fifth Avenue
Pittsburgh, PA, 15213
United States
Phone: 1 412 692 7518
Email: kristin.ray@chp.edu

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

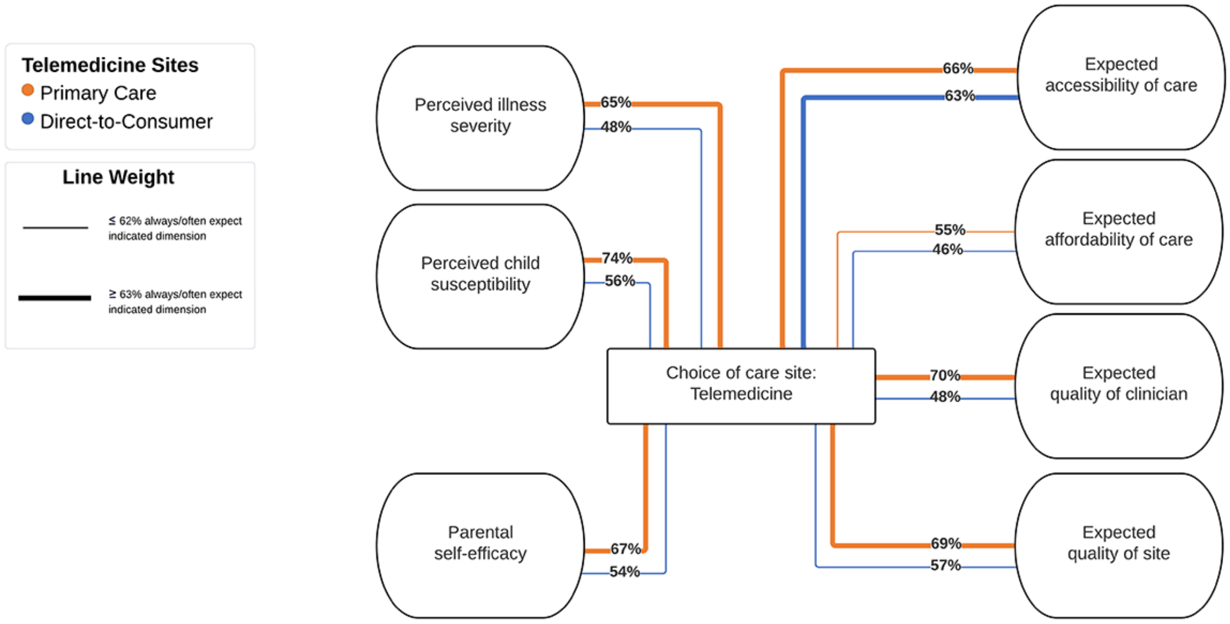
[a] For each item, we calculated the weighted percentage of nonmissing responses indicating that the item was expected “always” or “often” at the specified site. We determined statistical significance using *t* statistics from weighted logistic regression models to compare responses for each item for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

Jill Glassman[1], MSW, PhD; Kathryn L Humphreys[2], PhD; Adam Jauregui[3], MS; Arnold Milstein[1], MPH, MD; Lee Sanders[4], MPH, MD

[1]Clinical Excellence Research Center (CERC), Stanford University School of Medicine, Stanford, CA, United States
[2]Department of Psychology and Human Development, Vanderbilt University, Nashville, TN, United States
[3]Oracle Life Sciences, Austin, TX, United States
[4]Departments of Pediatrics, Stanford University, Stanford, CA, United States

Corresponding Author:
Jill Glassman, MSW, PhD
Clinical Excellence Research Center (CERC)
Stanford University School of Medicine
453 Quarry Road
Stanford, CA
United States
Phone: 1 8314195302
Email: jill.r.glassman@stanford.edu

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^{2c} (%)
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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Electronic Medical Record Data Missingness and Interruption in Antiretroviral Therapy Among Adults and Children Living With HIV in Haiti: Retrospective Longitudinal Study

Andrew M Secor[1], MPH, PhD; Kemar Célestin[2], MSc; Margareth Jasmin[2], MD; Jean Guy Honoré[2], MD; Anjuli D Wagner[1], PhD; Kristin Beima-Sofie[1], PhD; Jillian Pintye[1], PhD; Nancy Puttkammer[3], PhD

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Corresponding Author:
Andrew M Secor, MPH, PhD

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

Darian Lawrence-Sidebottom[1*], PhD; Landry Goodgame Huffman[1*], PhD; Aislinn Brenna Beam[1], PhD; Rachael Guerra[1], PhD; Amit Parikh[1], MD; Monika Roots[1], MD; Jennifer Huberty[1,2], PhD

[1]Bend Health Inc, Madison, WI, United States
[2]FitMinded Inc LLC, Phoenix, AZ, United States
[*]these authors contributed equally

Corresponding Author:
Darian Lawrence-Sidebottom, PhD
Bend Health Inc
2801 Marshall Ct
Madison, WI, 53705
United States
Phone: 1 8005160975
Email: darian.lawrence@bendhealth.com

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

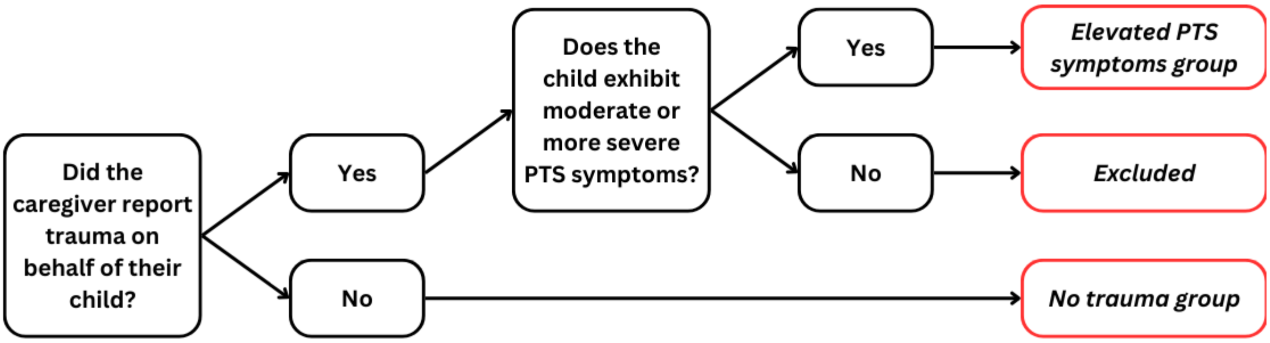
Responses to all items from the CPSS-V were aggregated for a total PTS score of 0 to 80. Using standardized criteria, PTS symptom severity was determined based on CPSS-V scoring norms [27], which are as follows: minimal (scores: 0 to 10), mild (score: 11 to 20), moderate (score: 21 to 40), severe (score: 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 ($\chi^2_1=5.33$; $P=.02$). 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: χ^2_1=1.33; *P*=.25 and depressive: χ^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.

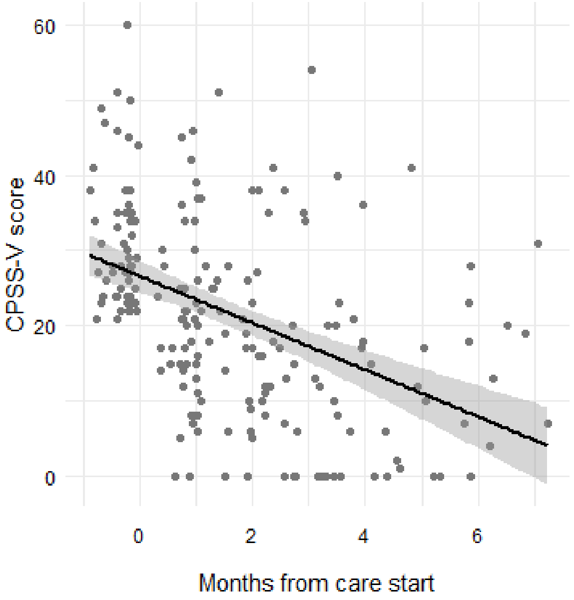
[e] Between-group comparison were performed with a 2-tailed *t* test.

[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: χ^2_1=3.97; *P*=.046) and female sex (LRT: χ^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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Effects of Food Depictions in Entertainment Media on Children’s Unhealthy Food Preferences: Content Analysis Linked With Panel Data

Jörg Matthes[1], Dipl-Psych, DPhil; Alice Binder[1], Mag, DPhil; Brigitte Naderer[2], Mag, DPhil; Michaela Forrai[1], MA; Ines Spielvogel[1], Mag, DPhil; Helena Knupfer[1], MA; Melanie Saumer[1], MA

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Corresponding Author:
Jörg Matthes, Dipl-Psych, DPhil

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.

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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

Jeffrey Tsz Hei So[1,2], BAppSc, MDietSt; Smita Nambiar[1,2], PhD; Rebecca Byrne[1,2], PhD; Danielle Gallegos[1,2], PhD; Kimberley A Baxter[1,2], PhD

[1]Centre for Childhood Nutrition Research, Faculty of Health, Queensland University of Technology, Brisbane, Australia
[2]School of Exercise and Nutrition Sciences, Faculty of Health, Queensland University of Technology, Brisbane, Australia

Corresponding Author:
Jeffrey Tsz Hei So, BAppSc, MDietSt
Centre for Childhood Nutrition Research
Faculty of Health
Queensland University of Technology
62 Graham Street
South Brisbane
Brisbane, 4101
Australia
Phone: 61 73069 7308
Email: jeffrey.so@hdr.qut.edu.au

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.

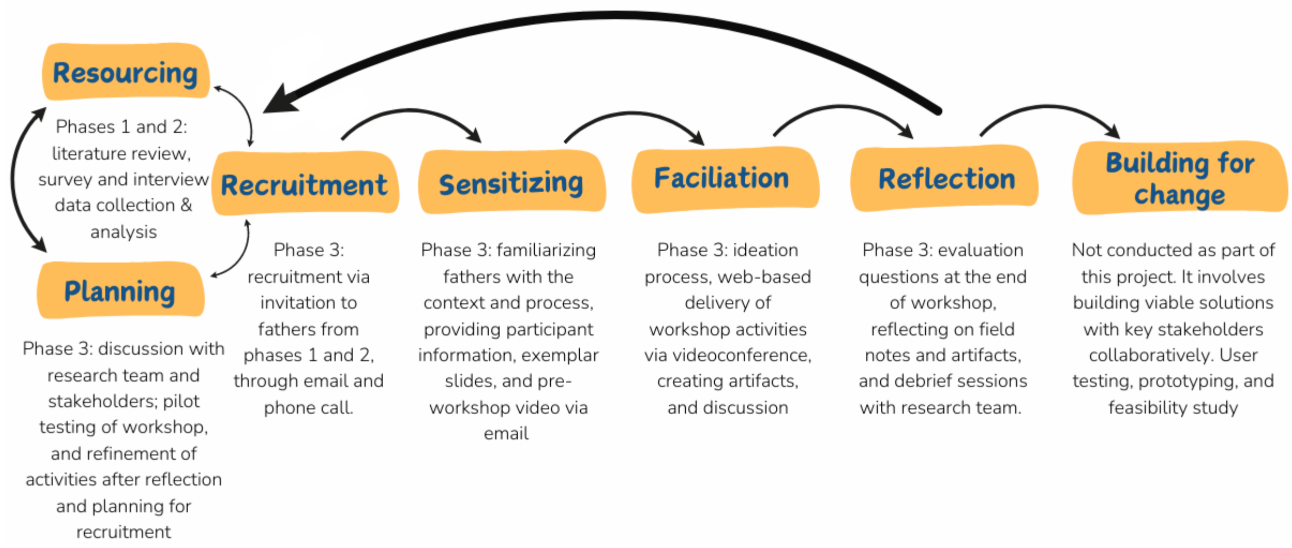
The interviews aimed to explore three aspects: (1) paternal roles and contributions in child feeding, (2) enablers and barriers to responsive feeding practices, and (3) experiences and perceived enablers and barriers in accessing support and information related to parenting, child feeding, and nutrition. 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.

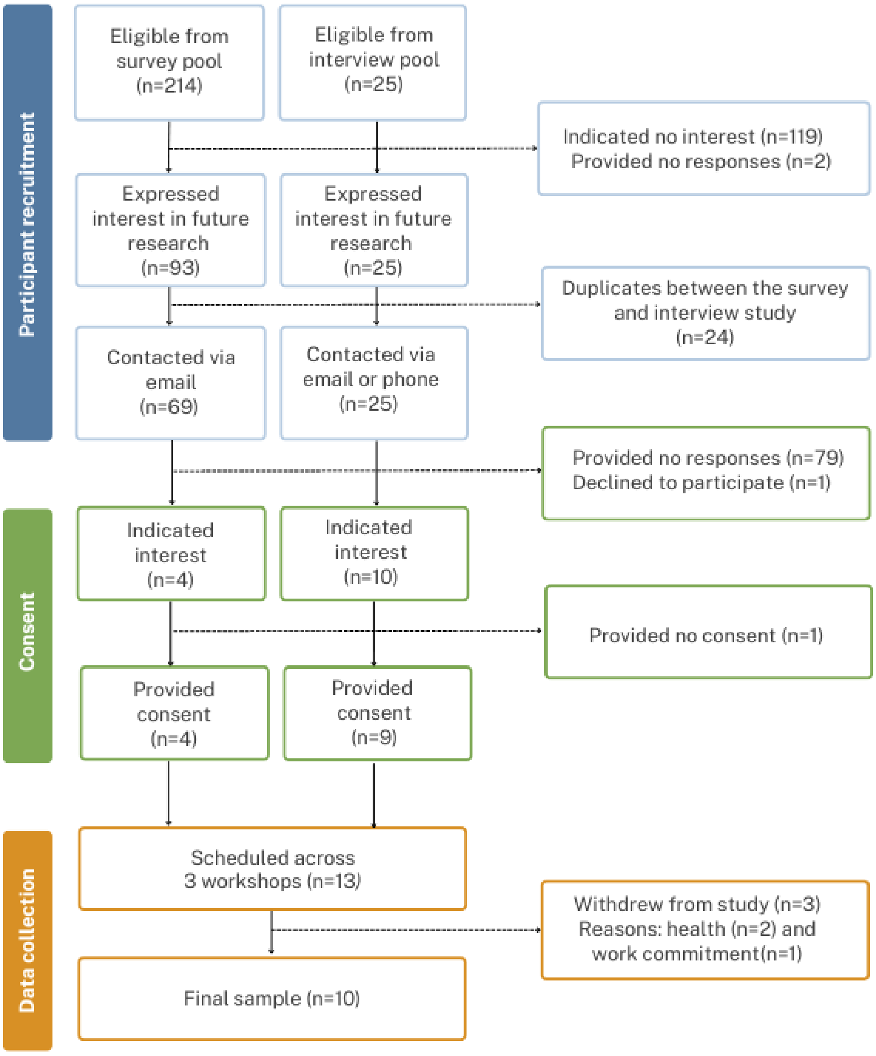
Co-Design Workshops

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.

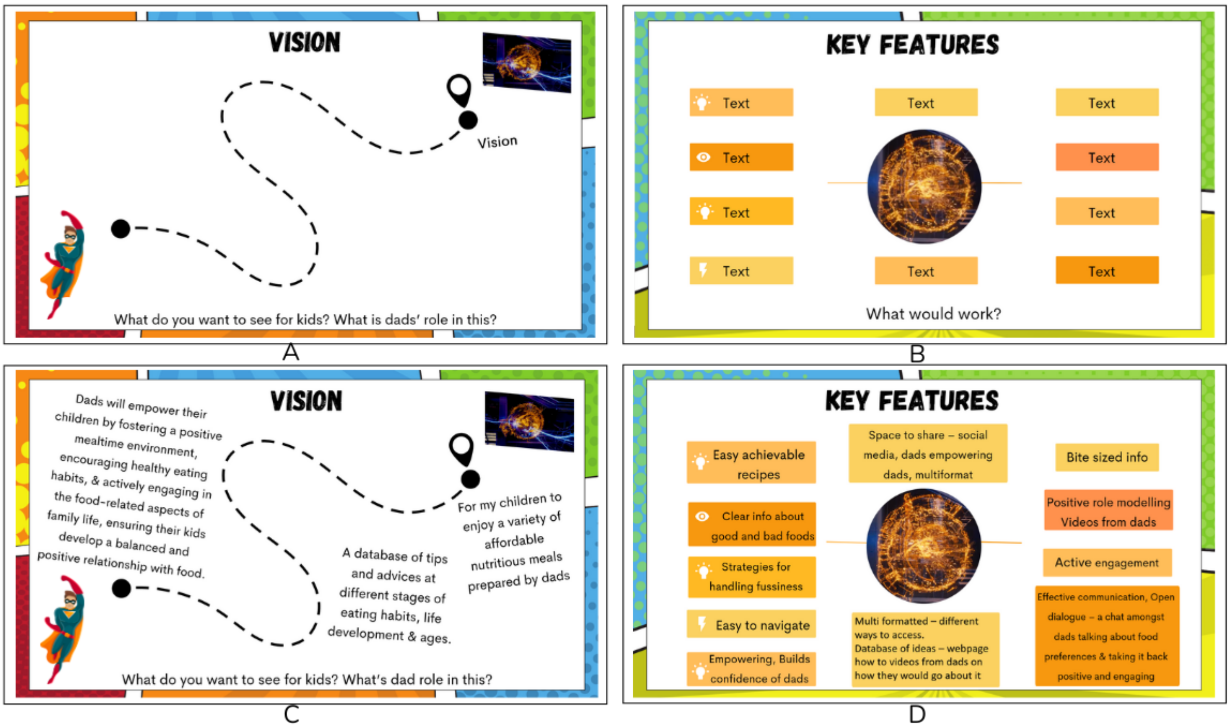
All workshops were video-recorded and transcribed verbatim using Otter.ai [29]. The first author (JS) also completed field notes on each workshop. Artifacts, including drawings, transcripts of chat conversations, and presentation slides (ie, visions and key features created on the slide with fathers), 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

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]

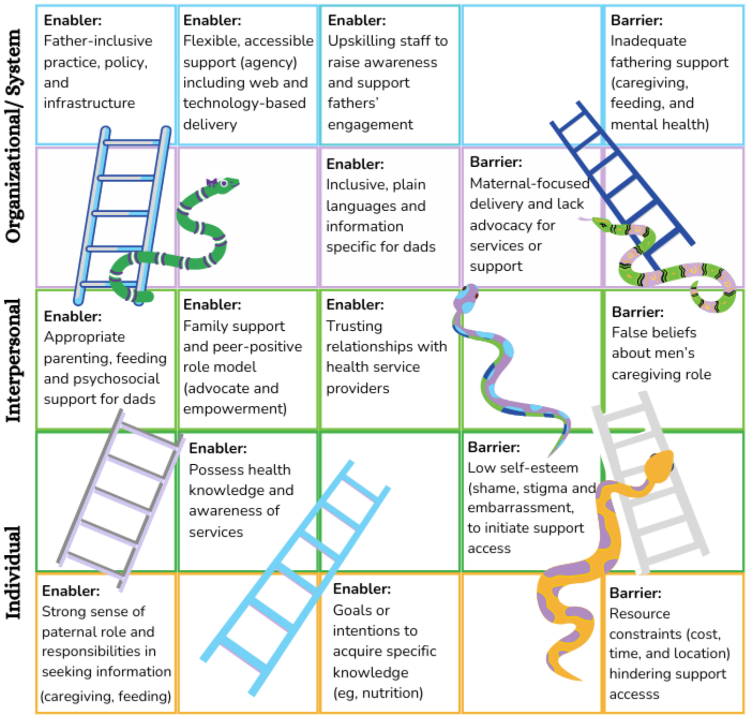
There was also a call for mothers to encourage fathers to fulfill the caregiver role and participate in feeding. For example, a father said the following:

> *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.

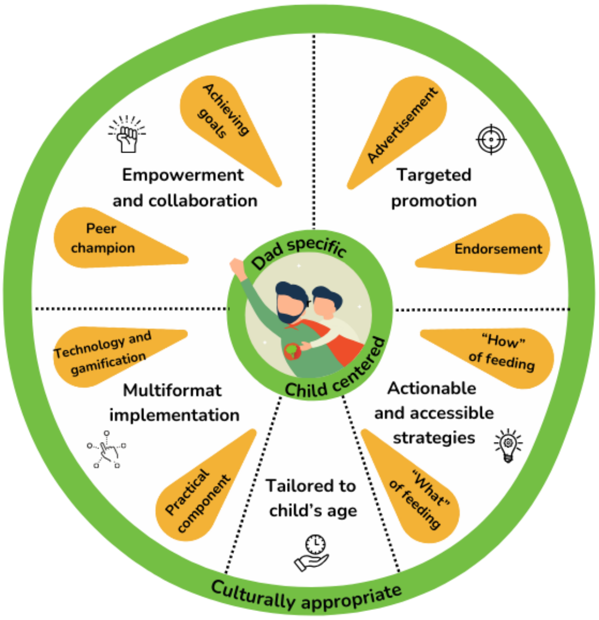


Co-Design Workshops

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

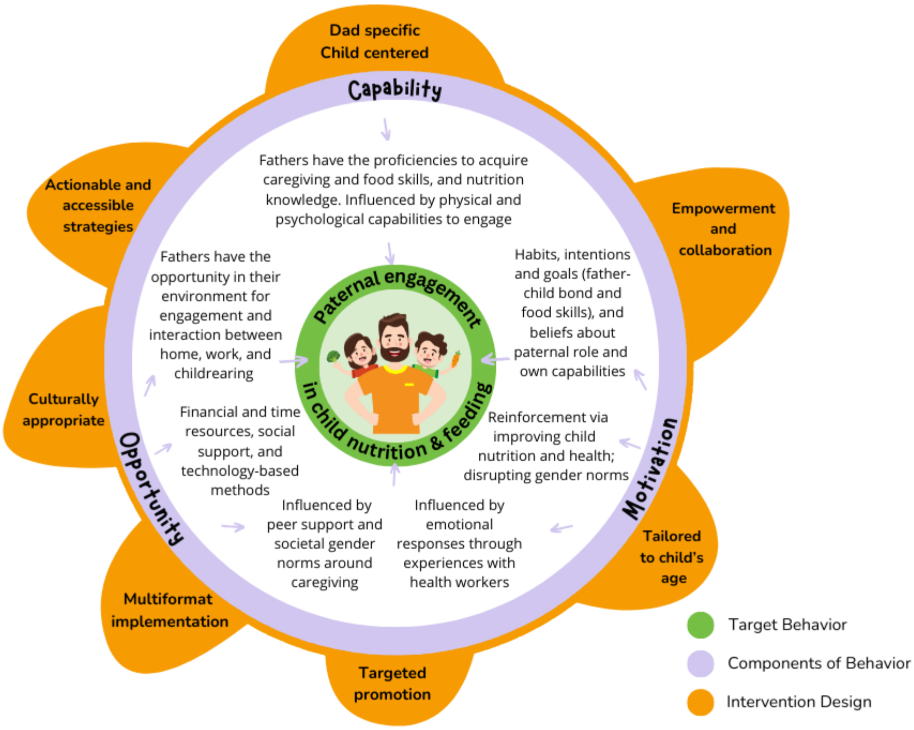
Fathers described a comprehensive, father-targeted promotion strategy using various channels. Marketing was recommended in places traditionally directed at men (eg, hardware and sports venues), web-based platforms (eg, YouTube and Facebook) and community spaces (eg, childcare centers, sports venues, 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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Review

Exploring Maternal and Infant Health App Development and Effectiveness Research: Scoping Review

J Craig Phillips[1], MSN, LLM, PhD; Alliete R Alfano[2], CCC-SLP, LSLS Cert AVT, PhD; Latisha C Barfield[3], CNM, ARNP, DNP; Lisa Cain[4], PhD; Masoud Sadjadi[5], PhD; Eduardo Morales[6], BS; Wanda Phillips-Beck[7], BN, RN, MSc, PhD; M Grisel Galarza[8], IBCLC, MD; Maritza Torres[8], MD; Sadaf Zindani[1], MScN; Ahmad Rayani[9], RN, PhD; Khalee Edwards[3], RN, BA, BSN; Sande Gracia Jones[3], RN, PhD; Jean Hannan[3], PhD, APRN

[1]School of Nursing, University of Ottawa, Ottawa, ON, Canada
[2]Department of Communication Sciences and Disorders, Florida International University, Miami, FL, United States
[3]Nicole Wertheim College of Nursing and Health Sciences, Florida International University, Miami, FL, United States
[4]Chaplin School of Hospitality &Tourism Management, Florida International University, North Miami, FL, United States
[5]Knight Foundation School of Computing and Information Sciences, Florida International University, Miami, FL, United States
[6]IBM, Miami, FL, United States
[7]First Nations Health and Social Secretariat of Manitoba, Winnipeg, MB, Canada
[8]Miller School of Medicine, Pediatrics/Neonatology, University of Miami, Miami, FL, United States
[9]College of Nursing, King Saud University, Riyadh, Saudi Arabia

Corresponding Author:
J Craig Phillips, MSN, LLM, PhD
School of Nursing
University of Ottawa
308-29 Main St
Ottawa, ON, K1S 1B1
Canada
Phone: 1 613 562 5800 ext 8612
Email: craig.phillips@uottawa.ca

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.

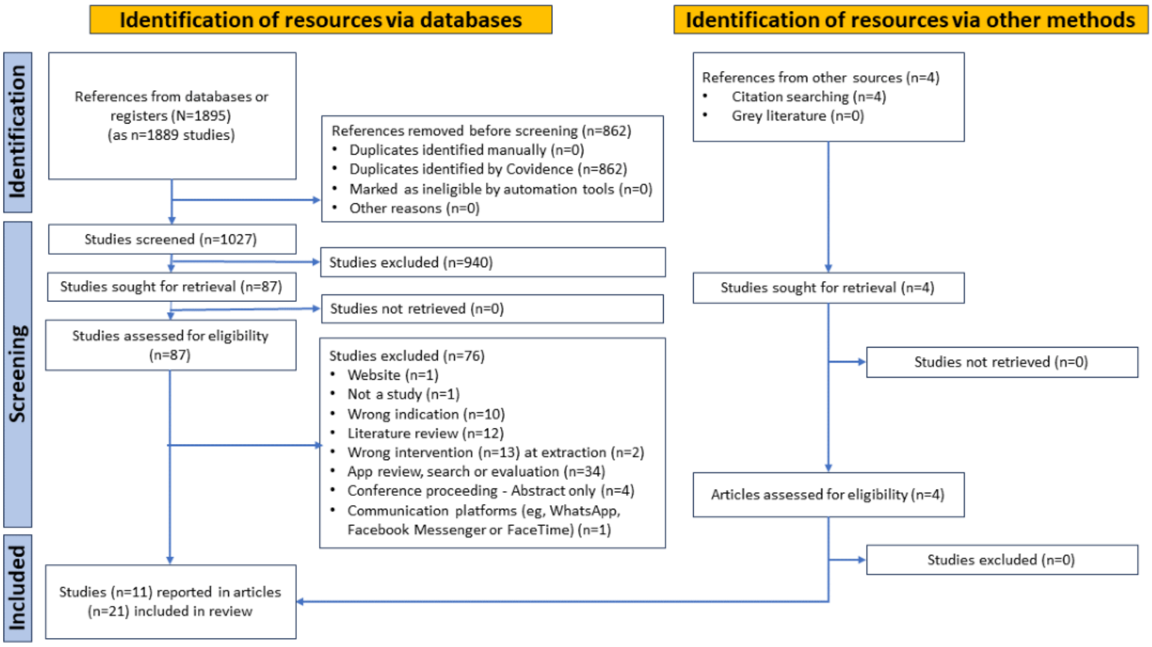
Quality assessment (step 7) is a potentially fraught process for scoping review studies, but efforts are underway to develop an appraisal tool for them [49]. Some researchers have included this step to enhance scoping review quality [44]. For the purposes of our review and given the early developmental 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 reviewed 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

A Risk Assessment and Planning Tool to Prevent Sudden Unexpected Death in Infancy: Development and Evaluation of The Baby Sleep Planner

Anna Pease[1], MA, MSc, PhD; Jenny Ingram[1], BSc, PhD; Becky Lambert[1], BA, MSc, PhD; Karen Patrick[2], BSc, MRes; Kieren Pitts[3], BSc, MSc, PhD; Peter J Fleming[1], MBChB, PhD; Peter S Blair[1], BSc, MSc, PhD; The Baby Sleep Project Family Advisory Group[1]

[1]Population Health Sciences, Bristol Medical School, University of Bristol, Bristol, United Kingdom

[2]Royal United Hospitals Bath NHS Foundation Trust, Bath, United Kingdom

[3]Research IT, University of Bristol, Bristol, United Kingdom

Corresponding Author:
Anna Pease, MA, MSc, PhD
Population Health Sciences
Bristol Medical School
University of Bristol
3.02 Canynge Hall
39 Whatley Road
Bristol, BS82PS
United Kingdom
Phone: 44 117 455 625
Email: a.pease@bristol.ac.uk

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.

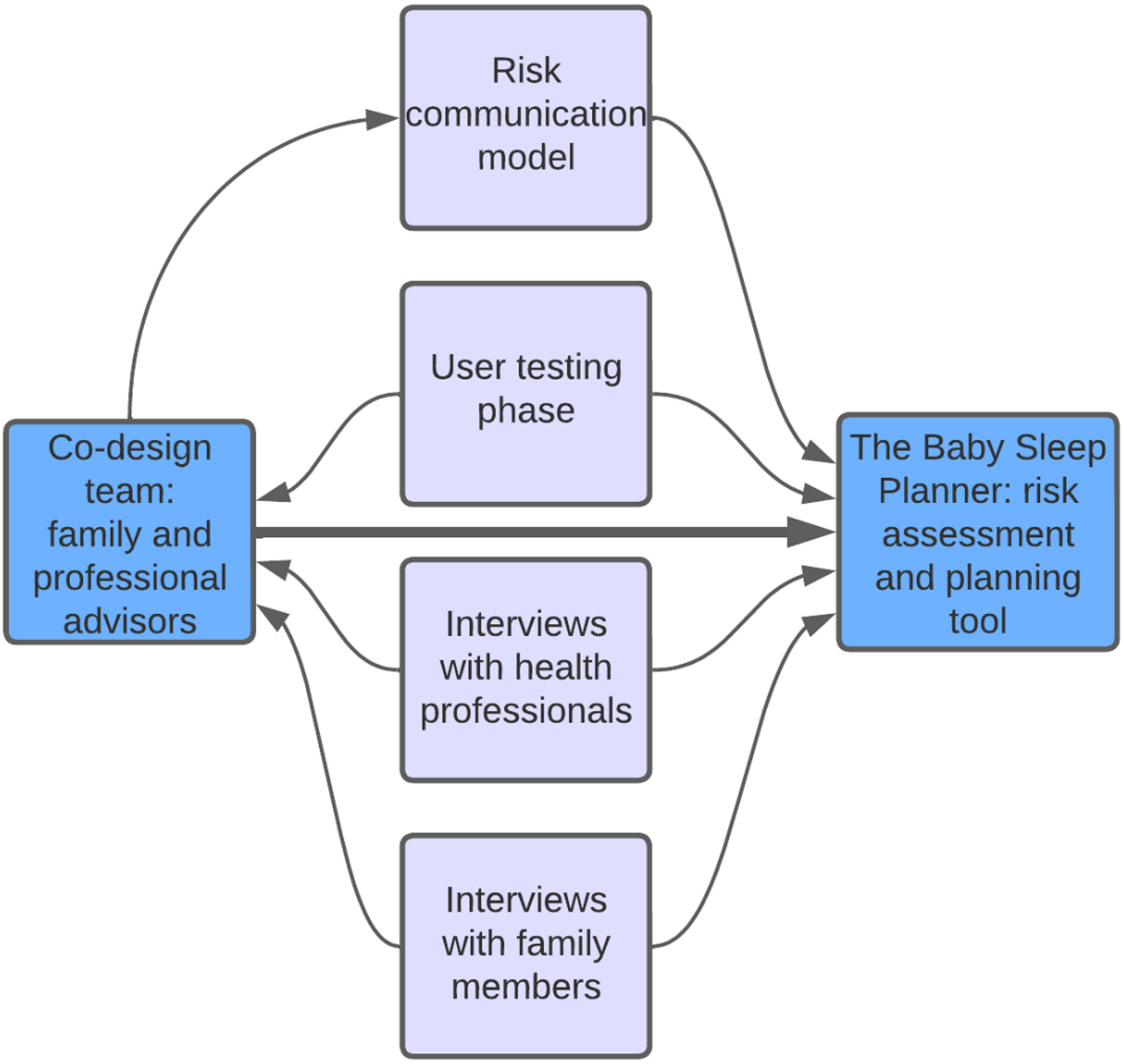
Professional Advisory Group

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.

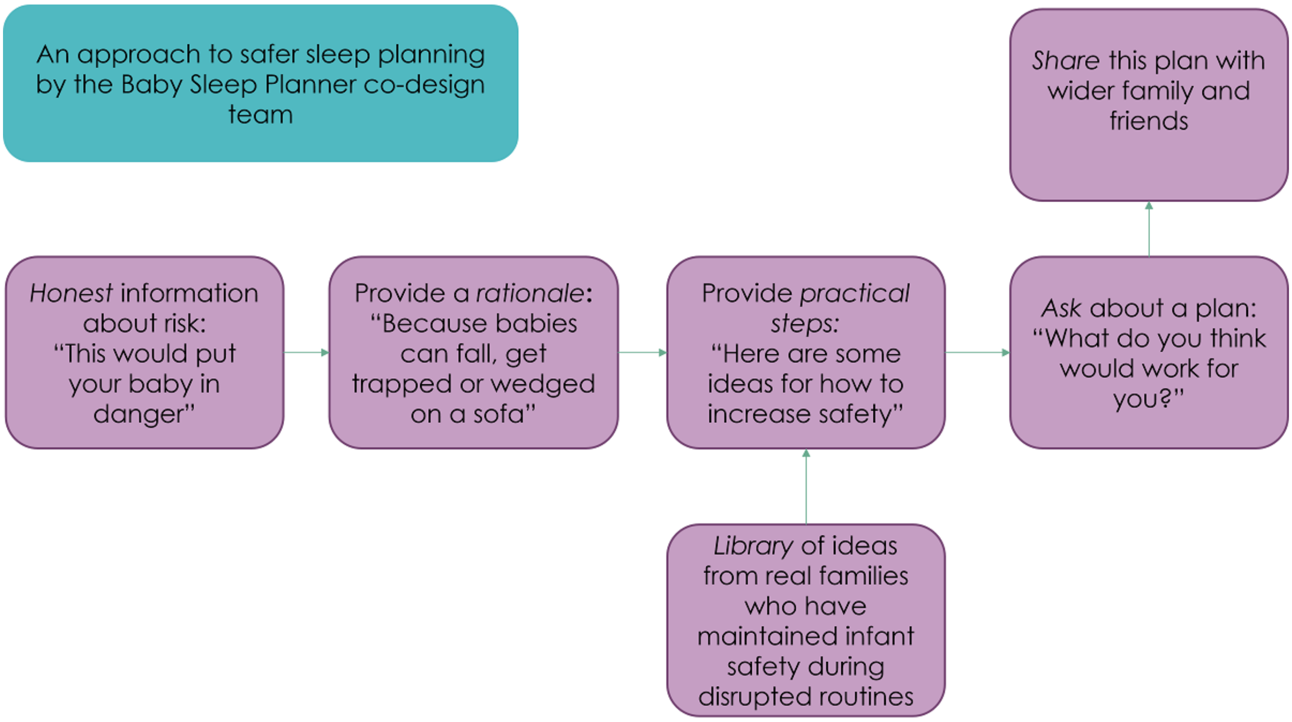


Table 2. Example changes from the co-design process and professional advisory groups.

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

Heather McGrane Minton[1], PhD; Linda Murray[2], BA; Marjorie J Allan[2], MPH; Roslyn Perry[3], BSN; Amie F Bettencourt[4], PhD; Deborah Gross[5], DNSc; Lauri Strano[2], MS; Susan M Breitenstein[3], PhD

[1]Wegmans School of Nursing, St. John Fisher University, Rochester, NY, United States
[2]Children's Institute, University of Rochester, Rochester, NY, United States
[3]College of Nursing, The Ohio State University, Columbus, OH, United States
[4]School of Medicine, Johns Hopkins University, Baltimore, MD, United States
[5]School of Nursing, Johns Hopkins University, Baltimore, MD, United States

Corresponding Author:
Susan M Breitenstein, PhD
College of Nursing
The Ohio State University
1577 Neil Ave.
Columbus, OH, 43210
United States
Phone: 1 6146884614
Email: breitenstein.5@osu.edu

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

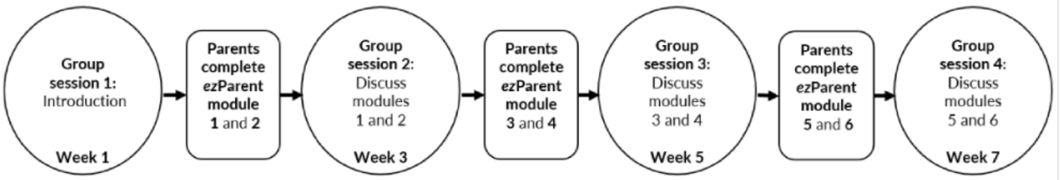
[a] FRAME: Framework for Reporting Adaptations and Modifications–Expanded.

[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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Photos Shared on Facebook in the Context of Safe Sleep Recommendations: Content Analysis of Images

Kelly Pretorius[1], MSN, MPH, RN, PhD; Sookja Kang[2], MSN, RN; Eunju Choi[3], MSN, RN, PhD

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Corresponding Author:
Kelly Pretorius, MSN, MPH, RN, PhD

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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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

Ting Yang[1], MEc; Yihan Wu[2], MiM; Nuo Han[3,4,5], PhD; Tianli Liu[1], PhD

[1]Institute of Population Research, Peking University, Beijing, China
[2]Graduate School of Education, Peking University, Beijing, China
[3]Chinese Academy of Sciences Key Laboratory of Behavioral Science, Institute of Psychology, Chinese Academy of Sciences, Beijing, China
[4]Department of Psychology, University of Chinese Academy of Sciences, Beijing, China
[5]School of Data Science, City University of Hong Kong, Hong Kong SAR, China

Corresponding Author:
Tianli Liu, PhD
Institute of Population Research
Peking University
Room 230
School of Economics Building
Beijing, 100871
China
Phone: 86 010 62751974
Email: tianli.liu@pku.edu.cn

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

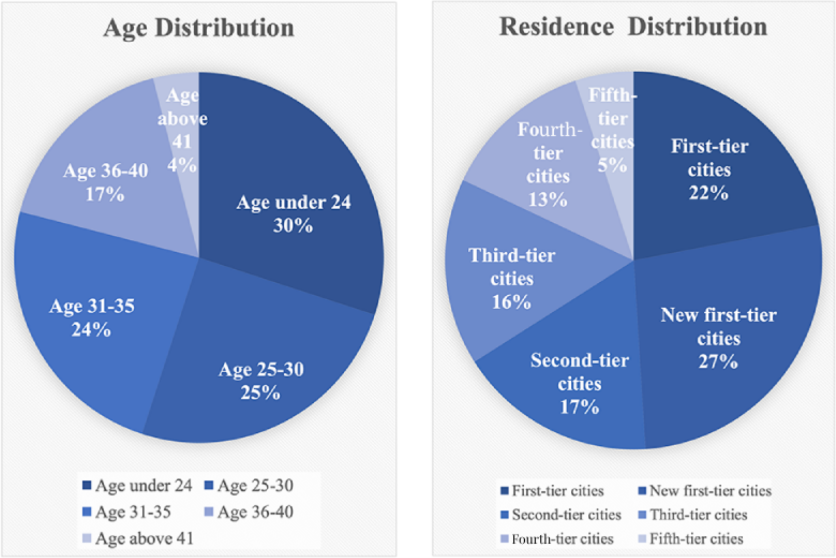
This paper selected Douban (Beijing Douwang Technology Co. Ltd.) as the source platform for data collection based on the considerations outlined in Textbox 1.

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

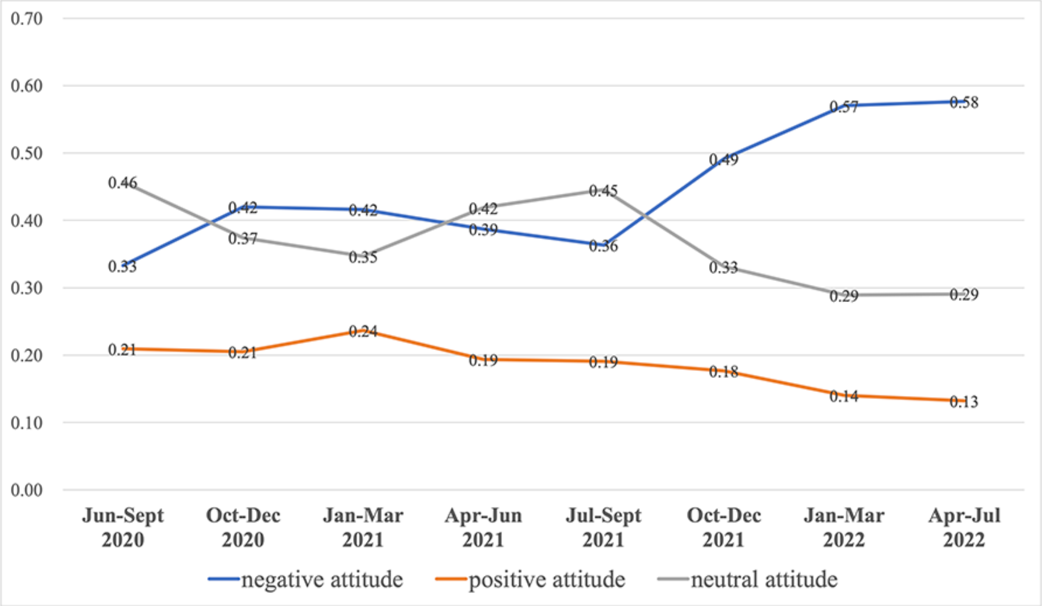
In the content analysis, we identified coding criteria related to attitudes toward childbirth, and Table 1 illustrates specific criteria and examples. The basic classification of the attitude toward childbirth showed that 1051/2634 (39.90%) posts had a negative attitude, 523/2634 (19.86%) posts had a 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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Original Paper

The Impact of Parental Electronic Health Literacy on Disease Management and Outcomes in Pediatric Type 1 Diabetes Mellitus: Cross-Sectional Clinical Study

Áron Hölgyesi[1,2]; Andrea Luczay[3], PhD; Péter Tóth-Heyn[3], PhD; Eszter Muzslay[3]; Eszter Világos[3]; Attila J Szabó[3], DSC; Petra Baji[4], PhD; Levente Kovács[5], PhD; László Gulácsi[2], DSC; Zsombor Zrubka[2], PhD; Márta Péntek[2], DSC

[1]Doctoral School, Semmelweis University, Budapest, Hungary
[2]Health Economics Research Center, University Research and Innovation Center, Óbuda University, Budapest, Hungary
[3]Pediatric Center, Semmelweis University, Budapest, Hungary
[4]Musculoskeletal Research Unit, University of Bristol, Bristol, United Kingdom
[5]Physiological Controls Research Center, University Research and Innovation Center, Óbuda University, Budapest, Hungary

Corresponding Author:
Márta Péntek, DSC
Health Economics Research Center
University Research and Innovation Center
Óbuda University
Bécsi St. 96/B
Budapest, 1034
Hungary
Phone: 36 16665603
Email: pentek.marta@uni-obuda.hu

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.

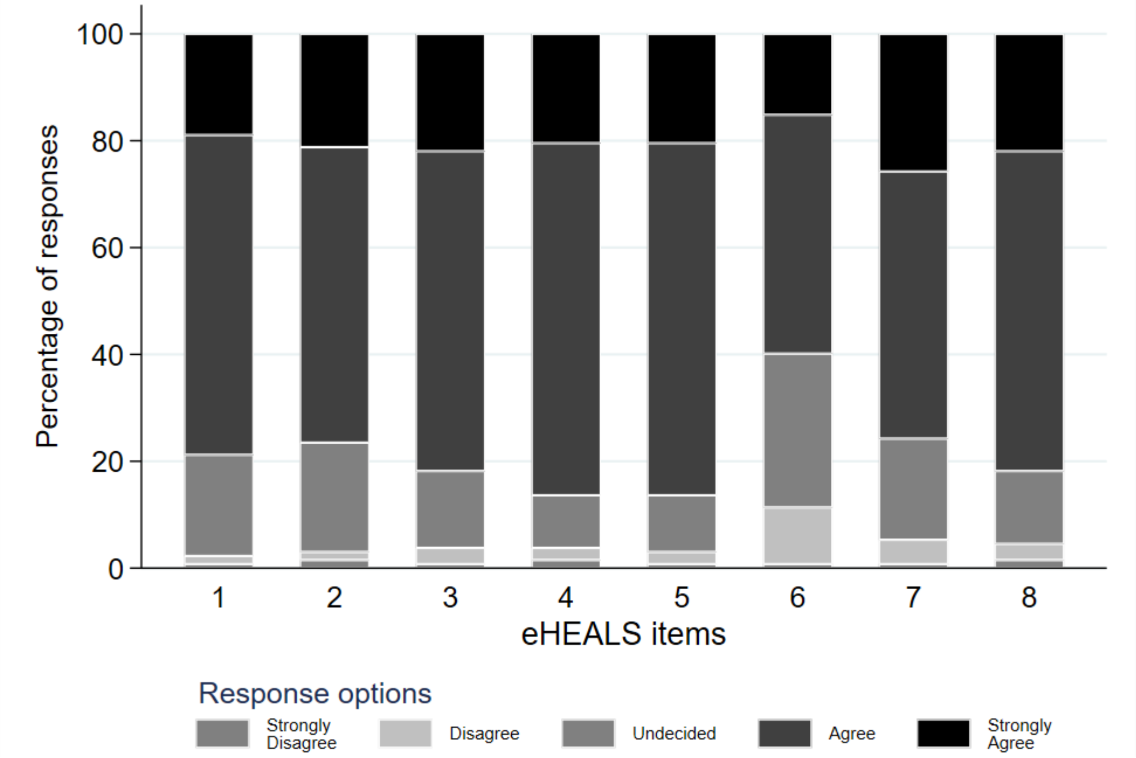
[f] HFS: Hypoglycemia Fear Survey.

[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.

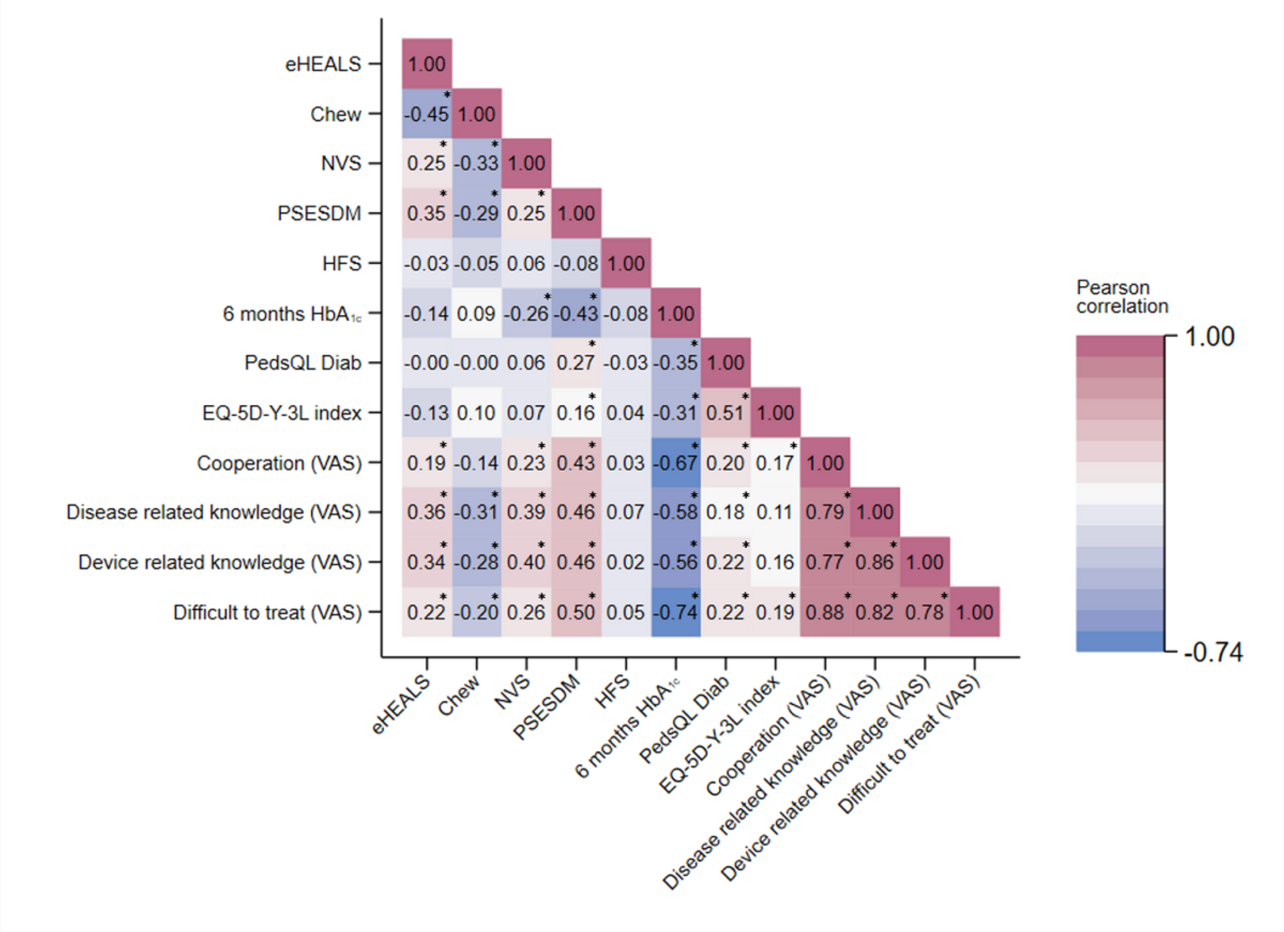
[i] The events reported by the diabetologists were hyperglycemia or ketoacidosis requiring medical intervention and device malfunction.

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 HbA_{1c}	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 HbA_{1c}	-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.

Acknowledgments

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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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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

Lynnette Lyzwinski[1,2], MPhil PH, PhD; Sheila Mcdonald[1,3], PhD; Jennifer Zwicker[2], PhD; Suzanne Tough[1], PhD

[1]Department of Paediatrics, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada

[2]The School of Public Policy, University of Calgary, Calgary, AB, Canada

[3]Department of Community Health Sciences, University of Calgary, Calgary, AB, Canada

Corresponding Author:
Lynnette Lyzwinski, MPhil PH, PhD
Department of Paediatrics
Cumming School of Medicine
University of Calgary
3330 Hospital Dr
Calgary, AB, T2N4N1
Canada
Phone: 1 403 220 6843
Email: Lynnette.Lyzwinski@ucalgary.ca

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.

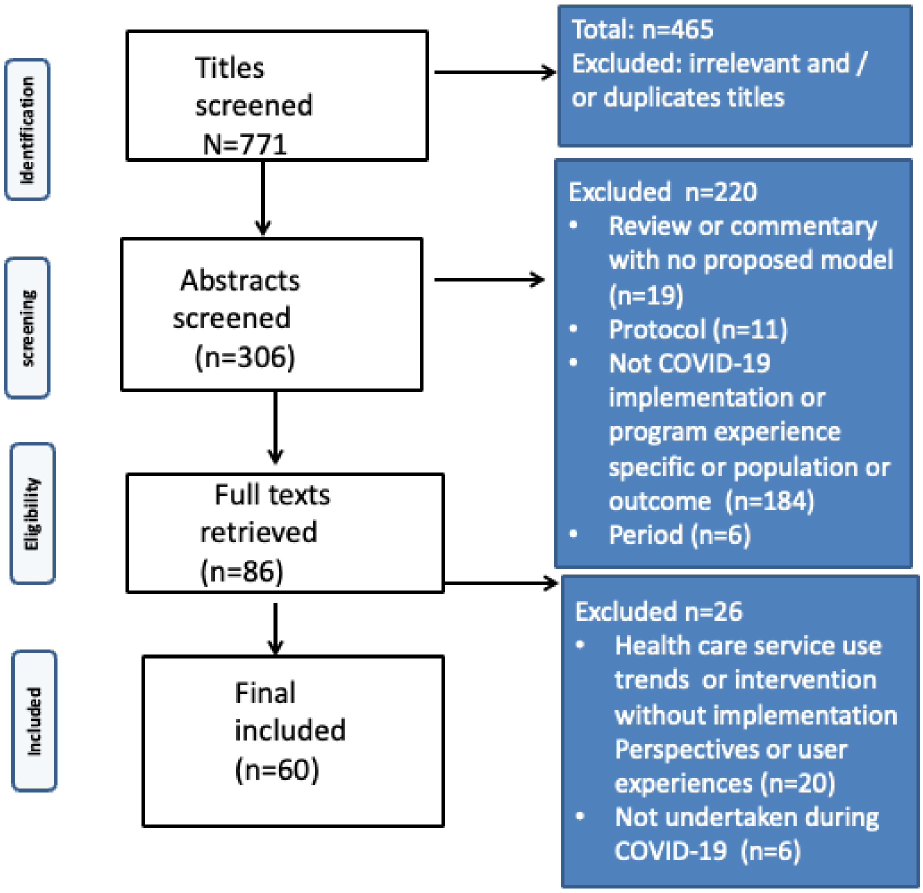
To ensure that the studies were undertaken during the pandemic period, we screened titles with the words “COVID-19” followed by checking the full texts to ensure that the programs were implemented within a COVID-19 context or with relevance to the pandemic, where lessons could be learned. Where it was 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)

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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

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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

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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

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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

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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

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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

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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

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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

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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

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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

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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

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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.

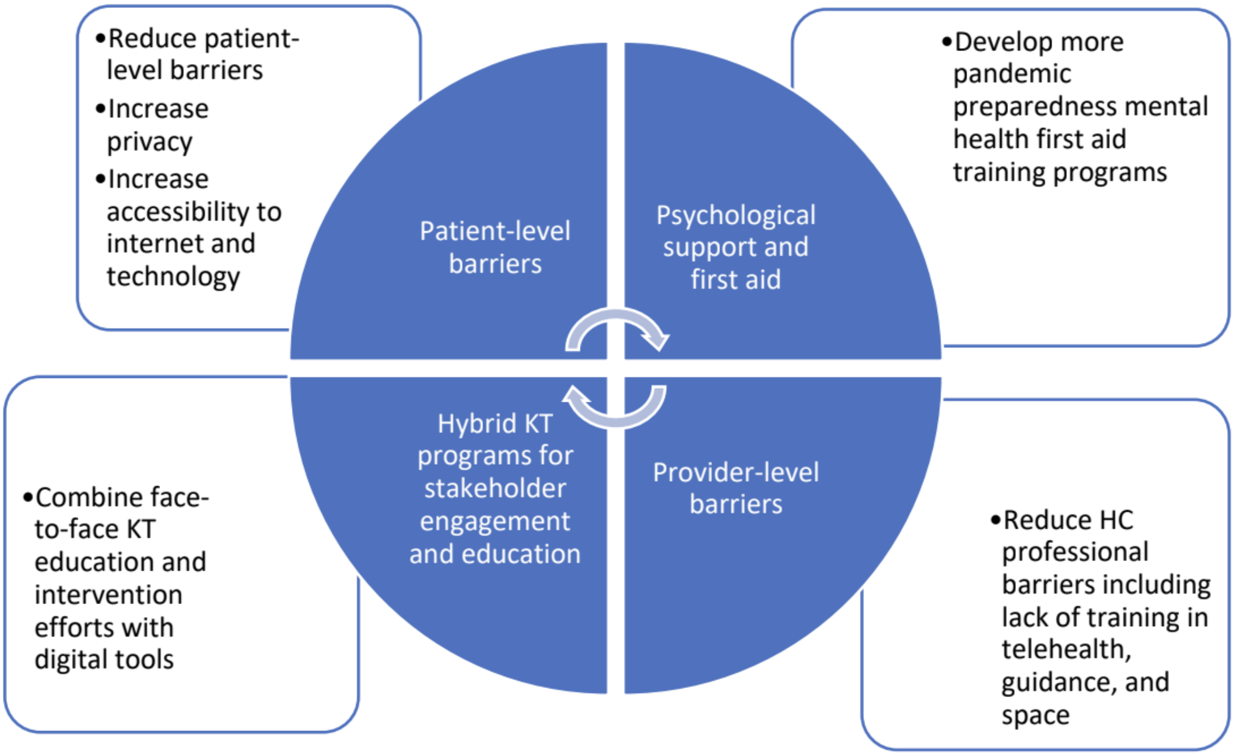
Recommendations

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

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

Yanan Ma[1], MSc; Kate Law[2], PhD; Lamiece Hassan[3], PhD; Goran Nenadic[1], PhD; Sabine N van der Veer[3], PhD

[1]School of Computer Science, The University of Manchester, Manchester, United Kingdom

[2]Division of Nursing, Midwifery & Social Work, The University of Manchester, Manchester, United Kingdom

[3]Division of Informatics, Imaging and Data Sciences, The University of Manchester, Manchester, United Kingdom

Corresponding Author:
Sabine N van der Veer, PhD
Division of Informatics, Imaging and Data Sciences
The University of Manchester
Centre for Health Informatics, Room 1.004
Manchester, M13 9GB
United Kingdom
Phone: 44 1613067767
Email: sabine.vanderveer@manchester.ac.uk

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.

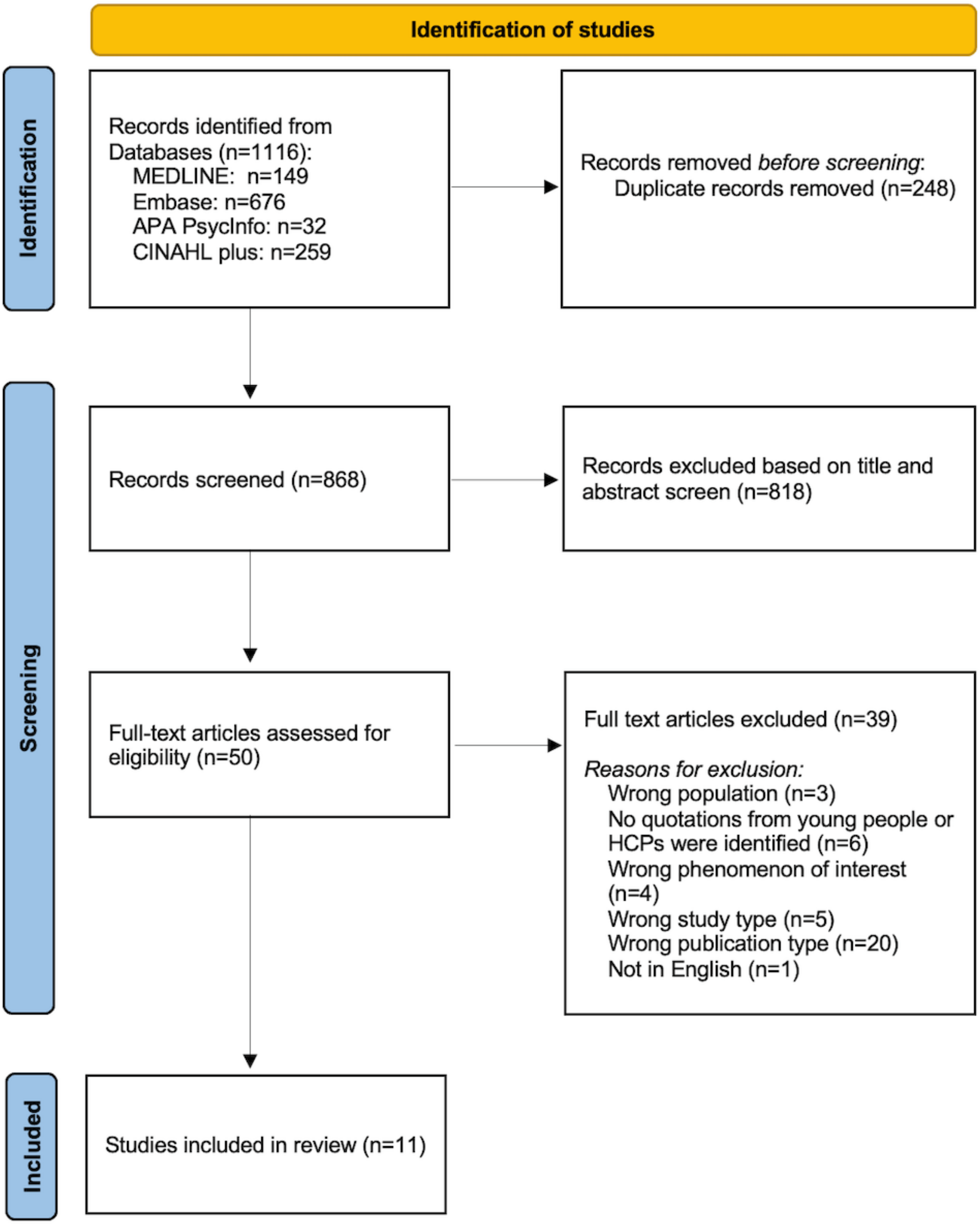
Third, generating analytical themes through a series of discussions within the team to explore how the descriptive themes related to our research aim and objectives, while endeavoring a novel interpretation and insights that expanded beyond simply summarizing the findings of individual-included studies.

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.

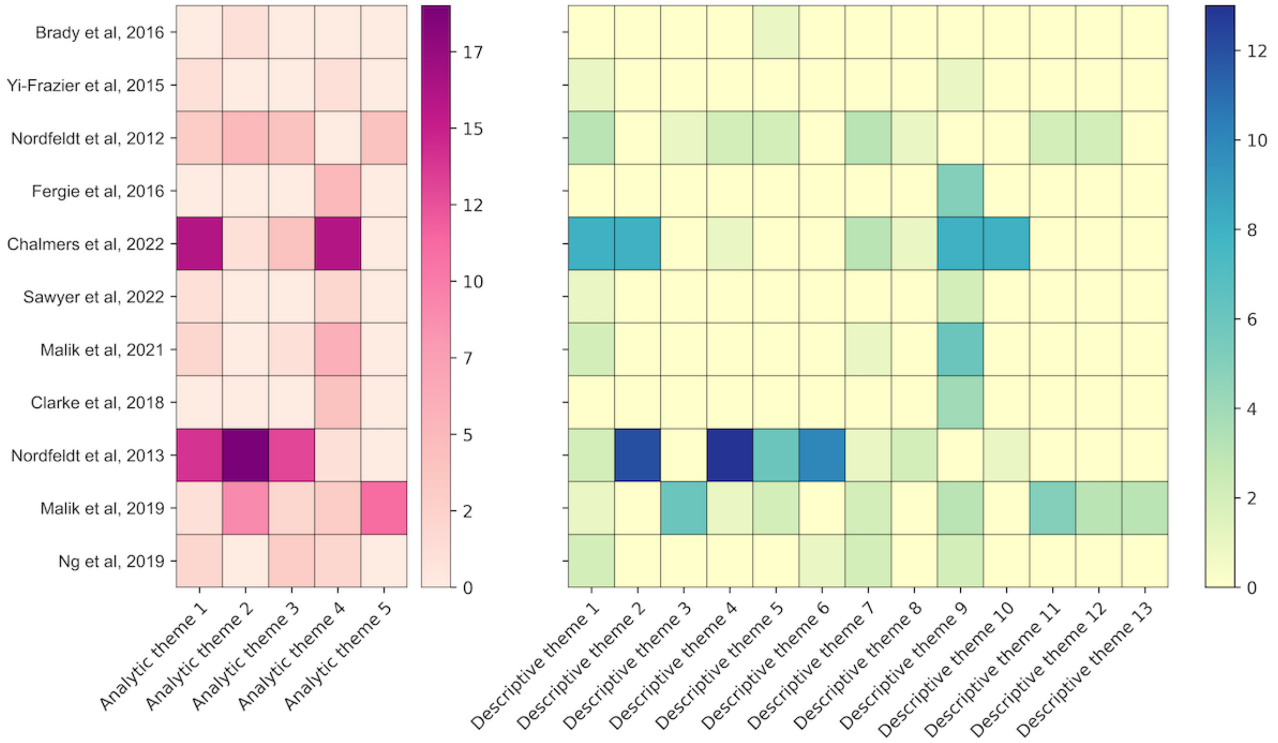
Analytic and descriptive themes	Additional illustrative quotations
Analytic theme 1: differences in how young people interact with social media (differences in how young people with T1DM[a] interacted with social media, including different levels of engagement and willingness to disclose information 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.

Acknowledgments

The authors would like to acknowledge Claire Hodkinson, a librarian at the University of Manchester, for supporting the search strategy.

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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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

Kristina Marie Kokorelias[1,2,3], PhD; Tin-Suet Joan Lee[1], BSc; Mark Bayley[1,3,4], MD; Emily Seto[5,6,7], PhD; Alene Toulany[8], MD; Michelle L A Nelson[5,9], PhD; Gina Dimitropoulos[10], MSW, PhD; Melanie Penner[11], MD, MSc; Robert Simpson[12], PhD; Sarah E P Munce[1,2,5,13], PhD

[1]KITE Research Institute, Toronto Rehabilitation Institute-University Health Network, Toronto, ON, Canada
[2]Department of Occupational Sciences and Occupational Therapy, Temetry Faculty of Medicine, University of Toronto, Toronto, ON, Canada
[3]Rehabilitation Sciences Institute, Temetry Faculty of Medicine, University of Toronto, Toronto, ON, Canada
[4]Division of Physical Medicine and Rehabilitation, University of Toronto, Toronto, ON, Canada
[5]Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, ON, Canada
[6]Center for Digital Therapeutics, University Health Network, Toronto, ON, Canada
[7]Toronto General Hospital Research Institute, University Health Network, Toronto, ON, Canada
[8]Department of Adolescent Medicine, The Hospital for Sick Children, Toronto, ON, Canada
[9]Lunenfeld-Tanenbaum Research Institute, Sinai Health, Toronto, ON, Canada
[10]Faculty of Social Work, University of Calgary, Calgary, AB, Canada
[11]Department of Pediatrics, Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, ON, Canada
[12]St. John’s Rehab Research Program, Sunnybrook Research Institute, Sunnybrook Health Sciences, Toronto, ON, Canada
[13]Rehabilitation Sciences Institute, Temetry Faculty of Medicine, University of Toronto, Toronto, ON, Canada

Corresponding Author:
Sarah E P Munce, PhD
KITE Research Institute
Toronto Rehabilitation Institute-University Health Network
Room 106
345 Rumsey Road
Toronto, ON, M4G 1R7
Canada
Phone: 1 416 597 3422
Email: sarah.munce@uhn.ca

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.

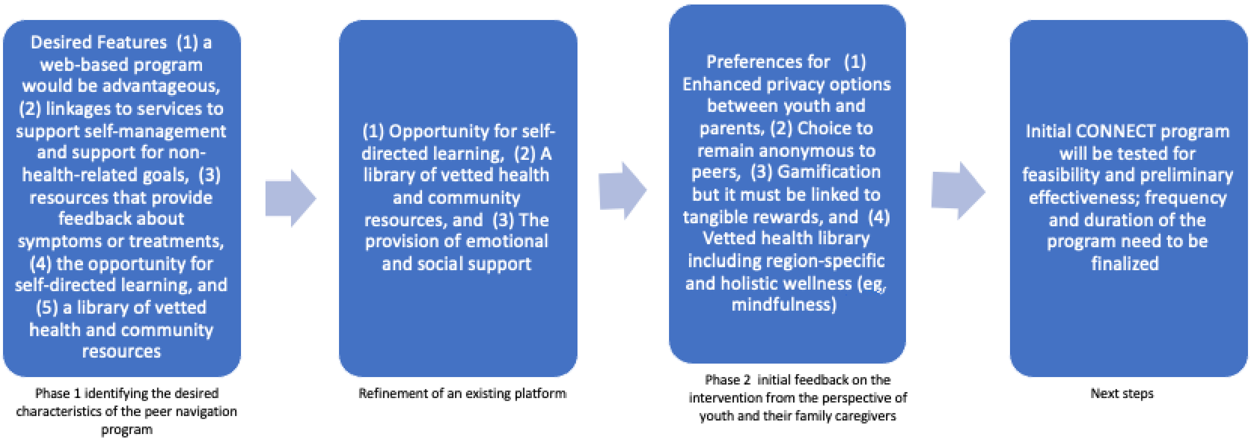


Table 2. Summary of themes.

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

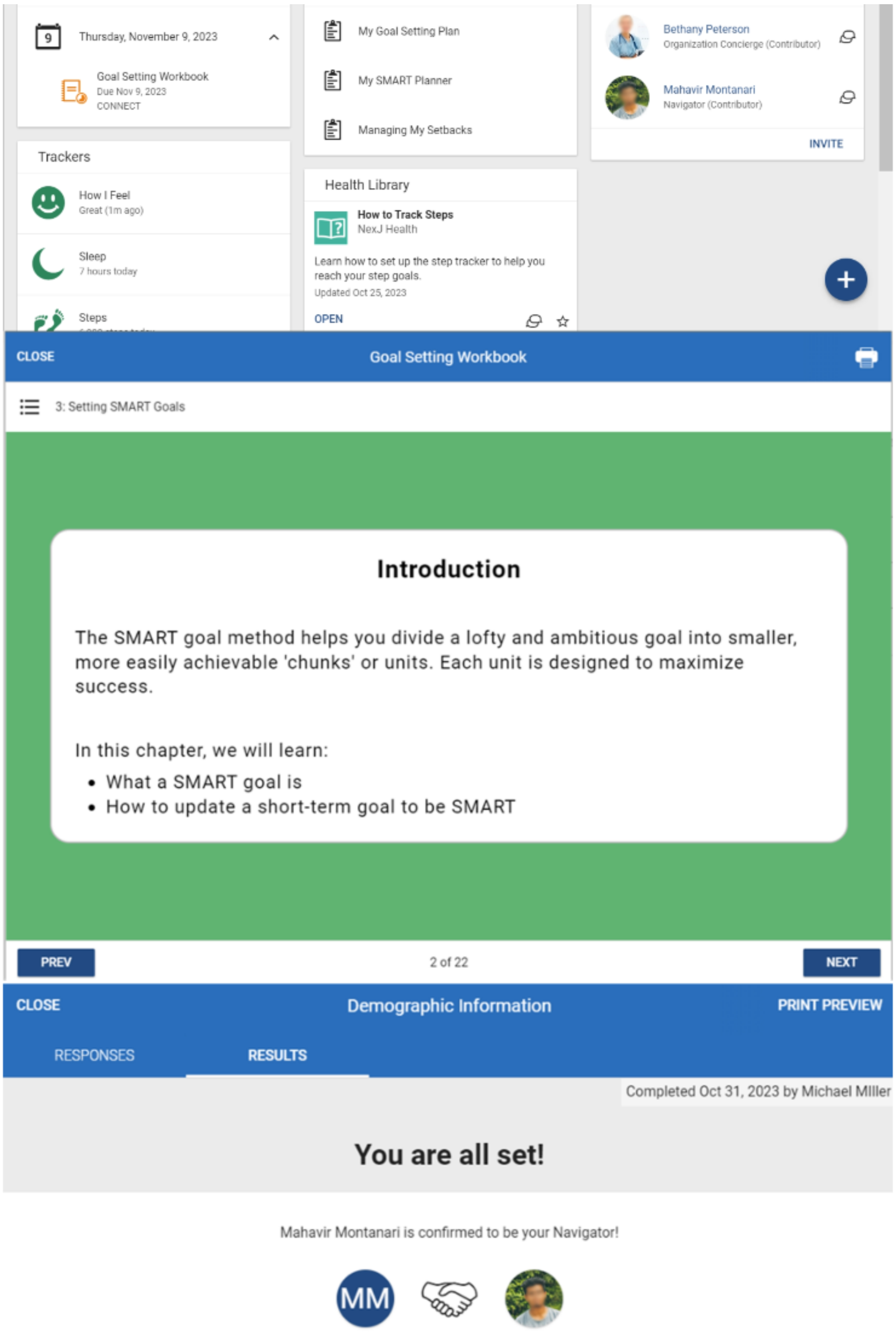
In this section, we have outlined the key themes related to the logistics, parental control, multimodal communication, and varied needs for support regarding the use of CONNECT. Figure 1 presents the collective learnings across phase 1 and phase 2.

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

Bryan Sisk[1,2], MD, MSc; Alison L Antes[1], PhD; Christine Bereitschaft[2], MSW; Madi Enloe[2], MPH; Fabienne Bourgeois[3,4], MD, MPH; James DuBois[1], DSc, PhD

[1]Bioethics Research Center, Department of Medicine, Washington University School of Medicine, St Louis, MO, United States
[2]Division of Hematology and Oncology, Department of Pediatrics, Washington University, St Louis, MO, United States
[3]Boston Children's Hospital, Boston, MA, United States
[4]Harvard Medical School, Boston, MA, United States

Corresponding Author:
Bryan Sisk, MD, MSc
Bioethics Research Center
Department of Medicine
Washington University School of Medicine
MSC 8116-43-10
660 S Euclid
St Louis, MO, 63110
United States
Phone: 1 3142739084
Email: siskb@wustl.edu

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

Juan J Gómez-Valverde[1,2], PhD; Ramón Sánchez-Jacob[3], MD; José Luis Ribó[4], MD; H Simon Schaaf[5], MD, PhD; Lara García Delgado[1], MSc; Alicia Hernanz-Lobo[6,7,8,9], MD; Daniel Capellán-Martín[1], MSc; Ángel Lancharro[10,11], MD; Orvalho Augusto[12,13], MD, MPH; Alberto L García-Basteiro[8,12,14], PhD; Begoña Santiago-García[6,7,8], MD, PhD; Elisa López-Varela[12,14], MD, PhD; María J Ledesma-Carbayo[1,2], PhD

[1]Biomedical Image Technologies, ETSI Telecomunicación, Universidad Politécnica de Madrid, Madrid, Spain
[2]Centro de Investigación Biomédica en Red de Bioingeniería, Biomateriales y Nanomedicina (CIBER-BBN), Madrid, Spain
[3]Department of Radiology, Children's National Hospital & George Washington University School of Medicine, Washington, DC, United States
[4]Hospital Universitari General de Catalunya, Barcelona, Spain
[5]Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University, Cape Town, South Africa
[6]Pediatric Infectious Diseases Department, Gregorio Marañón University Hospital, Madrid, Spain
[7]Gregorio Marañón Research Health Institute (IiSGM), Madrid, Spain
[8]Centro de Investigación Biomédica en Red de Enfermedades Infecciosas (CIBERINFEC), Instituto de Salud Carlos III, Madrid, Spain
[9]RITIP Translational Research Network in Pediatric Infectious Diseases, Madrid, Spain
[10]Radiología Pediátrica Hospital Materno Infantil Gregorio Marañón, Madrid, Spain
[11]Radiología Pediátrica, HM Hospitales, Madrid, Spain
[12]Centro de Investigacão em Saúde de Manhiça (CISM), Maputo, Mozambique
[13]Department of Global Health, University of Washington, Seattle, WA, United States
[14]ISGlobal, Hospital Clínic, Universitat de Barcelona, Barcelona, Spain

Corresponding Author:
Juan J Gómez-Valverde, PhD
Biomedical Image Technologies
ETSI Telecomunicación
Universidad Politécnica de Madrid
Avenida Complutense 30
Madrid, 28040
Spain
Phone: 34 910672210
Email: juanjo.gomez@upm.es

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 ($\chi 21>20.38$, $P<.001$). The study found varying levels of interreader agreement, with moderate/substantial agreement for air space opacification ($\kappa=0.54-0.67$) and pleural effusion ($\kappa=0.43-0.72$).

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.

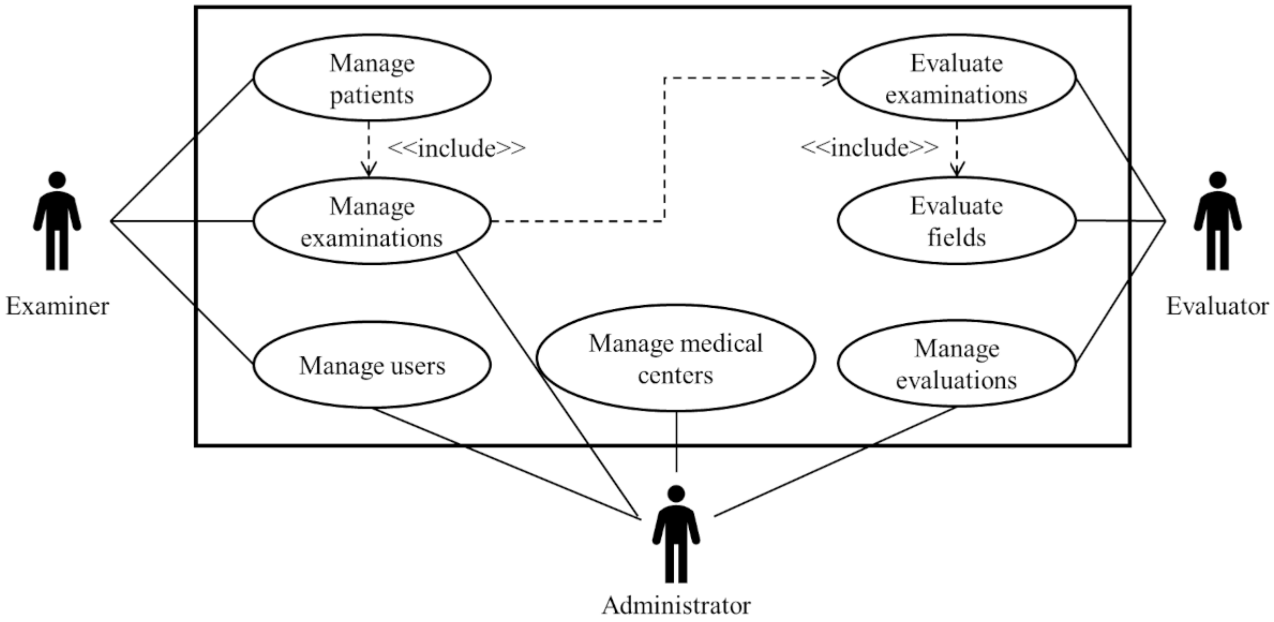
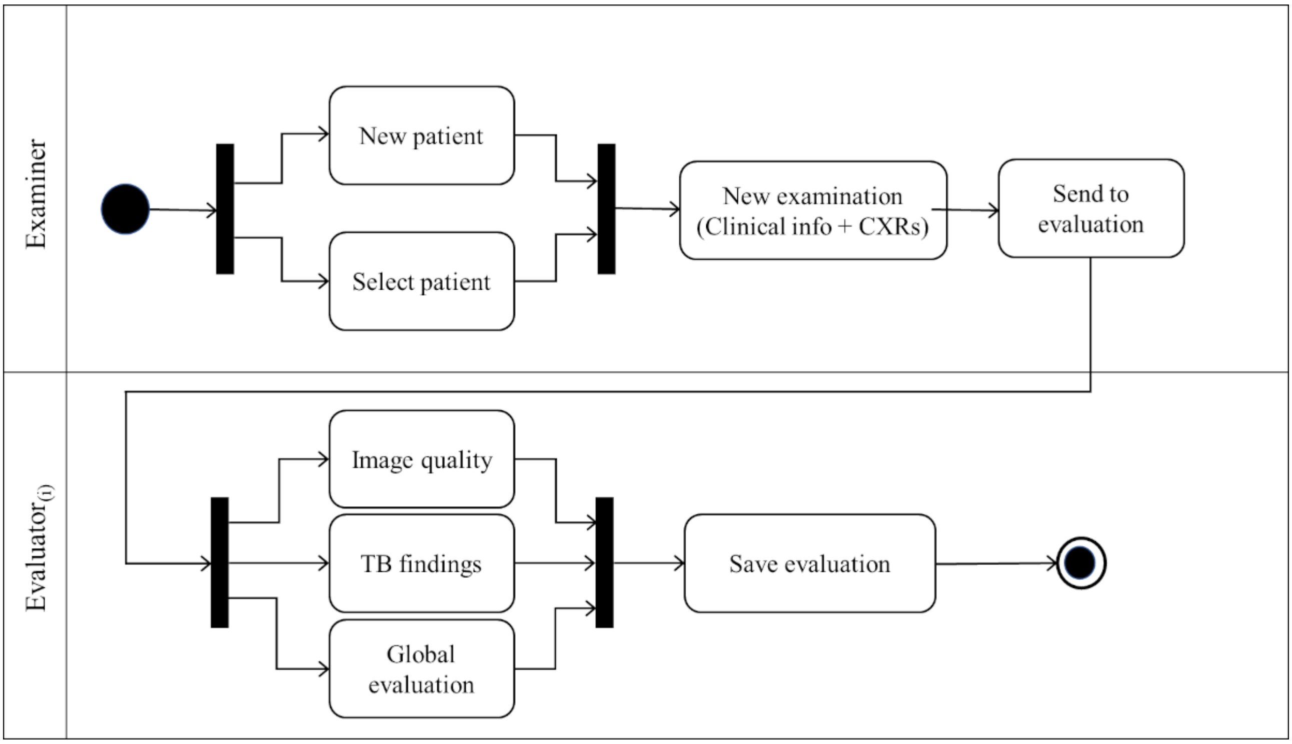


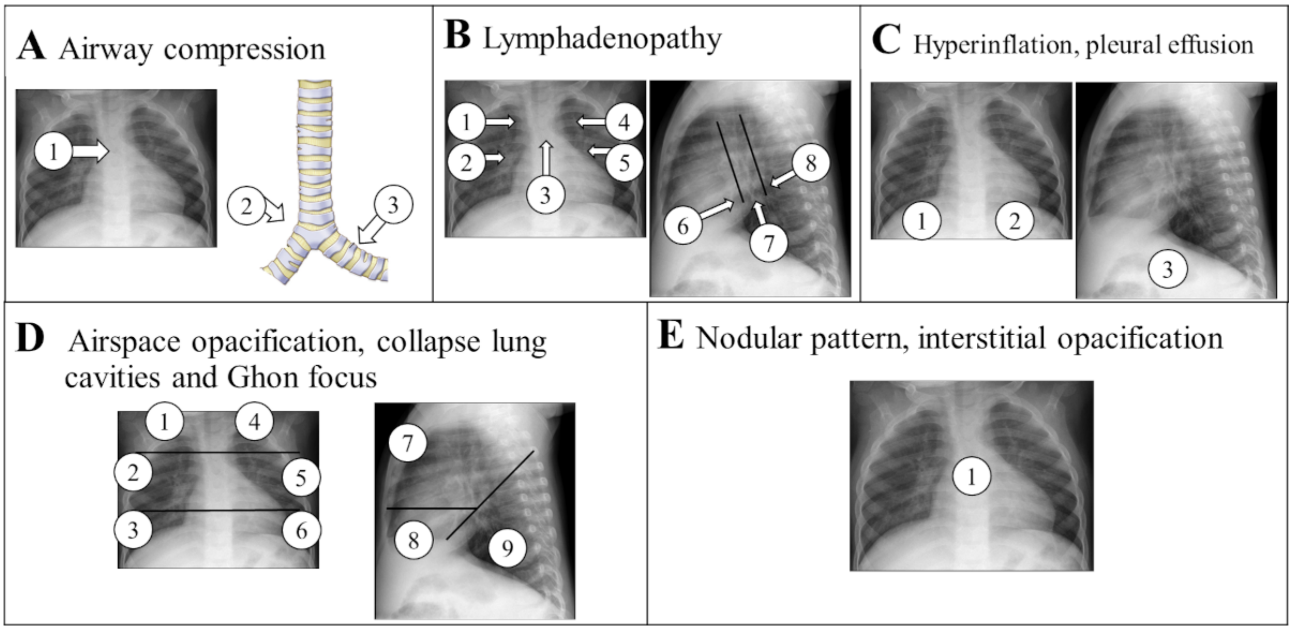
Figure 2 displays the activity diagrams designed to illustrate the process of uploading a new examination to the platform by an examiner, incorporating clinical information and CXR images, as well as the subsequent transmission of the corresponding examination to be evaluated by an evaluator user. The 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.

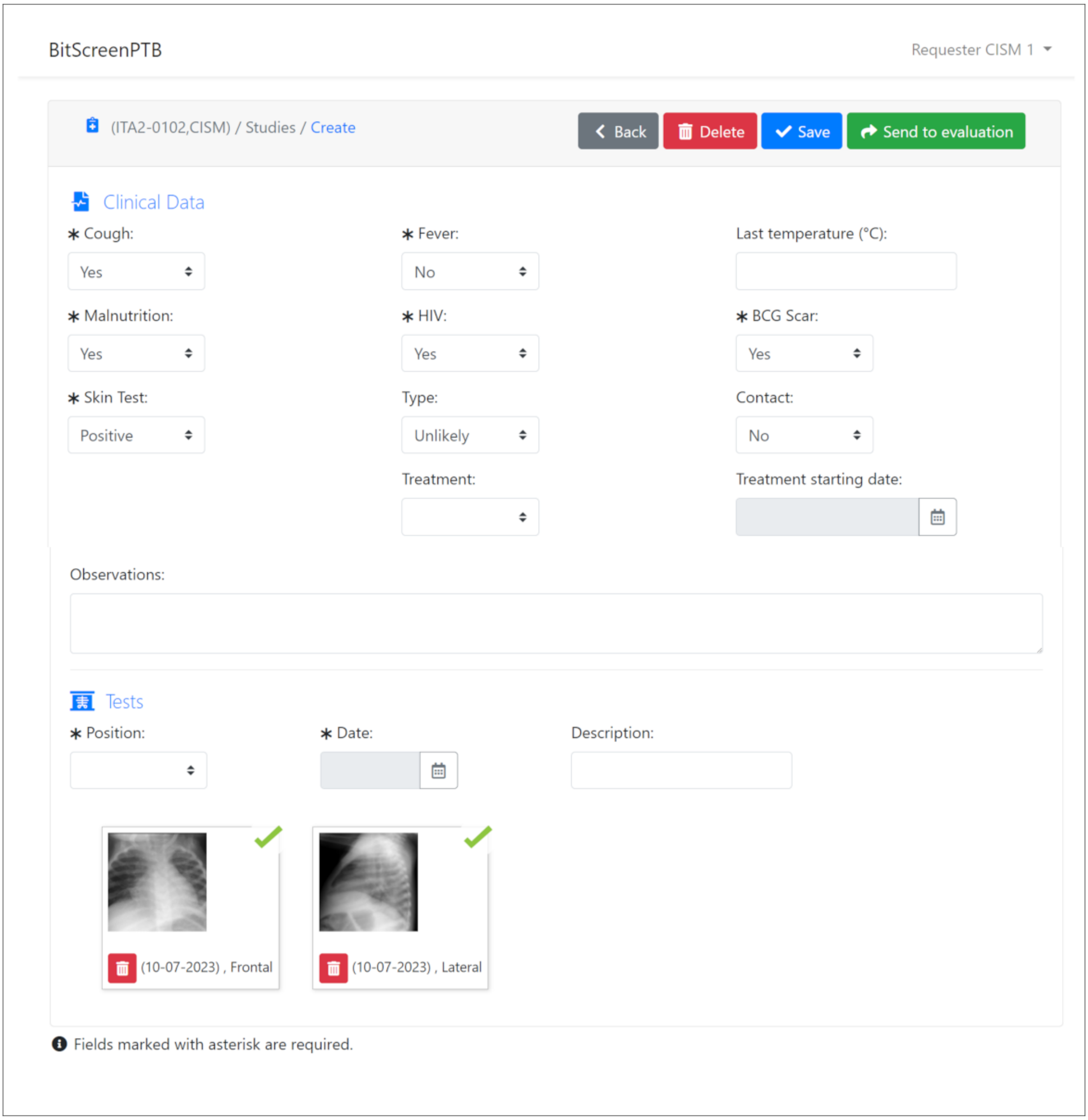
Platform Usability Evaluation

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:

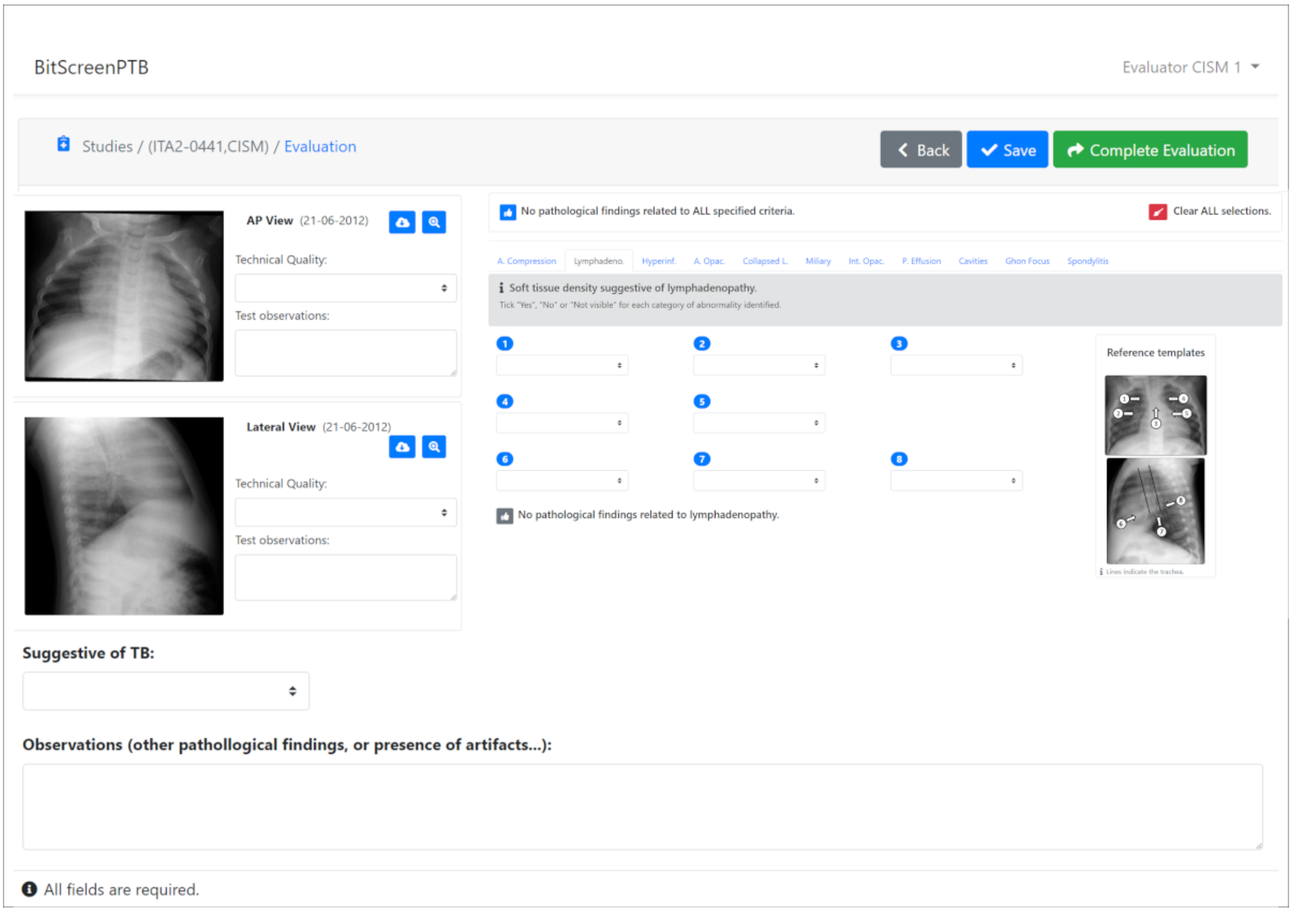
(10-07-2023) , Frontal

(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).

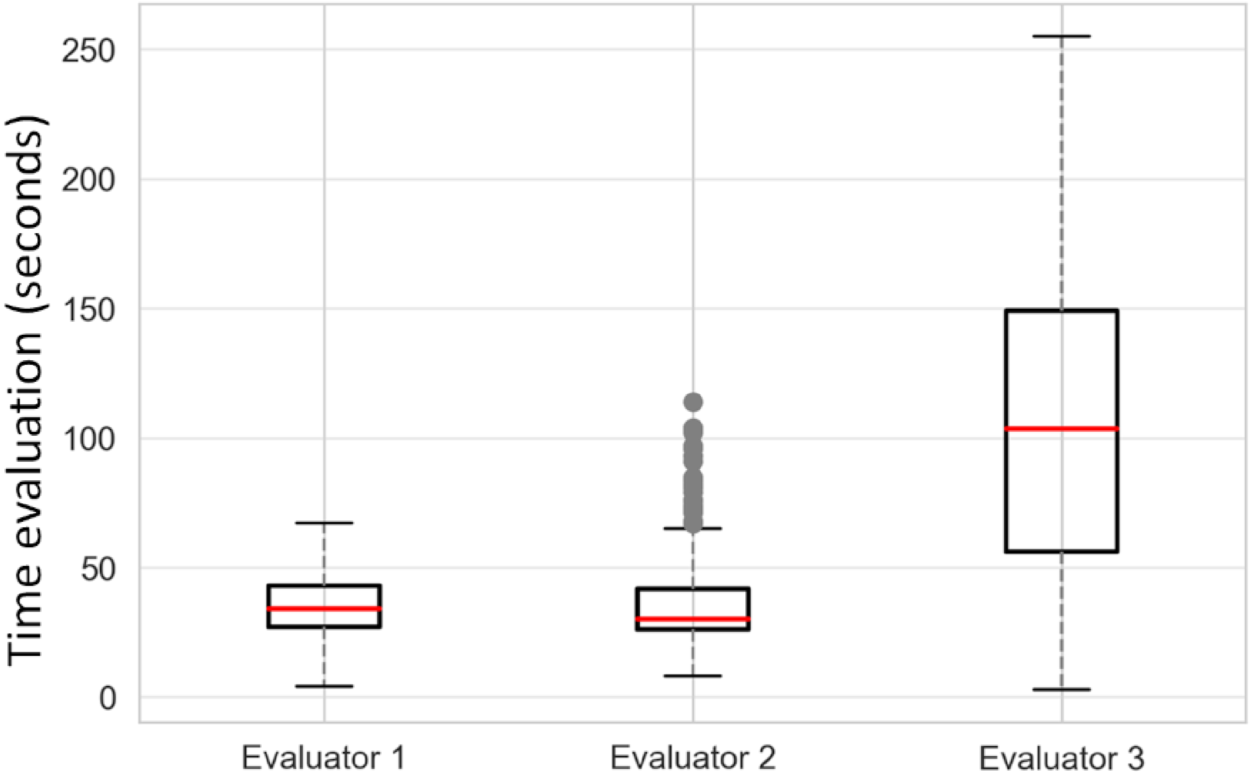
Section	Mean (SD)
Usefulness	4.42 (0.53)
1. It facilitates the assessment of CXRs[a] in pediatric TB[b] studies	4.64 (0.58)
2. It saves me time assessing CXRs in pediatric TB studies	4.31 (0.58)
3. It includes all the items I need to evaluate pediatric TB studies	4.31 (0.58)
Ease of use and learnability	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, *F*1-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.

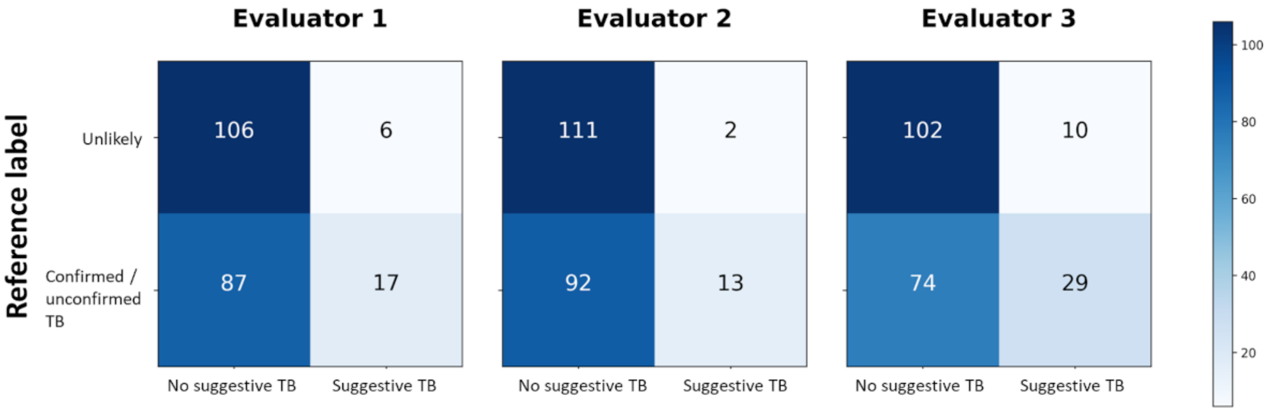


Table 5 displays the number of observations recorded by each of the 3 evaluators in the 3 diagnostic categories, namely, confirmed TB, unconfirmed TB, and unlikely TB, across the 10 examination fields. The total number of observations recorded by the 3 evaluators was 64, 59, and 150, highlighting a substantial 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).

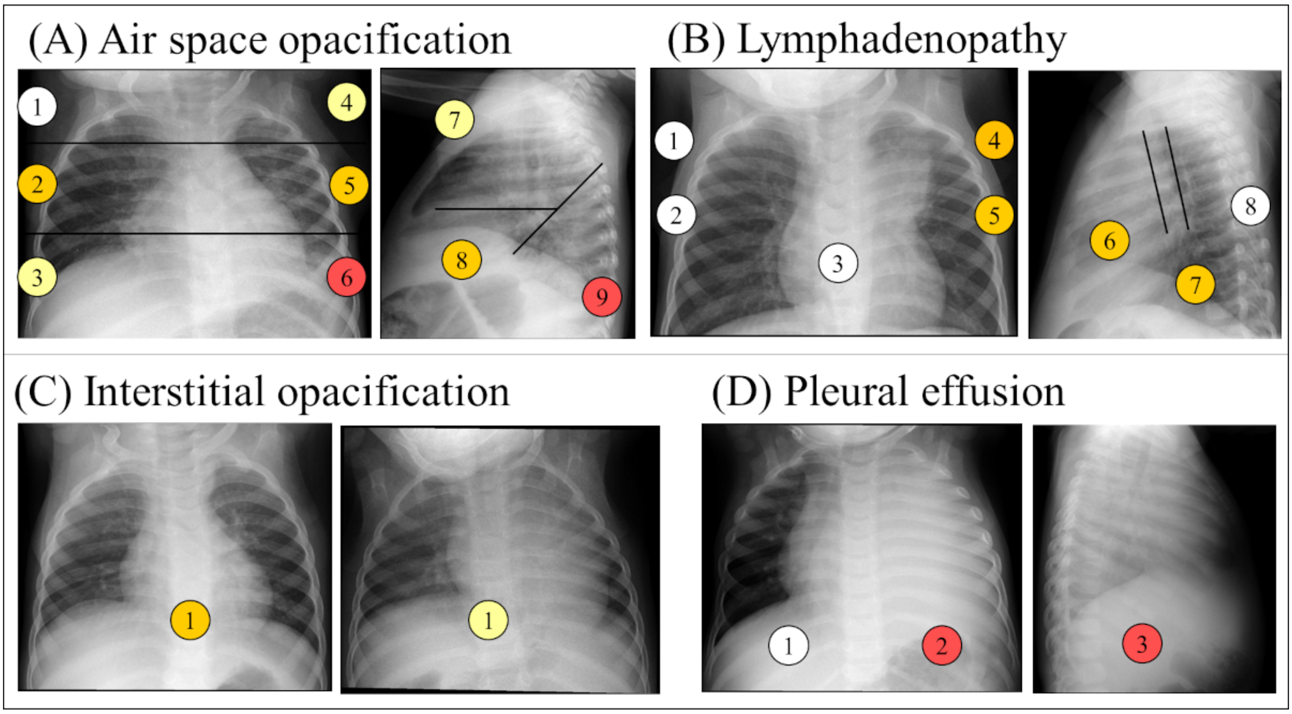
Results	Overall, n	Confirmed, n	Unconfirmed TB[c], n	Unlikely TB, n
Number of patients	218	10	95	113
Airway compression or tracheal displacement or both	4/0/7	2/0/0	2/0/4	0/0/3
Lymphadenopathy	7/7/34	3/1/4	4/4/22	0/2/8
Hyperinflation	4/0/3	2/0/0	2/0/2	0/0/1
Air space opacification	31/42/52	7/7/7	22/30/33	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

Lisa Whitehead[1,2,3,4,5], BSc, MA, PhD; Suzanne Robinson[1,3], BSc; Diana Arabiat[1,4,5], BSc, MSc, PhD; Mark Jenkins[1], PhD; Evalotte Morelius[1,4,6], BSc, MSc, PhD

[1]School of Nursing and Midwifery, Edith Cowan University, Joondalup, Australia
[2]Centre for Postgraduate Nursing Studies, University of Otago, Christchurch, New Zealand
[3]The Centre for Evidence Informed Nursing, Midwifery and Healthcare Practice, Joondalup, Australia
[4]Australian Research Council Centre of Excellence for the Digital Child, Joondalup, Australia
[5]Maternal and Child Nursing Department, Faculty of Nursing, The University of Jordan, Amman, Jordan
[6]Department of Health, Medicine and Caring Sciences, Linköping University, Linköping, Sweden

Corresponding Author:
Lisa Whitehead, BSc, MA, PhD
School of Nursing and Midwifery, Edith Cowan University
270 Joondalup Drive
Joondalup, 6027
Australia
Phone: 61 438145638
Email: l.whitehead@ecu.edu.au

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.

Trial Registration: PROSPERO CRD42020170874; https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=170874

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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

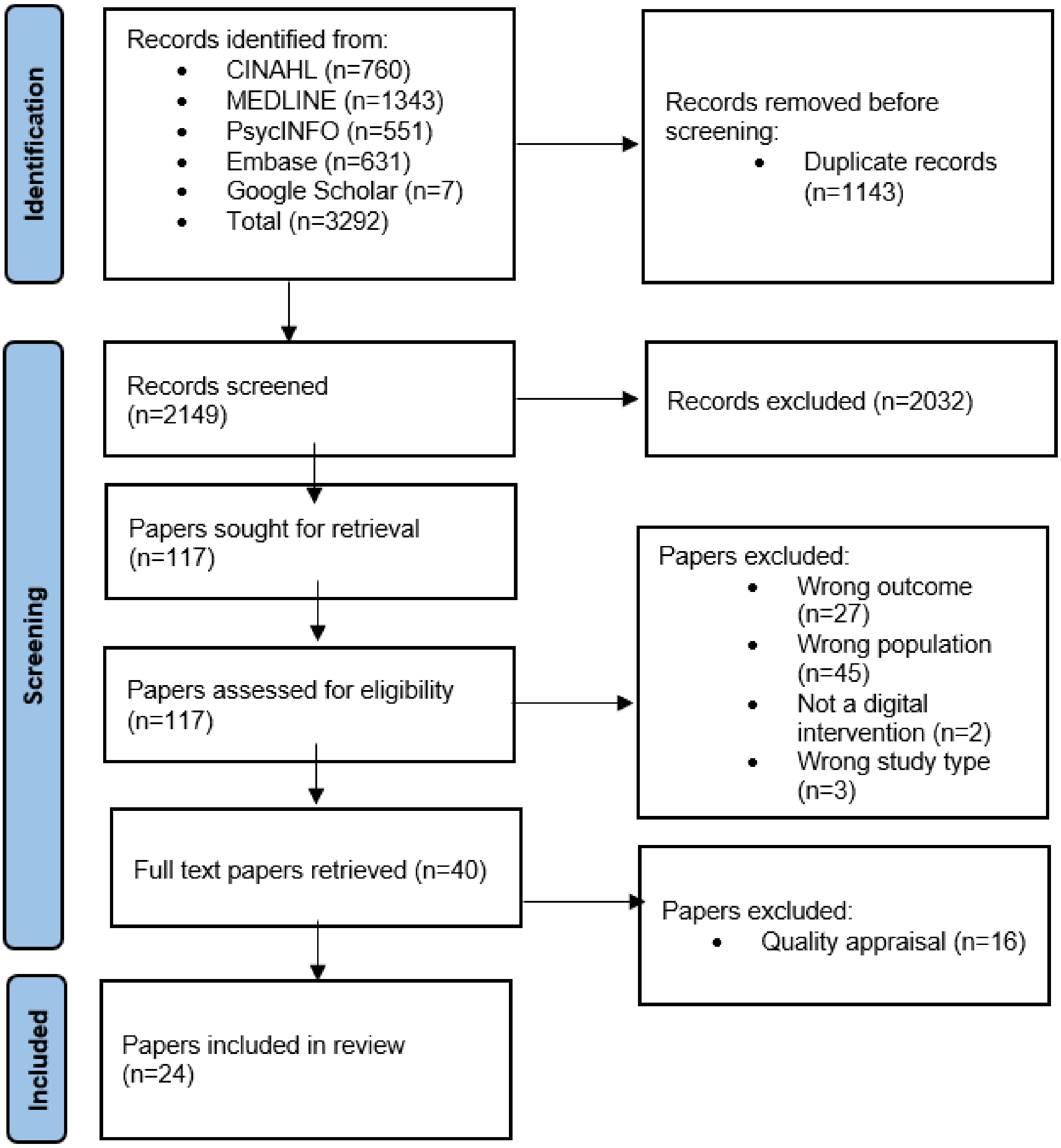
Owing to the heterogeneity between the studies on outcome measures, research design, and the intervention, a meta-analysis was not possible. The findings have been presented in narrative form including tables and figures to aid in data presentation. The process of data synthesis followed the JBI approach 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

Valeska Berg[1,2], BSc, MSc, PhD; Diana Arabiat[1,2,3], BSc, MSc, PhD; Evalotte Morelius[1,2,4], MSc, PhD; Lisa Kervin[2,5], PhD; Maggie Zgambo[1,2], PhD; Suzanne Robinson[1], BSc; Mark Jenkins[1], PhD; Lisa Whitehead[1,2,3,6], BSc, MA, PhD

[1]School of Nursing & Midwifery, Edith Cowan University, Joondalup, Australia
[2]Australian Research Council Centre of Excellence for the Digital Child, Brisbane, Australia
[3]Faculty of Nursing, University of Jordan, Amman, Jordan
[4]Department of Health, Medicine and Caring Sciences, Linköping University, Linköping, Sweden
[5]School of Education, University of Wollongong, Wollongong, Australia
[6]The Centre for Evidence Informed Nursing, Midwifery and Healthcare Practice: A JBI Affiliated Group, Joondalup, Australia

Corresponding Author:
Lisa Whitehead, BSc, MA, PhD
School of Nursing & Midwifery
Edith Cowan University
270 Joondalup Drive
Joondalup, 6027
Australia
Phone: 61 438145638
Email: l.whitehead@ecu.edu.au

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

Yansen Theopilus[1,2], MEng; Abdullah Al Mahmud[1], PhD; Hilary Davis[3], PhD; Johanna Renny Octavia[2], PhD

[1]Centre for Design Innovation, Swinburne University of Technology, Melbourne, Australia
[2]Centre for Ergonomics, Parahyangan Catholic University, Bandung, Indonesia
[3]Centre for Social Impact, Swinburne University of Technology, Melbourne, Australia

Corresponding Author:
Abdullah Al Mahmud, PhD
Centre for Design Innovation
Swinburne University of Technology
John St, Hawthorn
Melbourne, 3122
Australia
Phone: 61 39214383
Email: aalmahmud@swin.edu.au

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

Building a Sustainable Learning Health Care System for Pregnant and Lactating People: Interview Study Among Data Access Providers

Marieke J Hollestelle[1,2], MA; Rieke van der Graaf[1,2], PhD; Miriam C J M Sturkenboom[1,3], Prof Dr; Marianne Cunnington[4], PhD; Johannes J M van Delden[1,2], Prof Dr, MD

[1]Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, Utrecht, Netherlands
[2]Bioethics & Health Humanities, University Medical Center Utrecht, Utrecht, Netherlands
[3]Data Science & Biostatistics, University Medical Center Utrecht, Utrecht, Netherlands
[4]Analysis Group Inc, London, United Kingdom

Corresponding Author:
Marieke J Hollestelle, MA
Julius Center for Health Sciences and Primary Care
University Medical Center Utrecht
Heidelberglaan 100
Utrecht, 3508 CA
Netherlands
Phone: 31 88755555
Email: m.j.hollestelle-2@umcutrecht.nl

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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Response Rate Patterns in Adolescents With Concussion Using Mobile Health and Remote Patient Monitoring: Observational Study

Sicong Ren[1], PhD; Catherine C McDonald[1,2,3], RN, PhD; Daniel J Corwin[1,2,4], MSCE, MD; Douglas J Wiebe[5,6], PhD; Christina L Master[1,2,7], MD; Kristy B Arbogast[1,2,4], PhD

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Corresponding Author:
Sicong Ren, PhD

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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Evaluation of Parents' Use of a Child Health Care Information App and Their Health Literacy: Cross-Sectional Study

Masahiko Sakamoto*, MD; Hirono Ishikawa*, PhD; Asuka Suzuki, PhD

Teikyo University Graduate School of Public Health, Tokyo, Japan

*these authors contributed equally

Corresponding Author:
Masahiko Sakamoto, MD

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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Original Paper

Mobile App/Web Platform for Monitoring Food Oral Immunotherapy in Children: Longitudinal Clinical Validation Study

Sergio Sánchez-Fernández[1*], MD; Eva María Lasa[2*], MD, PhD; Soledad Terrados[3], MD; Francisco Javier Sola-Martínez[3], MD; Sara Martínez-Molina[2], MD; Marta López de Calle[1], MD; Paula Cabrera-Freitag[4,5], MD, PhD; María José Goikoetxea[1,6,7], MD, PhD

[1]Allergy and Clinical Immunology Department, Clínica Universidad de Navarra, Pamplona, Spain
[2]Pediatric Allergy Unit, Allergy Service, Hospital Universitario Donostia, Donostia-San Sebastián, Spain
[3]Department of Pediatric Allergy, Ramón y Cajal Hospital, Madrid, Spain
[4]Pediatric Allergy Unit, Allergy Department, Hospital General Universitario Gregorio Marañón, Madrid, Spain
[5]Gregorio Marañón Health Research Institute, Madrid, Spain
[6]Instituto de Investigación Sanitaria de Navarra, Pamplona, Spain
[7]RICORS Red De Enfermedades Inflamatorias - RD21/0002/0028, Madrid, Spain
[*]these authors contributed equally

Corresponding Author:
María José Goikoetxea, MD, PhD
Allergy and Clinical Immunology Department
Clínica Universidad de Navarra
Pío XII, 36
Pamplona, 31008
Spain
Phone: 34 948255400
Email: mjgoiko@unav.es

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

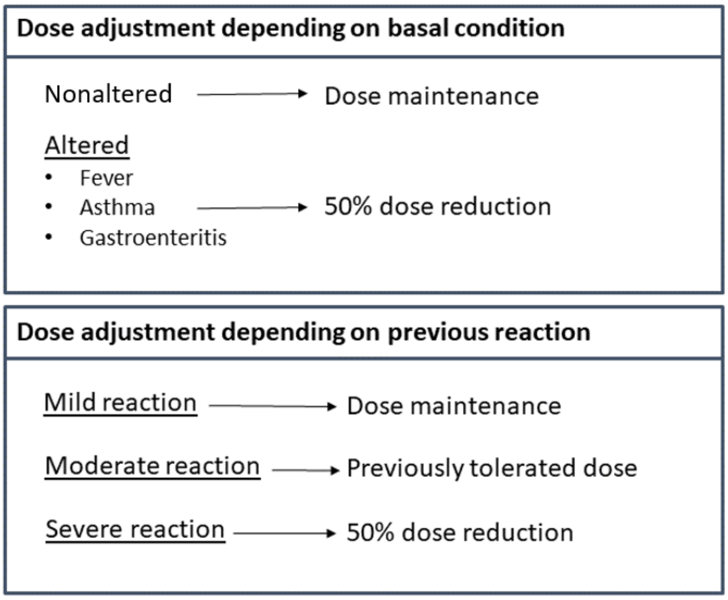
Patients underwent treatment with initially grouped dosing schedules at the hospital, in accordance with the Spanish OIT guidelines [14]. Subsequently, weekly increments in hospital doses were administered. The allergen dose that was tolerated at the hospital was then maintained daily at home between 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:

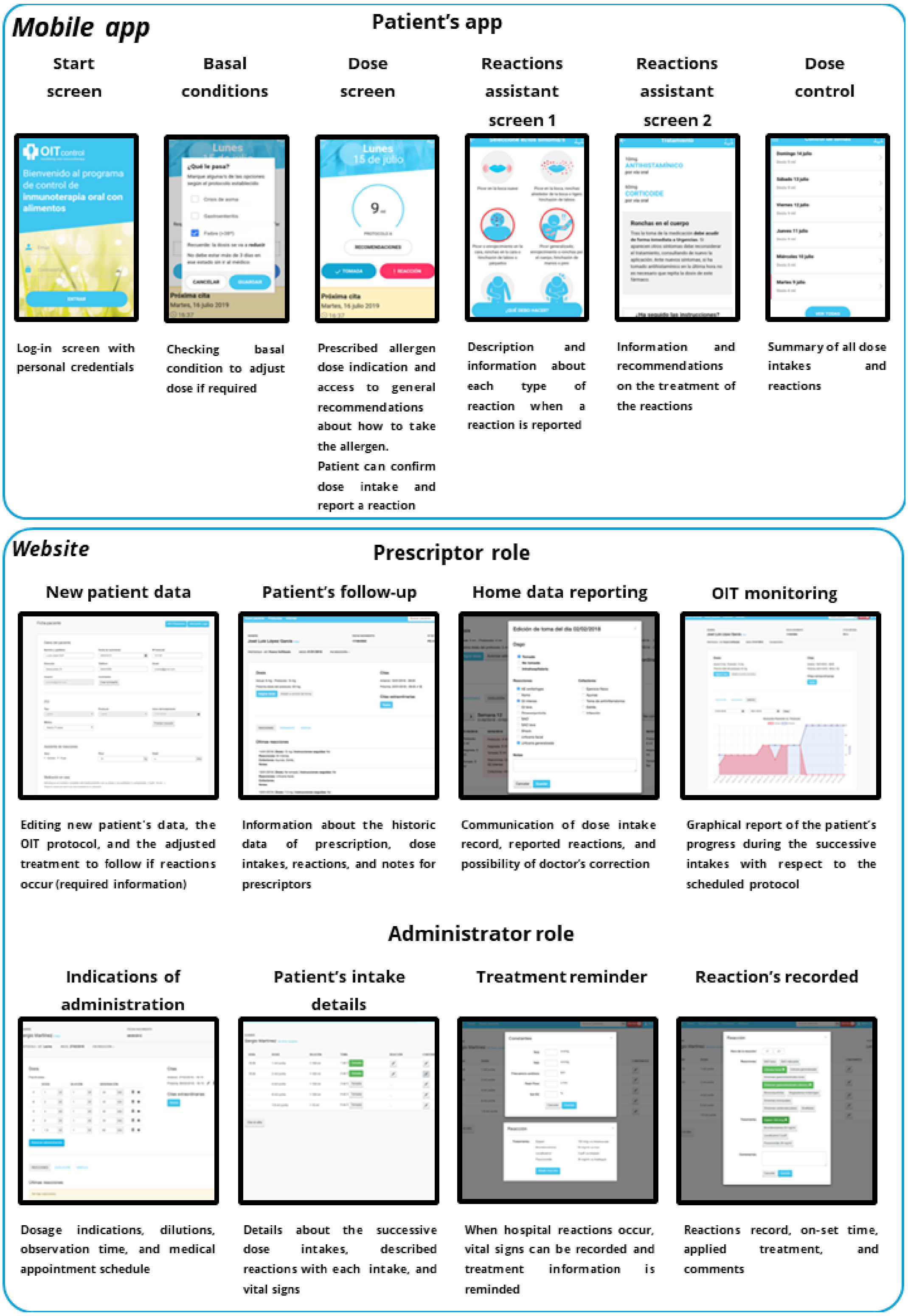
- When the basal condition is linked to a reaction, such as in the presence of gastroenteritis, fever, or an asthma attack, the app automatically decreases the dose to half of the scheduled amount [8,10].
- In the event of a moderate/severe reaction, the app adjusts the dose for the next day [8,26] (Figure 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.



Mobile app

Patient's app

Start screen: Log-in screen with personal credentials

Basal conditions: Checking basal condition to adjust dose if required

Dose screen: Prescribed allergen dose indication and access to general recommendations about how to take the allergen. Patient can confirm dose intake and report a reaction

Reactions assistant screen 1: Description and information about each type of reaction when a reaction is reported

Reactions assistant screen 2: Information and recommendations on the treatment of the reactions

Dose control: Summary of all dose intakes and reactions

Website

Prescriptor role

New patient data: Editing new patient's data, the OIT protocol, and the adjusted treatment to follow if reactions occur (required information)

Patient's follow-up: Information about the historic data of prescription, dose intakes, reactions, and notes for prescriptors

Home data reporting: Communication of dose intake record, reported reactions, and possibility of doctor's correction

OIT monitoring: Graphical report of the patient's progress during the successive intakes with respect to the scheduled protocol

Administrator role

Indications of administration: Dosage indications, dilutions, observation time, and medical appointment schedule

Patient's intake details: Details about the successive dose intakes, described reactions with each intake, and vital signs

Treatment reminder: When hospital reactions occur, vital signs can be recorded and treatment information is reminded

Reaction's recorded: 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.

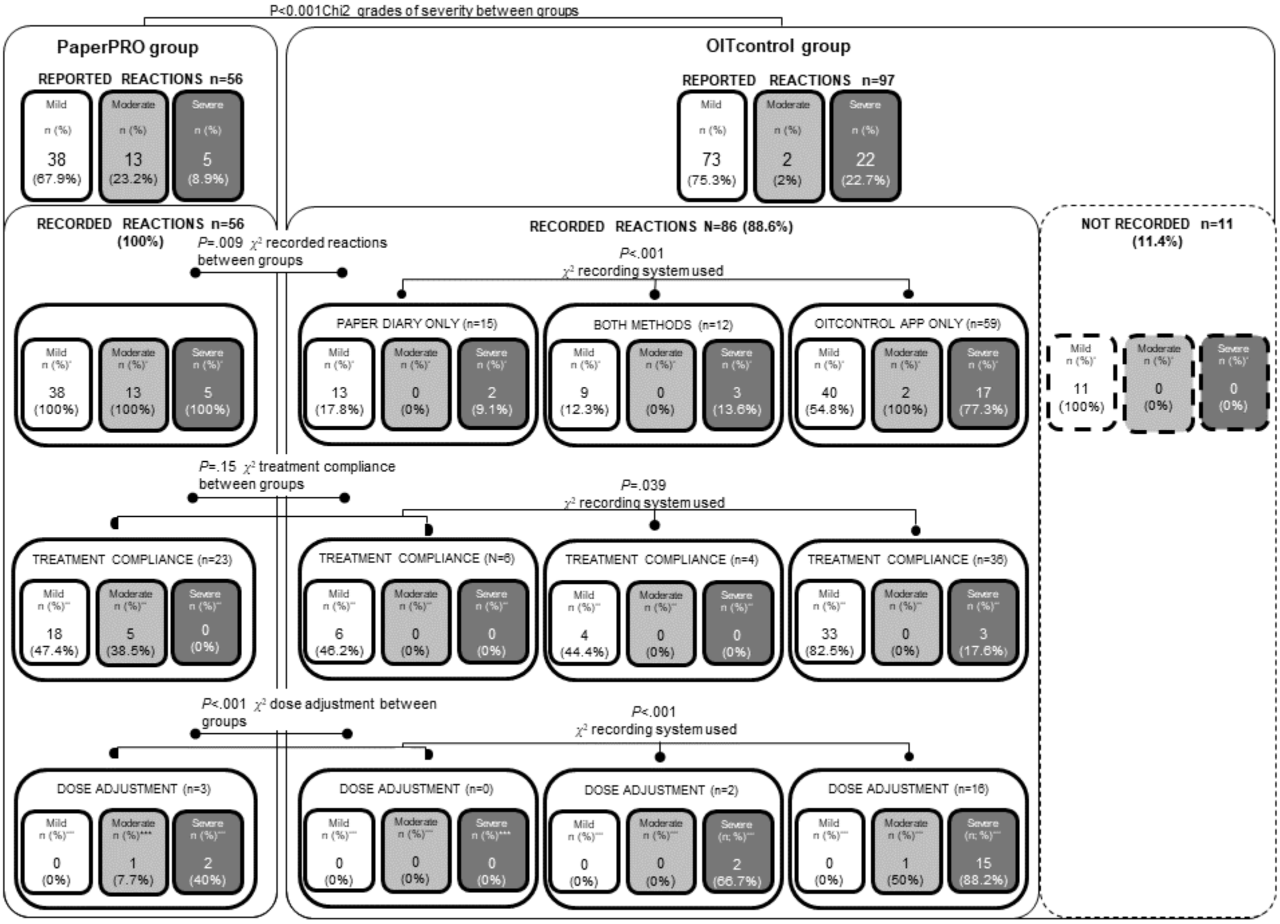
[b] OAS: oral allergy syndrome.

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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An Electronic Teen Questionnaire, the eTeenQ, for Risk Behavior Screening During Adolescent Well Visits in an Integrated Health System: Development and Pilot Implementation

Shannon Neale[1,2,*], MD; Ella Chrenka[3,*], MS; Abhilash Muthineni[3], MS; Rashmi Sharma[3,*], BA; Mallory Layne Hall[3], BA; Juliana Tillema[4], MPA; Elyse O Kharbanda[3,*], MPH, MD

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[*]these authors contributed equally

Corresponding Author:
Elyse O Kharbanda, MPH, MD

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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Digital Gaming and Exercise Among Youth With Type 1 Diabetes: Cross-Sectional Analysis of Data From the Type 1 Diabetes Exercise Initiative Pediatric Study

Susana R Patton[1], PhD; Robin L Gal[2], MSPH; Simon Bergford[2], MS; Peter Calhoun[2], PhD; Mark A Clements[3], MD, PhD; Jennifer L Sherr[4], MD, PhD; Michael C Riddell[5], PhD

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Corresponding Author:
Susana R Patton, PhD

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

Michelle M Gagnon[1], PhD; Alexandra R Brilz[1]; Nicole M Alberts[2], PhD; Jennifer L Gordon[3], PhD; Tracie L Risling[4], RN, PhD; Jennifer N Stinson[5,6], RN, PhD

[1]Department of Psychology and Health Studies, University of Saskatchewan, Saskatoon, SK, Canada
[2]Department of Psychology, Concordia University, Montreal, QC, Canada
[3]Department of Psychology, University of Regina, Regina, SK, Canada
[4]Faculty of Nursing, University of Calgary, Calgary, AB, Canada
[5]Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, ON, Canada
[6]Child Health Evaluative Sciences, Research Institute, Hospital for Sick Children, Toronto, ON, Canada

Corresponding Author:
Michelle M Gagnon, PhD
Department of Psychology and Health Studies
University of Saskatchewan
9 Campus Drive, Arts 154
Saskatoon, SK, S7N5A2
Canada
Phone: 1 306 966 2052
Fax: 1 306 966 6630
Email: michelle.gagnon@usask.ca

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

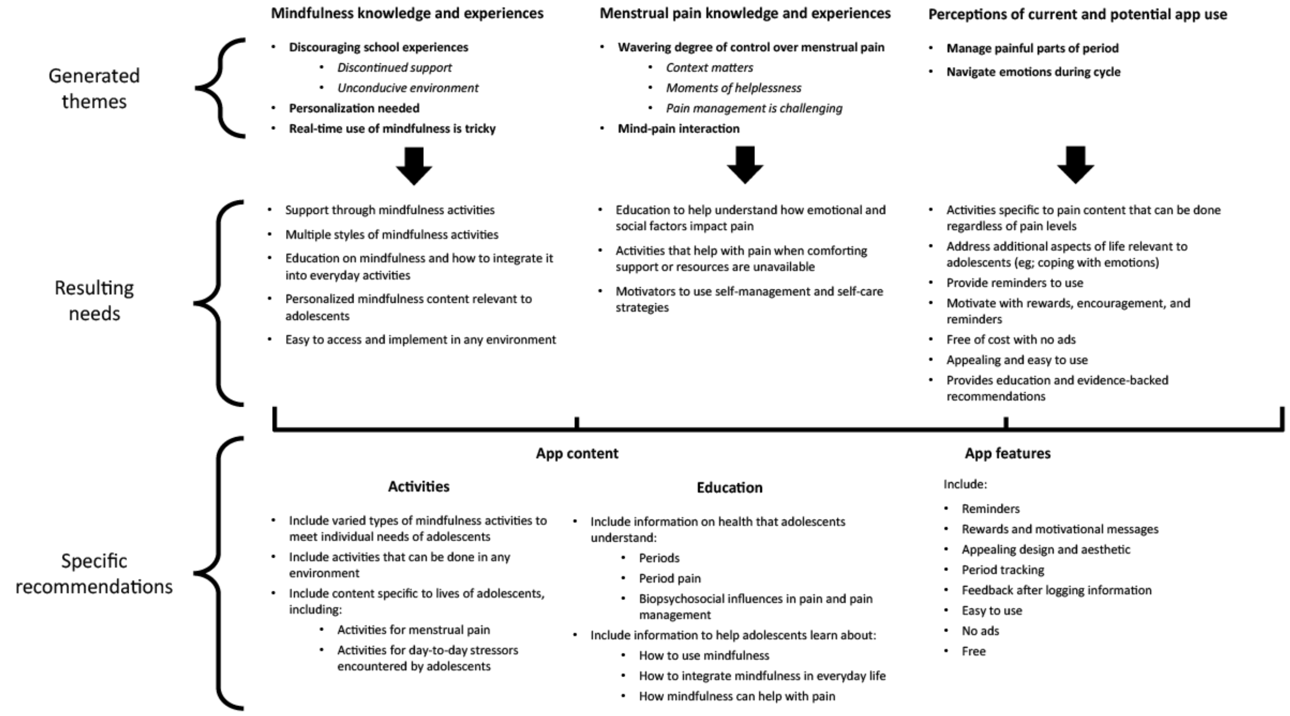
Participants frequently mentioned that emotions that occurred around the time of their period could lead to challenges in their lives. Participants discussed that having tools to manage these emotions would be useful and that they would be motivated to use an app that addressed aspects of their lives 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.

Acknowledgments

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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

Margaret Weisblum[1,2*], BS; Emma Trussell[1,3,4*], BA; Traci Schwinn[1], PhD; Andrea R Pacheco[1,5], BA; Paige Nurkin[1]

[1]School of Social Work, Columbia University, New York, NY, United States
[2]Department of Psychology, Georgetown University, Washington, DC, United States
[3]School of Medicine, University of Queensland, Brisbane, Australia
[4]School of Medicine, Ochsner Health, New Orleans, LA, United States
[5]National Institute of Allergy and Infectious Diseases, International Center of Excellence in Research, Phnom Penh, Cambodia
*these authors contributed equally

Corresponding Author:
Margaret Weisblum, BS
School of Social Work
Columbia University
1255 Amsterdam Avenue, Room 1204
New York, NY, 10027
United States
Phone: 1 212 851 2280
Email: mw3314@columbia.edu

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.

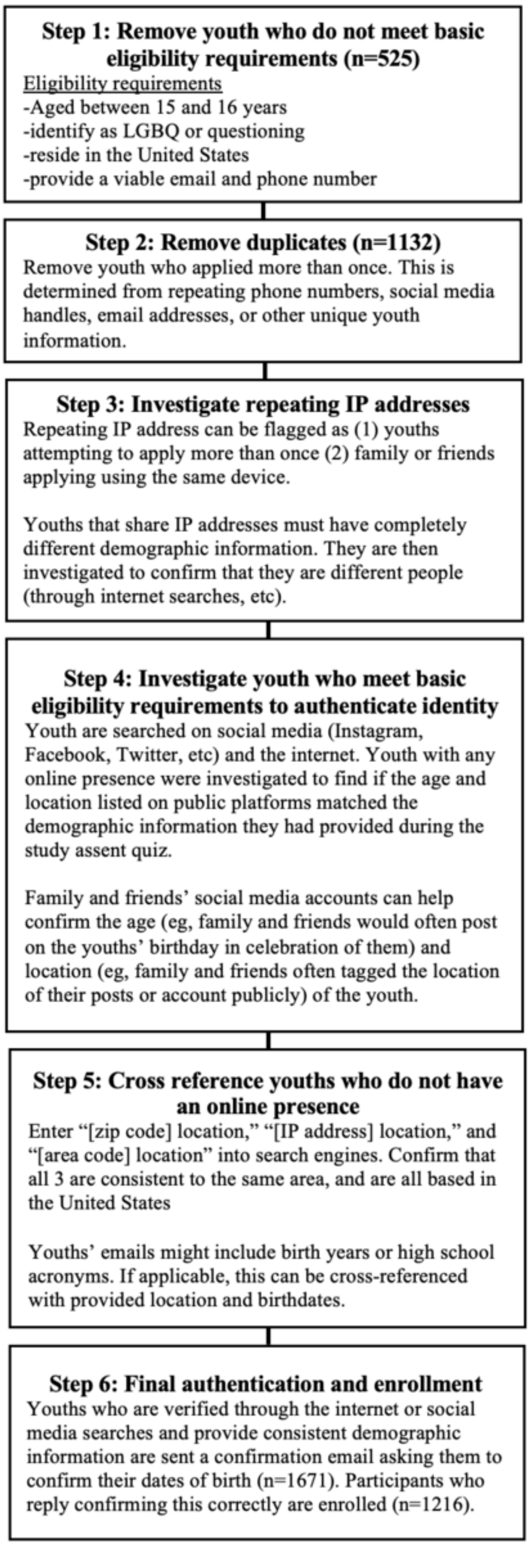
Eligibility Screening and Enrollment

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).

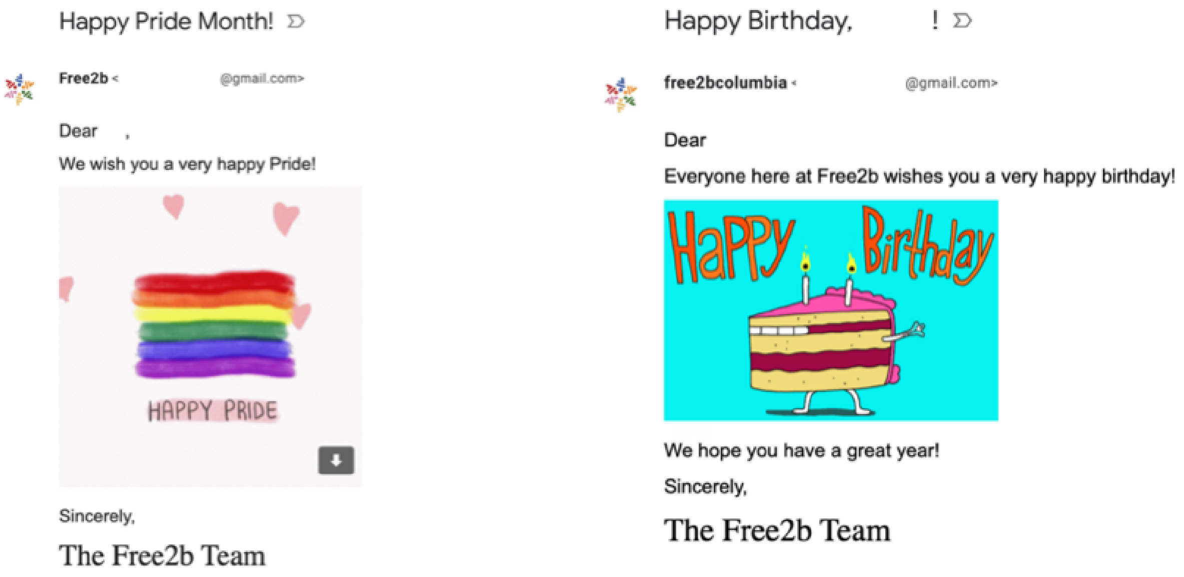
Building Positive Relationships With Participants

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.

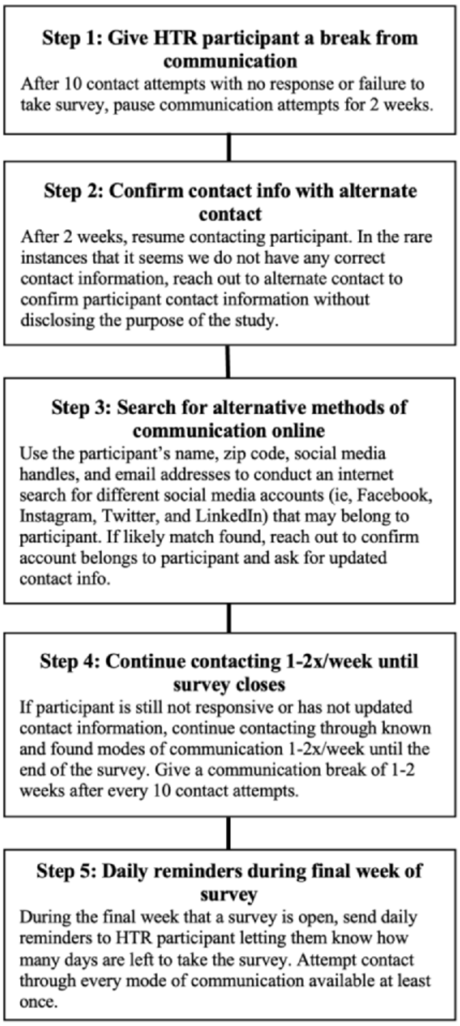
Finally, RAs were instructed to maintain frequent communication and reminders without overwhelming participants. As described earlier, they often started texts and phone calls with understanding language. Additionally, most reminders to take surveys included a link so participants would not have to go 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.

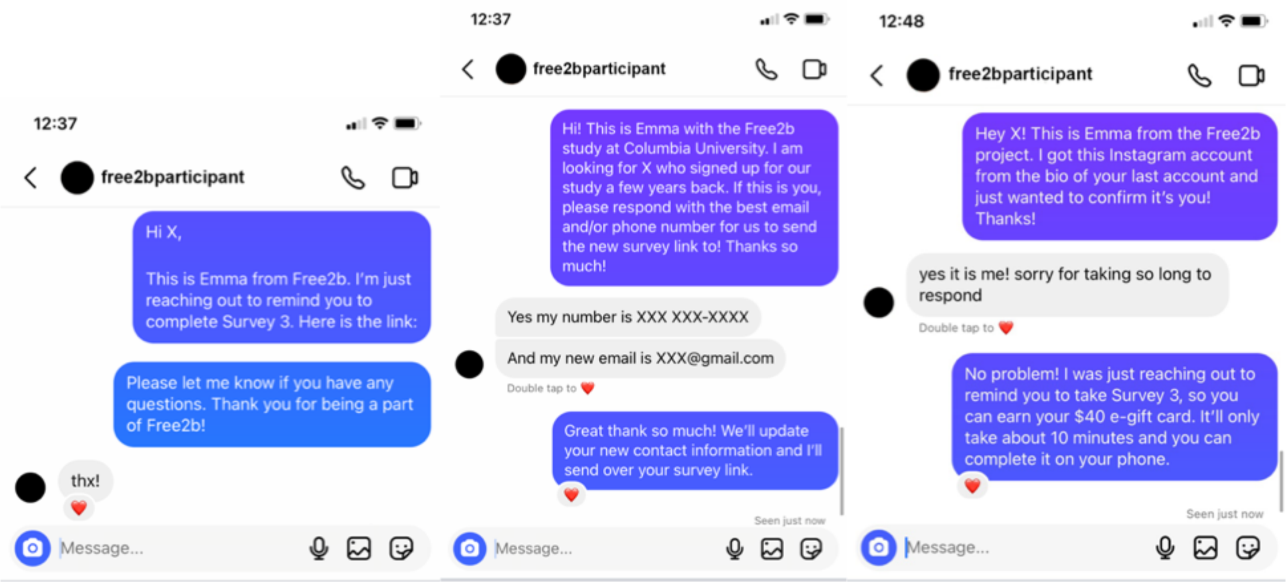
Survey number	Combination of traditional and social media contacts, n (%)	Traditional contacts (phone and email), n (%)
Survey 1 (n=17)	0 (0)	17 (100)
Survey 2 (n=102)	29 (28.4)	73 (71.6)
Survey 3 (n=100)	23 (23)	77 (77)
Survey 4 (n=121)	22 (18.2)	99 (81.8)

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.

Acknowledgments

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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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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

Marta Castillo-Rodenas[1], MSc, MD; José Ángel Vicente Gómez[2], MPhil; Aïna Fuster-Casanovas[3], MSc, RPh; Queralt Miró Catalina[3,4], MSc; Josep Vidal-Alaball[3,4,5], MPH, MD, PhD; Francesc López Seguí[6], PhD

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Corresponding Author:
Francesc López Seguí, PhD

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.

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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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The Finnegan Score for Neonatal Opioid Withdrawal Revisited With Routine Electronic Data: Retrospective Study

Till Rech[1], MD; Kerstin Rubarth[2], MSc; Christoph Bührer[1], MD; Felix Balzer[2], MD, PhD; Christof Dame[1], MD

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Corresponding Author:
Christof Dame, MD

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

Yiwei Yan[1*], MA; Congyan Xing[2*], MSc; Jian Chen[3], PhD; Yingbin Zheng[1], MSc; Xiaobin Li[3], BSc; Yirong Liu[4], BSc; Zhanxiang Wang[1], MD; Kai Gong[1], MD

[1]Biomedical Big Data Center, The First Affiliated Hospital of Xiamen University, Xiamen, China
[2]Equipment and Materials Department, The First Affiliated Hospital of Xiamen University, Xiamen, China
[3]Zoe Soft Corp Ltd, Xiamen, China
[4]School of Health Management, Fujian Medical University, Fuzhou, China
[*]these authors contributed equally

Corresponding Author:
Kai Gong, MD
Biomedical Big Data Center
The First Affiliated Hospital of Xiamen University
10 Shanggu Road, Siming District
Xiamen, 361003
China
Phone: 86 15160003918
Email: freatink@xmu.edu.cn

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].

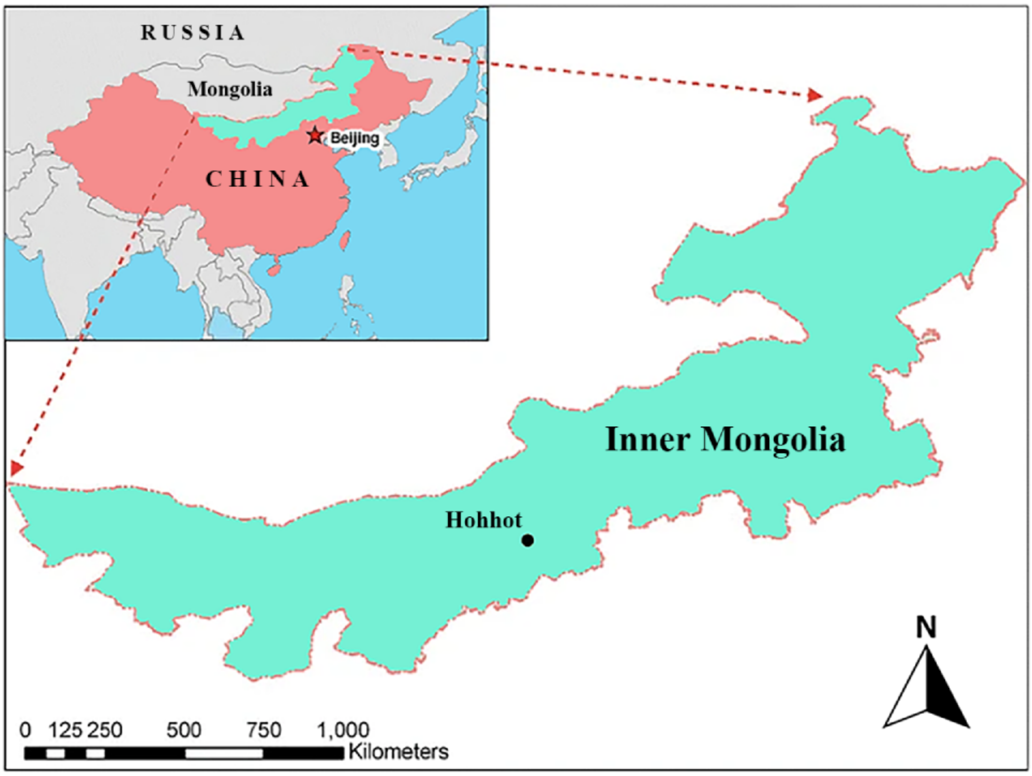
China has emphasized MCH as an essential component of China’s health care system [3]. In October 2016, the Healthy China Action Plan (2019-2030) set clear requirements that the MMR and the NMR should be reduced to 12/100,000 and 5/1000 by 2030 [4]. In the past few years, the MMR of China has dropped 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

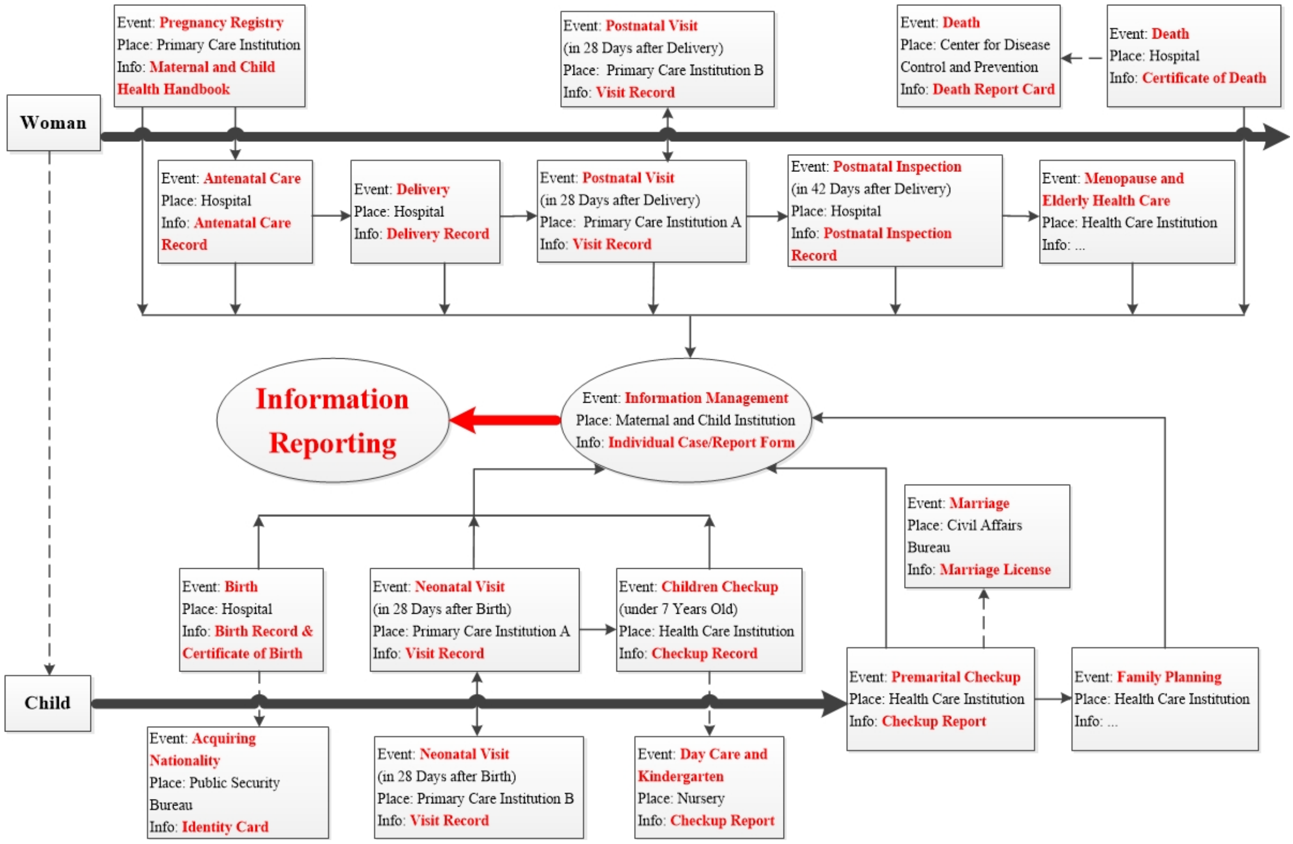
Intrapartum care refers to a process of comprehensive and dynamic assessment of maternal health, monitoring of mother and fetus, and prevention and treatment of complications during labor and delivery.

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

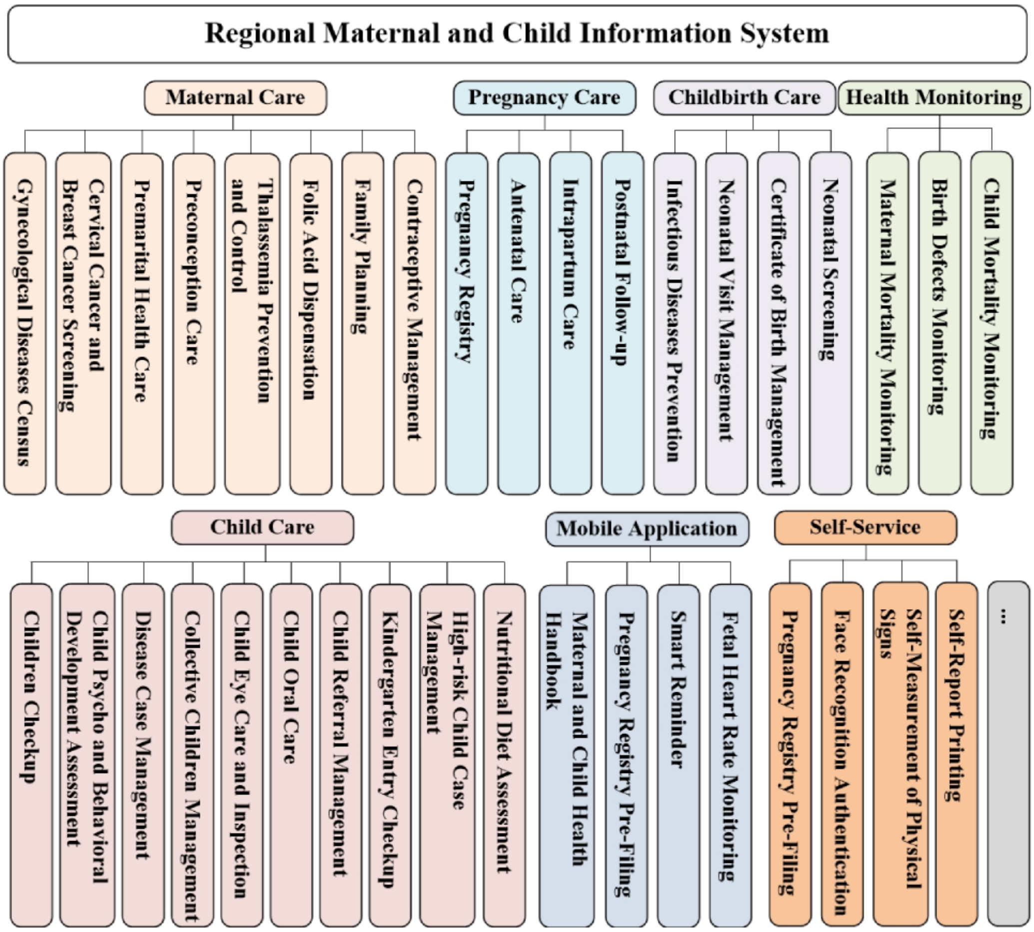
The essence of an RMCIS is to achieve data interconnection between medical institutions and provide coherent services for the whole health care process based on standardization. Core services were classified into 4 dimensions: basic health care services, special case management, health support, and administration 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).

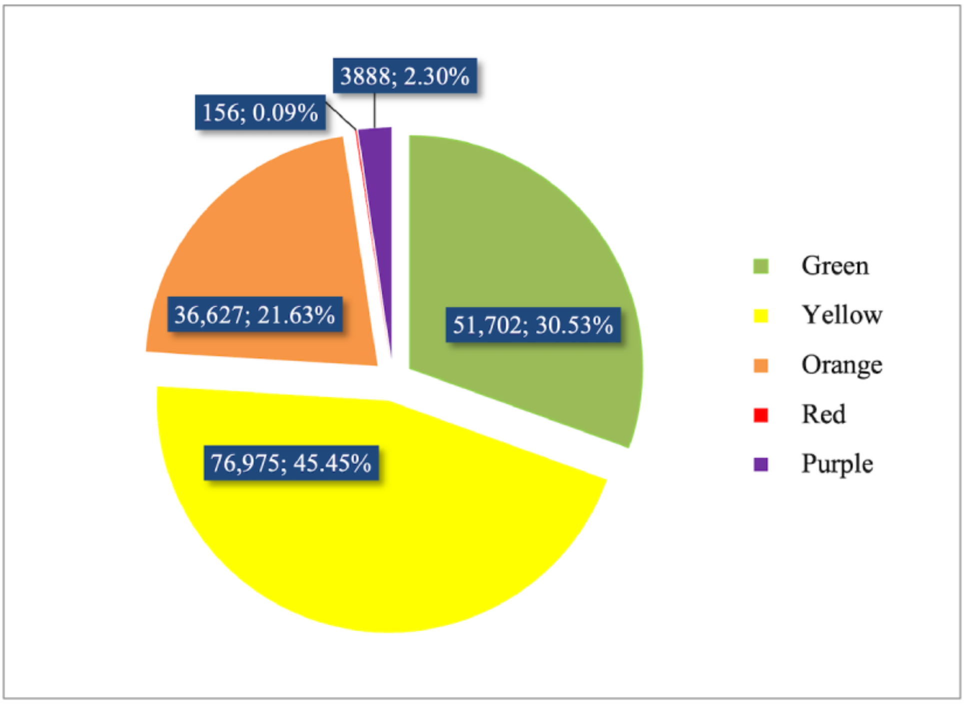
[c] Not applicable.

[d] N=147,510 (number of pregnancies in delivery care).

Pregnancy Risks and Factors

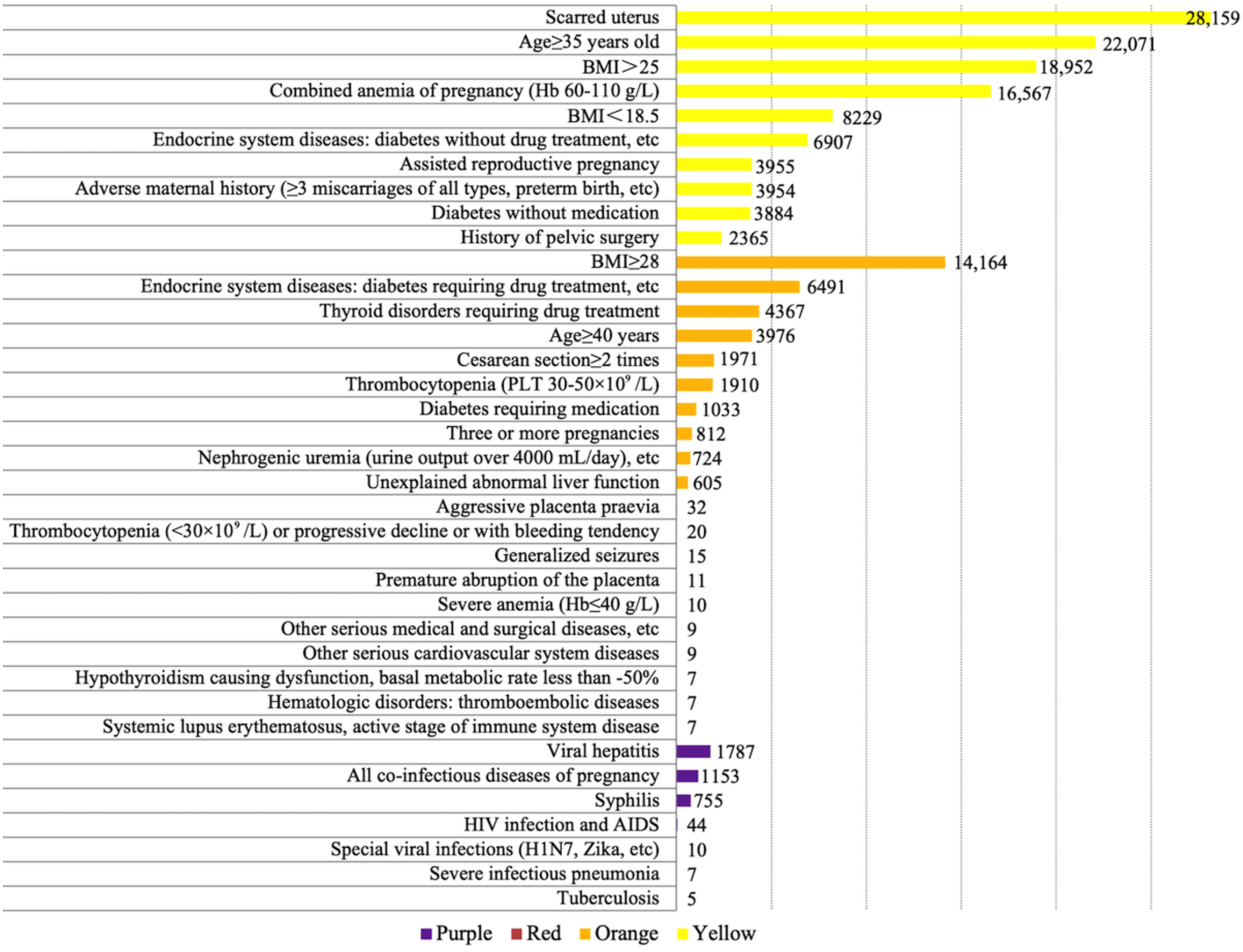
The RMCIS provided statistics for 5-color management. In total, 51,702 (30.53%) pregnancies were marked green (no pregnancy complications). Pregnancies marked yellow (general risk) accounted for the largest proportion (n=76,975, 45.45%), and 36,627 (21.63%) pregnancies were marked orange (relatively 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		2022[a]	
	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

Catarina Santos-Silva[1,*], MD; Henrique Ferreira-Cardoso[1,*], MD; Sónia Silva[2], MD; Pedro Vieira-Marques[3], PhD; José Carlos Valente[4], BSc; Rute Almeida[5], PhD; João A Fonseca[4,5], MD, PhD; Cristina Santos[5], PhD; Inês Azevedo[2,6,7], MD, PhD; Cristina Jácome[5], MSc, PhD

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[*]these authors contributed equally

Corresponding Author:
Cristina Jácome, MSc, PhD

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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Correction: Caregivers' Perceptions, Needs, and Data Sharing Concerns in mHealth Research on Pediatric Asthma: Cross-Sectional Survey Study

Glen Meng[1], DCS; Maliha Jan Ali[1], MD; Sze Man Tse[1,2], MPH, MD

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Corresponding Author:
Sze Man Tse, MPH, MD

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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

Riti Shimkhada[1,*], MPH, PhD; Ninez A Ponce[1,2,*], MPP, PhD

[1]

[2]

[*]all authors contributed equally

Corresponding Author:
Riti Shimkhada, MPH, PhD

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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Review

Internet-Based Interventions for Preventing Premature Birth Among Pregnant Women: Systematic Review

Sun-Hee Kim[1], RN, PhD; Jin-Hwa Park[1], RN, PhD; Sun-Young Jung[1], RN, PhD; Jennie C De Gagne[2], RN, DNP, PhD

[1]College of Nursing, Research Institute of Nursing Science, Daegu Catholic University, Daegu, Republic of Korea
[2]School of Nursing, Duke University, Durham, NC, United States

Corresponding Author:
Sun-Young Jung, RN, PhD
College of Nursing
Research Institute of Nursing Science
Daegu Catholic University
Duryugongwon-ro 17-gil 33, Nam-gu
Daegu, 42472
Republic of Korea
Phone: 82 53 650 4977
Fax: 82 53 650 4392
Email: syjung@cu.ac.kr

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

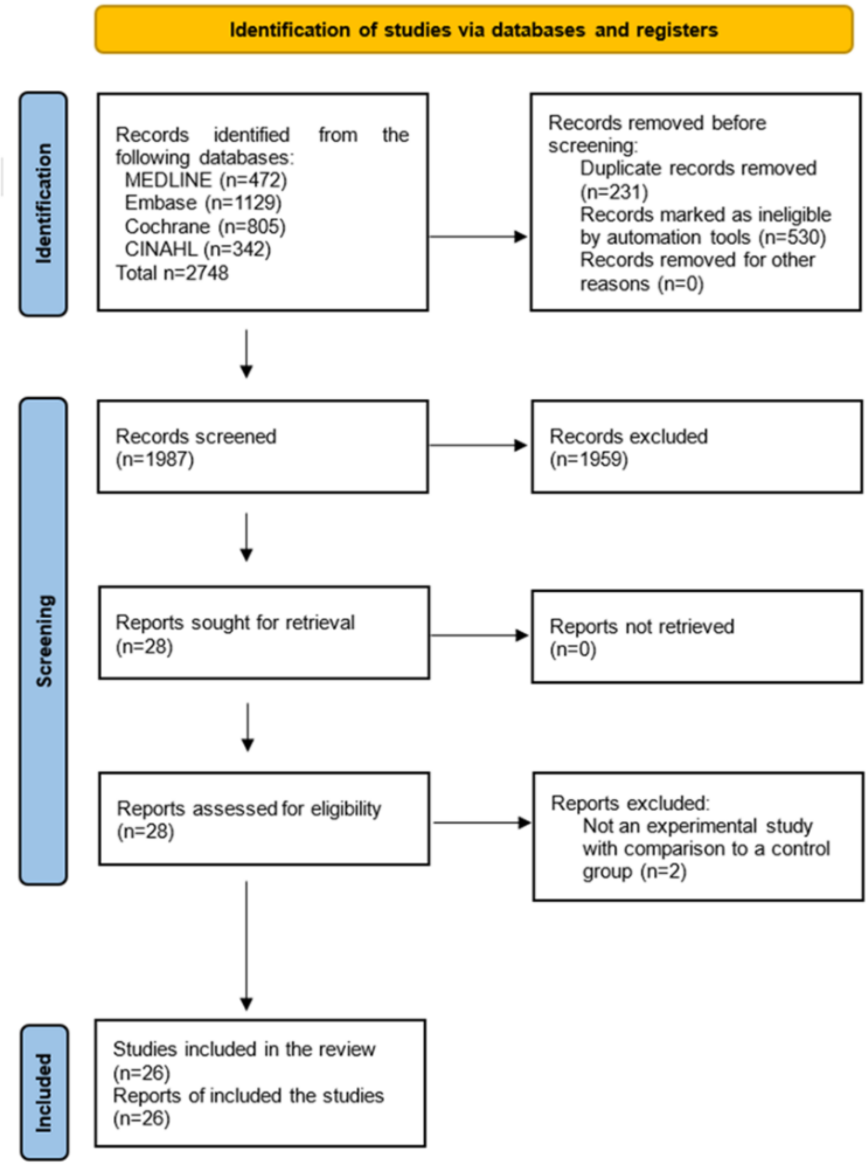
Owing to the heterogeneity in interventions and participant characteristics, we opted for a narrative synthesis instead of a meta-analysis. When available, effect sizes were calculated using data from the studies, using various metrics such as Cohen *d*, Cohen *f*, Morris *d*, Hedges *g*, Cohen *h*, 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.

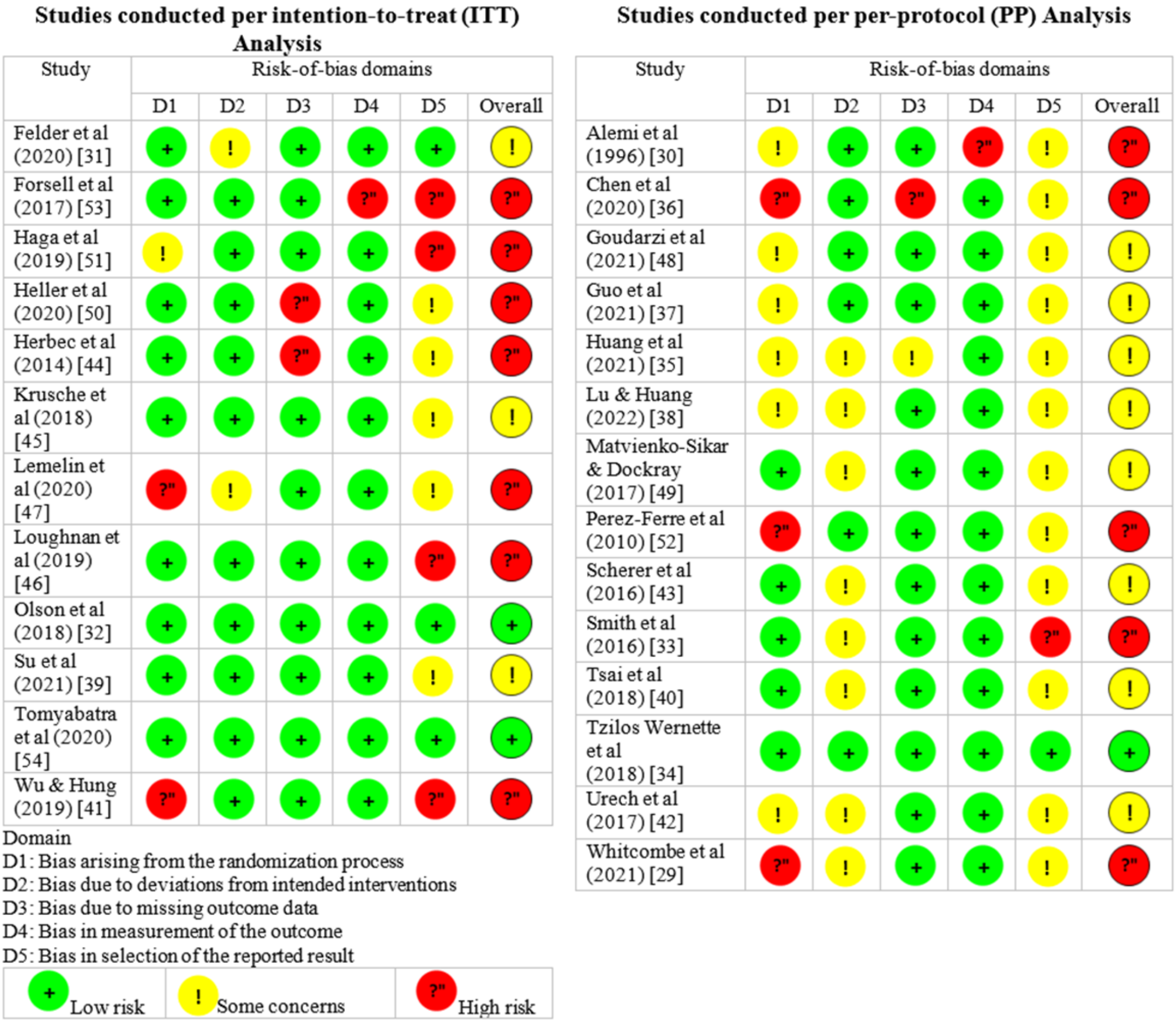
Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram showing the selection of included studies.



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.

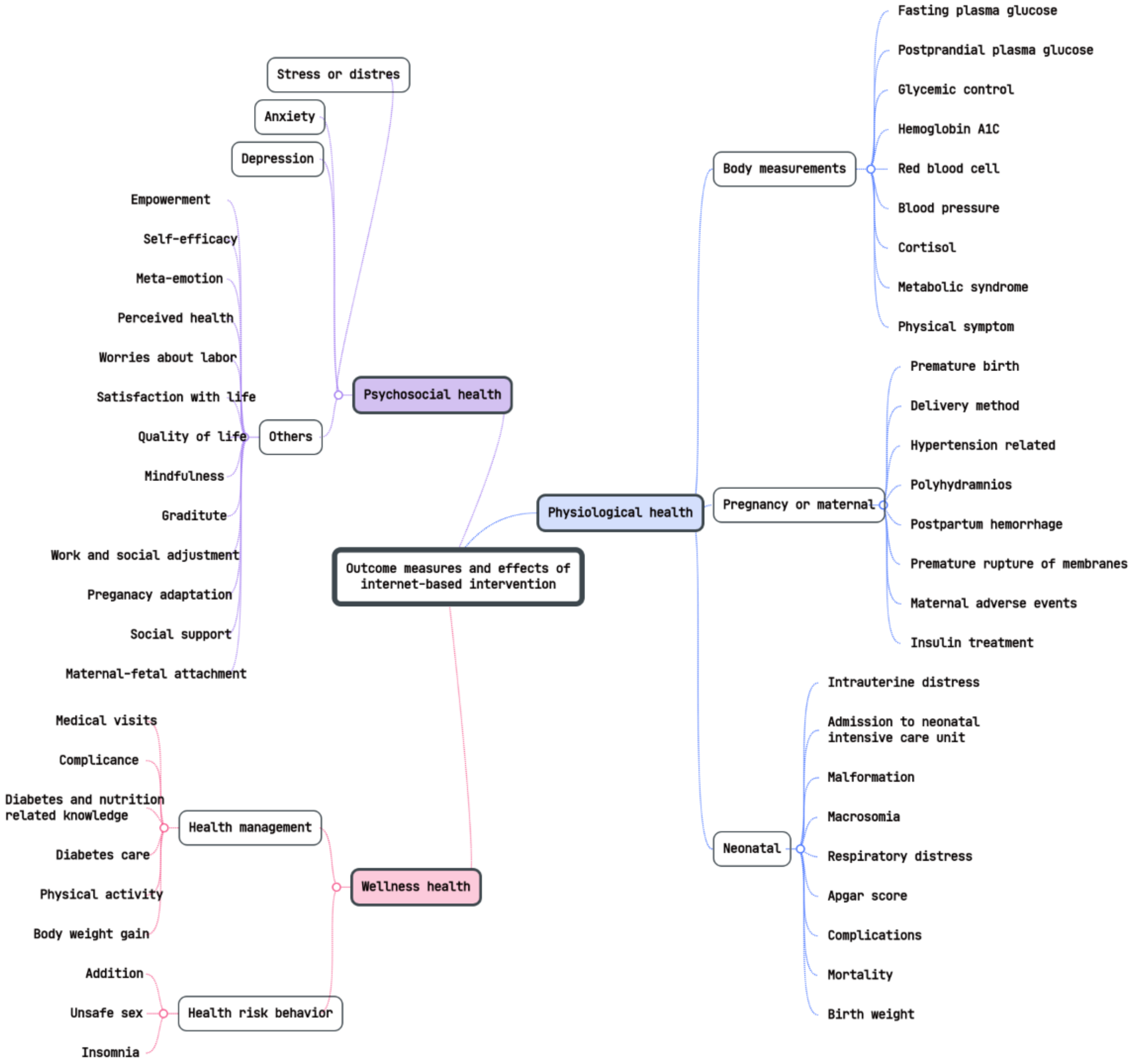
Intervention Timing, Duration, and Comparative Approaches

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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