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Original Paper

Engaging Parents and Health Care Stakeholders to Inform Development of a Behavioral Intervention Technology to Promote Pediatric Behavioral Health: Mixed Methods Study

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Abstract

Background: Despite effective psychosocial interventions, gaps in access to care persist for youth and families in need. Behavioral intervention technologies (BITs) that apply psychosocial intervention strategies using technological features represent a modality for targeted prevention that is promising for the transformation of primary care behavioral health by empowering parents to take charge of the behavioral health care of their children. To realize the potential of BITs for parents, research is needed to understand the status quo of parental self-help and parent-provider collaboration to address behavioral health challenges and unmet parental needs that could be addressed by BITs.

Objective: The aim of this study is to conduct foundational research with parents and health care stakeholders (HCS) to discover current practices and unmet needs related to common behavioral health challenges to inform the design, build, and testing of BITs to address these care gaps within a predominantly rural health system.

Methods: We conducted a convergent mixed-parallel study within a large, predominantly rural health system in which the BITs will be developed and implemented. We analyzed data from parent surveys (N=385) on current practices and preferences related to behavioral health topics to be addressed in BITs along with focus group data of 48 HCS in 9 clinics regarding internal and external contextual factors contributing to unmet parental needs and current practices. By comparing and relating the findings, we formed interpretations that will inform subsequent BIT development activities.

Results: Parents frequently endorsed several behavioral health topics, and several topics were relatively more or less frequently endorsed based on the child's age. The HCS suggested that BITs may connect families with evidence-based guidance sooner and indicated that a web-based platform aligns with how parents already seek behavioral health guidance. Areas of divergence between parents and HCS were related to internalizing problems and cross-cutting issues such as parenting stress, which may be more difficult for health care HCS to detect or address because of the time constraints of routine medical visits.

Conclusions: These findings provide a rich understanding of the complexity involved in meeting parents' needs for behavioral health guidance in a primary care setting using BITs. User testing studies for BIT prototypes are needed to successfully design, build, and test effective BITs to empower parents to take charge of promoting the behavioral health of their children.

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KEYWORDS

primary care; parenting; targeted prevention; behavioral intervention technology; behavioral health

Introduction

High Behavioral Health Need for Youth and Intractable Gaps in Access to Care

Behavioral health problems are common among children and adolescents [1,2]. More than 13% of preschool–age children present with disruptive behavioral problems [3], and the onset of approximately half of all lifetime cases of clinically diagnosable disorders occurs by the age of 14 [4]. Short-term consequences associated with behavioral health problems include significant impact on family functioning [2,5,6] and educational achievement [3,7]. In the long term, children with behavioral health problems have a higher lifetime risk for conduct problems, antisocial behavior, early pregnancy, drug use, and school failure [7-9]. Symptoms and impairment falling below the cutoff for diagnosis or treatment also carry a significantly higher risk for psychopathology years later. This is especially concerning considering that the prevalence of subclinical cases is twice that of those reaching clinical thresholds [10,11].

Despite the increased risk for short- and long-term negative outcomes, most children who would benefit from behavioral health care do not receive services [12,13]. Barriers to service use include structural barriers, such as shortage of behavioral health care providers, particularly in rural areas, and barriers related to stigma and negative perceptions regarding mental health problems and accessing mental health services [14,15]. In the pediatric health care setting, primary care clinicians (PCCs) often do not make appropriate referrals [16], and even when referrals are placed, many families never engage with the services [17].

Furthermore, initiatives directly aimed at increasing access to services often fail to accomplish this goal. For example, despite the efficacy of school-based programs in preventing and decreasing aggressive behavior [18,19], ongoing efforts to provide services in schools are mitigated by a variety of factors including availability of trained staff [20], stakeholder attitudes about services [21], and the attendance and participation of those students who may benefit the most [22]. Similar or higher rates of behavioral health problems in rural communities [23-25] are compounded by even lesser access to and use of behavioral health services than those in urban communities [26].

Leveraging Innovations in Service Delivery and Technology Can Help to Close Access Gaps

Behavioral intervention technologies (BITs) have emerged as an option that may expand access to individuals for whom structural and consumer-level barriers prevent engagement with traditional face-to-face (FTF) therapy and telehealth services [27]. Most adults have a mobile phone and home internet access, far outreaching the number of individuals who live in areas with accessible behavioral health care [28]. BITs have the potential to provide better access to underserved populations and eliminate distance or transportation barriers, and they are not necessarily subject to shortages of trained staff [29,30].

Most BITs for prevention and treatment of behavioral health problems in youth have included adolescents as the primary or sole users, and promising BITs exist for a range of presenting concerns, including anxiety, depression, and chronic health conditions [31-34]. BITs designed for parents may expand access and use of behavioral health further because of the potential to engage families who may not seek FTF behavioral health care because of fear of stigma or barriers of perception and those families who may be more willing to engage in BITs that are often self-directed and relatively more private [35,36]. Indeed, looking to the internet for parenting support and behavior change strategies is an emerging trend among parents [37-40].

BITs for parents have predominantly focused on translating evidence-based parent training interventions originally developed and tested through FTF implementation [41]. There are examples of BITs for parents of children with disruptive behavior concerns that have successfully been adapted from FTF implementation for web-based platforms and have shown positive outcomes [29,35,37]. Overall, parents report a high rate of interest in and satisfaction with available BITs [40,42], yet the scope and availability of existing BITs need more development to realize this potential. One notable line of research has been conducted on the *ez*Parent Program, which is a tablet-based preventive behavioral parent training intervention adapted from the Chicago Parent Program [43] tailored for youth aged 2 to 5 years in primary care settings. An advantage of the development strategy for *ez*Parent is that many of its aspects, including implementation factors, adherence, and parental perceptions of engaging with the program, have been studied [44-46]. Nevertheless, when tested in a randomized controlled trial, *ez*Parent was not more effective on child outcomes than enhanced usual care [47]. These findings suggest that BITs such as *ez*Parent may work best in primary care settings when offered along with a range of more intensive interventions tailored to salient family characteristics that influence interest and engagement.

Realizing the Potential for BITs to Improve Targeted Prevention in Primary Care

There is a strong potential to expand the use of BITs across a wide range of developmental, behavioral, and emotional needs beyond parenting guidance for challenging behaviors [29,35,37,40,42]. Targeted prevention in the primary care setting may help to address an important care gap because PCCs routinely engage in anticipatory guidance as part of well-child visits, but it is impractical and potentially unhelpful for PCCs to discuss every relevant domain. For example, it is estimated that if PCCs addressed every relevant prevention target with every patient according to evidence-based guidelines, then it would comprise 7.4 hours of their workday [48]; however, only 52 of 2161 recommended topics for well-child visits are considered actionable [49].

The importance of targeted prevention becomes even more salient when considering that PCCs are routinely asked to increase their roles and responsibilities (eg, developmental and behavioral health screening), yet visit lengths have not changed [50]. BITs that help PCCs *do more with less* must also consider parents' preferences for guidance to be maximally effective. Parents often want more and different types of guidance and information than are typically provided by their child's PCC [51,52]. Schuster et al [51] found that most surveyed parents endorsed having unmet needs regarding subjects that PCCs routinely discuss, such as crying, learning, discipline, and toilet training, and many endorsed needing more information. Combs-Orme et al [53] found that even though discipline was one of the most frequently discussed topics with PCCs, this was the area in which parents had the most questions. Therefore, research to develop BITs must also carefully examine the determinants of maladaptive parenting behaviors, such as lack of information regarding typical development and behavior or lack of parenting skills that promote healthy behavioral and emotional growth for children [54-56].

Intentionally developing BITs from the outset to meet the range of needs of families and PCCs working to address behavioral health problems may help to address the limitations of extant BITs. Research on elements of effective implementation and scaling of FTF behavioral health services in primary care has robustly shown that effectiveness is influenced by contextual factors such as provider knowledge and skills about and attitudes toward behavioral health topics, motivation to change, management and leadership practices, and financial resources [57]. This has also been shown to be relevant to BITs, as clinic personnel implementing the *ez*Parent Program reported that despite supporting the program, substantial contextual barriers impeded referrals to the program because of time, workflow, and organizational factors [58].

This Study

This paper reports the initial stages of development for a targeted prevention BIT to empower parents to take charge of their child's behavioral health care in pediatric primary care clinics within a predominantly rural health system in the Northeast United States. Developing targeted prevention BITs is part of an overarching approach to extend the continuum of primary care behavioral health services, including integrating behavioral health–health care stakeholders (HCS) into pediatric primary care locations and improving the scope and quality of training for PCCs in behavioral health topics.

Our approach to developing these BITs is informed by the approach described by Lyon et al [59] for adapting evidence-based psychosocial interventions for implementation in naturalistic settings. We describe the findings of the *discover* phase of development to identify the needs and perspectives of stakeholders and potential barriers to usability and implementation in the targeted intervention context. The goal is for the findings of this study to identify modification targets in extant evidence-based interventions and then apply this knowledge to iterative *design and build* cycles used to redesign interventions using prototypes and stakeholder feedback in preparation for developing a polished prototype to rigorously *test* for effectiveness in naturalistic setting. This approach is compatible with recommendations to improve BIT implementation measurement in part by distinguishing between BIT development and implementation, enhancing responsiveness to stakeholder outcomes, and integrating the BIT into existing services in the implementation context [60].

Therefore, the primary objective of this study is to identify the needs and preferences of parents and HCS within the health system that the BITs will ultimately implement, as these are the 2 key stakeholder groups which the BITs are intended to serve. We obtained input from parents and HCS using different methods to maximize the depth of information from each stakeholder group. For parents, we developed and administered a survey of parent preferences to be addressed in BITs. In addition, we developed a survey of current needs and practices for handling behavioral health concerns and administered it to a market research panel of parents within the health system. We chose to conduct a series of focus group interviews with a range of HCS to allow for more flexibility and depth of explanation of the intervention context and any associated barriers and facilitators to the implementation of BITs.

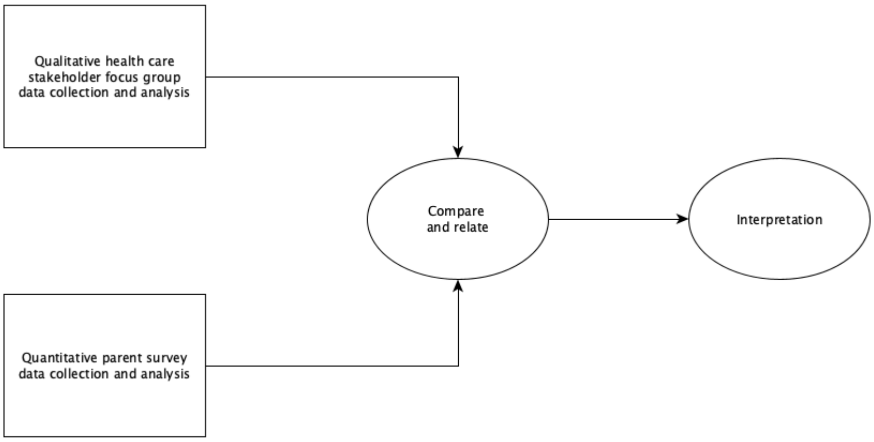
Methods

Design and Data Analysis Plan

We used the Pragmatic Robust Implementation and Sustainability Model (PRISM) [61] framework to inform our development activities, as it is an implementation science framework that encompasses the diverse priorities of the *design* phase by expanding the conceptualization and measurement of RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) [62] implementation outcomes by explicitly including contextual factors, overarching issues, and interdependency among components of the model. Additionally, PRISM has been shown to be compatible with qualitative methods throughout the intervention development and implementation continuum [63].

We integrated quantitative survey data obtained from parents regarding their views and experiences on a variety of behavioral health topics with qualitative focus group interview data of HCS on their perceptions of unmet needs and current practices of parents regarding managing their child's behavioral health care. To accomplish this, we employed a convergent mixed-parallel design [64] as depicted in Figure 1.

Figure 1. The data collection and analysis process in this study using a convergent mixed-parallel design.



Setting and Participants

Focus groups were conducted between April 23, 2019 and June 24, 2019 in 9 child-serving clinics within a large, predominantly rural health system. A total of 83% (48/58) of HCS participated. Participants comprised HCS from 5 primary care sites and 1 developmental medicine clinic; 2 primary care sites invited to participate declined. The primary care site focus groups were each completed in a single session in the clinic over lunch. Of these, 2 focus groups were conducted with the developmental medicine clinic stakeholders during monthly administrative meetings to accommodate the availability of participants. The focus group participants comprised a range of roles and professional backgrounds, including 16 pediatricians, 2 pediatric psychologists, 2 genetic counselors, 1 speech pathologist, 2 behavior analysts, 5 licensed nurse practitioners, 6 registered nurses, 7 physician or medical assistants, 4 patient access representatives, 1 family liaison, 1 operations manager, and 1 pediatric technician.

An electronic parent survey was conducted using Qualtrics in Spring 2019 from a geographically representative patient panel within a rural health system in the Northeast United States who had previously opted in a program to be contacted to complete web-based surveys regarding their perspectives on health care services offered within the health system in which the study was conducted. To be eligible to complete the survey, the respondent had to endorse screening items indicating that they were the parent or guardian of at least one minor child (0-18 years of age) at the time of completing the survey and were somewhat or very interested (as opposed to not at all interested) in using web-based resources to research issues and concerns they may have about their children and parenting. Invitations were distributed twice with the goal of acquiring 400 completed surveys. Of the 2240 respondents who initiated the survey, 411 met the inclusion criteria and proceeded to the rest of the survey. However, 6.3% (26/411) of these respondents abandoned the survey before completing the initial content questions. Table 1 shows the demographics of the remaining 385 respondents.

Table 1. Demographic characteristics of parent survey respondents (N=385).

Characteristic	Respondents, n (%)
Age (years)	
18-24	6 (1.6)
25-34	90 (23.4)
35-44	142 (36.9)
45-54	97 (51.2)
55-64	38 (9.9)
65-74	7 (1.8)
75+	1 (0.3)
Prefer not to say	2 (0.5)
Missing data	2 (0.5)
Number of children[a]	
1	184 (47.8)
2	139 (36.1)
3	40 (10.4)
4	12 (3.1)
5	5 (1.3)
Missing data	5 (1.3)
Education level	
High school graduate (high school diploma or equivalent including GED[b])	37 (9.6)
Some college	44 (11.4)
Associate's degree in college (2-year program)	19 (4.9)
Bachelor's degree in college (4-year program)	61 (15.8)
Master's degree	44 (11.4)
Doctoral degree	7 (1.8)
Professional degree (JD[c], MD[d])	3 (0.8)
Prefer not to say	4 (1)
Missing data	116 (30.1)
Sex	
Female	245 (63.6)
Male	66 (17.1)
Missing data	74 (19.2)
Annual income (US $)	
Less than 10,000	12 (3.1)
10,000-29,999	27 (7)
30,000-49,999	30 (7.8)
50,000-79,999	37 (9.6)
80,000-99,999	26 (6.8)
100,000 or more	58 (15.1)
Prefer not to say	29 (7.5)
Missing data	166 (43.1)
Race or ethnicity	

Characteristic	Respondents, n (%)
American Indian or Native Alaskan	0 (0)
Asian	4 (1)
Black or African American	4 (1)
Hispanic, Latino, or Spanish	4 (1)
White	347 (90.1)
Other	2 (0.5)
Prefer not to say	6 (1.6)
Missing data	18 (4.7)
Has children in each age range (years)	
0 to 5	143 (37.1)
6 to 12	143 (37.1)
13 to 18	175 (45.5)
Insurance type	
Private	44 (11.4)
Public (Medicaid, Medicare)	35 (9.1)
Missing data	306 (79.5)

[a] Eighteen years of age or younger.

[b] GED: General Education Development.

[c] JD: Juris Doctor.

[d] MD: Doctor of Medicine.

Measures

Health Care Provider Focus Groups

The focus group moderator guide (Multimedia Appendix 1) was developed by the study authors using PRISM [61], which aims to identify and leverage multiple dimensions of internal and external contextual factors that contribute to stakeholder influence and implementation outcomes. Prompts were designed to evoke discussion among participants about the topic of unmet parental needs, including healthy development and social, emotional, and behavioral functioning of their children. The moderator introduced the study and its objectives, read prompts, and encouraged discussion among the focus group participants. Prompts also included uncovering what the HCS perceived that parents were doing to address unmet needs, and how the BIT platform website might help. In line with PRISM, participants were also asked about institutional leadership and what barriers health care HCS foresee the study team encountering in developing a mobile responsive website as a behavioral health intervention directed toward parents.

Parent Quantitative Survey

Questions were developed by the study authors and additional study personnel who were engaged as content experts in relevant disciplines. Given our emphasis on evidence-based content and aim to complement and expand upon the behavioral health care support provided by PCCs, content topics were selected from the American Academy of Pediatrics (AAP) anticipatory guidance recommendations described in *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* [65]. The anticipatory guidance described in *Bright Futures* covers a wide range of health, developmental, and behavioral topics across infancy, childhood, and adolescence. The study authors adopted relevant behavioral health survey topics from the *Bright Futures* topics based on their strong potential for delivery using a BIT. For example, the anxiety in children, behavioral challenges, and mood or depression in children survey topics were selected from the broader Promoting Mental Health anticipatory guidance topics from *Bright Futures*. Table 2 depicts the Bright Futures content domains and the resulting parent survey topics.

Table 2. Parent survey topics.

Bright Futures health promotion topics	Parent or caregiver survey topics
Promoting lifelong health for families and communities	—[a]
Promoting family support	Parenting stress; family communication
Promoting health for children and youth with special health care needs	—
Promoting healthy development	Speech or language skills, independence and activities of daily living; academic skills and intelligence; social skills; motor skills; toileting
Promoting mental health	Anxiety in children; behavioral challenges; mood or depression in children
Promoting healthy weight	Nutrition and eating
Promoting healthy nutrition	—
Promoting physical activity	—
Promoting oral health	—
Promoting healthy sexual development and sexuality	Sex and sexual development
Promoting the healthy and safe use of social media	The internet and social media
Promoting safety and injury prevention	Child safety; drugs and substance abuse

[a] Bright Futures health promotion topic not covered in parent or caregiver survey topics.

Procedures

Health Care Stakeholder Focus Groups

The project manager and research assistant traveled to each clinic to conduct in person focus groups. The project manager was trained in interviewing techniques and led the focus group discussions based on the guide included in Multimedia Appendix 1. Focus groups were audio recorded and transcribed by a skilled research assistant using Start-Stop Universal software and then deidentified for analysis. Transcripts were coded by the project manager, research assistant, and 2 psychology postdoctoral fellows using Microsoft Word. The order in which the focus group interviews were coded by the study team was randomly selected using a web-based randomizing service to remove bias from the coding. An a priori codebook based on the interview guide was created to identify and code common topics within each transcript; emergent codes and themes were also identified during the course of coding. The coders individually analyzed each interview and met every week to review and establish interrater agreement. The final coded transcripts were then uploaded to Atlas.ti 8.4.15 (ATLAS.ti Scientific Software Development GmbH) for Windows, where thematic quotes could be exported into spreadsheets based on individual codes for further analysis.

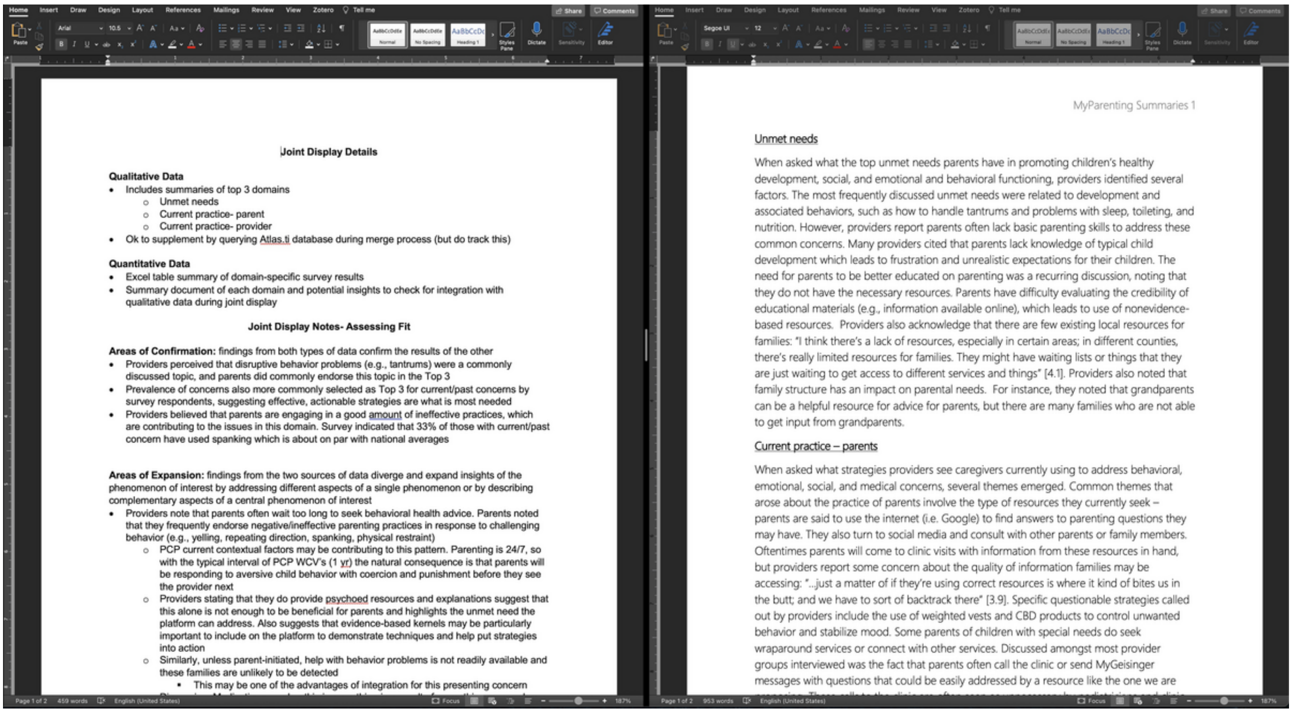
Parent Survey

Survey respondents who met the inclusion criteria for the study rated up to 3 of the 17 topics as their top choices for content that they would be interested in learning more about through a BIT. To understand if the topic was a current challenge or if the respondent wanted more information for future reference, respondents then identified whether the topic of interest had or had not been a challenge that they had encountered so far. Next, for each of the top 3 topics, respondents were provided a list of subtopics and were asked to identify which subtopics were a problem or concern. Next, respondents were provided with a list of common strategies for addressing the broad topic (eg, anxiety in children) and asked to rate if they had used the strategies and the extent to which they perceived each strategy to be helpful. Common strategies included those with an empirical evidence base as well as those without one in the interest of learning about the prevalence and preference of a range of strategies. The survey is included in Multimedia Appendix 2.

Data Analysis Plan

Parent quantitative survey data and HCS qualitative interview data were analyzed in parallel. For survey data, summaries were created using descriptive statistics for the most frequently endorsed content topics in the total sample. Descriptive statistics summarized the prevalence of endorsements for topics representing parental concerns and engagement with and perceived helpfulness of the strategies listed. Three qualitative topics from focus groups were selected for use in data integration: unmet needs, current practice providers, and current practice-parents because of their relevance to the quantitative data collected from parents. Each of these topics was analyzed and summarized by the study team based on the codes and topics identified. Each quote was then subcoded to expand on popular topics within each main code. The subcodes were utilized as framework for the overall summaries of all 3 topics. Once the parallel analyses were completed, the results were merged using a joint display to identify areas of confirmation, expansion, and discordance (Figure 2). We randomly selected 2 team members to integrate data for each survey topic, and the results were based on the comparing and relating these findings. To supplement these analyses, including those for parent survey topics that were not selected for data integration by joint display, we queried the qualitative interviews for mentions of parent survey topics and related keywords to make additional interpretations.

Figure 2. Joint display.



Joint Display Details

Qualitative Data

- Includes summaries of top 3 domains
    - Unmet needs
    - Current practice- parent
    - Current practice- provider
- Ok to supplement by querying Atlas.ti database during merge process (but do track this)

Quantitative Data

- Excel table summary of domain-specific survey results
- Summary document of each domain and potential insights to check for integration with qualitative data during joint display

Joint Display Notes- Assessing Fit

Areas of Confirmation: findings from both types of data confirm the results of the other

- Providers perceived that disruptive behavior problems (e.g., tantrums) were a commonly discussed topic, and parents did commonly endorse this topic in the Top 3
- Prevalence of concerns also more commonly selected as Top 3 for current/past concerns by survey respondents, suggesting effective, actionable strategies are what is most needed
- Providers believed that parents are engaging in a good amount of ineffective practices, which are contributing to the issues in this domain. Survey indicated that 33% of those with current/past concern have used spanking which is about on par with national averages

Areas of Expansion: findings from the two sources of data diverge and expand insights of the phenomenon of interest by addressing different aspects of a single phenomenon or by describing complementary aspects of a central phenomenon of interest

- Providers note that parents often wait too long to seek behavioral health advice. Parents noted that they frequently endorse negative/ineffective parenting practices in response to challenging behavior (e.g., yelling, repeating direction, spanking, physical restraint)
    - PCP current contextual factors may be contributing to this pattern. Parenting is 24/7, so with the typical interval of PCP WCV's (1 yr) the natural consequence is that parents will be responding to aversive child behavior with coercion and punishment before they see the provider next
    - Providers stating that they do provide psychoed resources and explanations suggest that this alone is not enough to be beneficial for parents and highlights the unmet need the platform can address. Also suggests that evidence-based kernels may be particularly important to include on the platform to demonstrate techniques and help put strategies into action
    - Similarly, unless parent-initiated, help with behavior problems is not readily available and these families are unlikely to be detected
        - This may be one of the advantages of integration for this presenting concern

MyParenting Summaries 1

Unmet needs

When asked what the top unmet needs parents have in promoting children's healthy development, social, and emotional and behavioral functioning, providers identified several factors. The most frequently discussed unmet needs were related to development and associated behaviors, such as how to handle tantrums and problems with sleep, toileting, and nutrition. However, providers report parents often lack basic parenting skills to address these common concerns. Many providers cited that parents lack knowledge of typical child development which leads to frustration and unrealistic expectations for their children. The need for parents to be better educated on parenting was a recurring discussion, noting that they do not have the necessary resources. Parents have difficulty evaluating the credibility of educational materials (e.g., information available online), which leads to use of nonevidence-based resources. Providers also acknowledge that there are few existing local resources for families: "I think there's a lack of resources, especially in certain areas; in different counties, there's really limited resources for families. They might have waiting lists or things that they are just waiting to get access to different services and things" [4.1]. Providers also noted that family structure has an impact on parental needs. For instance, they noted that grandparents can be a helpful resource for advice for parents, but there are many families who are not able to get input from grandparents.

Current practice – parents

When asked what strategies providers see caregivers currently using to address behavioral, emotional, social, and medical concerns, several themes emerged. Common themes that arose about the practice of parents involve the type of resources they currently seek – parents are said to use the internet (i.e. Google) to find answers to parenting questions they may have. They also turn to social media and consult with other parents or family members. Oftentimes parents will come to clinic visits with information from these resources in hand, but providers report some concern about the quality of information families may be accessing: "...just a matter of if they're using correct resources is where it kind of bites us in the butt; and we have to sort of backtrack there" [3.9]. Specific questionable strategies called out by providers include the use of weighted vests and CBD products to control unwanted behavior and stabilize mood. Some parents of children with special needs do seek wraparound services or connect with other services. Discussed amongst most provider groups interviewed was the fact that parents often call the clinic or send MyGeisinger messages with questions that could be easily addressed by a resource like the one we are

Results

Parallel Analyses of Qualitative and Quantitative Data

Health Care Stakeholder Focus Groups

Focus group participants reported that the most common unmet behavioral health needs of the parents they work with related to common parenting challenges such as disruptive behaviors, sleep, toileting, and nutrition. Participants commonly reported a perception that lack of foundational knowledge in promoting healthy development across behavioral health topics represented vulnerability. Other contextual factors, such as lack of easy access to credible information, were commonly reported to compound the barriers to accessing local behavioral health resources. There was also a common theme noted among participants that social networks within the family (eg, grandparents) are often resources to help with common parenting challenges.

Focus group participants noted that parents frequently turn first to web-based resources (eg, web searches and social media) to find ideas and strategies to address behavioral health needs, which often led to unproven techniques being tried first (eg, weighted vests and cannabidiol products) and, in turn, maintaining or exacerbating behavioral health problems over time. Parents' desire for a *quick fix* was posited as an underlying reason for these choices, whereas focus group participants also noted that another subset of parents seem to follow a *wait and see* approach, in which they may wait several months to seek advice at the next routine visit, which was reported to unintentionally contribute to problems becoming ingrained and intractable. Ultimately, participants reported that this contributed to increased frustration for parents and more challenge for HCS implementing a more comprehensive and effortful course of treatment. For their part, HCS in focus group interviews reported that they made concerted efforts to spend extra time in their visits to provide guidance and psychoeducation on foundational parenting strategies. They also reported making specialty referrals when appropriate and acknowledged that they do not always have the time or resources to be responsive to parent concerns.

Parent Survey

Table 3 provides the frequency of each topic area selected by respondents across child age ranges of 1-5, 6-12, and 13-18 years. Across all respondents, the most frequently endorsed topics included anxiety in children (111/380, 29.2%), behavioral challenges (106/380, 27/9%), nutrition or eating (105/380, 27.6%), mood or depression in children (100/380, 26.3%), and the internet and social media (99/380, 26.1%). Responses were further examined based on whether respondents endorsed having a child of 1-5, 6-12, or 13-18 years. Anxiety in children, behavioral challenges, and nutrition and eating continued to be highly endorsed topics, regardless of child age. Respondents who reported having a child in the 6-12-year age range and the 13-18-year age range also frequently endorsed mood or depression in children and the internet and social media. Respondents who indicated they had a child aged 1-5 years also showed interest in speech or language skills, academic skills and intelligence, parenting stress, and sleep or bedtime routine.

Multimedia Appendix 3 provides descriptive statistics for the responses to each of the top 6 content topics. Most respondents endorsed each topic because of a past or current parenting challenge, as opposed to interest related to general guidance. With a few exceptions, the challenging topics listed within each topic were also endorsed by a substantial proportion of respondents, indicating that the issues parents face within each topic are often multifaceted. Similarly, respondents endorsed a variety of common strategies to help with the identified topics within each topic. Few strategies were endorsed as tried and was helpful by more than half of the respondents, suggesting that respondents are likely to try several strategies and find that few of them make a positive difference. Strategies rated as potentially problematic by the investigators are noted in the supplementary tables, and, overall, were some of the least likely strategies to be endorsed as helpful by respondents.

At the end of the survey, parents were asked if there were any additional topics they would like to see in a BIT. Of the 36 free-text responses, 7 pertained to topics that fit within the scope of the survey topics (eg, *language and speech* and *behavior*). Of the 385 respondents, 4 indicated that additional information about puberty would be helpful. Moreover, 9 responses were highly specific concerns that were outside the scope of a BIT for targeted behavioral health prevention (eg, caring for a child with a chronic illness). Several parents responded that they would have selected more or all the survey topics. Other responses pertained to coparenting, dealing with divorce, dealing with death and grief, and attachment.

Table 3. Parent endorsement of survey topics by age ranges of children.

Topic	Age range (years), n (%)			
	All (n=380)	1-5 (n=143)	6-12 (n=176)	13-18 (n=175)
Anxiety in children	111 (29.2)	33 (23.1)	66 (37.5)	55 (31.4)
Behavioral challenges	106 (27.9)	43 (30.1)	57 (32.4)	40 (22.9)
Nutrition and eating	105 (27.6)	51 (35.7)	44 (25)	38 (21.7)
Mood or depression in children	100 (26.3)	16 (11.2)	49 (27.8)	67 (38.3)
The internet and social media	99 (26.1)	24 (16.8)	47 (26.7)	50 (28.6)
Parenting stress	79 (20.8)	36 (25.2)	33 (18.8)	31 (17.7)
Academic skills and/or intelligence	76 (20)	28 (19.6)	40 (22.7)	35 (20)
Social skills	68 (17.9)	21 (14.7)	31 (17.6)	31 (17.7)
Family communication	63 (16.6)	19 (13.3)	28 (15.9)	34 (19.4)
Speech or language skills	45 (11.8)	29 (20.3)	14 (8)	10 (5.7)
Independence and activities of daily living	42 (11.1)	12 (8.4)	21 (11.9)	24 (13.7)
Sex and sexual development	41 (10.8)	6 (4.2)	19 (10.8)	29 (16.6)
Sleep or bedtime routine	38 (10)	28 (19.6)	13 (7.4)	3 (1.7)
Drugs and substance abuse	35 (9.2)	3 (2.1)	11 (6.3)	29 (16.6)
Child safety	28 (7.4)	22 (15.4)	13 (7.4)	3 (1.7)
Toileting	27 (7.1)	24 (16.8)	8 (4.5)	1 (0.6)
Motor skills	13 (3.4)	10 (7)	0 (0)	3 (1.7)

Interpretations Based on Comparing and Relating Health Care Stakeholder Focus Groups and Parent Surveys

Overview

After parallel analyses of the qualitative health care stakeholder focus group data and the quantitative parent survey data, we compared and related features of these data to integrate and make interpretations to guide further development efforts for the BIT. The results of the data integration phase are described next according to each of the parent survey topics. Multimedia Appendix 4 presents a summary of the areas of confirmation, expansion, and discordance for selected behavioral health topics with substantial data from both sources.

Anxiety

Anxiety was the most prevalent concern endorsed by parents; although HCS did not identify anxiety as a pressing unmet need, there were 6 mentions of anxious or *anxiety* in the qualitative data. There was agreement between parents and HCS in the demand for more web-based resources. HCS reported that parents lack resources for behavioral health concerns, yet parents rated psychotherapy as the most helpful strategy for anxiety management. From these data, it is unclear how many families access these services. Additionally, other commonly reported parental strategies (eg, comforting the child) are not typically effective in the long term or when used as a standalone strategy, which may relate to health care stakeholder observations that parents are seeking a quick fix and need more support in long-term behavior change.

Behavioral Challenges

HCS and parents reported that disruptive behaviors are a common concern, but parents tend to use ineffective behavior management strategies. HCS also lacked some awareness of key parental challenges within the disruptive behavior topic. It appears that primary care provider strategies alone are not enough to be beneficial for parents. This highlights the potential benefits of a BIT to address parental needs in this area more effectively. Demonstration of specific behavior management techniques may be helpful to include in a BIT to help parents put strategies into action.

Nutrition and Eating

Nutrition and eating concerns were commonly reported by both HCS and parents. HCS reported that parents tended to use unhelpful strategies to manage eating concerns, but parents reported a mix of helpful and unhelpful strategies. HCS were also unaware of several common strategies parents endorsed to manage nutrition and eating concerns, and many parents indicated that they did not discuss nutrition and eating concerns with their primary care HCS. Of the queries of qualitative data returned, 3 mentions of *nutrition*, 2 mentions of *food*, and 9 mentions of *eat* were made.

Parenting Stress

HCS and parents both reported that parenting stress is a common concern, although parents and HCS had differing perspectives on the factors contributing to parental stress. HCS tended to discuss parental stress in terms of parental frustration with child behavior as opposed to parent-specific factors (eg, coping with emotions). The strategies parents use to manage stress may impact their use of primary care resources. Addressing parental stress is beyond the traditional scope of pediatric primary care, and HCS are likely to lack the knowledge of how to deal with more complex cases. Therefore, a BIT addressing parental stress may help HCS direct parents to useful resources.

Family Communication

Family communication was a commonly endorsed topic for parents, and HCS mentioned this as a concern. Furthermore, it also related to collaborative communication with HCS about child behavioral health needs. HCS perceptions of parental communication strategies were discordant with the parent-reported strategies. HCS did discuss how family structure may impact parental communication in the qualitative topics reviewed, and further queries of the qualitative data returned several mentions of *divorce*, *mixed households*, and *nontraditional families*. Interestingly, HCS expressed concern about both a lack of parental communication and excessive parental communication, whereas parents were most concerned about a lack of communication among family members. It was observed the HCS found it challenging to find common ground with parents. Similarly, parents also faced difficulty in finding common ground with other caregivers.

Additional Interpretations of Parent Survey Topics Not Selected for Joint Display

For parent survey topics without substantial HCS qualitative data in the codes that we analyzed in the parallel phase, we searched for key terms in the qualitative data to determine if we could further compare and relate these data to make interpretations.

Sleep or Bedtime Routine

The parent survey topic of sleep or bedtime routine was noteworthy, in that although it was not commonly endorsed overall (38/380, 10%), it was more prevalent (28/243, 19.6%) for respondents with a child in the age range of 1-5 years. We also found 13 mentions of *sleep*, which co-occurred with our unmet needs code 7 times. More specifically, sleep patterns and sleep hygiene at different ages were brought up during at least 2 focus groups as something with which parents discussed struggling or not understanding what is normal, whether it be newborn sleep or even sleep patterns throughout childhood and adolescence. This is confirmed through coding, in that mentions of *sleep* co-occurred with the lack of knowledge code 4 times throughout the 7 focus groups.

This suggests multiple opportunities to target BIT content for young children on this topic to be most efficient with resources.

Mood and Depression in Children

Results regarding mood were discordant between parents and HCS. Parents commonly identified depression or mood as a top concern, but HCS did not discuss mood and depression concerns as unmet needs or in terms of strategies parents use to manage mood concerns. The qualitative data included 4 mentions of words beginning with *depress*. These mentions often co-occurred with mentions of anxiety and may suggest that HCS tend to conceptualize these as related (eg, internalizing problems) or find them frequently co-occurring in their patients. These results were somewhat surprising and may indicate a domain which improved clinical training for HCS in clinical interviewing and behavioral health screening may be helpful.

Drugs and Substance Abuse

Similarly, the parent survey topic of drugs and substance abuse was rated more commonly by parents with a child in the 13-18-year age range (29/175, 16.6%) than the overall prevalence (35/380, 9.2%). In reviewing the 3 mentions we found in the qualitative data of *drug*, there was poignant discussion among participants in one of the focus groups highlighting the complexity of addressing this topic with parents who are suspicious or concerned about drug abuse, how they might rely on AAP guidelines, and publications that discuss how HCS can help parents (Textbox 1).

Respondent 1 is most likely referring to the AAP clinical report by Levy et al [66]. This resource provides guidance on how pediatricians can navigate this complex and important topic for which there is presently minimal empirical literature available. Further BIT development efforts may help to design a BIT module that can provide high-quality information and resources to parents in need of guidance on this topic that they commonly reach out to their pediatrician to address.

Textbox 1. Exemplary quotes related to drugs and substance abuse.

> *The others--the teenager who is non-compliant either at school and outperforms in other areas where they like things and how do we manage that behavior because they don't want to take away the good activities; what do I do? Or you have a parent who's suspicious of particular drug use; what do I do in this particular situation? Can we drug-test them, which is almost universal: No. However, what do we do in these situations?* [Respondent 1]
>
> *Why can't you do that?* [Respondent 4]

> *We can talk about that, but just ethically, no we don't do that. Ask me later...or, getting back to the drug-testing, having an explanation of, here's how to handle if you're concerned about your child's drug use, here's what you can do at home...* [Respondent 1]
>
> *You don't want to know what I do at home.* [Respondent 2]
>
> *I guarantee he's not coming to see you.* [Respondent 4]
>
> *Here's the formal policy of the national organization called the American Academy of Pediatrics on how to address this with your child and our stance on drug-testing teens. It is understood that it is not just a clinic, but also nationally what is done. It would be cool to see what that does for parents.* [Respondent 1]

Parent Survey Topics With Substantive Additional Qualitative Data

Among other parent survey topics not selected for joint display, we found some useful additional information within the qualitative data that may inform future BIT development. Regarding the topic of child safety, we found that this was commonly endorsed by parents with a child in the 1-5-year age range (22/143, 15.4%); however, only 1 mention of this topic was found in the qualitative data. Speech and language skills were also commonly endorsed by parents of children in the 1-5-year age range (29/143, 20.3%), and the only mentions within the qualitative data related to accessibility of the website for parents for those who are speakers of languages other than English or may have lower educational attainment. Independence and activities of daily living were more commonly endorsed by parents of youth aged 6-12 years (21/176, 11.9%) and 13-18 years (24/175, 13.7%). The qualitative data included mentions self-help, hygiene, daily routines, and chores, which may indicate the topics that HCS most commonly discuss with parents. Finally, toileting was another topic commonly endorsed by parents of children aged 1-5 years (27/380, 7.1%); although no related mentions were found within the codes we analyzed in joint display, other qualitative data did include mentions of *toileting* (3 mentions) and *potty* (2 mentions).

Parent Survey Topics Without Substantive Additional Qualitative Data

The topic of academic skills and/or intelligence was commonly endorsed across age ranges (range 20%-23%), but was not selected for joint display because of a lack of discussion in the qualitative topics we included. The qualitative data also did not include terms related to child intelligence, so no more details for interpretation are available. In the focus group data, the same was true for social skills (0 mentions), the internet and social media (1 mention), sex and sexual development (0 mentions), and motor skills (0 mentions).

Discussion

Principal Findings

This paper on the mixed-methods study reports the initial development of a targeted prevention BIT focused on behavioral health topics for parents to be implemented in pediatric primary care within a large, predominantly rural health system. We used the *discover*, *design and build*, and *test* framework [59] to inform our development efforts. In this manuscript, we report the outcomes of the *discover* phase to gather information on the implementation context and current issues facing parents and HCS navigating behavioral health topics in pediatric primary care that a BIT can address.

Overall, the approach we selected shows promise that taking both parent and HCS input into consideration at the outset of BIT development in the *discover* phase provides unique insights that may help to address the limitations of the extant literature on BITs for parents of children with behavioral health problems. For example, research on the *ez*Parent Program, a parent-focused BIT adaptation of the Chicago Parenting Program [43], stands out among the research on BITs for parents for having carefully studied implementation and sustainability factors from the parent perspective [45,46], yet, when tested in a randomized controlled trial, it did not demonstrate superiority to enhanced usual care [47]. Findings from other research on *ez*Parent suggest that inconsistent referrals to the program were discovered only after rolling out the program in primary care and were attributed to operational workflow issues for primary care staff, and these issues were unforeseen [67]. By first studying the unmet needs of parents and HCS that a BIT might address, in the implementation context that the BIT is being developed and for the expressed purpose of extending the continuum of primary care behavioral health services already available, we may be able to obviate comparable setbacks through work in our *design* and *build* and *test* phases.

The analysis of parent and HCS data in this study provided unique insights that will help in focusing the resources on developing and conducting preliminary testing on prototypes of BITs to better meet the behavioral health needs of parents using pediatric primary care within the health system. While the extant BIT literature in this area has primarily focused on engaging adolescents with a range of behavioral health problems, including anxiety, depression, and chronic pain, in adaptations of empirically supported treatments delivered in a BIT [31-34], our results indicate that BITs for parents also have the potential to greatly expand the reach and impact of evidence-based behavioral health care. Parents reported interest in BITs across several behavioral health topics, and we learned that parent interest sometimes varied across the pediatric age range. Owing to space constraints, we highlight 1 example next. Although only 10% (38/380) of parents endorsed the sleep or bedtime routine among the top 3 concerns, twice as many parents with a child aged 1-5 years endorsed this topic (28/143, 19.6%) and relatively fewer parents of children in the 6-12-year age range (13/176, 7.4%) or 13-18-year age range (3/175, 1.7%) endorsed the topic (Table 3). The implications of such findings for resource allocation for subsequent BIT development and clinical uptake are substantial. If guided solely by the overall prevalence of endorsement, we may not have selected sleep or bedtime routine as a topic for further BIT development. By extension, knowing that 19.6% (28/143) of parents with a child between 1-5 years are interested in this topic helps us to focus our BIT development efforts on topics most relevant for this age range even though research supports the effectiveness of behavioral sleep interventions for school-age youth [68]. Insights like these deepen our understanding of more detailed feedback from parents within each behavioral health topic and help the development efforts in the *design* and *build* phase, and these may increase the likelihood of BIT uptake in clinical settings for those found to be efficacious in the *test* phase [69].

Limitations

Our findings should be interpreted with recognition of the methodological limitations inherent to our approach, which focused on the initial development of a BIT to fit a specific implementation context. Therefore, surveys based primarily on selected *Bright Futures* topics that the research team felt would be a good fit for a BIT may not comprehensively represent the needs and preferences of parents related to empowerment to guide child development and behavioral well-being. A related limitation is that the study population is representative of the population in the region; survey respondents are mostly White and middle class; therefore, these findings may not be generalized to the needs and preferences of parents from other demographic and socioeconomic backgrounds. The sample of focus group interviewees was also recruited from the health system in which the BIT is being developed, which also introduces the possibility of limited generalizability. Finally, some caution in interpreting the findings of the data integration is warranted, given that we have not yet conducted any empirical studies to triangulate our interpretations with parent and provider interactions with BIT prototypes. Awareness of these potential limitations is also important to address in our future BIT development research because of the potential of unintentionally driving disproportionality in access to behavioral health care by developing a BIT that may not be engaging to historically excluded groups, who already face difficulties in accessing behavioral health care in rural areas [69,70]. Oversampling in the *design andbuild* and *test* phases may help in guarding against this unwanted outcome.

Suggestions for Future Research

Our approach to the *discover* phase for the development of a BIT to empower parents to take charge of their child's behavioral health care was shaped by our perspectives on contributing factors to the longstanding issue of limited access to high-quality behavioral health care in primary care settings. This approach may also be useful for future research developing BITs with different goals in mind. Although evidence-based treatments are often conceptualized and developed as packaged intervention products, there is usually an observed *voltage drop* when taking efficacious psychosocial treatments out of the laboratory into community practice settings [71]. This undermines the conceptualization of psychosocial treatments as a product per se, whereas conceptualization as a cocreated service between parents and HCS suggests that reduced effectiveness is not inevitable [72]. High-value behavioral health care designed with input from transdisciplinary researchers, clinicians, and patient stakeholders in the setting intended for use may provide a better chance at comparable efficacy and effectiveness [73]. The findings from our *discover* phase support the notion that usual care is a cocreated service between parents and HCS within the health system, although one which often leads to unmet needs for both stakeholder groups in the health system in which the study was conducted. Therefore, the value of a BIT can be measured against the degree to which the implementation of BITs contributed to these needs being met. Research has demonstrated that parental comfort in discussing behavioral health concerns is shaped by the quality of the PCC response; that is, when PCCs dismiss these concerns, parents report that they are less comfortable discussing these topics [74]. BITs may help in this regard, as these conversations have been shown to be brief and work well when combined with videos to illustrate effective interventions for child discipline [75].

At this juncture, we have entered the *designandbuild* phase to triangulate our mixed-methods findings with parent and provider feedback on the prototypes of the BIT [59]. We are currently collecting data for 2 mixed-methods user testing studies to triangulate these findings for the content topic of behavioral challenges. In 1 study, we recruited a group of parents who completed the survey and endorsed this topic in their top 3 (n=9) and another group of parents who completed the survey but did not endorse this topic in their top 3 (n=9). We chose to recruit from the parents who completed the quantitative survey to aid in triangulating findings from this study and from the behavioral challenges topic because there is substantial extant BIT literature for parents on this topic [41,47]. Another study was conducted with PCCs within the health system (n=16) to determine the usability and acceptability of provider-facing BIT to address behavioral challenges and how this can be incorporated into the electronic health record and clinic workflow.

Conclusions

This mixed-methods study provided some unique insights into the needs and preferences of parents and HCS. These results appear useful for designing a BIT platform to enhance access to effective self-help to empower parents to take charge of their child's behavioral health care. Future research will triangulate these mixed-methods findings with parent and health care provider reactions to BIT prototypes in preparation for an effectiveness trial on a fully functional BIT prototype.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Focus group moderator guide.
[DOCX File , 27 KB - pediatrics_v4i4e27551_app1.docx]

Multimedia Appendix 2
Parent survey.
[PDF File (Adobe PDF File), 361 KB - pediatrics_v4i4e27551_app2.pdf]

Multimedia Appendix 3
Parent survey descriptive statistics.
[PDF File (Adobe PDF File), 106 KB - pediatrics_v4i4e27551_app3.pdf]

Multimedia Appendix 4
Data integration summary.
[DOCX File , 24 KB - pediatrics_v4i4e27551_app4.docx]

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Abbreviations

AAP: American Academy of Pediatrics
BIT: behavioral intervention technology
FTF: face-to-face
HCS: health care stakeholders
PCC: primary care clinician
PRISM: Pragmatic Robust Implementation and Sustainability Model
RE-AIM: Reach, Effectiveness, Adoption, Implementation, and Maintenance

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Original Paper

A Chatbot to Engage Parents of Preterm and Term Infants on Parental Stress, Parental Sleep, and Infant Feeding: Usability and Feasibility Study

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Abstract

Background: Parents commonly experience anxiety, worry, and psychological distress in caring for newborn infants, particularly those born preterm. Web-based therapist services may offer greater accessibility and timely psychological support for parents but are nevertheless labor intensive due to their interactive nature. Chatbots that simulate humanlike conversations show promise for such interactive applications.

Objective: The aim of this study is to explore the usability and feasibility of chatbot technology for gathering real-life conversation data on stress, sleep, and infant feeding from parents with newborn infants and to investigate differences between the experiences of parents with preterm and term infants.

Methods: Parents aged ≥21 years with infants aged ≤6 months were enrolled from November 2018 to March 2019. Three chatbot scripts (stress, sleep, feeding) were developed to capture conversations with parents via their mobile devices. Parents completed a chatbot usability questionnaire upon study completion. Responses to closed-ended questions and manually coded open-ended responses were summarized descriptively. Open-ended responses were analyzed using the latent Dirichlet allocation method to uncover semantic topics.

Results: Of 45 enrolled participants (20 preterm, 25 term), 26 completed the study. Parents rated the chatbot as “easy” to use (mean 4.08, SD 0.74; 1=very difficult, 5=very easy) and were “satisfied” (mean 3.81, SD 0.90; 1=very dissatisfied, 5 very satisfied). Of 45 enrolled parents, those with preterm infants reported emotional stress more frequently than did parents of term infants (33 vs 24 occasions). Parents generally reported satisfactory sleep quality. The preterm group reported feeding problems more frequently than did the term group (8 vs 2 occasions). In stress domain conversations, topics linked to “discomfort” and “tiredness” were more prevalent in preterm group conversations, whereas the topic of “positive feelings” occurred more frequently in the term group conversations. Interestingly, feeding-related topics dominated the content of sleep domain conversations, suggesting that frequent or irregular feeding may affect parents’ ability to get adequate sleep or rest.

Conclusions: The chatbot was successfully used to collect real-time conversation data on stress, sleep, and infant feeding from a group of 45 parents. In their chatbot conversations, term group parents frequently expressed positive emotions, whereas preterm group parents frequently expressed physical discomfort and tiredness, as well as emotional stress. Overall, parents who completed the study gave positive feedback on their user experience with the chatbot as a tool to express their thoughts and concerns.

Trial Registration: ClinicalTrials.gov NCT03630679; https://clinicaltrials.gov/ct2/show/NCT03630679

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KEYWORDS

chatbot; parental stress; parental sleep; infant feeding; preterm infants; term infants; sleep; stress; eHealth; support; anxiety; usability

Introduction

Caring for infants can lead to parental anxiety and psychological distress especially for first-time parents and particularly within the first 6 months after birth [1]. Multiple studies have demonstrated that parental stress, anxiety, and psychological distress are not only short-term problems but may also have long-lasting effects on the child's emotional, behavioral, and cognitive development [1]. These are more prominent for parents of preterm infants than for parents of term infants [2]. An assessment of maternal psychological distress in singleton versus multiple-birth preterm infants found that mothers with multiple births had greater posttraumatic stress symptoms, anxiety at discharge, and depressive symptoms at 6 months as compared to mothers of singletons [3]. In a follow-up clinic evaluation of parents and their preterm infants, many reported parental concerns about medical and developmental outcomes that were unsupported by their child's diagnosis [4]. Among mothers of school-aged children who were born late preterm and admitted to an intensive care unit (ICU), there was a significant 18-fold increase in total stress compared to stress among mothers of term children [5]. In a parallel study group involving mothers of school-aged children who were born late preterm but not admitted to the ICU, there was also a 24-fold increase in total stress when compared to the mothers of term-born children [5].

Besides experiencing initial stress directly after birth, parents need to adapt to the new situation after hospital discharge (or at home) and develop confidence in caring for their newborns themselves. These adjustments and care transition from a medical facility to home may be associated with increased stress and loss of sleep. Although sleep disturbance is most commonly associated with the early postpartum period, parents may continue to experience disturbed sleep for some months after birth [6,7]. In addition to sleep disturbance, infant feeding, including the frequency and type of nutrition, is another potential stressor and is associated with depressive symptoms and higher stress ratings [8]. Parents of preterm infants often face issues with frequency of feeding, and their infants also often start solid food later in life [9]. Relatively little knowledge is available on the parental experience in the areas of stress, sleep, and infant feeding during this period of change in family life.

Web-based interventions for mental health have shown some success in conditions such as depression and anxiety [10]. The remote presence of human support through these interventions has been shown to outperform self-guided interventions and achieve higher rates of participant adherence [10]. Studies have shown that these positive outcomes were achieved by implementing periodic prompts and frequent interactions with participants [11]. However, such interactive features are highly therapist intensive. Chatbot apps which can simulate humanlike conversations [12] have become popular in recent years. These kind of chatbot apps can provide computer-generated responses to a user in real time, mimicking conversational interactions with another human via instant electronic messaging [13]. This technology, coupled with use of mobile devices, presents possibilities to collect data in real time while reducing the workload of the therapist. Although chatbots are used in many apps, one of the more innovative areas of development is for interactive data collection in the health care sector [14].

In this study, chatbot technology was used to provide an interactive conversation platform to engage parents of newborn infants who were recently discharged from hospital in the areas of parental stress and sleep, and infant feeding. To our knowledge, there have been no studies published on the use of a chatbot as an interactive conversational tool for parents to provide information in these subject areas. The objective of this study is to explore the feasibility and usability of chatbot technology to gather real-life, in-home conversation data on 3 domains (parental stress, sleep, and infant feeding) from parents with newborn infants and investigate the differences between parents of preterm and term infants in these 3 domains using these conversation data.

Methods

This observational study was conducted from November 2018 to March 2019. Participants were recruited from a tertiary referral maternity hospital in Singapore. The study was approved by the SingHealth Centralised Institutional Review Board, Singapore, and registered at ClinicalTrials.gov (NCT03630679).

Study Population

The study population comprised parents aged ≥21 years with healthy infants who were ≤6 months of age and had been discharged from the hospital at the time of enrollment. Eligible parents had to be proficient in the English language, have in-home access to a reliable internet connection, own a tablet or a mobile device suitable for electronic communication and assessment, and be able to comply with the required study tasks. Nonsingleton infants or those known to have current or previous illnesses or conditions which might interfere with the study outcome or who were participating in any other clinical studies were excluded. Parents with a past or present history of mental illness, single parents, or parents who had any acute or chronic illnesses or who were assessed by the investigators to be unable or unwilling to comply with the study protocol requirements were excluded. Written informed consent was obtained from all eligible parents.

Study Design

Participants for this observational study were screened based on the above inclusion and exclusion criteria. After providing informed consent, eligible participants were given access to download the ClaimIt app (ObvioHealth), which provided access to electronic questionnaires (eQuestionnaires) and the study chatbot, on to their mobile devices. ClaimIt is a commercially available mobile app for data collection in virtual or hybrid research studies that require no or minimal use of physical study sites. Participants completed an electronic Screening eQuestionnaire in ClaimIt to confirm their eligibility for enrollment. The study population included 2 groups: "preterm" (parents of preterm infants at gestational age <37 weeks) and "term" (parents of term infants at gestational age ≥37 weeks).

Collection of Conversation Data, Ease of Use, and Satisfaction Ratings

ClaimIt was made available to participants so they could perform specific study-related tasks and receive study information. The participants were given instructions via the ClaimIt app on how to use the chatbot and were asked to interact with the chatbot at least 3 times a week over a maximum 28-day period. The chatbot is an interactive conversational app that was built as a component of the ClaimIt app specifically for this study. The chatbot conversed with users through an online platform. The chatbot was programmed using scripts to respond appropriately whenever a user initiated a conversation. The chatbot scripts included open-ended and closed-ended (multiple-choice) questions and responses. There were 3 conversation scripts, 1 for each of the 3 domains of interest, which included stress, sleep, and feeding (Multimedia Appendix 1).

Participants also received notifications on the first day of each week to remind them to complete the required number of interactions with the chatbot at their convenience. Reminder notifications were triggered on the first day of each week for the participant to complete 3 interactions over the week. Study compliance was monitored by the study team and principal investigator, and contact with the participants was made electronically, and if needed, by telephone. All study data were collected via the ClaimIt app running on participants' mobile devices. Transcripts of the chatbot conversations were accessed and reviewed by the study team.

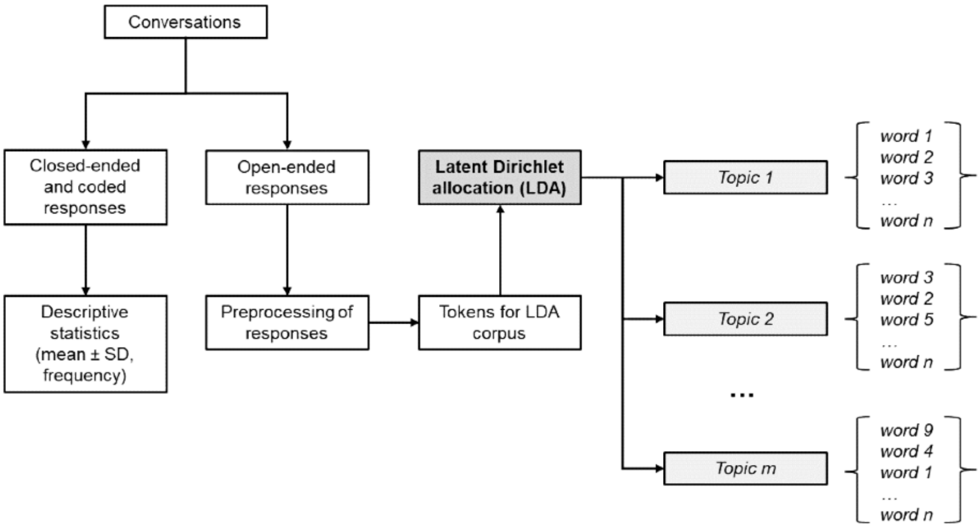
Each participant completed the Usability eQuestionnaire in the ClaimIt app at the end of the study (Multimedia Appendix 2). The questionnaire comprised 16 questions, including closed-ended (binary or 5-point Likert scale) and open-ended responses. Participants were asked to rate ease of use and satisfaction separately for the ClaimIt and chatbot components.

Conversation Data Processing and Descriptive Statistical Analysis of Closed-Ended Questions

A sample size of 40 participants was planned to permit reporting of descriptive summary statistics for the categorical and quantitative response data collected using the chatbot. The expected dropout rate was 25%. If this threshold was exceeded despite the investigators' efforts to contact participants who were lost to follow-up, a maximum of 10 additional participants could be enrolled to replace the participants who dropped out. Completed chatbot interactions from participants who dropped out were included in the conversation analysis.

Each raw chatbot conversation was processed by separating open-ended responses from responses to closed-ended questions and suitably coded open-ended questions (Figure 1). Descriptive statistics were used to summarize the responses for closed-ended and coded open-ended responses from the Usability eQuestionnaire and chatbot conversations. Continuous data are presented using mean and SD or range, and categorical responses are presented using frequency and percentage. Descriptive summaries are also presented by group (preterm and term). No significance testing was performed. Statistical analyses were performed using SAS 9.4.

Figure 1. Workflow for conversation data processing and semantic analysis by latent Dirichlet allocation (LDA) topic modeling.



Semantic Analysis of Chatbot Conversations

We used the latent Dirichlet allocation (LDA) [15] method to model and extract knowledge about semantic topics within our corpus (body of text), which was derived from open-ended responses within the chatbot conversation data. In the context of LDA, each conversation is represented as a mixture of topics, and each topic is associated with a collection of words. Each word is represented as belonging to a topic with a certain probability, and different words in a conversation may belong to different topics. The objective is to find a set of representative words for each topic. In LDA-based topic modeling, the actual semantic meaning of each topic cannot be automatically inferred from the data. Instead, the link between a topic and its semantic meaning (a concept that a human would understand) has to be made by a person based on subjective judgement. A valid topic model, however, makes linking a semantic meaning to a topic a trivial task; for example, the words "beach," "sand," "sun," and "relax" once grouped together by the LDA algorithm, would be easily recognized by most persons as a concept for "holiday."

Besides LDA, other natural language processing methodologies that have been explored for topic modeling include latent semantic analysis/indexing (LSA/LSI) [16], probabilistic latent semantic analysis (pLSA) [17], and nonnegative matrix factorization (NMF) [18]. In general, these methods infer topics from document-level word co-occurrences by modeling each document as a mixture of topics. However, such inference is limited by the sparsity of word co-occurrence patterns when learning from short texts, for example, those on social network platforms. Other issues encountered with short texts include slang, spelling or grammatical errors, and nonmeaningful or noisy words.

LSA/LSI is nonprobabilistic and relies on a mathematical procedure, known as singular value decomposition [19], and can make use of a term frequency-inverse document frequency matrix which assigns large weights to terms that occur frequently within a document but rarely within the corpus, and vice-versa. As LSA/LSI techniques typically require a large corpus in order to produce accurate groupings or topic models, they were not considered an appropriate methodology for this study. Another approach, pLSA, replaces the singular value decomposition procedure with a probabilistic one. Although pLSA represents a valid alternative to LDA, overfitting is known to be less controllable when using pLSA in its basic form [20]. NMF uses a matrix factorization method to simultaneously perform dimension reduction on a term-document matrix and clustering of terms to extract topics [21].

Albalawi et al [22] evaluated a number of topic modelling methods for short texts and concluded that LDA and NMF provided the best learned descriptive topics and addressed the limitations affecting the other topic modeling methods. Compared with NMF, LDA has produced more consistent results [22] and has been applied to studies in various domains with a number of toolkits readily available for its implementation. Based on these considerations, LDA was deemed the most suitable method for analyzing conversation data from the chatbot.

Chatbot conversations were analyzed independently for the stress, sleep, and feeding domains. As with online apps, the user-generated texts in this study were often limited in length. Therefore, the average conversation length was increased by merging multiple conversations collected from the same participant over the study period into a single conversation for each domain (Multimedia Appendix 3). These merged conversations were then used for LDA topic modeling.

Preprocessing of Open-Ended Responses

The first preprocessing step was to eliminate stop words (ie, those that do not carry information about topics). Stop words for the English language [23] were removed as were additional stop words identified as being specific to each of the 3 domains under consideration. We converted composite words into single words; for example, "not well" was converted to "not_well." Local terms ("want," "know," "need," "twice," "not_well," "well," "need," "went," "couldn," "occasion," "not," "babi," "feel," "okai," "carri," "unab," "veri," "left," "right," "care," "affect," "manag," "everi," "felt," "time," "sometim," "sure," "onli," and "usual") were also added to the stop word list.

Stemming of the remaining words in conversations was performed using the Gensim library [24]. Only stem tokens with a length greater than 3 letters were retained; shorter tokens were discarded. Tokens that appeared in fewer than 2 conversations in a single domain were also discarded as were tokens that appeared in more than 50% of the conversations of the domain. For conversations belonging to the feeding domain, product names and brand names were also removed. The resulting tokens formed the conversation corpus for the knowledge extraction to be performed by LDA-based topic modeling (Gensim 3.7.1 implementation [24]). The preprocessing workflow to derive the corpus for LDA machine learning is shown in Multimedia Appendix 3. The aim was to obtain a reduced set of words (corpus) for consideration when the LDA was used to extract topics from the chatbot conversations.

Knowledge Extraction

For each domain, 8 modeling sessions were performed, with the number of latent topics to be extracted set to a value from 2 through 9. Thus, a model was created for each setting (2 through 9 latent topics extracted). To obtain each model, we performed 10 learning runs by randomly changing the value of the random seed used to initialize the LDA procedure (ie, allocating a word to a topic), while the number of training passes (to determine the probability of the word belonging to a topic) was set at 100 for all runs. The best models for each domain could not be unequivocally identified based on a perplexity measure [25], and therefore human interpretation by domain experts was used. Human experts identified models with 3 or 4 topics as the most interpretable ones. Topics were visualized using LDAvis [26].

As a topic is a probability distribution over the entire dictionary of the corpus, only words with the highest probability values were deemed to be representative of the semantic meaning for that topic. We chose the 3 highest probability words within a topic to be most representative of the semantic concept associated with that topic. In simpler terms, one can think of these 3 highest probability words as the most frequently used words within that topic.

Results

Participants

A total of 48 parents were screened. Of these, 45 participants were enrolled in the study. This included 5 participants with term infants who were recruited to replace participants withdrawn from the study due to noncompliance. There were 45 infants (23 females, 51%; 20 preterm and 25 term infants).

In all, 19 participants withdrew from the study: 13 (68%) participants failed to complete at least 5 interactions, 4 (21%) were withdrawn at the investigator’s decision, and 2 (11%) withdrew consent. A total of 26 participants, 13 in each group, completed the study (Figure 2).

All parents (n=45) were female. The mean age of the participants was 31.7 (SD 4.3) years while their infants were a mean 1.1 (SD 1.3) months old (Table 1). Participants completed 256 interactions with the chatbot, which included 259, 257, and 267 conversations on stress, sleep, and feeding, respectively.

Figure 2. Participant flowchart.

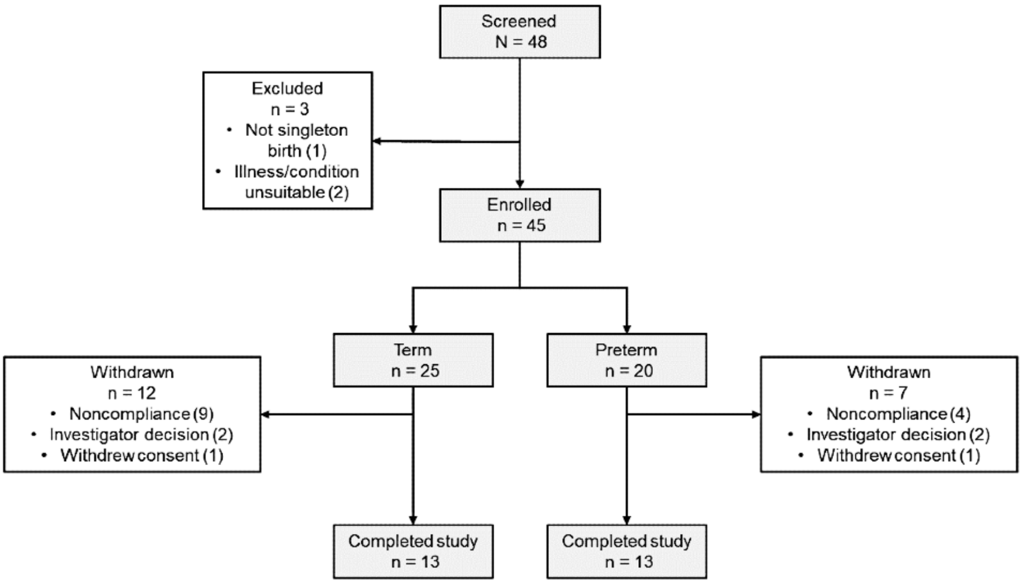


Table 1. Characteristics of participants and chatbot responses.

Characteristic	Term (N=25)	Preterm (N=20)	Total (N=45)
Female gender (parent), n (%)	25 (100)	20 (100)	45 (100)
Female gender (infant), n (%)	13 (52)	10 (50.0)	23 (51)
Age of parents (years), mean (SD)	31.1 (4)	32.5 (5.0)	31.7 (4)
Age of infants (months), mean (SD)	1.1 (1)	1.2 (1)	1.1 (1)
Completed conversations, n			
Stress domain	126	133	259
Sleep domain	125	132	257
Feeding domain	130	137	267
Interactions (all 3 domains), n	125	131	256
Merged conversations for LDA[a] topic modeling[b], n			
Stress domain	17	22	39
Sleep domain	17	22	39
Feeding domain	18	22	40

[a] LDA: latent Dirichlet allocation.

[b] Within each of the 3 domains, conversations belonging to the same participant were merged into a single conversation. Completed chatbot interactions from participants who dropped out were included in the conversation analysis.

Ease of Use and Satisfaction With the Chatbot

Of the 45 parents enrolled, 26 completed the study and the usability eQuestionnaire. Responses from these 26 participants (on a 5-point Likert scale; 1=very difficult, 5=very easy) showed that the chatbot was rated as "easy" to use (mean 4.08, SD 0.74). Preterm and term group parents who completed the study rated it similarly (preterm: mean 3.9, SD 0.86; term: mean 4.2, SD 0.60). The ClaimIt app was also perceived as "easy" to use (mean 4.19, SD 0.85) by both the preterm and term group parents (preterm: mean 4.0, SD 1.0; term: mean 4.38, SD 0.65).

Parents were "satisfied" with the chatbot (mean 3.81, SD 0.90; 1=very dissatisfied, 5=very satisfied) and also with the ClaimIt app (mean 3.81, SD 0.80). Participants in the preterm group registered between "neutral" and "satisfied" with the chatbot (mean 3.62, SD 0.96) and ClaimIt (mean 3.69, SD 0.85) app. Higher mean scores were observed in the term group for the chatbot (mean 4.0, SD 0.82) and also the ClaimIt (mean 3.92, SD 0.76) app.

The preterm group felt that the length of interactions was between "long" to "neutral" (mean 2.92, SD 1.19; 1=too long, 5=easily manageable), while the term group felt that the length of interactions was between "manageable" and "easily manageable" (mean 4.31, SD 0.48). Furthermore, 46% (6/13) of the preterm parents and 23% (3/13) of the term parents experienced technical issues when using the chatbot.

Overall, participants were not worried about sharing their information (mean 4.04, SD 1.08; 1=very worried, 5=not at all worried) and were likely to use the chatbot again (mean 3.35, SD 0.75; 1=not at all likely, 5=very likely). Parents in both the term and preterm groups were generally not worried about data sharing and reported between "neutral" and "likely to use" chatbot technologies again to provide input on similar topics.

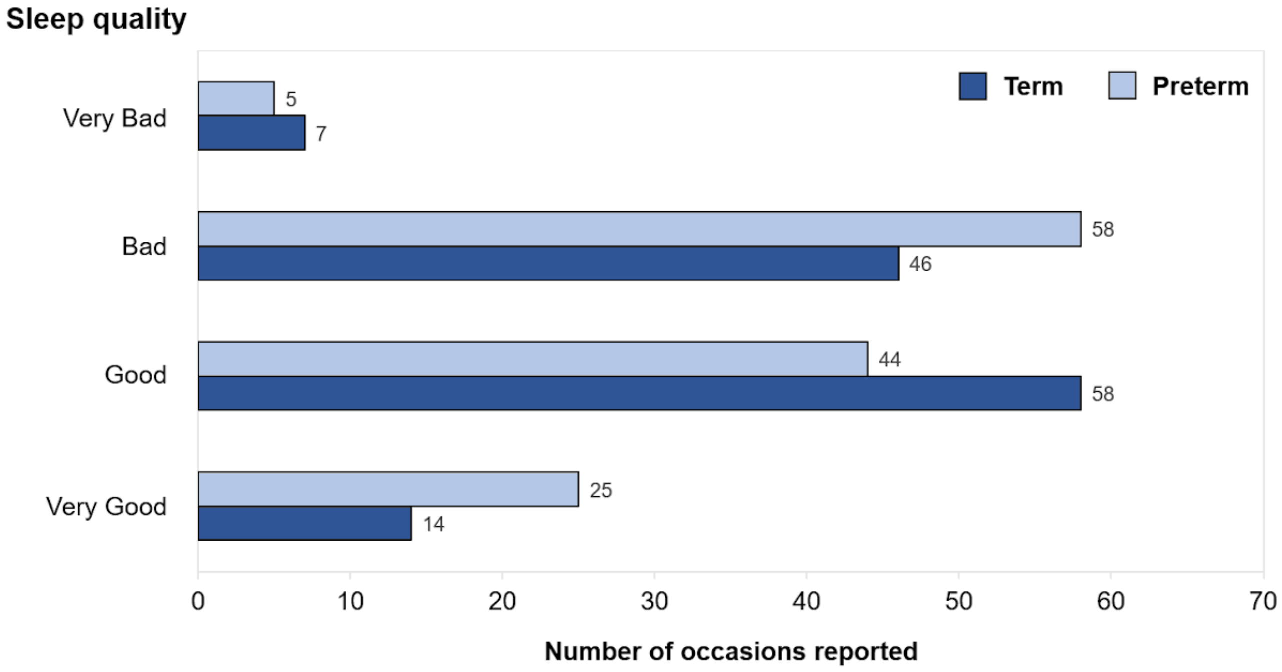
Responses to Closed-Ended Questions on Stress, Sleep, and Feeding

Conversations from the 45 enrolled parents were analyzed. Parents with preterm infants reported emotional stress more frequently compared to parents with term infants (33 vs 24 occasions). Parents with term infants reported physical stress more frequently compared to parents with preterm infants (30 vs 10 occasions). When the cause of stress was not directly linked to their infants, parents with term infants reported stressors on more occasions (27 vs 18 occasions for the preterm group). Common stressors experienced by both preterm and term parents were breastfeeding, work, and relationships. Only parents of term infants reported breast-related issues (7 occasions).

In general, parents perceived their sleep quality to be satisfactory although the preterm group reported good sleep slightly less frequently than did the term group (Figure 3). In terms of total sleep hours per day, preterm parents reported an average of 5.8 hours, while term parents reported an average of 6.1 hours.

Among parents who gave their infants breast milk, the most commonly reported feeding frequency was 8 to 11 times per day. This was true for both the preterm and term group. Among parents who gave their infants infant formula, the most commonly reported feeding frequency was 4 to 7 times per day in both the preterm and term groups. Feeding problems, such as irregular feeding, were more frequently reported by preterm group parents than by the term group parents (8 vs 2 occasions, respectively).

Figure 3. Rating of overall sleep quality by term and preterm group parents.



Knowledge Inferred From Semantic Analysis of Chatbot Conversations

Open-ended responses to the conversation scripts from the 45 enrolled participants were used for the semantic analysis. Due to the limited length of the raw conversations, conversations belonging to the same participant were merged into a single conversation. This resulted in 39 conversations for the stress domain (17 term, 22 preterm) with an average conversation length of 27.4 words, 39 conversations for the sleep domain (17 term, 22 preterm) with an average conversation length of 28.5 words, and 40 conversations for the feeding domain (18 term, 22 preterm) with an average conversation length of 16.9 words (Table 1).

For the stress and sleep domains, in each LDA-derived model, the top 3 most representative words for each topic were found to be consistent across the 10 learning runs performed. For the feeding domain, topic composition across the 10 learning runs was characterized by a high degree of variability; that is, the top 3 most representative words of each topic varied across learning runs. Thus, an optimal and reproducible set of topics could not be learned from the conversations in the feeding domain. This could be due to the shorter length of feeding conversations compared with conversations from the stress and sleep domains.

For all 3 domains, models with 3 or 4 semantic topics were identified by human experts as being the most interpretable. The semantic topics for the stress (4 topics) and sleep (3 topics) domains inferred using the LDA topic modeling are shown in Figures 4 and 5, respectively. Only the top 3 most representative words for each topic are shown.

Figure 4. Three most representative words for each topic learned from conversations in the stress domain.

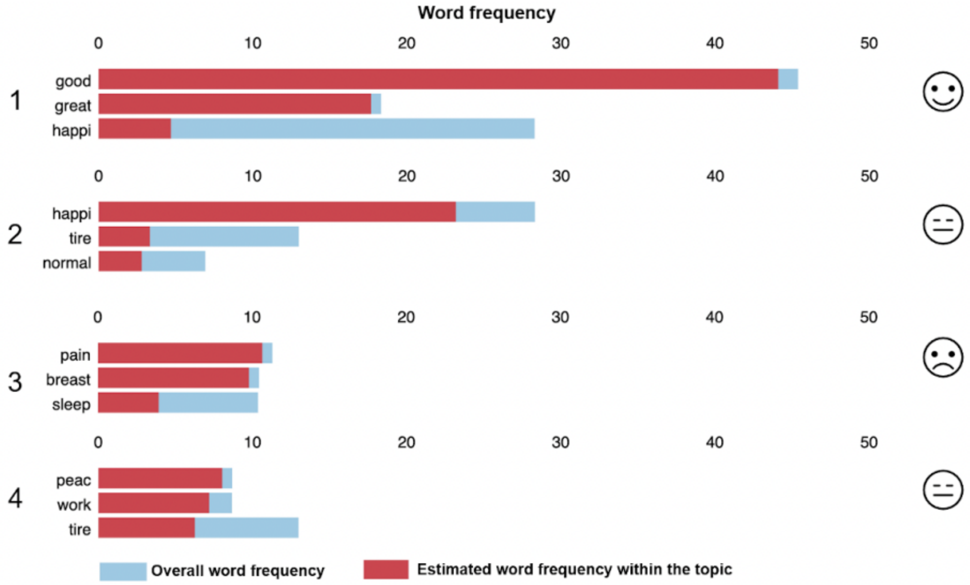
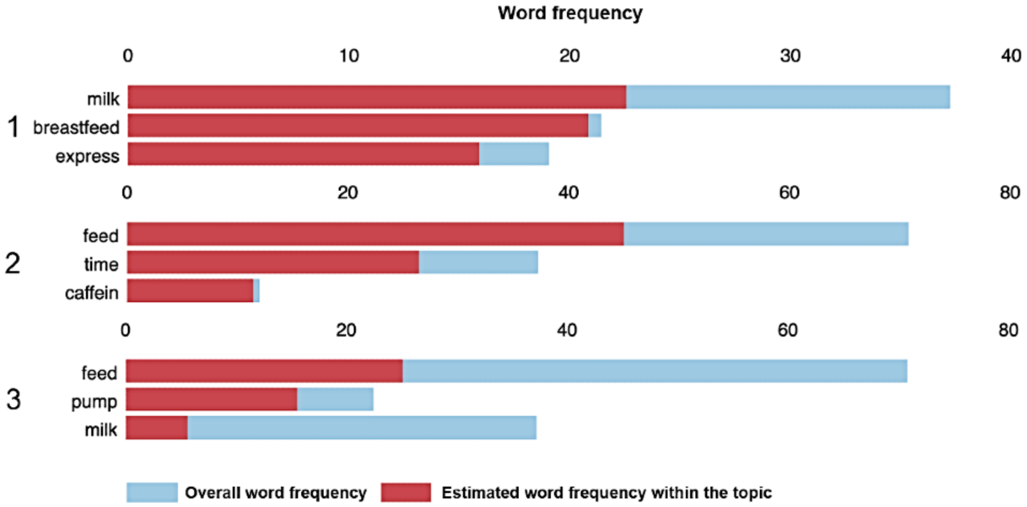


Figure 5. Three most representative words for each topic learned from conversations in the sleep domain.

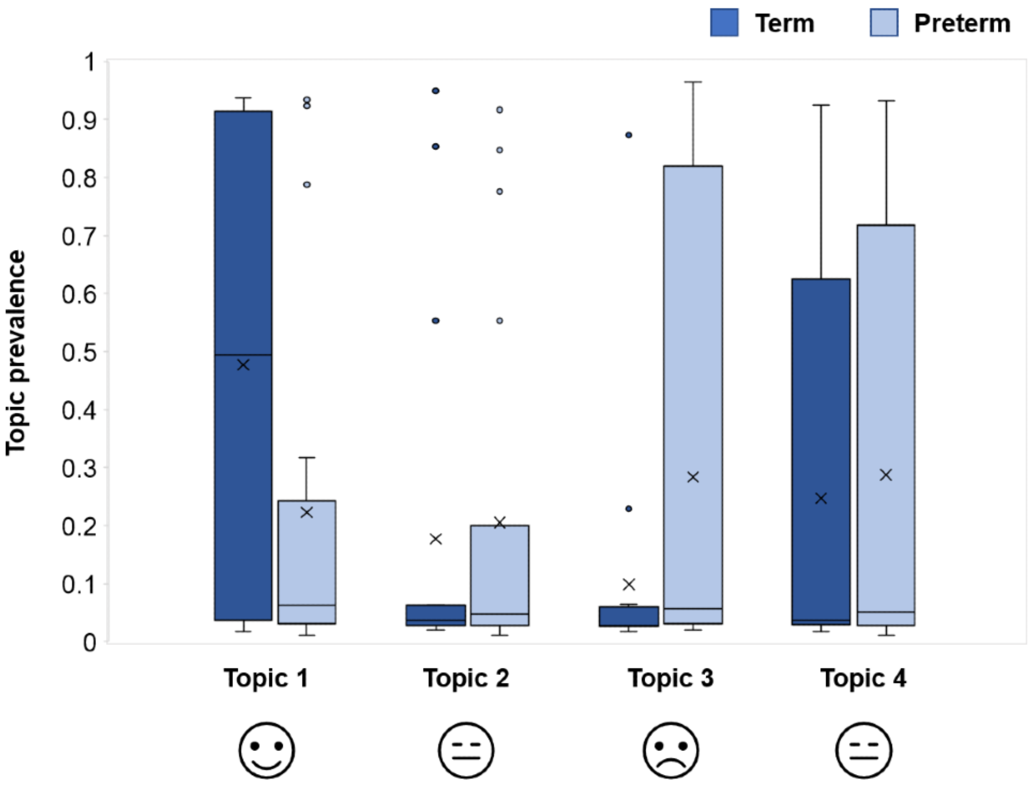


Stress Domain

In Figure 4, topic 1 appears to be linked to positive emotions and less stressful situations. Both topics 2 and 4 reflect “mixed feelings” of moderate well-being coupled with tiredness, whereas topic 3 appears to be associated with feelings of physical discomfort.

When the distribution of conversations over the 4 topics was calculated for each group (Figure 6), topics associated with opposite feelings (topic 1 and topic 3) exhibited dissimilar patterns for the term and preterm parents: topic 1 (positive) was the most prevalent topic in conversations of term parents, whereas preterm parents used words associated with this topic less frequently in their conversations. On the other hand, topic 3 (physical discomfort) appeared less frequently in conversations from term parents, whereas preterm parents made much more use of words belonging to this topic. The frequent occurrence of representative words for the "discomfort"-related topic ("pain," "breast," and "sleep") in conversations from preterm group parents suggests this group experienced a higher degree of physical stress and discomfort.

Figure 6. Topic prevalence in stress domain conversations from term and preterm group parents.



Sleep Domain

Within the sleep domain, topic 1 appeared to be linked to breastfeeding, topic 2 to feeding in generic terms, and topic 3 to feeding using a milk pump (Figure 5). This showed that when parents were asked to comment on their sleep, their responses revolved around some aspects of feeding, suggesting that feeding might be interfering with parents' ability to get an adequate amount of sleep or rest. When the distribution of conversations over the 3 topics (ie, the prevalence of the topics for each conversation) was calculated by group, term and preterm parents did not exhibit different semantic patterns in their conversations unlike those seen for the stress domain.

Feeding Domain

For this domain, the average conversation length was shorter than for the other 2 domains, resulting in a smaller feeding conversation data set. As a result, an optimal and reproducible set of topics could not be learned for the feeding domain. It is nonetheless interesting to note that feeding-related words and topics dominated the content of conversations collected for a different domain, sleep (Figure 5), suggesting close interactions between these 2 domains as perceived by parents in caring for their infants.

Discussion

Principal Findings

This study collected real-life, in-home data on parental stress, sleep, and infant feeding from parents of preterm and term infants using a chatbot. Participants who completed the study were satisfied with their online interactions with the chatbot and found the chatbot easy to use. Importantly, they were not worried about sharing such information through an interactive tool and were willing to use the chatbot to provide input on similar topics in the future. This finding helps to validate the use of chatbots on mobile devices as a convenient and accessible means of supporting parents of newborn infants and collecting data on topics that are important for the health and well-being of both infants and parents.

For the stress domain, the top conversation topic extracted from the semantic analysis showed strong positive emotions among parents with term infants. The other topics captured mixed feelings of moderate well-being and being tired, as well as general discomfort. Parents with preterm infants were more likely to express experiences of physical discomfort and tiredness through representative topic words like "pain," "breast," and "sleep." The semantic analysis thus revealed a state of high physical stress in parents of preterm infants. In addition, they also reported emotional stress more frequently compared with term group parents. Similar experiences have been reported in earlier studies [2,3], especially in cases where the preterm infant was admitted to the ICU [5]. In our study, parents with term infants expressed positive emotions more frequently than did those in the preterm group. However, they were not spared the stress of caring for their infants, reporting physical stress on more occasions than the preterm group. With the addition of a new member to the family, noninfant-related stressors involving work and relationships were reported by both preterm and term group parents in this study.

An interesting insight from our semantic analysis of chatbot conversations on sleep was that the 3 most frequent topics of conversation for all parents (both the term and preterm groups) were related to feeding. This observation implies that parents intuitively linked feeding activities with their inability to have adequate rest. This could be explained by the need to feed their infants at regular intervals over the day and night. Indeed, the most commonly reported frequency of feeding was 8 to 11 times per day for breast milk and 4 to 7 times per day for infant formula. The close links between feeding and sleep revealed by semantic analysis adds another dimension to the closed-ended responses on sleep. Although both groups reported satisfactory sleep quality overall, preterm group parents reported good sleep quality slightly less frequently. Preterm group parents also reported feeding problems, such as irregular feeding, on more occasions than did term group parents.

Limitations and Future Work

A total of 11 out of 45 enrolled participants (24%) were withdrawn from the study due to noncompliance (failing to complete the required number of chatbot interactions). For some participants, there were delays (up to 29 days) between enrolment and their first interaction with the chatbot. These delays could possibly be due to the stress experienced by parents and additional responsibilities of caring for a newborn at home after discharge. Although reminder notifications were sent on day 1 of each week, the next notification was only triggered on day 4 if the participant had not started a chat by that point. The high rates of noncompliance could be an indication of limited usability; for this reason, results for the usability questionnaire (answered by completers only) are presented descriptively and without attempting to perform statistical testing. Implementation of earlier and more frequent reminder notifications may improve participant compliance with chatbot interactions. Manual reminders via phone and external messaging platforms (WhatsApp and email) were implemented during the study to improve compliance and were well received. These reminders could be implemented in future work, along with further optimization of the technical performance of the mobile app and chatbot, to improve overall user experience and engagement in providing real-time data.

There were variations in word patterns believed to convey similar constructs that could pose some problems for completely unsupervised analysis. For example, in the stress and sleep scripts, participants were asked about how they were feeling and gave answers such as “good,” “not bad,” “doing well,” “god,” and “hood”. Intuitively, “good,” “not bad,” and “doing well” could be interpreted as saying that the person who responded felt “good,” However, without appropriate manual preprocessing, words such as “god” and “hood” might not be appropriately handled by the LDA algorithm. The conversation length was increased by merging multiple conversations to improve the efficiency of the LDA algorithm as discussed earlier. For the feeding domain, the average merged conversation length (16.9 words) was much shorter than for the other 2 domains (27-28 words). This resulted in a smaller feeding conversation data set and may explain why a reproducible set of topics could not be learned for this domain. Future studies should seek to validate the findings of this exploratory work with larger conversation data sets both in terms of the number or length of conversations and the number of participants. Additional topic modeling methods for short-text data could also be explored to improve handling of short or variable conversation length.

Although the 3 chatbot scripts (stress, sleep, and feeding) collected a large breadth of information, the depth of information was limited. The scripts explored the immediate concerns of parents and their high-level daily activities, but further studies are required to gain deeper insights. Future work could expand the scope of the chatbot to examine conversation topic patterns associated with other infant or family characteristics such as single or multiple births, parental age or age group, number of primary caregivers, or differences between first-time parents and those with more than one child. If data from different geographical regions can be collected, it may also be of interest to the explore similarities and differences among parents in different regions.

Our study shows that the application of machine learning to open-ended conversations elicited by a chatbot can provide additional insights beyond those provided by closed-ended questionnaire responses or descriptive statistics. Appropriately guided by human expert interpretation, unsupervised classification approaches such as LDA can reveal links or topics of interest within conversation data that may not have been anticipated. In addition, it has been suggested that conversational agents such as chatbots also help fulfil other emotional needs [10]. In our context, conversing with a chatbot could help parents overcome feelings of isolation, cope with negative feelings and obtain encouragement, and, at the same time, refine the process of communication on the daily issues they are struggling with.

Conclusions

In this study, a chatbot was successfully used to collect real-time, open-ended conversation data on parental stress, sleep, and infant feeding. Using machine learning, our analysis of semantic patterns revealed differences between preterm and term group parents in conversation topic prevalence, notably for the stress domain. Positive emotions were more often expressed by parents with term infants, whereas parents with preterm infants more frequently expressed feelings of discomfort and tiredness, suggesting they were experiencing higher levels of stress. Topics involving infant feeding dominated the content of sleep domain conversations. Taken together with the results for self-reported sleep quality and feeding problems, these links between sleep and infant feeding suggest that preterm parents could have been more affected by poorer sleep related to frequent feeding or feeding problems. Overall, there was positive feedback from parents who completed the study on the usability experience of the chatbot as a tool to express their thoughts and concerns.

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Authors' Contributions

JW contributed to study conception and design, analysis and interpretation of data, and manuscript drafting and revision.
ACF contributed to study conception and design, analysis and interpretation of data, and manuscript drafting and revision.
ST contributed to analysis and interpretation of data as well as manuscript drafting and revision.
EA contributed to analysis and interpretation of data as well as manuscript drafting and revision.
RMVE contributed to study conception and design, analysis and interpretation of data, and manuscript drafting and revision.
CMC contributed to the study conception and design. She was responsible for the study implementation, acquisition of the study resources including participant recruitment, data collection, and analysis and data interpretation. She also contributed to the drafting and revision of the manuscript.
All authors contributed to the writing and critical revision of the manuscript for important intellectual content and approved the final version for publication.

Conflicts of Interest

ACF was affiliated with Danone Nutricia Research, Precision Nutrition D-lab, Singapore, at the time the work was performed. JW was affiliated with Danone Nutricia Research, Precision Nutrition D-lab, Singapore, at the time the work was performed. ST was affiliated with Danone Nutricia Research, Precision Nutrition D-lab, Singapore, at the time the work was performed and is currently affiliated with Cytel Singapore Private Ltd. EA was affiliated with Danone Nutricia Research, Precision Nutrition D-lab, Singapore, at the time the work was performed and is currently affiliated with NLYTICS Pte. Ltd, Singapore. RMvE was affiliated with Danone Nutricia Research at the time the work was performed and is currently affiliated with Emma Children’s Hospital, Amsterdam University Medical Center, The Netherlands; and Nutrition4Health, Hilversum, The Netherlands. CMC has no conflicts of interest to declare.

Multimedia Appendix 1
Chatbot scripts for stress, sleep, and feeding.
[DOCX File , 62 KB - pediatrics_v4i4e30169_app1.docx]

Multimedia Appendix 2
Usability eQuestionnaire for the chatbot and ClaimIt app.
[DOCX File , 42 KB - pediatrics_v4i4e30169_app2.docx]

Multimedia Appendix 3
Preprocessing of conversations to extract corpus for the latent Dirichlet allocation.
[DOCX File , 62 KB - pediatrics_v4i4e30169_app3.docx]

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Abbreviations

eQuestionnaire: electronic questionnaire
ICU: intensive care unit
LDA: latent Dirichlet allocation
LSA/LSI: latent semantic analysis/indexing

NMF: nonnegative matrix factorization
pLSA: probabilistic latent semantic analysis

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Original Paper

US Parents' Acceptance of Learning About Mindfulness Practices for Parents and Children: National Cross-sectional Survey

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Abstract

Background: Mindfulness practices are associated with improved health and well-being for children. Few studies have assessed parents' acceptance of learning about mindfulness practices.

Objective: This study aims to assess parents' beliefs and interest in learning about mindfulness, including from their health care provider, and differences across demographic backgrounds.

Methods: We conducted a national cross-sectional survey of parents with children aged 0-18 years in October 2018. Measures included beliefs and interest in learning about mindfulness. These measures were compared across demographic backgrounds using chi-square analysis. Multivariate linear and logistic regression analyses were used to perform adjusted comparisons between demographic backgrounds.

Results: Participants (N=3000) were 87% (n=2621) female and 82.5% (n=2466) Caucasian. Most (n=1913, 64.2%) reported beliefs that mindfulness can be beneficial when parenting, 56.4% (n=1595) showed interest in learning about mindfulness to help their child stay healthy, and 40.8% (n=1214) reported interest in learning about mindfulness from their health care provider. Parents with a college degree 49.6% (n=444) were more likely to report interest in learning about mindfulness from a health care provider compared to those without 37.1% (n=768; $P<.001$). Parents interested in learning about mindfulness were more likely to be male 62.6% (n=223; $P<.001$). There was no significant difference in interest in learning about mindfulness from a health care provider based on race.

Conclusions: This study indicates that many parents believe mindfulness can be beneficial while parenting and are interested in learning how mindfulness could help their child stay healthy. Findings suggest there is an opportunity to educate families about mindfulness practices.

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KEYWORDS

mindfulness; mental health; general pediatrics; pediatrics; children; parents; acceptability; well-being; parenting

Introduction

Anxiety and depression affect an estimated 1 in 20, or 2.6 million, children in the United States [1]. The high prevalence of these mental health conditions in our nation's youth adversely impacts overall physical health, school attendance and achievement, alcohol and drug use, family discord, violence, suicide, and health care costs [2,3]. It is imperative for health care systems to use a variety of approaches to the prevention and treatment for these and other mental health conditions [4].

Mindfulness techniques represent one approach showing promise in the prevention and treatment of mental illness. Mindfulness is generally defined as "paying attention in a particular way: on purpose, in the present moment and nonjudgmentally" [5]. Formal mindfulness approaches include a variety of activities including mindful breathing, mindful walking, meditation, and yoga. Informal mindfulness practices include bringing a mindful approach to activities of everyday living, including mindful eating or mindful washing of dishes [6]. Mindfulness therapies address emotional self-regulation and are a commonly used psychological approach to reduce stress and discomfort [7].

Mindfulness interventions may benefit children directly, through their own practice, and indirectly, when their parents use this technique [8,9]. Previous studies show that mindfulness interventions for children reduce anxiety and stress [10,11]. A growing body of literature suggests mindfulness techniques practiced by parents can reduce parenting stress [12,13] and have positive mental health impacts on children [8,14-16] and on parent-child interactions [17].

Although there is increasing evidence supporting mindfulness as an approach to improve mental health, this practice has been most used by women, particularly women who identify as White and are of higher socioeconomic status [18]. However, mindfulness may be especially beneficial for socially marginalized families (ie, based on race and ethnic background), families with lower socioeconomic status, and those with limited access to mental health resources who may be at higher risk of mental health conditions [19]. Understanding the views of diverse groups toward mindfulness is an important step toward teaching these practices to improve the mental health of all children.

However, the acceptance of parents from diverse backgrounds toward learning about mindfulness independently or from their health care provider remains unknown. This exploratory study aims to understand parental acceptance of mindfulness including the prevalence of parents who believe mindfulness could be beneficial in parenting and would be interested in learning about mindfulness. Further, the study aims to understand differences in beliefs and interest in learning about mindfulness among parents across parent gender, race, ethnicity, education, and income.

Methods

This national cross-sectional survey study was conducted in October 2018 as part of a larger study involving parents' perspectives of pediatric health care, which was estimated to take 10 to 20 minutes to complete. The University of Wisconsin Education and Social/Behavioral Sciences Institutional Review Board deemed this study as exempt from institutional review board approval (#2018-1051).

Participants

We recruited a national panel of parents representing all regions of the United States. Survey panels are an approach to research in which individuals sign up to be on lists to receive survey invitations. Previous studies have supported these survey panels as an effective approach with broader geographic reach than traditional survey approaches [20,21]. We selected the online survey platform Qualtrics to conduct this study. Qualtrics recruits from geographically diverse areas of the United States to generate panels of participants who are interested in receiving invitations to participate in future surveys. Upon joining Qualtrics, panelists complete demographic assessments so that survey invitations can be targeted to eligible survey populations. As participation incentive, participants receive "Qualtrics Points" for survey completion, which can be applied toward purchases such as gift cards and airline miles.

We requested that Qualtrics recruit 3000 parents. Survey invitations were sent by email to relevant panels of potentially eligible adult participants. Interested panelists then completed screening questions with eligibility criteria specific to this study: English-speaking, 18 years or older, and parent of a child younger than 18 years. Participants completed written informed consent through the online Qualtrics platform. The survey closed when the goal sample size of 3000 participants meeting eligibility criteria was reached.

Measures

We provided a series of statements assessing parent acceptance of mindfulness that participants rated using Likert scales. To assess parental beliefs about the benefits of mindfulness, the following statement was provided: I believe mindfulness techniques can be beneficial when parenting my child/children. Statements about interest in learning more about mindfulness included: I am interested in learning about how mindfulness could lead to benefits for my child as an individual, I am interested in learning about how mindfulness could help my child stay healthy, I am interested in learning about how mindfulness could lead to benefits for myself as an individual and in my abilities to parent my child, and I am interested in learning about mindfulness from my health care provider.

Statements for this survey were developed by the study team. After development, these were piloted among a group of general pediatricians and parents, and modified based on their feedback. All survey items were framed as statements with which participants indicated their agreement on a 5-point Likert scale from "strongly disagree" to "strongly agree." An option of "don't know" was also offered.

Demographic variables included parent gender, race, ethnicity, education, and income.

Analysis

Descriptive statistics were calculated for demographics and measures pertaining to mindfulness benefits and interest in learning about mindfulness practices. Analyses were focused on assessing proportions of participants with positive views about mindfulness practices. Thus, participants reporting mindfulness-related perceptions were categorized into three groups: (1) those indicating positive beliefs or interest in learning about mindfulness (answered “agree/strongly agree”), (2) those indicating neutral or negative beliefs or interest in learning about mindfulness, and (3) those indicating “don’t know.”

Beliefs and interest toward mindfulness were compared across demographic categories (parent gender, race, ethnicity, education, income) using chi-square analysis. Multivariate linear and logistic regression analyses were used to perform adjusted comparisons between demographic categories. Demographic characteristics (age, gender, education, income, race, ethnicity), excluding the demographic characteristic of the primary comparison, were included as covariates in the multivariate linear and logistic regression models. For example, when comparing response patterns of beliefs and interest toward mindfulness between males versus females, age, education, income, race, and ethnicity were included as covariates. All reported *P* values were 2-sided, and *P*<.05 was used to define statistical significance. Statistical analyses were conducted using SAS software (SAS Institute), version 9.4.

Results

Our sample included 3000 participants. Among them, 87.9% (n=2621) were female, 82.5% (n=2466) were White, 88.7% (n=2645) were non-Hispanic, 69.9% (n=2093) had no college degree, and 47.2% (n=1410) had a family income less than US $50,000. All 50 US states and all four regions were represented (Table 1).

Table 1. Demographic characteristics of parent participants (N=3000).

	Participant, n (%)
Gender	
Female	2621 (87.9)
Male	360 (12.1)
Other/missing	19 (0.006)
Race	
White	2466 (82.5)
Black	266 (8.9)
Other	167 (5.6)
Asian	90 (3.0)
Other/missing	11 (0.003)
Ethnicity	
Non-Hispanic	2645 (88.7)
Hispanic	338 (11.3)
Missing	17 (0.005)
Education	
No college degree	2093 (69.9)
College degree	900 (30.0)
Missing	7 (0.002)
Income (US $)	
<20,000	400 (13.4)
20,000-34,999	533 (17.8)
35,000-49,999	477 (16.0)
50,000-74,999	494 (16.5)
75,000-99,999	362 (12.1)
100,000-149,999	320 (10.7)
150,000-199,999	168 (5.6)
≥200,000	122 (4.1)
Prefer not to say	114 (3.8)

Belief That Mindfulness Can Be Beneficial in Parenting

In total, 64.2% (n=1913) of the 3000 participants agreed that mindfulness can be beneficial when parenting, 30.2% (n=906) of participants reported they disagreed or were neutral, and 5.3% (n=159) of parents stated they “don’t know.” Multivariate analysis showed that those with a college degree were more likely to believe that mindfulness can be beneficial when parenting compared to those without a college degree (*P*<.001) when adjusting for age, gender, and ethnicity. There was no significant difference in the belief that mindfulness can be beneficial while parenting based on parent gender. Parents who reported an income of less than US $20,000 were less likely to report a belief that mindfulness can be beneficial compared to those who reported earning US $50,000-$75,000 (*P*=.004); US $100,000-$149,999 (*P*=.01); US $150,000-$199,999 (*P*=.02); and over US $200,000 (*P*=.004; see Multimedia Appendix 1 for all findings on parent beliefs about mindfulness).

Interest in Learning About Mindfulness

Among all 3000 participants, 53.1% (n=1581) reported they agreed that they were interested in learning how mindfulness can lead to benefits for their child, while 42.2% (n=1259) reported they disagreed or were neutral and 4.5% (n=135) answered “don’t know.” Over half of participants (n=1595, 53.7%) reported they agreed they were interested in learning about how mindfulness could help their child stay healthy, while 41.5% (n=1232) disagreed or were neutral and 4.9% (n=145) answered “don’t know.” About half of participants (n=1499, 50.4%) responded that they were interested in learning about how mindfulness could lead to benefits for themselves and their abilities to parent their child, while 44.8% (n=1330) disagreed or reported they were neutral to this statement and 5.3% (n=159) answered “don’t know.” Overall, 40.8% (n=1214) of participants reported interest in receiving information about mindfulness from their health care provider, while 54.5% (n=1621) reported they disagreed or were neutral and 4.7% (n=139) answered “don’t know.”

Parents with a college degree (n=444, 49.6%) were more likely to report interest in learning about mindfulness from their health care provider than those without a college degree (n=768, 37.1%; *P*<.001). Parents interested in learning about mindfulness from their health care provider were also more likely to identify as male (n=223, 62.6%) than female (n=987, 38.0%; *P*<.001). A total of 51.1% (n=46) of Asian, 41.0% (n=1003) of White, and 39.3% (n=104) of Black parents reported interest in receiving information about mindfulness from their health care provider; these differences were not significant. Parents who earned less than US $20,000 were less likely to report interest in learning about mindfulness from a health care provider than those reporting US $35,000-$49,999 (*P*=.03); US $100,000-$149,999 (*P*=.045); and those who earned over US $200,000 (*P*=.005; see Multimedia Appendices 1 and 2).

Discussion

This exploratory study provides insight into parents’ beliefs and interest toward learning about mindfulness. Over half of parents reported believing that mindfulness can be beneficial while parenting and indicated interest in learning more about how mindfulness could keep their child healthy. Males and college-educated parents were more likely to report that they were interested in learning about mindfulness from their health care provider. Our study did not find differences in interest in receiving information about mindfulness from parents’ health care provider based on race but did find that some higher income groups were more likely to show interest in learning about mindfulness than those making less than US $20,000 a year.

Our findings suggest that most parents (n=1913, 64.2%) believe mindfulness can be beneficial while parenting and are interested in learning about mindfulness to benefit their child, but some parents (n=1259, 42.3%) may not be interested in learning about how mindfulness could benefit their child. A possible reason these parents did not show interest in learning about mindfulness is that some may believe mindfulness includes only formal practices, which take time, without realizing that informal mindfulness practices can be incorporated easily into their day. Some may also have had previous experience with practicing mindfulness and may not desire any further education. Similar to previous research, these findings highlight that adults may have different levels of readiness to learn about and engage with mindfulness practices [18]. For some parents, more education may be needed to inform parents of the benefits. For parents who may have tried formal mindfulness techniques and not continued the practice, an understanding of their experiences is needed. Additional research is needed to develop strategies to educate and engage families about mindfulness practices both formal and informal.

Although many parents reported interest in learning about mindfulness, less than half were interested in learning about mindfulness from their health care provider. There may be several possible reasons for this finding. It is possible many parents think of health care providers as focused mainly on physical health and do not perceive their health care provider as a knowledgeable source of information about mindfulness. Furthermore, parents may not perceive the busy health care provider’s office as a desired setting to learn about mindfulness and may prefer to learn about it through another venue. There are increasing numbers of online resources that offer mindfulness and meditation practices, which could potentially benefit children and families. Sharing these digital resources (web sites and apps for smartphones) with families may increase accessibility by reducing the barriers of cost and transportation. Although digital resources offer one option, more consideration needs to be given to how parents can access information about mindfulness training. For those parents who are interested in receiving information from their health care provider, future studies should explore preferences in how they prefer to learn about mindfulness in a health care setting.

This study indicated that males were more likely to be interested in receiving information about mindfulness from their health care provider compared to females. This contrasts with a recent (2017) national survey in which more women reported using yoga and meditation in the past 12 months compared to men [22]. The findings from this study that men reported more interest in learning about mindfulness is especially important given the positive impact that fathers’ mental health can have on child health outcomes from infancy to adolescence and the increasing contribution that fathers play in caring for their children [23]. A recent meta-analysis of fathers’ mental health showed that paternal depression was correlated with child and adolescent internalizing symptoms [24], which suggests the importance of supporting paternal mental health to positively impact children’s mental health. Given the impact of the paternal mental health on children, and fathers’ interest to learn about mindfulness, mindfulness education may be an important tool for supporting fathers in caring for their children.

This study did not find evidence that parents’ interest in learning about mindfulness from their health care provider differed across racial background. In contrast, previous work has suggested that Black populations engage less frequently with mindfulness than White populations [18]. It is possible this difference is due to racial bias resulting from health care providers assuming that non-White parents lack interest in mindfulness practice. Examined critically, it may be that historically less frequent engagement in mindfulness may reflect a lack of referral from health care providers (unconscious bias). More research is needed to understand the reasons why non-White families may engage less in mindfulness practices when their interest in learning about the practice may not differ.

The study also found differences in participants’ beliefs and interest in learning about mindfulness from their health care provider based on income. Those families who earned less than US $20,000 per year (approximately equivalent to the US poverty level for a family of 3 people) [25] were less likely to believe mindfulness could be beneficial and less likely than other income groups to be interested in learning about mindfulness from their health care provider. It is possible that parents living below the poverty line may not have access to health care, and this may affect their interest in learning about mindfulness from a health care provider. This finding is important since studies suggest that people with low incomes have risks that correlate with higher diagnoses of mental illness [26] and might benefit from mindfulness practices more than in other income groups. Addressing mental health issues with mindfulness practices, both formal and informal, may offer an additional resource to support the mental health of parents living in poverty. However, additional work is needed to explore approaches of providing access to mindfulness resources for these families.

Our study has limitations to consider. First, there were demographic differences between our sample and representation in the United States. For example, over 87% of participants identified as female. Further, about 8% of participants identified as Black, while in the United States, those identifying as Black make up 13% of the population [27]. Similarly, in our study, individuals identifying as Hispanic represented about one-tenth of the sample compared to over 18% of the US population [27]. Second, this study did not include parents who were non–English-speaking, while those who speak a language other than English at home comprise more than one-fifth of the US population [27]. Future studies investigating the perspectives of these populations would be of the utmost importance to capture a more representative sample of families in the United States. Finally, parents who chose to participate in this survey through the Qualtrics platform all had access to the internet, and perspectives of those without internet access may not be represented.

This study indicates that a majority of parents believe mindfulness can be beneficial while parenting, and many parents are interested in learning how mindfulness could help their child stay heathy. With the growing body of literature showing associations between mindfulness practice and mental wellness, further research should examine the perceptions and experiences of those who do not consider mindfulness beneficial. For the parents who are interested in learning more, particularly fathers, additional research is needed about how parents would like to learn about these resources. Future studies should also examine effective methods for delivering mindfulness information and resources to parents of lower household incomes including how to develop accessible mindfulness training programs.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Parents who believe mindfulness is beneficial when parenting.

[PNG File , 92 KB - pediatrics_v4i4e30242_app1.png]

Multimedia Appendix 2

Parents reporting interest in learning about mindfulness from their health care provider.

[PNG File , 94 KB - pediatrics_v4i4e30242_app2.png]

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Original Paper

Consumption of Ultraprocessed Foods in a Sample of Adolescents With Obesity and Its Association With the Food Educational Style of Their Parent: Observational Study

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Abstract

Background: Both parental education and the food environment influence dietary intake and may therefore contribute to childhood obesity.

Objective: We aimed to assess the consumption of ultraprocessed foods (UPFs) in a convenience sample of adolescents with obesity and to determine its association with the food educational style of their parent.

Methods: This observational study included 24 participants, 12 adolescents (8 boys and 4 girls) aged from 12 to 14 years and their 12 parents, who were followed in a specialized pediatric obesity clinic in the French-speaking part of Switzerland. The adolescents were asked to take a photograph with a smartphone application of all meals and beverages consumed in their daily routine over 14 consecutive days. They evaluated their parent's food educational style using the Kids' Child Feeding Questionnaire. The parent who was present at the study visits also completed the Feeding Style Questionnaire. A dietitian analyzed the pictures to extract food group portions and to identify UPFs using the NOVA classification. A nonparametric statistical test was used to investigate associations between UPF intake and food educational style.

Results: Overall, the adolescents had unbalanced dietary habits compared to national recommendations. They consumed an insufficient quantity of vegetables, fruits, dairy products, and starchy foods and an excessive amount of meat portions and sugary and fatty products compared to the current Swiss recommendations. Their consumption of UPFs accounted for 20% of their food intake. All adolescents defined their parent as being restrictive in terms of diet, with a mean parental restriction score of 3.3±SD 0.4 (norm median=2.1). No parent reported a permissive food educational style. A higher intake of UPFs was associated with a lower parental restriction score (*P*=.04).

Conclusions: Despite being followed in a specialized pediatric obesity clinic, this small group of adolescents had an unbalanced diet, which included 20% UPFs. The intake of UPFs was lower in participants whose parent was more restrictive, suggesting the importance of parents as role models and to provide adequate food at home.

Trial Registration: ClinicalTrials.gov NCT03241121; https://clinicaltrials.gov/ct2/show/NCT03241121

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KEYWORDS

adolescent; obesity; ultraprocessed foods; qualitative food intake; food educational style; smartphone application

Introduction

Childhood obesity is a significant public health challenge, with an increasing prevalence worldwide and multiple long-lasting consequences [1]. Its causes are multiple, with the environment and behaviors interacting with the individual genetic background [2]. Excessive consumption of calorie-dense foods containing high levels of saturated fats, trans-fatty acids, free sugars, or salt contribute to obesity and diabetes, as well as other noncommunicable diseases [3-5].

In the past decades, the level of food processing has significantly increased [6]. Recent studies in adults and children have suggested an association between the consumption of ultraprocessed foods (UPFs) and an increased risk of being overweight or obese and having metabolic disorders [6-9]. A systematic review found that UPF consumption was positively associated with body fat during childhood and adolescence in 14 of the 26 included studies [7]. The authors concluded that there is a need to use a standardized classification that considers the level of food processing to promote comparability between studies, such as the recent food NOVA classification. The NOVA classification divides food items into four groups according to their degree of processing: (1) low or unprocessed foods, (2) culinary ingredients, (3) processed foods, and (4) UPFs [9]. UPFs are industrial products that not only contain fat, sugar, and salt but also include additives or ingredients not normally used in home food preparation, such as hydrogenated or unesterified oils, protein isolate, maltodextrin, casein, and gluten [10,11]. One study showed that Swedish children increased their UPF consumption by 142% from 1960 to 2010 [9]. UPF consumption accounted for 25%-60% of the total daily energy intake in adults of 19 European countries [12]. Currently, experts recommend limiting UPF consumption, even though no recommendation has yet been determined for the maximal amount or frequency [6].

Both the education and the environment influence dietary intake in general, and in addition, in children, parental education and the food environment provided are crucial. Ellyn Satter [13] described a model of the division of responsibilities between children and parents. Fundamental to the parental tasks is trusting children to determine *how much* and whether to eat from *what* parents provide. This model is complementary to the concept of the food educational style, developed by Johnson and Birch in 1994 [14], demonstrating that a high degree of parental control over a child's intake is associated with decreased dietary regulation and a higher weight of the child. The so-called authoritative parenting style is associated with a favorable food environment, as opposed to the permissive or authoritarian style [15]. Based on a model published in 2017, a child's eating behavior and the parents' food educational style could explain the onset of obesity in 19% of the cases [16]. A study published in 2019 showed a positive effect of healthy parental eating practices and the authoritative food educational style on the food habits of 13-year-old adolescents who were overweight or obese [17].

In this observational study, we aimed to assess the consumption of UPFs in a group of Swiss adolescents with obesity and to determine its association with the food educational style of their parent.

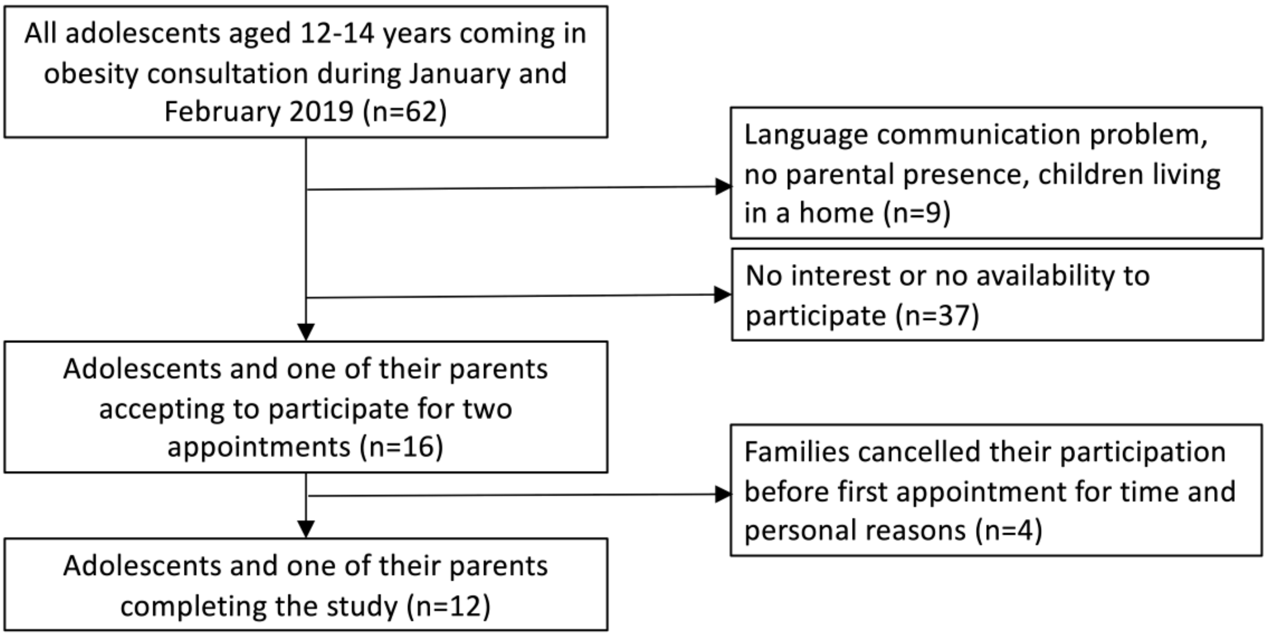
Methods

Setting and Participants

This observational study included adolescents aged 12-14 years who were followed in a specialized pediatric obesity clinic at the Lausanne University Hospital, Lausanne, Switzerland, and one of their parents. The study was an observational nested study of the SwissChronoFood trial [18] (Clinicaltrials.gov registration no NCT03241121). The protocol was approved by the ethics committee of the Canton of Vaud, Lausanne, Switzerland. Each adolescent participant and their parent were informed of the study details and signed written consent.

The families were sent to the pediatric obesity clinic by their pediatrician. At the time of inclusion, the senior dietician (author SB) had followed the adolescents for several months. She invited all adolescents aged 12-14 years who had an appointment at the clinic from January to February 2019 to participate in the study. Of the 62 adolescents aged 12-14 years informed about the study, 37 declined because of a lack of interest or time to attend the study visits and 9 because of a language barrier or the lack of a parent available to attend the study visits (Figure 1). Of the 16 adolescents and their respective parent who agreed to take part in the study, 4 families had to cancel their participation before inclusion, thus leading to a final sample size of 12 adolescents and 12 parents. The nutritional intake of the adolescents was assessed over a 2-week period, including 2 face-to-face visits with a senior dietician (SB) and a phone meeting in the interval, between January and March 2019.

Figure 1. Recruitment process of adolescents and one of their parents.



Demographic and anthropometric data were collected in the first visit. After 1 week, the dietician had a phone meeting with the adolescents to question them about the use of the smartphone application (explained later) and to encourage them to continue taking pictures conscientiously. At the last visit, the dietitian checked the pictures collected by the smartphone application and performed a 24-hour food recall.

The z score of the body mass index (BMI) according to age was used to define overweight and obesity. According to the World Health Organization [19], overweight is defined as a BMI z score of >1, obesity as a BMI z score of >2, and extreme obesity as a BMI z score of >3. For parents, the adult categories of overweight (BMI=25-30 kg/m^2) and obesity (BMI>30 kg/m^2) were used [1].

Assessment of Food Intake

All adolescents used a smartphone application to take pictures of all consumed food and beverages, except water, over 14 consecutive days. They could annotate each picture with a text description. We compared the food pictures collected by the food application and the 24-hour food recall performed at the second visit. The senior dietician (SB) manually counted the number of food portions consumed each day by each adolescent and estimated the number of servings from each picture. Food items were grouped according to the Swiss food pyramid [19] as follows: fruit, vegetables, starchy food, meat/fish/egg/tofu, dairy products, sugary products, fatty food, and sugar-sweetened beverages. The intake of cooking fats, sauces, and salad dressings was not analyzed, as these could not be accurately assessed from the pictures collected and the text annotations. The frequency of consumption of each food group was then compared to the Swiss Nutrition Society (SNS) recommendations [20]. Finally, UPFs were identified from food pictures and the 24-hour food recall, according to the NOVA classification [10].

Assessment of the Parental Food Education Style

The parental food education style was assessed from the perspectives of both the adolescents and their parent. At the first visit, the adolescents completed the Kids' Child Feeding Questionnaire in a separate room from the accompanying parent [14]. This questionnaire explores an adolescent's perspective of two dimensions, parental pressure and parental restriction on their feeding, and has been validated in French [21]. The scale ranges from 0 to 4: 0 meaning no pressure and no restriction and 4 meaning maximal pressure and maximal restriction. Our results with the Kids' Child Feeding Questionnaire were compared with the median scores of 2.1 for restriction and 1.99 for pressure, which were obtained in a French pediatric population that we considered as a norm [21].

Although the adolescents were completing the questionnaire in a separate room, the parents answered the Feeding Style Questionnaire, which explores a parent’s perspective in eight problematic situations (eg, your child wants to eat pasta, when you intended to cook vegetables) and is also validated in French [22]. This questionnaire assesses three dimensions, described as authoritarian, authoritative, and permissive [16]. In short, the *authoritarian style* includes strict rules given by parents without discussion, the *authoritative style* is a more democratic style with rules and a discussion of these rules, and the *permissive style* has few or no rules, thus following the wishes of the adolescent more. Each dimension received a score on a 4-point scale from very unlikely to very likely. The dimension with the highest score determined the dominant feeding style of each parent.

Statistical Analysis

Data are reported as the mean±SD, unless stated otherwise. Nonparametric tests were used due to the small sample size. We compared the rank-sum test between UPF intake and food educational style (restriction, pressure to eat, and authoritarian, authoritative, and permissive dimensions) with the

Wilcoxon-Mann-Whitney test. For analysis of the perceived parental dietary restriction, we defined groups of low restriction and high restriction using the median value of 3.25. *P*<.05 was considered statistically significant. The Stata 15 software package (College Station, TX, USA) was used. No missing data were found for the variables of interest.

Results

Characteristics of the Participants

We included 12 adolescents, 8 boys and 4 girls, aged 12-14 years and 12 parents, 8 mothers and 4 fathers, aged 37-55 years. At the time of the study, the adolescents had been followed in the specialized pediatric obesity clinic for several months. Of the 12 adolescents, 11 (91.6%) were obese and 1 (8.4%) had lost weight, thus changing from the obese category to the overweight category. Most parents were overweight or obese (n=11), and 10 (83.3%) worked at an activity level of ≥70%, except for 2 (16.7%) parents on disability insurance. Five of the included parents (42%) were separated, but the adolescents spent almost all of their time with the parent who was present at the study visits. Table 1 shows the characteristics of adolescents and parents.

Table 1. Characteristics of adolescents and parents.

Characteristics	Value
Adolescents' characteristics	
Number	12 (4 girls/8 boys)
Age (years)	13.3±0.6 (12.0-14.3)[b]
BMI[a] (kg/m^2)	30.0±2.6 (24.9-33.7)[b]
BMI (z score)[c]	2.7±0.4 (1.9-3.4)[b]
Parents' characteristics	
Number	12 (8 mothers/4 fathers)
Age (years)	45.3±4.6 (37.0-55.0)[b]
BMI (kg/m^2)	29.1±3.2 (23.2-35.8)[b]
Married or in a relationship with the other parent (%)	58.3
Time spent with child (%)	97.9±7.0 (75-100)[b]
Training after compulsory school (years)	3.2±2.9 (0-7)[b]
Professional activity rate (%)	70.0±30.0 (0-100)[b]

[a] BMI: body mass index.

[b] Data are presented as the mean±SD (minimum-maximum range), unless stated otherwise.

[c] Obesity in adolescents was defined as a z score of BMI>2.

Food Intake

Overall, the adolescents had unbalanced dietary habits compared to national recommendations (Table 2). Their consumption of fruit, vegetables, dairy products, and starchy foods was below the recommended frequencies for adolescents [20], while the consumption of the meat/fish/egg/tofu group, fatty products, and sugary products was above the recommendations [20]. The number of meals was close to 3 meals per day (2.8±0.5), although 5 adolescents skipped breakfast. A mean 1.6±0.6 portions of UPFs were consumed each day, representing 20% of the food portions consumed.

Table 2. Comparison of food consumption with the Swiss recommended daily portions [20].

Food groups	Number of portions per day (mean±SD)	Swiss national recommendations for 13-14-year-old adolescents (n)
Fruit[a]	0.4±0.3	2
Vegetables	1.2±0.6	3
Starchy foods	2.5±0.8	4.5
Meat, fish, egg, tofu	1.4±0.4	1
Dairy products[b]	1.1±0.3	3
Sugary products[c]	1.2±0.7	1
Fatty products[d]	1.3±0.7	1
Sweet beverages	0.2±0.3	0
UPF[e] intake	1.6±0.6	—[f]
UPF portions/total number of food portions (%)	20.9±3.6	—

[a] Including a maximum of 1 glass of fruit juice per day and a maximum of 1 fruit compote per day.

[b] Including milk, yogurt, cheese, and milk drinks.

[c] Including jam, honey, chocolate, cookies, cakes, fruit yogurt, candies, sodas, ketchup, sweet sauce for nems.

[d] Including sausages, crisps, breaded meat, chocolate, cookies, raclette, fondue, fat-containing sauces (carbonara, mayonnaise), lasagna, and pizza.

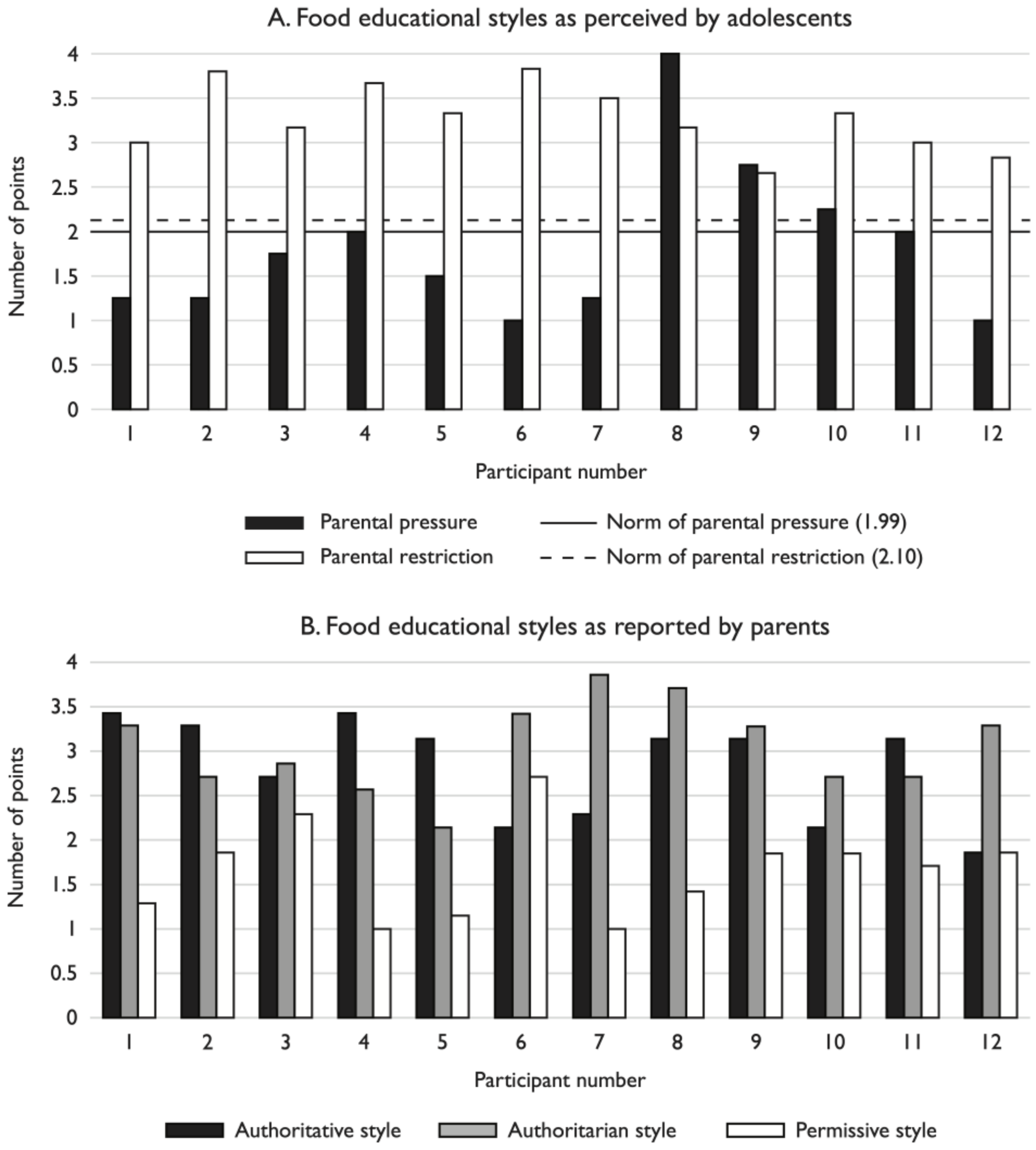
[e] UPF: ultraprocessed food (includes industrial prepackaged snacks, sweets, commercial biscuits, chips, sausages, ham, sodas, filled croissants, ravioli, tortellinis, spätzlis, fajitas, ketchup, mayonnaise, sweet and sour sauce, nems, milk drinks [eg, Danao®, Actimel®], toasted bread, pizza, dessert cream, and chocolate spread).

[f] No Swiss recommendations for UPF food group

Food Educational Styles

According to the Kids' Child Feeding Questionnaire [21] completed by the 12 adolescents, the mean parental restriction score was 3.27±0.37 (Figure 2A) and the mean parental pressure score was 1.83±0.87 (norm=1.99). For seven adolescents, the perceived parental pressure to eat was below the norm.

Figure 2. (A) Food educational styles perceived by the adolescents. Results of the Kids' Child Feeding Questionnaire [20] completed by the adolescents. (B) Food educational styles reported by the parents, measured by the Feeding Style Questionnaire [21] completed by the parents.

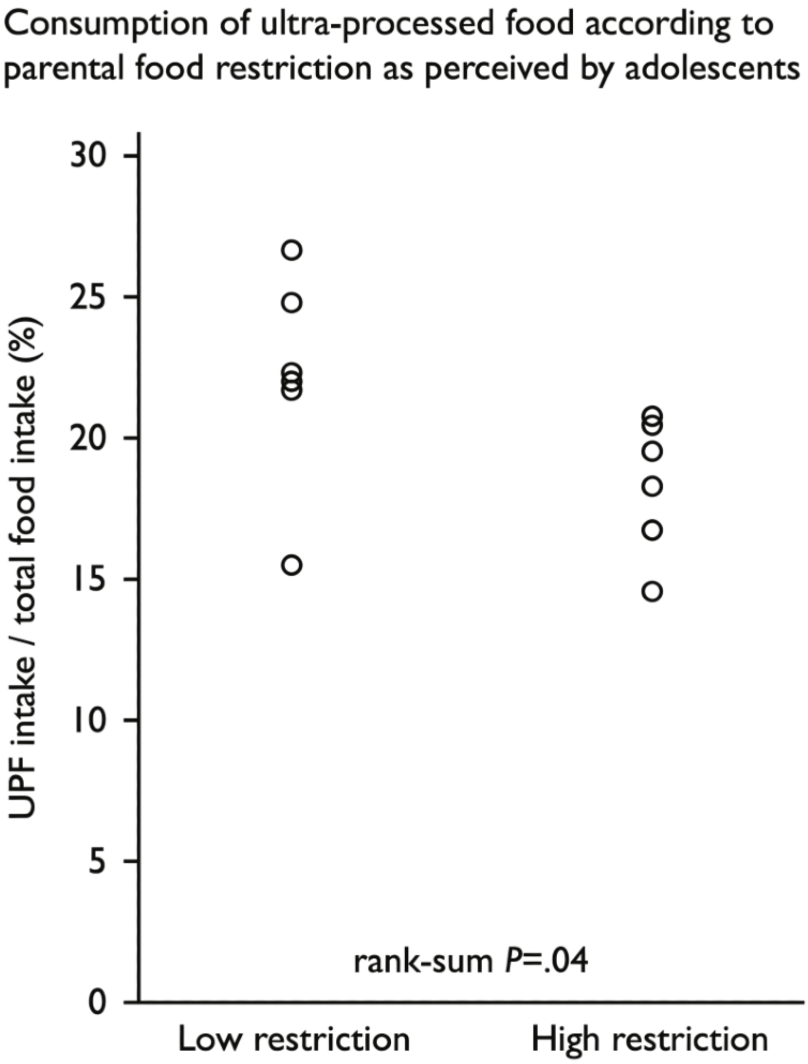


The Feeding Style Questionnaire completed by the 12 parents showed that the most common dietary educational style was the authoritative style, with a mean score of 3.05±0.51, followed by the authoritarian style (2.82±0.57). The permissive style had the lowest score (1.67±0.52). The authoritative style was predominant in seven parents, and the authoritarian style was predominant in five parents (Figure 2B). The permissive style was not dominant in any parent.

Association Between UPF Consumption and Parents' Food Educational Styles

When analyzing the adolescents' dietary intake and the respective parent's food educational styles, we found a significant association between the proportion of UPF intake compared to the total food intake and the level of parental dietary restriction (Figure 3).

Figure 3. Consumption of UPFs according to the parental dietary restriction perceived by the adolescents. Association between the proportion of UPF intake out of the total food intake and the level of parental dietary restriction (rank-sum *P*=.04). UPF: ultraprocessed food.



Discussion

Principal Results

In this observational study conducted in the French-speaking part of Switzerland, the small group of adolescents with long-standing obesity had unbalanced eating habits, including excessive UPF consumption, despite being followed in a specialized pediatric obesity clinic. The adolescents perceived their parent as more restrictive than the norm, and none of the parents had a permissive food educational style. Lower UPF consumption was associated with a higher parental dietary restriction.

The reported diet was unbalanced, including 0.4 portions of fruit per day instead of the 2 portions recommended by the Swiss national recommendations [19], 1.2 portions of vegetables per day instead of 3, and 1.1 portions of dairy products instead of 3. To put this in perspective, these results are similar to those found in the Swiss adult general population, who also have self-reported intakes below the national recommendations [23]. In this study, UPF consumption was high, with 1.6 portions consumed per day, representing 20% of the foods consumed.

Comparison With Prior Work

The comparison of these findings with other studies is limited, as UPF consumption is often reported as a percentage of daily energy intake and not in terms of portions per day. A study in adults found that UPFs reached an average 26% of daily energy intake, ranging from 10% to 50%, depending on the 19 European countries assessed [12]. A Brazilian study in school-age children observed that 48% of daily energy intake was provided by UPF consumption [7]. UPF consumption shows an upward trend across multiple countries and cultures, as seen in Swedish children who increased their UPF consumption by 142% between 1960 and 2010 [9]. In a large prospective cohort of French adults, UPF consumption was associated with increased weight gain [24].

UPFs contribute to an unbalanced diet due to their low nutritional quality, including a high content of added sugars, fats, or additives and a low content of fiber. The lack of prospective studies precludes a definitive conclusion on the causal relationship between UPF consumption and obesity [25]. However, observational studies have shown an association between UPF consumption and overweight, obesity, or metabolic disorders [6,24,25]. Therefore, many experts, such as the Canadian government [26], have called for a limit of their intake, without providing precise quantified recommendations [26]. One suggestion to reduce UPF consumption in children and adolescents is to develop parents' skills in identifying UPFs and provide them with practical tips on how to limit the UPFs' frequency, reduce their portions, or replace them with raw foods. Moreover, parental food practices influence child practices [27,28]. A European survey in eight countries observed that the poor example of parents was a predictor of children's eating habits [28]. Similarly, a recent systematic review showed that parents' own food consumption behavior and food availability at home are factors with the strongest association with food consumption of adolescents in the same household [28]. Another systematic review concluded that the availability of unhealthy foods at home is positively associated with snack intake [29]. Thus, a global family approach is necessary.

A permissive food educational style is recognized as promoting obesity [30]. In our study, all adolescents perceived their parent as highly restrictive in terms of diet, and the Feeding Style Questionnaire completed by the parents showed that the permissive educational style was the least common. The restrictive food educational style experienced by adolescents may be explained by the fact that parents wish to control their children's excess weight by using dietary restriction. Several studies have shown that parental restriction is more frustrating than parental pressure and is associated with increased weight in children and adolescents with normal weight or who are overweight [21,30,31]. However, some degree of restriction may be beneficial to limit UPF intake. Interestingly, in this study, we found that adolescents who perceived a higher dietary restriction from their parent consumed significantly less UPFs. In addition, the consumption of sweet beverages was low (0.2 portions per day instead of the 2.4 portions in the Swiss adult population [23]) and could be explained by the fact that parents limited their access, as this is part of the advice given in the follow-up at the obesity clinic.

Limitations

The main limitation of this study was the limited sample size, which included 12 adolescents and 12 parents. We contacted 62 adolescents followed in our pediatric obesity clinic and their parent to participate in the study. A total of 50 refused to participate, 37 due to a lack of interest or time and 9 due to a language barrier or the lack of a parent available to attend study visits; in addition, 4 families had to cancel their participation before the first visit. This shows the difficulty of recruiting this population in dietary studies involving longitudinal data collection. This could have led to a type I error, but our results are mostly exploratory and will help future studies in the form of preliminary results for sample size calculation and new hypotheses generation. Other limitations were the low response rate and the potential social desirability of participants who would only take pictures of the food they wished to show. Although the long duration of the data collection period provided detailed information about dietary habits and was a strength of this study, it might also be a limitation. Indeed, 2 weeks might have been too long for adolescents, leading to potential missing data, as shown by the comparison with the 24-hour food recall. The 24-hour food recall showed the consumption of more foods, such as highly processed foods, which accounted for 26% of the foods in the recall instead of 20% with the smartphone application. The data were collected between January and March, which might have affected the availability of fresh products. However, the availability and price of fresh products in Switzerland do not differ widely between seasons. Finally, the studied adolescents were followed in a specialized pediatric obesity clinic in the French-speaking part of Switzerland; thus, our findings may not be applicable to adolescent populations in other parts of the world or followed in other clinical settings. The main strengths of the study were the review of UPF consumption by a senior dietitian, which allowed an estimation of the number of UPFs compared to other foods; the use of a smartphone application to take food pictures; and the assessment of parental feeding practices, perceived by both the adolescents themselves and one of their parents. Our study relied on a smartphone application to collect data on eating behavior and food content. This is consistent with the current trend in remote data collection from patients, as recently demonstrated during the COVID-19 pandemic [32]. This small study opens future avenues for clinical research about UPF consumption in children with obesity and the use of applications with pictures to collect nutritional intakes. Of note, our study was conducted prior to the COVID-19 pandemic and cannot thus address the psychosocial challenges of youth during the pandemic [33].

Conclusions

In our study, the small group of adolescents had unbalanced eating habits despite being in a treatment program. They all defined their parent as being restrictive in terms of diet, and no parent reported a permissive food educational style. The consumption of UPFs was lower among adolescents whose parent was more restrictive, suggesting that adolescents have fewer opportunities to eat when some degree of restriction is applied by their parent. The parent's food educational style and food choices available at home, including UPFs, may be a key target for personalized nutritional interventions in adolescents with obesity.

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Authors' Contributions

SB, SBDT, CJC, and THC contributed to the design of the study; SB and THC collected the data; SB, THC, SBDT, and CJC performed data analysis and interpretation; SB drafted the manuscript; SB, SBDT, CJC, and THC contributed substantially to the revision of the final manuscript; and SB and THC had full access to the dataset and are guarantors of the data integrity. The datasets used during this study are available from the corresponding author upon reasonable request.

Conflicts of Interest

The authors declare that they have no potential competing interest.

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Abbreviations

BMI: body mass index
PI: principal investigator
SNS: Swiss Nutrition Society
UPF: ultraprocessed food

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Review

Digital Interventions to Promote Healthy Eating in Children: Umbrella Review

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Abstract

Background: eHealth and web-based service delivery have become increasingly common during the COVID-19 pandemic. Digital interventions may be highly appealing to young people; however, their effectiveness compared with that of the usual face-to-face interventions is unknown. As nutrition interventions merge with the digital world, there is a need to determine the best practices for digital interventions for children.

Objective: The aim of this study is to examine the effectiveness of digital nutrition interventions for children on dietary outcomes compared with status quo interventions (eg, conventional face-to-face programming or nondigital support).

Methods: We conducted an umbrella review of systematic reviews of studies assessing primary research on digital interventions aimed at improving food and nutrition outcomes for children aged <18 years compared with conventional nutrition education were eligible for inclusion.

Results: In total, 11 systematic reviews published since 2015 were included (7/11, 64%, were of moderate quality). Digital interventions ranged from internet, computer, or mobile interventions to websites, programs, apps, email, videos, CD-ROMs, games, telehealth, SMS text messages, and social media, or a combination thereof. The dose and duration of the interventions varied widely (single to multiple exposures; 1-60 minutes). Many studies have been informed by theory or used behavior change techniques (eg, feedback, goal-setting, and tailoring). The effect of digital nutrition interventions for children on dietary outcomes is small and inconsistent. Digital interventions seemed to be the most promising for improving fruit and vegetable intake compared with other nutrition outcomes; however, reviews have found mixed results.

Conclusions: Owing to the heterogeneity and duration of digital interventions, follow-up evaluations, comparison groups, and outcomes measured, the effectiveness of these interventions remains unclear. High-quality evidence with common definitions for digital intervention types evaluated with validated measures is needed to improve the state of evidence, to inform policy and program decisions for health promotion in children. Now is the time for critical, robust evaluation of the adopted digital interventions during and after the COVID-19 pandemic to establish best practices for nutrition interventions for children.

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KEYWORDS

children; healthy eating; eHealth; nutrition intervention; nutrition education; food literacy; digital health; virtual delivery; digital interventions; nutrition interventions; best practices; education; mobile phone

Introduction

Background

Poor nutrition is a leading risk factor for noncommunicable diseases, such as cardiovascular disease, cancer, stroke, and diabetes [1]. Dietary risks (eg, diets low in fruits, vegetables, whole grains and high in red and processed meat, and sugar-sweetened beverages [SSBs]) are among the top 3 risk factors for global attributable deaths [2]. Proper child nutrition is foundational in preventing chronic disease later in life [3]. However, child wasting, underweight, and stunting remain among the top 10 leading contributors to disability-adjusted life years for children aged 0-9 years globally [2]; iron deficiency was the top risk factor of attributable disability-adjusted life years for individuals aged 10-24 years in 2019 [2].

Dietary intake is determined by a plethora of factors ranging from individual characteristics such as nutrition knowledge, self-efficacy, and income to societal factors such as food marketing and media, and supportive environments to access affordable healthy food [4-6]. Food literacy is an umbrella concept related to food skills and knowledge necessary to perform healthy eating behaviors and links individual-level attributes to the food environment in which eating behaviors take place [7]. As a determinant of diet, food literacy is a focus of nutrition interventions to improve individual and population diets.

Although face-to-face interventions are accepted, evidence-based approaches to deliver nutrition interventions [8] and the adoption of digital technologies, particularly during the COVID-19 pandemic, have required practitioners and policy makers to explore novel approaches to support healthy practices. The use of mobile apps by dietitians and their clients is emerging—57% of 117 dietitians surveyed in Canada used apps in their practice and 84% of those who did not use apps were interested in adopting them in the future [9]. A growing number of nutrition and diet apps are available on app stores (eg, Google Play), which provide unique features to users, such as self-monitoring, goal-setting, education, push notifications, message forums, personalized messages, and rewards, to promote healthy behavior change [10-13]. Credible on-demand nutrition information has previously been available for consumers and health professionals in Canada through websites, social media, apps, and telephone platforms. One web-based and telephone nutrition service in Canada yielded 1000 telephone calls, 1000-1500 email inquiries, and >240,000 website page views each month [14]. However, the effectiveness of digital interventions to improve diet and lifestyle, compared with conventional educational approaches, has not been well established [8,15,16].

As *digital natives*, today's youth may find digital approaches to nutrition education more meaningful and impactful than the conventional approaches [17]. The internet, telehealth, gaming, social media, mobile apps, and wearable devices are few digital platforms that have been used to promote health among the youth, with varied impacts [18]. Before the COVID-19 pandemic, digital interventions were already rapidly developing as anonymous, accessible, and cost-effective interventions appealing to the youth [16]. During the pandemic, most health care, public health, and community services rapidly transitioned to the web, attempting to mimic traditional services through digital means. Digital technologies can improve equitable health service delivery; however, several knowledge gaps hinder the practitioners' ability to optimize their use [19]. The opportunity for service providers to develop and implement evidence-based digital health care or health promotion interventions, including those who serve children and youth [20], must be met with evaluating the existing evidence to guide real-world decisions in real time.

Objective

The primary aim of this review is to examine the effectiveness of digital nutrition interventions on food literacy outcomes in children (<18 years) compared with the status quo interventions (eg, face-to-face programming or nondigital support). Second, this review aims to explore the features of digital nutrition interventions that are most effective in promoting food literacy.

Methods

We conducted an umbrella review of systematic reviews. This approach was used to synthesize high-level evidence to support health-related programs and policy decision-making [21]. Following recommended practices for umbrella reviews, we stated a clear objective informed by stakeholders; defined *systematic review*; specified relevant inclusion and exclusion criteria; structured our search strategy; and conducted dual screening, explicit data extraction, and quality appraisal [22].

Search Strategy

A literature search was conducted in November 2020 by a librarian for articles published between 2015 and the search date. These year limits were used to minimize the inclusion of archaic digital *innovations*. Eight databases were searched (Ovid MEDLINE, PsycINFO, Global Health, CINAHL, SocINDEX, AgeLine, Child Development and Adolescent Studies, and Scopus) with the following search terms: digital interventions, telehealth, telemedicine, videoconferencing, social media, apps, health promotion, public health, preventive health services, diet, food, eating, nutrition, and breastfeeding. References from the included articles were hand searched for additional relevant reviews. A forward search of relevant review protocols was completed in December 2020 to include the published results. The full search strategy is available upon request.

Study Inclusion and Exclusion Criteria

An a priori population-intervention-comparison-outcome statement [23] guided the inclusion and exclusion criteria: systematic reviews of studies of digital interventions aimed at improving food and nutrition outcomes for children <18 years compared with conventional nutrition education were eligible for inclusion.

Types of Participants

Reviews were included if they evaluated digital interventions aimed at children <18 years and reported separate results for children. Reviews that focused on interventions for children with a chronic disease, with the exception of overweight and obesity, were excluded.

Types of Interventions

Only digital interventions or interventions with both digital and nondigital (eg, print or face-to-face) components were included. An unrestricted definition of *digital* was used to obtain evidence that can increase the relevance of the umbrella review for decision-makers [21]. Interventions that used eHealth, mobile health (mHealth), telehealth (Textbox 1), or other electronic or internet-based programs, applications, or games where participants engaged through portable computers, desktop computers, mobile devices, and wearable devices were included. Reviews were excluded if they only reported on face-to-face interventions or aggregated results from face-to-face or print interventions with digital interventions.

Textbox 1. Definitions of eHealth, mobile health (mHealth), and telehealth.

Definitions

- eHealth: "the use of information communications technology in support of health and health-related fields." [24]
- mHealth: "an element of eHealth which focuses solely on mobile technology and is defined as 'the use of mobile wireless technologies for public health'." [24]
- Telehealth: "various types of health care when patient and provider are geographically separated—it can involve videoconferencing, telephone calls, electronic data transmission, and other ways of communicating over the Internet." [25]

Comparators

We included reviews that compared digital interventions with no intervention, minor interventions (eg, wait list), nondigital nutrition interventions (eg, print), nonnutrition digital interventions (eg, physical activity website), and conventional face-to-face programming or usual education. It was not possible to restrict our analysis to only reviews with conventional face-to-face programming because the relevant systematic reviews included a wide range of controls and comparison types.

Types of Studies

Systematic reviews (including non-Cochrane reviews) and meta-analyses were included; narrative and scoping reviews were excluded. We defined *systematic reviews* as a review of evidence with clearly stated research questions, search strategy that is reproducible, inclusion and exclusion criteria, selection methods, quality and risk of bias assessment, and evidence synthesis [26]. Various study designs included in the systematic reviews were acceptable, including randomized controlled trials (RCTs), quasi-experiments, and cross-sectional studies, as these are common designs in nonclinical research. Reviews of qualitative evaluations of digital interventions were excluded. Systematic reviews that reported only on intervention design and characteristics with no report on intervention effects were excluded. Only reviews of human studies published in English with the majority conducted in developed countries were included.

Types of Outcomes

The primary outcomes were food and nutrition behaviors (eg, dietary intake and eating habits), knowledge (eg, how to read a food label), and attitudes (eg, self-efficacy and intentions). Outcomes related to breastfeeding, weight status (eg, BMI, fat mass, waist circumference, and childhood obesity), health (eg, blood pressure and blood glucose), and nonnutrition topics (eg, physical activity, sedentary behavior, and sleep) were excluded. The secondary outcomes were food and nutrition outcomes according to the behavior change theory and techniques.

Screening and Quality Appraisal

Titles and abstracts were screened by 3 reviewers with 20% of the results double-screened to ensure high interrater agreement. Full-text articles were retrieved and reviewed by 2 reviewers and confirmed by a third reviewer. Consensus on the included studies was achieved through discussion.

A MeaSurement Tool to Assess systematic Reviews 2 (AMSTAR 2) was used to assess the quality of the systematic reviews [27]. Quality appraisal was completed on all the included articles, with a subsample of reviews completed by 2 independent reviewers to test interrater reliability. No discrepancies in the quality appraisal between the reviewers were identified.

Data Extraction and Data Synthesis

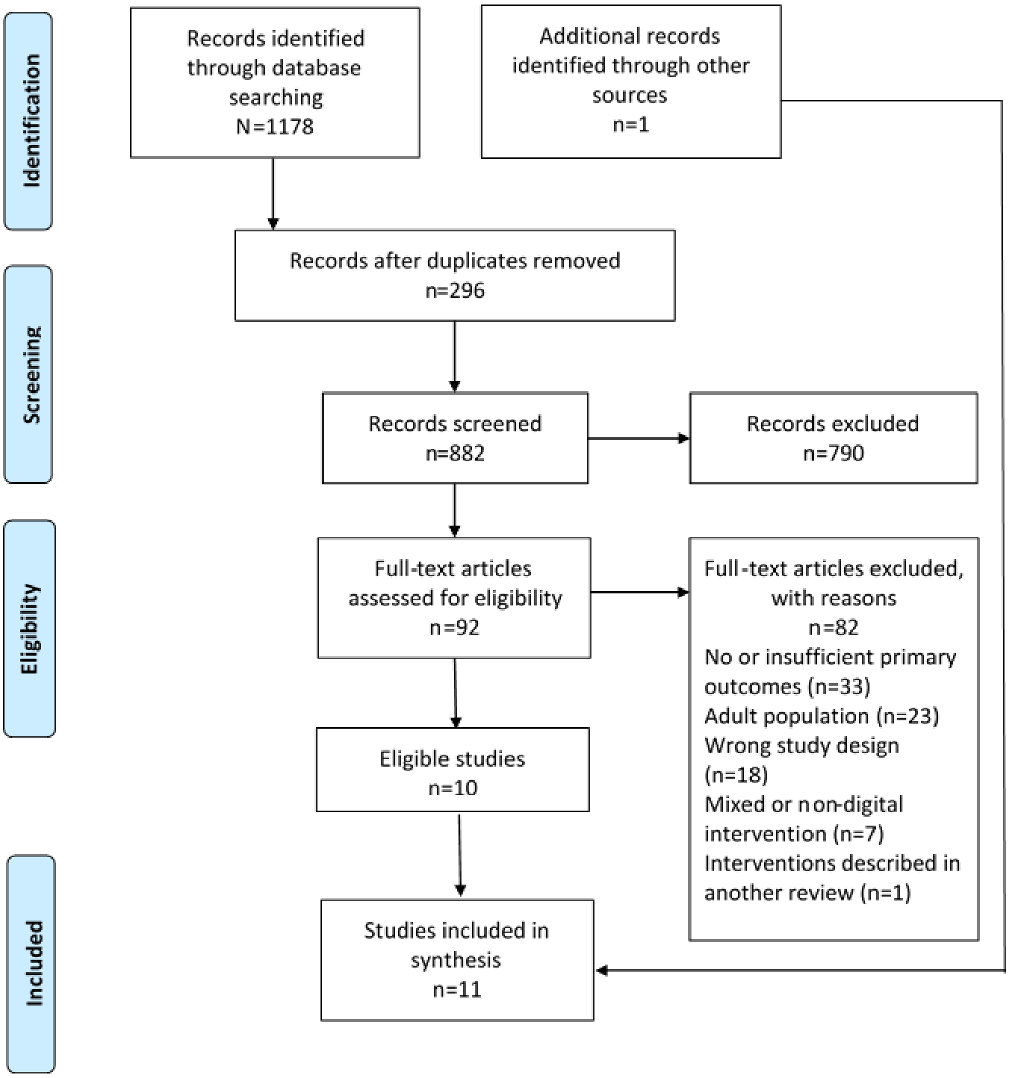
Relevant information was extracted by 1 author, including study design; methods; population; intervention type; dose; and duration, outcome measurement, results, and limitations. The findings were reviewed and summarized using the systematic review results and conclusions as the primary units of analysis [21]. Where possible, the outcome effect sizes (ESs) were extracted and assessed by intervention type (eg, internet, mobile, and social media) and by outcome type (eg, fruit and vegetable intake). When this was not possible, the overall impact of digital interventions on food and nutrition outcomes was assessed.

Results

Study Characteristics

The search identified 1178 articles, of which 92 (7.81%) were selected for full-text review, 80 (6.79%) did not meet the inclusion criteria, and 1 (0.08%) was excluded because all interventions were reviewed in a more recent, higher-quality review. As a result, 11 of the 1178 reviews (0.93%) were included to be examined for the impact of digital interventions on nutrition outcomes in children and youth [28-38] (Figure 1). Of the 11 reviews, 3 (27%) included meta-analyses [28,29,32]; 7 (64%) of the reviews were of moderate quality [28-30,33-36], 1 (9%) was of low quality [37], and 3 (27%) were of critically low quality [31,32,38].

Figure 1. PRISMA (Preferred Reporting for Systematic Reviews and Meta-Analyses) diagram.



The reviews included children between the ages of 7 and 19 years. Of the 11 reviews, 1 (9%) focused on parents of children aged 1 year to early adolescence [30], and 2 (18%) reported separate findings for children and adults [28,31]. These articles were retained because of their quality and unique research focus (single digital modality meta-analyses and behavior change technique (BCT) evaluation [28] and social media [31]).

Interventions ranged from internet, computer, or mobile interventions to websites, programs, apps, emails, videos, CD-ROMs, games, SMS text messages, telehealth, and social media. Most reviews included studies in which the digital intervention was a component of a larger intervention [29-33,36,38], with some including face-to-face components [32,34].

The dose and duration of the digital interventions ranged from a single exposure to multiple sessions (1-60 minutes in length) over 1 or 2 years. Most outcomes were evaluated immediately after the interventions, with few reviews reporting on effects at medium (eg, 2 months) or long (eg, 2 years) follow-ups [29,31,34,35,37]. Interventions were compared with no intervention, nonnutrition digital interventions (eg, websites on physical activity), nondigital nutrition interventions (eg, print healthy eating information and usual nutrition education), and face-to-face interventions, and were often mixed within reviews. Further details on the intervention characteristics can be found in Multimedia Appendices 1 and 2 [28-38].

Impacts Across All Digital Interventions

In general, reviews have highlighted the promise of the digital interventions to improve diets; however, the evidence of its impact on dietary outcomes in children remains inconclusive. Tallon et al [37] and Wickham and Carbone [38] reported that all studies reported at least 1 positive result in favor of the intervention; however, the findings were mixed when collated across the studies. Do Amaral e Melo et al [33], Zarnowiecki et al [30], and Rose et al [36] also reported a mix of positive, null, and negative impacts of digital interventions across the reviewed studies. Rodriguez Rocha and Kim [28] reported that digital interventions were effective in improving fruit and vegetable intake among adolescents (ES=0.26; SE 0.06; 95% CI 0.14-0.38; P<.001) but not among children (ES=0.11; SE 0.11; 95% CI and P value were not reported). In studies that evaluated the maintenance of digital intervention effects, positive results from immediate impacts of the interventions were generally not sustained over time [28,29,33,36,37]. Refer Multimedia Appendix 2 for details of the review findings.

Impact by Digital Modality

Internet

Internet-based interventions (eg, websites, social media, or email) were reported in 7 reviews [28-30,34,36,38]. Meta-analyses by Rodriguez Rocha and Kim [28] and Champion et al [29] found small significant impacts of internet-based interventions. Rodriguez Rocha and Kim [28] reported an ES of 0.19 (SE 0.05; 95% CI 0.09-0.29; $P<.001$) on fruit and vegetable intake across 10 internet-based interventions for adults, adolescents, and children (all ages assessed together). Champion et al [29] reported a standard mean difference of 0.11 (95% CI 0.03-0.19; $P=.007$) of digital interventions (14 internet-based; 2 CD-ROMs) delivered in schools on mean servings of fruits and vegetables per day to those aged 11-18 years; however, this effect was not sustained at follow-ups between 2 and 36 weeks. Some positive impacts of the digital interventions (where the majority were internet-based) on fruit and vegetable intake were also reported by Zarnowiecki et al [30] and Hsu et al [34]; however, the results were inconsistent across all studies in these reviews.

Hsu et al [34] also reported mixed results for internet-based interventions on other dietary intake outcomes (eg, SSBs, junk food, and breakfast in those aged 11-18 years from meta-analyses with 3 studies each). Websites (n=7) and apps (n=1) geared toward using parents as agents of change for children's nutrition were found to have positive impacts on parents' and children's knowledge, attitudes, and feeding practices, but had mixed findings on dietary intake [30]. Wickham and Carbone [38] reported mixed findings of digital interventions used for adolescent food literacy programming (7/8, 88% were internet-based) on nutrition knowledge, attitudes (eg, self-efficacy), skills (eg, planning), and intake (eg, fruit and vegetable intake). Finally, Rose et al [36] found that of the 10 website interventions, only 3 (30%) had significant improvements in diet while the remaining 7 (70%) reported null or inconclusive findings.

Computer

Tallon et al [37] included 12 computer-based interventions (eg, programs, games, websites, or email) and 1 mobile intervention and found mixed results for nutrition knowledge and dietary changes among those aged 12-18 years.

Mobile

From the 3 interventions included in a meta-analysis, Rodriguez Rocha and Kim [28] found that SMS text messaging interventions had a moderate impact on fruit and vegetable intake (ES=0.41; SE 0.1; 95% CI 0.21-0.63; $P<.01$) for adults, adolescents, and children (all ages assessed together). Darling and Sato [32] evaluated mobile interventions (3 SMS text messaging interventions and 4 mobile app interventions) that included self-monitoring of behaviors. This critically low-quality review found a very small effect on fruit and vegetable and SSB intake (assessed together; Cohen $d=0.10$; 95% CI 0.002-0.024) in children with overweight or obesity [32]. Darling and Sato [32] concluded that the true effect of the mobile interventions with self-monitoring was difficult to determine, as few studies were RCTs. Rose et al [36] included only 1 study that evaluated the effect of SMS text messaging on diet and found that there was no impact on fruit and vegetable intake compared with a control condition.

Gaming

In a review of 21 digital gaming interventions on nutrition outcomes, most studies reported improvements in nutrition knowledge, eating habits (eg, increased fruits and vegetables, decreased fat, and sugar), and attitudes (eg, intentions, and self-efficacy) [35]. The reported ESs ranged from small to large across a subsample of 6 studies [35]. Rose et al [36] reported on a game-based intervention that found positive impact on fruit and vegetable intake; however, the impacts on other dietary outcomes were unclear. Rodriguez Rocha and Kim [28] assessed gamified interventions on CD-ROMs, mobile apps, and video games, but reported that there was no statistically significant effect on fruit and vegetable intake for all ages. Wickham and Carbone [38] reported mixed findings across all the studies.

Social Media

Only 1 critically low review (as per A MeaSurement Tool to Assess systematic Reviews 2) reported that 50% (8/16) of studies found at least 1 positive impact of social media interventions on dietary outcomes (eg, fruit and vegetable intake and SSB intake) [31]; however, it is unclear whether the results were consistent across studies. The authors noted that the social media interventions were highly heterogenous, often with various BCTs and as a component of a multicomponent intervention; thus, the impact of social media itself is difficult to determine [31].

Impacts by BCT

Six reviews discussed the use of theories or frameworks in primary studies and found that most interventions were informed by some theory or framework. The most commonly mentioned theories were social cognitive theory [28,31,33,34] and the transtheoretical model (stages of change) [28,31,33,34,39]. A variety of BCTs were incorporated into the digital interventions. Rodriguez Rocha and Kim [28] identified 20 unique BCTs used in 19 studies (mean 4; range 1-7). Instruction or education were used by most interventions [28,30,34,36-38]. Other common BCTs were personalized feedback [28-30,34], goal-setting [28-30,34,36], tailoring interventions to individuals [28] and self-monitoring [29,30,32,36].

Rodriguez Rocha and Kim [28] concluded that digital interventions that incorporated 7 or 8 BCTs had larger effects (ES=0.42; SE 0.1; 95% CI 0.21-0.62; $P<.001$) than digital interventions that used fewer techniques to improve fruit and vegetable intake. However, they did not find any difference in the effectiveness of digital interventions on fruit and vegetable intake by the 5 common BCTs: instruction, feedback, goal-setting, identifying barriers, and explaining consequences of behavior. Interventions that were tailored (ES=0.27; SE 0.05; 95% CI 0.16-0.37; $P<.001$) and nontailored (ES=0.22; SE 0.11; 95% CI 0.00-0.44; $P=.05$) were both effective and not significantly different. Rose et al [36] reported that significant improvements in at least one diet outcome were found more often in digital interventions that included goal-setting; digital interventions that included self-monitoring techniques were more effective if they also included goal-setting.

Do Amaral e Melo et al [33] stated that all studies that used the social cognitive theory showed immediate significant positive outcomes but could not conclude that the impacts were due to the use of this theory. Similarly, Champion et al [29] stated that better outcomes were found when interventions were guided by the transtheoretical model and provided personalized feedback to students; however, this was not analyzed in the review.

Discussion

Principal Findings

There is substantial evidence on digital nutrition interventions; however, there was significant heterogeneity in the research regarding the types of digital interventions included, intervention duration, follow-up evaluation timing, comparison groups, and dietary outcomes. As a result, the evidence on their effectiveness remains unclear and inconsistent. Although the evidence was limited, the use of BCTs and techniques appeared to be important in increasing the effectiveness of the digital interventions [28,29,33].

The digital nutrition interventions seemed to be the most promising for improving fruit and vegetable intake; however, many reviews have found mixed results. For example, a moderate quality review by Rodriguez Rocha and Kim [28] that focused solely on vegetable and fruit intake found a small overall impact of digital interventions on adolescents but not children. There was limited evidence on the impact of digital interventions on other food literacy outcomes, including nutrient intake, food and nutrition knowledge, attitudes, and skills. The inconsistent and mixed results from the included reviews may be due to the variability in quality, study design, and outcomes measured. In addition, owing to the heterogeneity of the interventions, few reviews performed meta-analyses to estimate the overall ESs.

The observed positive effects of digital interventions on dietary outcomes ranged from small to medium [28,29,32] and were comparable with the ESs of the traditional nutrition interventions for children [40,41]. In a review of nondigital nutrition interventions, less than one-third of the reported ESs were above 0.2 and statistically significant [40]. Another systematic review and meta-analysis of the traditional school-based nutrition education interventions showed small to medium effects (between 0.14 and 0.40) on fruit and vegetable intake, sugar intake, energy intake, and nutrition knowledge [41]. Thus, it is reasonable to expect digital nutrition interventions to generate ESs in the small to medium range. Similarly, digital nutrition interventions appeared to moderately improve dietary outcomes immediately after the intervention but were not well maintained over time. The long-term success of both traditional [40,42,43] and digital [28,29,33,35,44] nutrition interventions have not been well-studied.

It is unclear whether certain types of digital interventions are more effective than others, as most studies were unable to compare individual modalities and many interventions were multicomponent. Multiple digital intervention types have often been assessed collectively in reviews, making it impossible to distill the impacts by the digital modality and separate the effect resulting from digital aspects from other aspects of the intervention [31,37,38]. Even when digital interventions are assessed independently, inconsistency between reviews impedes the evaluation of the strength of evidence. For example, a website may have been counted as an internet-based intervention in 1 review and a computer-based intervention in another; a mobile app may be counted as a mobile-based intervention or a gaming intervention. Other important features of digital nutrition interventions that may be important for effective interventions are personalized feedback, participant interaction with researchers, duration of at least 3 months, and objectives and activities aligned with specific target behaviors [44]. A meta-analysis of mobile apps aimed at improving the diets in children <18 years found that modeling and social support were significant predictors of intervention ES on dietary outcomes (eg, fruit and vegetable intake and nutrient intake); practicing target desirable behaviors (eg, eating vegetables) was a significant predictor of intervention ES for children but not adolescents [45].

Research on adults found that digital engagement using the telephone or SMS text messaging was more effective than other modalities such as websites, which the authors posit may be attributable to the use of direct communication [46]. Similarly, Brigden et al [16] found that children's direct connections with a health professional during the digital interventions to manage chronic diseases made a difference in its effectiveness on nutrition outcomes for those aged between 5 and 12 years. There are several factors that impact user engagement with technology (eg, personal traits, beliefs, privacy, and technological challenges) [47], which vary widely across interventions included in the reviews; thus further muddying our understanding of the promise of digital interventions. Nonetheless, the pandemic has expanded opportunities to use eHealth interventions for multiple populations (eg, rural communities, lower socioeconomic status, and youth) [20].

Consistent with another review of web-based nutrition interventions [44], the use of behavior change theories and techniques was associated with increased intervention effectiveness [28,29,33]. This may be different from face-to-face interventions; Murimi et al [48] found that the theory-based face-to-face nutrition interventions for children aged between 2 and 19 years did not perform better than those interventions that were not theory-based. Black et al [40] also stated that the theoretical basis of family, school, and childcare nutrition interventions delivered in a conventional format was not associated with their effectiveness. Other factors such as parent engagement, supportive environments and policies, and activities aligned with specific target behaviors may be more important than the use of a theory in the design of childhood nutrition interventions [48]. Furthermore, Duan et al [46] recommended that the digital interventions target multiple levels of the socio-ecological model to generate a greater impact. Owing to the number and variety of determinants of diet, an intervention that targets only 1 level (eg, individual knowledge) may not be expected to generate large impacts [46].

Many questions remain regarding the best practices to implement digital interventions. The evidence reviewed did not yield information on digital accessibility, acceptability, usability by participants, intervention logistics (eg, how to provide food and cooking equipment to participants in a remote cooking program), participant engagement, privacy and security, equity, and cost-effectiveness [36]. Digital accessibility may be particularly important as some populations do not have the means to access technology, and if those with greater access to resources are better able to engage with digital interventions, there is potential for these digital interventions to increase health inequities. Moreover, the *scale-up penalty* of adopting interventions must be considered, as the effects seen in RCTs may not be effective to the same extent in real-life implementation [49]. Nutrition interventions, including digital interventions, should be carefully designed and implemented [40,41] and rigorously evaluated using RCTs, should contribute to a series of supporting interventions for healthy eating [40,48,50], and strive to reduce health and diet inequities.

Limitations

There are many challenges in conducting umbrella reviews [22]. Our conclusions are limited by the inability to assess the strength of evidence, such as using Grading of Recommendations Assessment, Development and Evaluation, owing to heterogeneity. Weaknesses in the primary studies in the reviews further reduce certainty in the conclusions. Many reviews included studies with nonrandomized or quasi-experimental designs, cross-sectional studies, and pre-post study designs. Reviews often collectively evaluated poorly described heterogenous interventions with various comparison group types and multiple outcomes, which limited our ability to aggregate findings by individual digital intervention type across the reviews. In general, the included studies had very small sample sizes and often used convenience sampling. ESs were rarely published, which limited our ability to draw conclusions about the effectiveness of digital nutrition interventions. These challenges are not unusual; Murimi et al [44] also cited inconsistent comparison groups, lack of intervention details (eg, dosage), lack of tracking participant engagement, subjective outcome measurement, and lack of follow-up as challenges in reviewing the digital nutrition interventions.

The findings of this review are further limited by the speed at which technology advances and the current evidence on digital interventions that may not have sufficiently evaluated the digital modalities that are popular today, such as videoconferencing or social media. In contrast, despite including the most recent reviews on this topic, CD-ROM interventions were evaluated in reviews published in 2019. Nonetheless, the feasibility and effectiveness of the digital interventions is valuable to explore, as they may have benefits regarding population reach or cost-effectiveness [44]. Owing to these limitations, we have been careful not to overstate the promise of digital interventions as the positive findings may have been inflated due to publication bias, overlap between reviews, and research quality.

Conclusions

The effect of digital interventions on food and nutrition outcomes is small and inconsistent. Nevertheless, digital adaptations or additions to these interventions based on behavior change theory and techniques may be considered, as web-based service delivery has become increasingly common worldwide. Digital technologies provide an opportunity to increase the reach of interventions and reduce costs, resources, and efforts required to produce or deliver programing. High-quality evidence with common definitions for digital intervention types and evaluation with validated measures is needed to improve the state of evidence to inform policy and program decisions for health promotion in children. Now is the time for critical, robust evaluation of the digital interventions adopted during and after the COVID-19 pandemic to establish effective best practices for eHealth nutrition interventions for children.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Characteristics of digital nutrition interventions for children.
[DOC File , 48 KB - pediatrics_v4i4e30160_app1.doc]

Multimedia Appendix 2
Study characteristics and findings of digital nutrition interventions for children.
[DOCX File , 23 KB - pediatrics_v4i4e30160_app2.docx]

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Abbreviations

AMSTAR 2: A MeaSurement Tool to Assess systematic Reviews 2
BCT: behavior change technique
ES: effect size
RCT: randomized controlled trial
SMD: standard mean difference
SSB: sugar-sweetened beverage

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Original Paper

The Content and Quality of Publicly Available Information About Congenital Diaphragmatic Hernia: Descriptive Study

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Abstract

Background: Congenital diaphragmatic hernia (CDH) diagnosis in an infant is distressing for parents. Parents often feel unable to absorb the complexities of CDH during prenatal consultations and use the internet to supplement their knowledge and decision making.

Objective: We aimed to examine the content and quality of publicly available, internet-based CDH information.

Methods: We conducted internet searches across 2 popular search engines (Google and Bing). Websites were included if they contained CDH information and were publicly available. We developed a coding instrument to evaluate websites. Two coders (FS and KS) were trained, achieved interrater reliability, and rated remaining websites independently. Descriptive statistics were performed.

Results: Searches yielded 520 websites; 91 met inclusion criteria and were analyzed. Most websites provided basic CDH information including describing the defect (86/91, 95%), need for neonatal intensive care (77/91, 85%), and surgical correction (79/91, 87%). Few mentioned palliative care, decisions about pregnancy termination (13/91, 14%), or support resources (21/91, 23%).

Conclusions: Findings highlight the variability of information about CDH on the internet. Clinicians should work to develop or identify reliable, comprehensive information about CDH to support parents.

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KEYWORDS

congenital diaphragmatic hernia; prenatal counseling; fetal care; online information; parental decision making

Introduction

With an incidence of 1:2500 live births, congenital diaphragmatic hernia (CDH) is a relatively common, yet complicated and potentially devastating diagnosis [1]. CDH can cause neurodevelopmental delays, chronic lung disease, gastroesophageal reflux, hearing loss, and even death [1]. As a result, parents whose fetus or newborn is diagnosed with CDH face decisions about extracorporeal membrane oxygenation (ECMO), management of long-term CDH complications, and potential plans for end-of-life care.

A diagnosis of CDH triggers numerous emotions, making it difficult for parents to absorb and process the information initially presented to them during a clinical visit [2-6]. Typically, parents receive this diagnosis and the complex information in a single prenatal visit. Many parents do not feel that one consultation provides enough time to learn about the diagnosis and its implications [6]. However, most parents want to engage in decisions regarding their baby's care during this time, working with clinicians to support the decision-making process [7-10].

When met with uncertainty, parents often search for medical information outside of clinical encounters to make informed choices [11-13]. The internet is a popular resource for patients and families facing a difficult diagnosis such as CDH [11-14]. Despite its popularity, little is known about the comprehensiveness of internet-based CDH information [15].

This study aimed to evaluate the content and quality of internet-based information parents might find about CDH. Results could support the development or updating of websites to facilitate parental education and decision making about CDH.

Methods

Internet Searches

We conducted searches using 9 different terms on Google: "Congenital diaphragmatic hernia", "CDH in a baby", "Congenital diaphragmatic hernia surgery", "Congenital diaphragmatic hernia NICU", "Baby with stomach in chest", "Baby with hole in diaphragm", "CDH support for parents", "Affording CDH/NICU costs", and "CDH parent support website". These search terms were chosen due to their use of lay-person terminology, and based upon clinical discussions with families of patients with CDH. We reviewed these terms with several practicing clinicians treating families facing this decision. We repeated searches on Bing until it was clear that the results produced the same websites. As most (91%) people do not look beyond the first page of search results [16], we included the first 3 pages for completeness.

Websites were included if they contained: (1) basic CDH information; (2) resources for patients with CDH or their parents; and (3) discussion boards, chat rooms, or social support information regarding CDH. Exclusion criteria included paid advertisements, legal sites, non-US sites, sites targeted to medical professionals, definition-only sites (ie, dictionary.com), sites requiring logins, and sites not about CDH.

We coded included sites' content on the first page plus 2 clicks from the first page. Content linked to external sites was not coded. The study did not involve human patients, thus institutional review board approval was unnecessary.

Website Coding

We developed a coding instrument of 133 items in the following categories: (1) basic definition or description of CDH; (2) prenatal care for CDH; (3) typical hospital course for patients with CDH; (4) ECMO procedure and complications; (5) CDH outcomes; (6) prenatal CDH surgery; (7) postnatal CDH surgery; and (8) financial, emotional, or personal support. This instrument was reviewed for accuracy and completeness by 2 neonatologists with experience in treating CDH.

The first 7 websites were coded by 2 raters (FS and KS) to check for consistency in coding. Cohen κ was 0.75 with a 79% agreement at this stage. The 2 raters met, discussed discrepancies, and reached consensus, revising the codebook where necessary. Once Cohen kappa showed a high level of agreement (κ>0.80; agreement >90%), remaining sites were divided and scored by 1 of the 2 coders (FS or KS). The 2 coders remained in contact throughout the process to ensure consistency. We analyzed the data using descriptive statistics.

Results

Internet Searches

The searches yielded 520 websites. A total of 368 websites were excluded initially because they were duplicates (n=264, 71.7%), advertisements (n=91, 24.7%), or scholarly articles intended for medical professionals (n=37, 10.1%). Of the remaining 152 websites, 61 (40.1%) did not meet additional inclusion criteria about CDH content. Of the 91 analyzed sites, most were developed by academic medical centers (n=53, 58%), general medical knowledge sources (n=10, 11%), or nonprofit organizations (n=10, 11%).

Website Coding

Most websites described basic CDH information (86/91, 95%), types of CDH (52/91, 57%), implications for prenatal care (55/91, 60%), or variation in clinical acuity (56/91, 62%; Table 1). Websites infrequently mentioned various complications of CDH. Many did not mention treatment options such as pregnancy termination, palliative care, or a compassionate delivery. Only 13/91 (14%) sites mentioned pregnancy termination as an option. Only 4/91 (4%) discussed the possibility of palliative care or compassionate delivery. There was a paucity of discussion around financial, emotional, or informational support for the family.

Table 1. Content of CDH[a] websites (N=91).

	Number of websites (%)
CDH information	
Gave description or definition of CDH	86 (95)
Mentioned types of CDH	52 (57)
Discussed how CDH is diagnosed	74 (81)
Discussed prenatal care for CDH	55 (60)
Mentioned admission to the neonatal intensive care unit	77 (85)
Discussed potential need for a breathing tube/intubation	73 (80)
Discussed postnatal surgery	79 (87)
Discussed variation in clinical acuity	56 (62)
Discussed possibility of death from CDH	60 (66)
Potential complication of CDH	
Discussed risk of neurodevelopmental delays from CDH	45 (49)
Discussed risk of chronic lung disease	46 (51)
Discussed risk of hearing difficulties due to CDH	26 (29)
Discussed risk of gastroesophageal reflux	49 (54)
Discussed the potential for the hernia to recur	19 (21)
Discussed risk of failure to thrive/inability to gain weight	35 (38)
Treatment option	
Discussed potential for ECMO[b]	66 (73)
If mentioned ECMO, site described complications of ECMO	21 (23)
Discussed the possibility of prenatal surgery	35 (38)
Discussed possibility of termination of pregnancy	13 (14)
Support system information	
Contained additional reading material for parents regarding the diagnosis of CDH	24 (26)
Discussed financial support	15 (16)
Discussed housing options while in the neonatal intensive care unit	12 (13)
Contained emotional/personal support resources for families	21 (23)
Provided information regarding mental health resources	9 (10)

[a] CDH: congenital diaphragmatic hernia.

[b] ECMO: extracorporeal membrane oxygenation.

Discussion

Access to comprehensive, accurate information about CDH is critical to supplement clinical visits and support parents with infants with a CDH diagnosis. We examined the quality of available CDH information on the internet. Many websites described basic information about CDH, including a description of CDH and possible medical interventions. However, few websites described possible negative outcomes, complications, and care options aside from full medical interventions.

When searching for CDH information, families can become overwhelmed with the number of results obtained. Our study used search terms and phrases similar to what a typical family might use. We found numerous websites that were not accessible or relevant to families, highlighting the difficulty in conducting generalized searches about CDH. Families could become frustrated when attempting to find comprehensive and reliable information; clinicians could supply a list of high-quality websites for parents. The use of websites with quality information about CDH hosted by reputable institutions or organizations can support families.

The scarcity of discussion around palliative care, compassionate delivery, and pregnancy termination should be noted, as these are reasonable options for families. One CDH parent advocacy website mentioned the lack of in-person discussion about palliative care or compassionate delivery [17]. At a time when parents desire involvement in care, they should have access to information about all reasonable options for their infants. Parents should also be aware of the complications of CDH to be as informed as possible when making care decisions.

These data should be considered within the context of some limitations. Searches were completed once (October 2019) with a single update (January 2020). Websites could have edited information after the search and coding process. We used 2 popular search engines (Google and Bing), but families could find additional sites not identified. We also used experience with previous CDH families to guide search term creation; however, parental input on search terms may have yielded different results. We excluded social media sites that required a login, although some social media sites could provide information or support through peer groups. We included information 2 clicks from the main page, but parents could go further into the sites. We did not analyze whether the information presented on websites was clear; future studies can use tools such as the Clear Communication Index or the Patient Education Materials Assessment Tool (PEMAT) to analyze specific sites once sources are identified and considered for use with patients. Finally, the coders were able to traverse the websites with relative ease, but parents might not be as savvy with the internet, and thus results could overestimate information available.

This study highlights a need for more comprehensive websites with information about CDH. Institutional or clinic-based materials might better support families than internet resources as families navigate through CDH information seeking and decision making.

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Conflicts of Interest

None declared.

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Abbreviations

CDH: congenital diaphragmatic hernia
ECMO: extracorporeal membrane oxygenation
PEMAT: Patient Education Materials Assessment Tool

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Original Paper

Recruitment and Retention of Parents of Adolescents in a Text Messaging Trial (MyTeen): Secondary Analysis From a Randomized Controlled Trial

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Abstract

Background: Parenting programs are well established as an effective strategy for enhancing both parenting skills and the well-being of the child. However, recruitment for family programs in clinical and nonclinical settings remains low.

Objective: This study aims to describe the recruitment and retention methods used in a text messaging program (MyTeen) trial for parents of adolescents (10-15 years) and identify key lessons learned. We aim to provide insights and direction for researchers who seek to recruit parents and build on the limited literature on recruitment and retention strategies for parenting program trials.

Methods: A recruitment plan was developed, monitored, and modified as needed throughout the course of the project. Strategies to facilitate recruitment were identified (eg, program content and recruitment material, staff characteristics, and study procedures). Traditional and web-based recruitment strategies were used.

Results: Over a 5-month period, 319 parents or caregivers expressed interest in our study, of which 221 agreed to participate in the study, exceeding our recruitment target of 214 participants. Attrition was low at the 1-month (4.5% overall; intervention group: n=5, 4.6%; control group: n=5, 4.5%) and 3-month follow-ups (9% overall; intervention group: n=10, 9.2%; control group: n=10, 8.9%).

Conclusions: The use of web-based recruitment strategies appeared to be most effective for recruiting and retaining parents in a text-messaging program trial. However, we encountered recruitment challenges (ie, underrepresentation of ethnic minority groups and fathers) similar to those reported in the literature. Therefore, efforts to engage ethnic minorities and fathers are needed.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12618000117213; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=374307

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KEYWORDS

parenting; mHealth; text messaging; recruitment

Introduction

Parenting programs, aimed at strengthening parenting skills and increasing knowledge on adolescent development, have shown positive effects on parent-adolescent relationships and parent-adolescent well-being [1-3]. However, recruitment for family programs in clinical and nonclinical settings remains low [4,5]. Studies have shown that only 10% to 31% of eligible parents enroll to participate in face-to-face programs—the most common mode of delivery for parenting intervention, with up to one-third of enrolled participants not attending a single session [6]. Many studies on parenting programs find it challenging to recruit an adequate number of participants for sample requirements and obtaining a representative sample of their target population [7,8]. Such challenges can result in extended recruitment time, increased costs, underpowered studies, or limited generalizability. Although an increasing number of strategies and approaches on how to boost or optimize recruitment are now known [4,6,7], the knowledge of experience from studies on parenting adolescent populations is limited.

Recently, there has been a surge of interest in the development of mobile health (mHealth) interventions as a means of expanding intervention reach [9-11]. Text messaging, in particular, has emerged as a fast and accessible mode for intervention delivery, as it minimizes many of the barriers contributing to the low uptake and attendance in traditional delivery models [9]. There is, however, limited evidence on the effectiveness of using text message as a mode of delivery for parenting programs [12]. Of those available, parenting programs have primarily targeted parents with young children [13,14]. Moreover, no study has reported on the experience with recruiting parents of adolescents into a text-messaging program trial. In 2018, we developed and trialed a text messaging program (MyTeen) with the goal to improve parenting competence and mental health literacy [2] for parents with adolescents (10-15 years of age). The 4-week-long program consisted of a series of one-way messages to participating parents that provided tips on a wide range of parenting-related matters—establishing and maintaining positive relationships with adolescents, strategies to increase adolescent autonomy, adolescent development, family functioning, parental self-care, recognizing depressive symptoms, understanding treatment options, and providing links to evidence-based support and informational resources. The text messages were derived from the Parenting Strategies Program [15], a set of evidence-based parenting guidelines developed through a systematic review and meta-analysis of parental factors associated with adolescent depression and anxiety, and international expert consensus achieved via a Delphi study about actionable strategies parents can use to reduce their child’s risk of depression and anxiety. We conducted a randomized controlled trial to evaluate the effectiveness of the MyTeen program in comparison with a “care as usual” control group [16].

In this paper, we describe the recruitment and retention methods used in the MyTeen trial. This is the first study to systematically document the process and identify key lessons learned from a text-messaging parenting program for parents of adolescents. We aim to report on our recruitment experience with MyTeen to support parents of adolescents. The paper provides insights and direction for researchers who seek to recruit parents and build on the limited literature on recruitment and retention strategies for parenting program trials.

Methods

This section provides an overview of the study design of the MyTeen trial, including the recruitment plan developed.

Study Design and Sample Size

The study was approved by the University of Auckland Human Participants Ethics Committee (UAHPEC, Ref 019659), and the study protocol has been published elsewhere [2]. Briefly, eligible parents or caregivers (hereafter referred to as parents) were randomly allocated to the MyTeen intervention program or care-as-usual condition. Data were obtained from all participants at baseline and at 1 month (end of intervention phase) and 3 months postrandomization. The trial is registered with the Australian New Zealand Clinical Trials Registry (ACTRN12618000117213).

We aimed to recruit a representative sample of 214 parents (n=107 per randomized group; 1 parent per household) residing in New Zealand across a 6-month period. This sample size provided 80% power (P=.05) to detect a group difference of 2.5 (SD 5.8) in the primary outcome measure of Parenting Sense of Competence scale (PSOC) score at the 1-month follow-up and allowing for an estimated 20% loss to follow-up. The majority of the New Zealand population is of European descent (70%), followed by indigenous Māori (16.5%), Asian (15.3%), and Pacific (9%) descent [17]. Effort was made to oversample ethnic subgroups in order to allow for subgroup analyses. Parents were eligible for inclusion in the study if they (1) had a child aged between 10 and 15 years, (2) had access to a mobile phone, (3) were not receiving any professional assistance for their own and/or child’s mental health problems, (4) possessed adequate knowledge of the English language, and (5) provided informed consent. Only 1 parent from each household was recruited for the study. Parents who showed high level of stress, as reported by the Parental Stress Index (ie, score ≥72), were excluded from the study and directed to professional services. Interested individuals completed a phone screening to assess eligibility criteria and provide contact information. Eligible individuals were sent an email through which they provided informed consent and completed a baseline survey.

Recruitment Plan

Strategies for successful recruitment and retention were considered at the onset of the project, and a recruitment plan was developed, monitored, and modified as needed throughout the project. Potential barriers (eg, budget constraints, timeframe, and attrition) and strategies to facilitate recruitment (eg, program content and recruitment material, staff characteristics, recruitment strategies, and study procedures) were identified. Each of these strategies are outlined below.

Program Content and Recruitment Material

A key factor to program success was to ensure that the program met the needs of the targeted population. To this end, formative work was conducted comprising 5 focus groups (n=45) of parents or primary caregivers of adolescents (10-15 years) to ensure the content, duration, and mode of delivery were acceptable and feasible for these parents. We examined the parents’ perspectives on youth well-being, parenting, and parenting support and their input on the development of MyTeen text messaging parenting program (details reported elsewhere [18]). We found that participants were concerned about their child's mental health, and a number of parenting challenges (ie, social expectations, time, impact of technology, changes in family communication pattern, and recognizing and talking about mental health issues) were noted. Importantly, participants reported the lack of services and support available for families, and many were not aware of services for parents themselves. Parents offered suggestions for the MyTeen program, including the tonality, content, and length of text messages, as well as their delivery frequency. These suggestions helped fine-tune the program with positively framed text messages that provided parents with strength-based parenting strategies, wordings of encouragement, and support. This also guided the wording and design of the recruitment material (eg, flyers and Facebook ads), including the use of positive and lay language (Multimedia Appendix 1). The intent was to normalize and reduce stigma to access parenting support and, in this case, the study trial. Contact details were obtained from focus group participants who expressed interest in being part of the text messaging program trial.

Research Staff Characteristics

One project manager and 2 research assistants conducted the recruitment, retention contacts, and logistical arrangements, with oversight by the principal investigator (JC). One of the research assistants who identified as Māori (indigenous people of New Zealand) actively engaged with ethnic minorities via her own networks, as well as promoted visibility of the program within the Māori community. Primary recruitment activities included communicating with various organizations and networks, reviewing enrolment reports, communicating the enrolment status to the steering committee, and monitoring social media and communications with our data management team.

Recruitment Strategies

Overview

The proposed recruitment period was 6 months. However, we reached our targeted sample within 5 months (March 2018 to August 2018). Table 1 details the recruitment strategies used over time. Recruitment strategies included a mix of traditional (eg, information provided to schools, distribution of flyers, word of mouth) and web-based (eg, advertising on websites, direct emails, and social media) methods. Each method was monitored on an ongoing basis and modified as needed based on recruitment success. All sources of recruitment directed interested individuals to contact us via email or phone managed by our research assistants.

Table 1. Recruitment strategies used over time[a].

Recruitment strategies	Week														
	0	2	4	6	8	10	12	14	16	18	20	22	24	26	28
Targeted minority recruitment	✓	✓	✓												
Flyers	✓	✓	✓												
Community event			✓			✓									
Social media (eg, Facebook)			✓		✓		✓								
Paid Facebook ad										✓					
Email Listserv				✓											
School newsletter						✓			✓		✓	✓			
Website advertisement							✓								

[a]Word of mouth is not shown in the table as it was used throughout the recruitment period.

Specifically, recruitment strategies varied by site or context, as described below.

Schools

Emails explaining the study process and asking for permission to advertise via schools were sent to 388 schools across New Zealand. Of those, 7 (1.8%) schools included our advertisement in their e-newsletter.

Flyers

Approximately 50 hard copies of flyers were distributed in the community via community events and local and community organizations. Community organizations and individuals were encouraged to forward or share the information among others who might be interested. The visibility of the flyers in the community helped provided legitimacy and familiarity of the study and made initial contacts more positive.

Word of Mouth

Participants were also recruited via word of mouth, with the message spread among local community organizations. Participants who enrolled in the study were also encouraged to share and inform others who might be interested, serving as agents to expand recruitment.

Advertising on Websites

A free editorial piece was written for a website that provided information, guides, and events in Auckland for families with children. The website was widely accessed by parents, with over 37,000 followers on their Facebook page. The study was also advertised on the University of Auckland's research opportunity website.

Email Listserv

A recruitment email describing the study was sent to demographically diverse email lists of organizations across New Zealand, including the University of Auckland and "Health Promoting School" (now inactive), with subscribers comprising educators and health professionals. Individuals were encouraged to forward the recruitment email to parents who might be interested.

Social Media

A number of community organizations were approached via email and personal network for permission to post our advertisement on their social media pages. Of the 47 organizations approached, 9 (19.1%) promoted our study and posted the advertisement on their social media pages. Furthermore, a paid Facebook ad post was set up during week 18 of recruitment, and it lasted for 2 weeks and targeted parents who resided in New Zealand. We monitored the performance of the ad campaign, as response drop-offs were common over time.

Targeted Minority Recruitment

Multiple strategies were used to recruit the ethnic minority. These included focused outreach efforts utilizing social networks of our research team and emphasized heavily on direct person-to-person contacts and community referrals. In addition to initiating contacts with key members of the community, our research staff also relied on other events and group settings that involved the target community, such as community events, church groups, and sports clubs, where they informally provided information about the study.

Study Procedures

Care was taken to minimize participant burden, a factor that likely contributes to study enrolment and retention [19], to engage participants throughout the trial, and to maximize retention. Specifically, we anticipated that the delivery of the program via text messages would be a possible way to minimize participant burden by reducing logistic barriers for parents. Efforts were made to ensure that data collection at each time point was brief and took no longer than 10 minutes for participants to complete. Overall, each participant needed to spend only 1 hour (including providing study information, screening, baseline, and 1- and 3-month follow-ups), across a 3-month period, to complete the study, over and above the time to receive the program.

Screening and eligibility of interested participants were assessed over the phone. Our research assistant provided information about the study and made sure that the participants understood the importance of follow-up data collection being essential and integral to the research. Participants were explicitly told that participation involves completion of 3 sets of questionnaires at various time points. Eligible individuals had 2 weeks to provide consent and complete the baseline assessment. Personalized reminder emails were sent to eligible individuals between 3 and 5 days postscreening if they had not completed the assessment. On day 10, a phone call was made to remind the study participants to complete the baseline assessment. Up to 3 emails and 2 phone calls were made before the eligible participant was deemed unable to contact or as someone who refused participation.

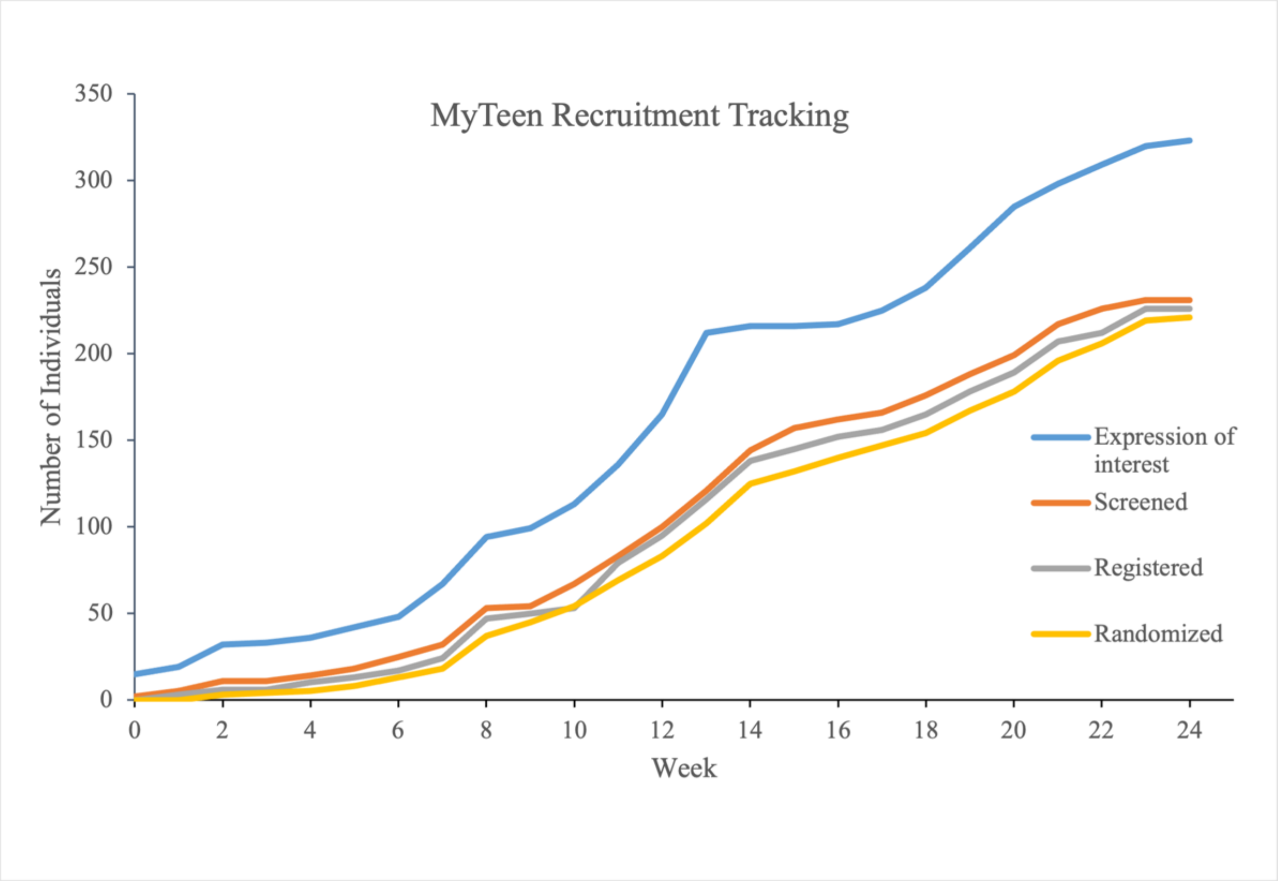
Assessments were conducted immediately post intervention (1 month) and 3 months after randomization. To maximize data retention at each assessment, multiple methods of communications were used to support participant retention, including texting, emailing, and phone calls. Five days before the assessment was due, participants were sent a reminder email to thank them for their participation and remind them about the upcoming assessment. For the control group, the email also specified that the participant would have the option to receive MyTeen text messages upon completion of the final assessment. For participants who did not complete the assessment within 3 days of the assessment email, up to 2 text message reminders (3-4 days apart) were sent and a final email or phone call was sent after 2 weeks of noncompletion. We incentivized participants with a NZ $20 (US $13.60) supermarket voucher upon completion of all assessments and the option to be included in a draw for a supermarket voucher valued at NZ $150 (US $102).

Results

Recruitment Tracking

Figure 1 shows the number of participants who expressed interest over time. We were unable to quantify successful enrolment for each strategy separately as they were not independent. Recruitment was tracked by the project manager (AW) and reported to the research team weekly. For the first 4 weeks, most of the recruitment effort focused on targeted minority recruitment. However, recruitment was slow, and only 22 individuals expressed interest, excluding those who expressed interest from the focus groups conducted during the development stage of the project (n=15). The research team therefore targeted the wider community and distributed advertising material through email lists and social media over the next 6 weeks, resulting in a surge in interest (n=93). By week 12, a total of 200 individuals had expressed interest, and our research assistants were at full capacity to screen all potential participants. Decision was therefore made to put recruitment on hold and resumed in week 16. After reviewing the demographic profile of all participants, a paid Facebook ad targeting ethnic minority groups was posted. A number of schools were also contacted for recruitment to increase the chance of recruiting minority groups. Over 22 weeks, 319 parents expressed interest in the study, at which point, all recruitment activities were ceased. Screening was conducted over the phone with all interested individuals; 50 (15.7%) participants were no longer contactable, 18 (5.6%) participants were no longer interested, and 15 (4.7%) participants were deemed ineligible prior to completing the screening process. In total, 236 (74%) participants completed screening, of which 48 (20.3%) reported hearing about the study via email; 64 (27.1%), via advertisements (websites); 64 (27.1%), via Facebook; 29 (12.3%), via referral, including word of mouth and face-to-face approaches; and 31 (13.1%), via other means (eg, schools). No specific strategy appeared to be more engaging for Māori and Pacific participants, which is likely due to the small sample of ethnic minorities. Similarly, due to the small sample of fathers, no difference was observed among different recruitment strategies. Data on demographics were obtained at baseline.

Figure 1. Number of participants who expressed interest in the study over time.



Sample Characteristics

Table 2 presents the demographic characteristics of the study sample. The final sample resulted in 221 randomized participants who met the eligibility criteria, exceeding our recruitment target of 214 participants. The sample comprised 210 (95%) mothers (including stepmothers), with a majority (167/221, 75.6%) of participants identifying themselves as European, followed by Māori (29/221, 13.1%), Pacific (17/221, 7.7%) and other (8/221, 3.6%).

Table 2. Demographic characteristics of the study sample classified by ethnicities.

Characteristic	Maori (n=29)	Pacific (n=17)	Non-Maori, non-Pacific (n=175)
Child's age (years), mean (SD)	12.4 (1.5)	12.2 (1.7)	12.3 (1.6)
Child's sex, n (%)			
Female	14 (48.3)	7 (41.2)	79 (45.1)
Male	15 (51.7)	10 (58.8)	96 (54.9)
Relationship to the child, n (%)			
Mother	27 (93.1)	15 (88.2)	166 (94.9)
Father	1 (3.4)	1 (5.9)	5 (2.9)
Stepparent	0 (0)	1 (5.9)	1 (0.6)
Grandparent	1 (3.4)	0 (0)	2 (1.1)
Close relative	0 (0)	0 (0)	1 (0.6)
Marital status, n (%)			
Married or de facto	20 (69)	14 (82.4)	183 (82.8)
Divorced, separated, or widowed	7 (24.1)	2 (11.8)	30 (13.6)
Never married	2 (6.9)	1 (5.9)	8 (3.6)
Education level, n (%)			
University	13 (44.8)	11 (64.7)	144 (82.3)
Trade or technical college	4 (13.8)	0 (0.0)	6 (3.4)
High school or less	7 (24.1)	5 (29.4)	19 (10.9)
Other	5 (17.2)	1 (5.9)	6 (3.4)
Family structure, n (%)			
Original family	17 (58.6)	12 (70.6)	130 (74.3)
Stepfamily	3 (10.3)	2 (11.8)	15 (8.6)
Sole parent family	6 (20.7)	2 (11.8)	22 (12.6)
Living with extended family	3 (10.3)	0 (0)	9 (3.4)
Other	0 (0)	1 (5.9)	2 (1.1)

Attrition

Attrition was low at the 1-month (4.5% overall; intervention group: n=5, 4.6%; control group: n=5, 4.5%) and 3-month (9% overall; intervention group: n=10, 9.2%; control group: n=10, 8.9%) follow-ups. On average, participants in the intervention and control groups took 3.72 (SD 5.43) and 2.33 (SD 3.83) days, respectively, to complete the 1-month assessment, and 3.82 (SD 6.74) and 4.09 (SD 7.71) days, respectively, to complete the 3-month assessment.

Discussion

Our recruitment efforts were successful—the target sample size was achieved, with a high completion rate for the trial and within the anticipated time frame. However, we did not achieve the representative demographic makeup (ethnicity and socioeconomic variables) in our trial. Below, we describe and reflect on the lesson learned.

Traditional Recruitment Strategies

First, reliance on traditional recruitment methods, such as distribution of flyers and posters, targeted minority recruitment via word of mouth, and community referral was not particularly effective. There were few referrals from community organizations where we had posted our flyers. Similarly, handing out flyers at community events resulted in limited responses. It is likely that merely posting and handing out these flyers was not enough in these settings. Recruitment of parents from schools attended by their children was also not very fruitful. In all, 388 schools nationwide were contacted for recruitment, but only a few responded. Nonetheless, those that did advertise our study spiked an increase in expression of interest. Our findings on engagement with schools are similar to that of other studies [20]. A previous study that recruited parents of primary school students into a smoking cessation trial reported similar challenges, wherein only 16.3% of the schools contacted agreed to distribute recruitment materials [20]. Although schools can be a valuable resource for recruitment, gaining access to schools proved to be very challenging and time consuming. Studies that have successfully worked with schools to recruit participants (usually students) suggest that it requires extensive planning (ie, fitting the timeframe of the school terms), building relationship with the school, connecting with key contacts, and contributing to the best interest of schools [21]. This may not be feasible for studies that are resource constrained.

Web-Based Strategies

Web-based strategies appear to have yielded the most response in our trial. A number of parents responded to our Facebook post and website advertisements. The use of email listserv also appeared to have yielded a spike in interest; however, it was not possible to know how many parents were reached, as individuals were encouraged to forward the email to others who might be interested in the study. It is worth noting that the ability of email lists to target a select population may result in a sample that is not representative of all parents. Our advertisement email sent to the University listserv resulted in sample of highly educated parents, which was thus less representative of the general population. Obtaining permission to post to listservs, which may accept posts only from group members, can also be challenging. Nonetheless, this approach required minimum staff effort. Studies examining web recruitment strategies have reported large variation in how many participants researchers can recruit, cost per participant, diversity of the sample, and the length of time required for recruitment [4,22]. This has implications for researchers and areas of study that may not have the funding required to enable large-scale recruitment using more traditional recruitment methods [4].

Reaching Ethnic Minorities

Second, although we actively sought to recruit ethnic minorities, we failed to attract interest. We were aware of our limitations at the onset of the project in recruiting minority populations but were restricted by resources and time to address the challenges. We recognize that recruitment strategies should be culturally sensitive and tailored to the needs of a given group. Time to build relationships and resources to comprehensively reach a community is a requisite. By developing a partnership with trusted individuals and organizations early during the research process, researchers can build a bridge to communities that may feel disenfranchised from traditional academic research [7,23,24]. Although these strategies are intensive and expensive to build and sustain [24], they are essential if the experience of these groups with interventions is to be evaluated.

Successful Recruitment Factors

In addition to the strategies used, the success of our recruitment and retention efforts may have been attributed to the following factors. First, careful planning and continuous monitoring throughout the recruitment process appeared to be critical for success. We set realistic recruitment targets, monitored progress, and modified our recruitment plan against those targets as needed. Recruitment was boosted when there was a decline in interest, whereas recruitment strategies were put on hold when there was a sudden increase in the expression of interest, leading to a backlog of participants requiring to be screened. A high degree of flexibility in the recruitment strategies was thus deemed necessary.

Second, our use of simple appreciation and reminder emails between assessments appeared to help with participant retention. On average, participants completed the follow-up assessment within 2 to 3 days of receiving the email link to the survey. These efforts encouraged participants to feel connected to the project, fostering an overall sense of commitment from the beginning through the completion of the study.

Third, the strength-based and delivery mode of the program may have attributed to achieving our target sample. The framing of the program as a strengthening approach to support families was important. This led to subsequent communication with potential participants in a positive way and reduced the stigma of help-seeking. For example, our formative work identified that the word “intervention” was off-putting for parents; hence, the word “program” was used in all subsequent advertising material for the trial. In addition, text messaging was a proactive approach to delivering parenting information to participants, requiring minimal effort and time commitment. The low attrition rate in our study is consistent with other studies on text messaging programs. Previous meta-analyses across a variety of text messaging–based programs found a mean retention rate of 86% [25], with retention rates ranging from 46% to 96% [26]. In our study, the ease of access is likely to have increased participation, as time constraints and logistical barriers are often raised by parents as barriers to continuation in parenting programs [27]. There has been growing acknowledgement in parenting program research for different modalities, including web-based alternatives and mHealth technology [12,28]. Our trial demonstrated the feasibility and effectiveness of providing brief preventative parenting support solely via text messages.

Finally, there was a demand for support for parents of adolescents in New Zealand. Our formative work reported that parents perceived a lack of support in the community and were interested in parenting support [18]. Many parents identified everyday parenting challenges and were interested in learning about positive parenting strategies, adolescent development, tips for improving parent-adolescent communication, and evidence-based resources. The findings were reinstated in our main trial, where parents expressed the need for more information and reported high satisfaction with the program [10].

Limitations

Our target population comprised parents of New Zealand adolescents. Therefore, the findings may not be generalizable to studies involving other populations. Different recruitment strategies also vary substantially in cost per participant recruited, but because the study was not designed to compare the effectiveness or cost-effectiveness of recruitment strategies, we are unable to estimate the cost-effectiveness and the investment yield ratio for these strategies. Rather, our findings provide lessons to inform future studies.

Despite efforts to recruit parents from diverse population groups, our sample was predominately female, married, and of high social economic status. Many of our participants have also completed tertiary education. This is consistent with past research that reported higher levels of parent education is a predictor of parent uptake in programs [7].

Fathers were underrepresented in our study. This is a common challenge in parenting research, with fathers considered as *hard-to-reach* parents [29]. A meta-analysis of the parenting program *Triple P* found that of 4959 participants in 21 studies conducted across several countries, only 20% were fathers [30]. Underrepresentation of fathers as participants in parenting programs is concerning. Qualitative studies conducted with fathers of young children found that many fathers perceived parenting programs to be designed for mothers and that they were reluctant to seek parenting support from any formal source, as help-seeking was perceived by men as a failure and conflicted with their views on masculinity [31]. Advertising efforts that are not directed at fathers, are not related to them, or are perceived as stigmatizing are unlikely to reach fathers. Other barriers included services deemed as untrustworthy, uninterested in, or even hostile toward fathers [32,33]. Overcoming the above barriers are important to successfully engage fathers in such research. Research to understand how their engagement and participation can be maximized is urgently needed.

We also did not obtain any information from those who did not participate. Parents who do not initially engage could reveal different barriers or characteristics to those recruited into the program. Their views are therefore important and should be captured in future studies.

Conclusions

Recruitment and retention are critical aspects of research for parenting programs, and it is unlikely that there will be a one-size-fits-all recommendation. It is therefore important that efforts are well documented to enable researchers to make more informed decisions on how and where to best recruit and therefore maximize outcome [34].

With the rapid development of technology and web-based platforms, the field would greatly benefit from empirical research designed to test the efficacy and necessity of different recruitment and retention strategies, as well as more detailed reports regarding recruitment and retention methods. Web-based recruitment strategies provide a viable means for obtaining a geographically diverse sample. Recruiting the most affected populations should be a priority, and more resources are needed to do so. Further research is needed to examine the effectiveness of tailoring recruitment strategies to different populations.

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Authors' Contributions

JTWC is the primary investigator of this study and wrote the first draft of the manuscript. AW oversaw the management and day-to-day operations of the project. JTWC and YJ reviewed and conducted the analyses. YJ, CB, KS, and MS contributed to the design of the study and were involved in revising the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Facebook ad and flyer designed for recruitment.
[DOCX File , 734 KB - pediatrics_v4i4e17723_app1.docx]

Multimedia Appendix 2
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 1088 KB - pediatrics_v4i4e17723_app2.pdf]

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Abbreviations

mHealth: mobile health
PSOC: Parenting Sense of Competence scale

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Original Paper

Using Social Media as a Research Tool for a Bespoke Web-Based Platform for Stakeholders of Children With Congenital Anomalies: Development Study

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Abstract

Background: Limited research evidence exists on the development of web-based platforms for reciprocal communication, coproduction research, and dissemination of information among parents, professionals, and researchers. This paper provides learning and the outcomes of setting up a bespoke web-based platform using social media.

Objective: This study aims to explore the establishment of a web-based, multicontextual research communication platform for parents and stakeholders of children with congenital anomalies using social media and to identify associated research and ethical and technical challenges.

Methods: The ConnectEpeople e-forum was developed using social media platforms with a stakeholder engagement process. A multilevel approach was implemented for reciprocal engagement between parents of children with congenital anomalies, researchers, health care professionals, and other stakeholders using private and invisible and public Facebook groups, closed Twitter groups, and YouTube. Ethical approval was obtained from Ulster University.

Results: Nonprofit organizations (N=128) were invited to engage with an initial response rate of 16.4% (21/128). Of the 105 parents contacted, 32 entered the private and invisible Facebook groups to participate in the coproduction research. Public Facebook page followers rose to 215, a total of 22 posts had an engagement of >10%, and 34 posts had a reach of over 100. Webinars included requested information on childhood milestones and behavior. YouTube coverage included 106 ConnectEpeople videos with 28,708 impressions. Project information was obtained from 35 countries. The highest Facebook activity occurred during the early morning hours. Achievement of these results required dedicated time management, social media expertise, creativity, and sharing knowledge to curate valuable content.

Conclusions: Building and maintaining a multilayered online forum for coproduction and information sharing is challenging. Technical considerations include understanding the functionality and versatility of social media metrics. Social media offers valuable, easily accessible, quantitative, and qualitative data that can drive the reciprocal process of forum development. The identification and integration of the needs of the ConnectEpeople e-forum was a key driver in the dissemination of useful, meaningful, and accessible information. The necessary dedicated administration to respond to requests and posts and collate data required significant time and effort. Participant safety, the development of trust, and the maintenance of confidentiality were major ethical considerations. Discussions on social media platforms enabled parents to support each other and their children. Social media platforms are particularly useful in identifying common family needs related to early childhood development. This research approach was challenging but resulted in valuable outputs requiring further application and testing. This may be of particular importance in response to COVID-19 or future pandemics. Incorporating flexible, adaptable social media strategies into research projects is recommended to develop effective platforms for collaborative and impactful research and dissemination.

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KEYWORDS

Facebook; YouTube; Twitter; social media; metrics; e-forum; congenital anomalies; coproduction; COVID-19

Introduction

Background

This is the second paper from the ConnectEpeople project. The first paper reported on project recruitment and findings from coproduction research [1]. This second paper sets out to share the overall learning from the research, technical and ethical obstacles, challenges, and successes in developing the ConnectEpeople e-forum.

An e-forum is defined as a “virtual space for online discussion, allowing deferred participation” [2]. The ConnectEpeople e-forum was an experimental, bespoke web-based community for coproduction research, discussion, information sharing, and dissemination established within social media platforms. The development and management of the e-forum was complex, and limited publications with practical guidance or evaluation methodologies are available. Elliott et al [3] stated that a “gap exists around best practices in establishing, implementing, and evaluating” social media for research purposes. Therefore, the research team’s findings and experiences are reported here to provide practical advice and recommendations for those planning to use social media for health research activities.

The ConnectEpeople e-Forum

The initial step was to identify the platform on which to host the e-forum. The ConnectEpeople e-forum was intended as a meeting place for stakeholders in the life world of children with one of four congenital anomalies (CAs): congenital heart defects (CHDs), cleft lip with or without cleft palate (CLP), Down syndrome (DS), or spina bifida (SB) from across 9 European countries. A scoping review conducted in 2017 of the most commonly used social media sites by CA and parent support organizations identified more than 97% of CA organizations used web-based communication, with Facebook (82%) and Twitter (56%) being the most popular [4]. In addition, the ease of use and ubiquity of social media distinguished them as ideal platforms for developing e-forums. Social media offer a range of functions to users, that is, creating a presence and identity, information exchange, and as a communication channel to build relationships or communities based on reputation or characteristics [5]. Trust in web-based communities is a direct function of credibility and impartiality [6], traits essential for successful research outcomes. Trustworthy web-based resources enhance viewers’ feelings of reassurance, control, and coping [6].

Literature Review

The next step was to review the literature to collate current knowledge and recommendations on designing and developing social media–based research. Connecting communities across geographical or institutional boundaries is a fundamental use of information and communication technology [7]. Community informatics includes several methodological pillars, including contexts, values, cases, processes, and systems [8]. Combined with these pillars, frameworks that systematically incorporate sociability and usability into the design and development process are an important element for building a web-based platform [9].

A rapid systematic review of the literature from 2012 to 2020 was undertaken (Multimedia Appendices 1 and 2) to identify papers that described the establishment of a web-based platform for patient, parent, or public and professional communication. CINAHL, MEDLINE (Ovid), Scopus, and hand searches identified 6 papers [10-15] that described the design and establishment of web-based communication platforms. Owens et al [10], Dyson et al [12], Greenwood et al [14], and Han et al [15] engaged with parents, patients, carers, and other stakeholders to generate research questions for children with special needs, respiratory conditions, and people with diabetes. A total of 4 studies used purpose-built websites [10,12,13,15], and 3 studies used social media [11,12,14]. In addition to their website, Dyson et al [12] used Facebook and Twitter to work with parents but with limited success. In contrast, Russell et al [11] used private and invisible Facebook only and established an active, engaged web-based community. Only 1 team had used multiple platforms for separate functions or to engage with different stakeholders, using Facebook, Twitter, Google Hangout, emails, and face-to-face, with considerable success [14]. However, no author has provided recommendations on the most suitable approach for developing a social media–based communication platform. Therefore, process data from the ConnectEpeople project are presented to provide unique insights for researchers planning to establish a multilayered, social media–based research e-forum.

Objectives

The objectives of this paper are to (1) explore the research, technical, and ethical challenges involved in developing a bespoke, experimental e-forum; (2) identify quantitative and qualitative data collection and analysis methods for social media–based research; and (3) discuss the practical issues of establishing a user-friendly, multicontextual, communication e-forum.

Methods

Overview

ConnectEpeople was developed as a complex, adaptive, web-based communication e-forum. It was the beta test of a social media–based network to connect with stakeholders in the lives of children with CHD, CLP, DS, and SB, through Facebook and Twitter as the key communication platforms. The key function of the e-forum was coproduction research and to become a communication and dissemination platform for research and information. There were three key members of the research team (MS, JEMMc, and DE) involved in the design, setup, and running of the ConnectEpeople social media accounts.

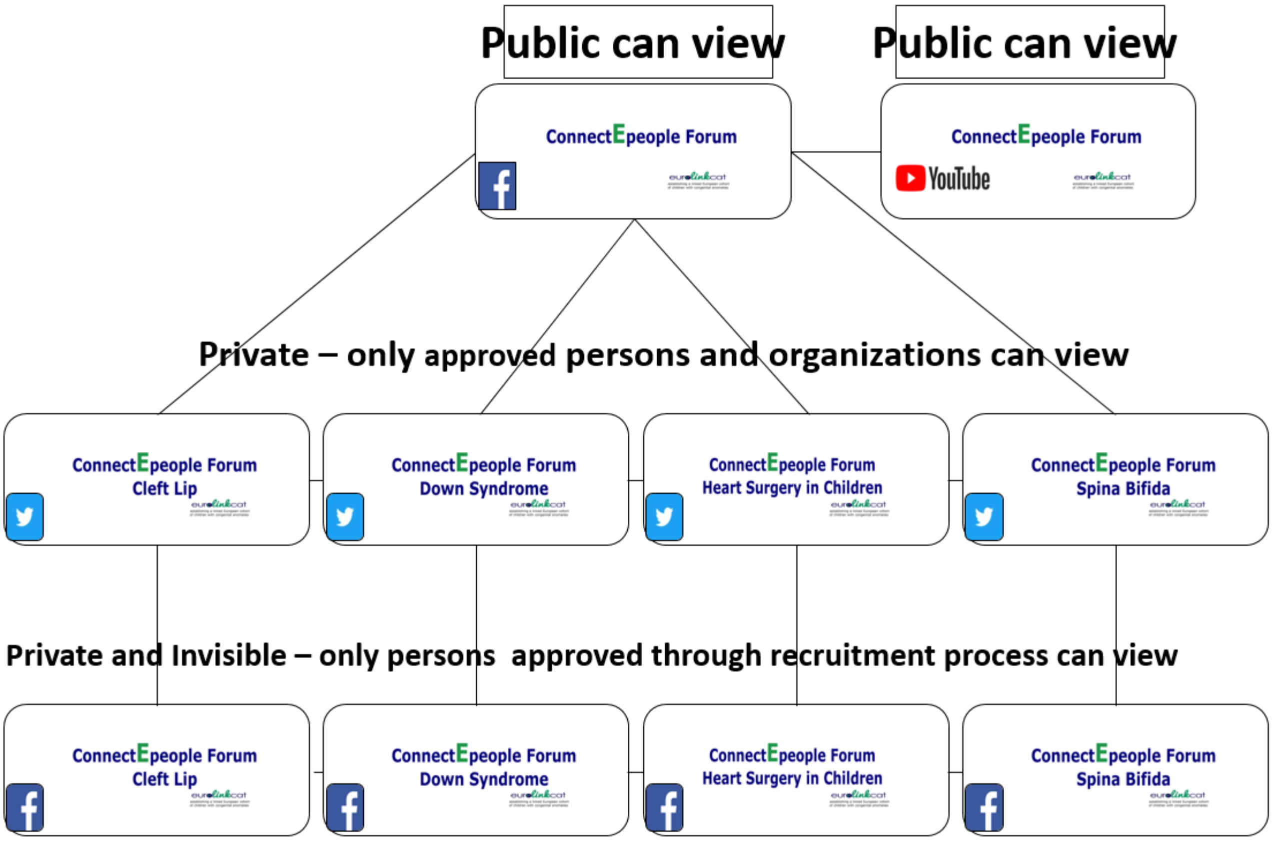
As previously reported [1], in the coproduction research stage, 32 research aware parents (RAPs) were recruited from 9 European countries via their parent support organization (n=18), CA registry leader (RL; n=7), ConnectEpeople project survey (n=5), and the project public Facebook page (n=1) and by word of mouth (n=1). On average, parents had two discussions with the researcher before agreeing to participate. The most popular method of meeting the researcher was Skype (n=13), followed by telephone (n=9), WhatsApp video calling (n=8), Facebook messenger (n=1), and FaceTime (n=1). Participants who preferred to use their phones lived in the United Kingdom. The recruitment process took an average of 51 days (SD 40.44), ranging from 6 to 129 days. Completion of the requisite consent form, different time zones across Europe, and children's health needs were contributing factors.

RAPs joined 1 of 4 condition-specific private and invisible Facebook groups [1]. Private and invisible Facebook groups are invisible to the public, and membership was by invitation only. Using a modified James Lind Alliance approach [16], RAPs in each of the four groups worked with researchers to develop a list of the 10 most important research questions relating to their child's CA [1] (Multimedia Appendix 3). All RAPs read and signed a social media policy and were offered training to use Facebook and Twitter.

Building the ConnectEpeople e-Forum

The ConnectEpeople social media–based e-forum (Figure 1) was developed to connect stakeholders of children with CHD, CLP, DS, or SB. The e-forum used four CA-specific private and invisible Facebook groups accessible via invitation only to parents of children with CAs engaging in coproduction research. A total of 4 CA-specific closed Twitter groups were accessible to any person requesting to join. A public Facebook page [17] and, as the project progressed, a YouTube channel [18] were accessible to any member of the public.

Figure 1. The ConnectEpeople e-forum structure.



Planned Process for Engagement With Stakeholders

The initial plan was to work with RLs across 9 European countries who would act as gatekeepers to connect the research team with local CA organizations, health care professionals (HCPs), and parent support organizations (Multimedia Appendix 4). This process was deemed essential, as they spoke the native language and were attuned to the culture. The intention was for RLs to inform these individuals about the ConnectEpeople project and invite them to engage with the project. An information technology readiness survey carried out with RLs identified the first technical challenge as the results demonstrated that they did not have the necessary social media profile or the internet access required to take part in or facilitate the work of ConnectEpeople. Therefore, parent support organizations across Europe were identified and approached directly via social media by the research team and invited to become gatekeepers for the research study.

Engaging With Stakeholders

Nonprofit organizations and parent support organizations for CAs across Europe initially identified as part of a scoping review [4] were contacted via email and Facebook messenger and provided with details of the ConnectEpeople project and invited to engage with the research team.

Organizations were invited to engage in four ways:

1. To act as gatekeepers to recruit parents to the ConnectEpeople coproduction research arm
2. To mutually follow Twitter accounts
3. To like, share, and post on the ConnectEpeople public Facebook posts
4. To actively participate in ConnectEpeople webinars

Following the introduction by organizational gatekeepers, potential RAPs were emailed to schedule a screening meeting using Skype, FaceTime, WhatsApp, Facebook Messenger, or telephone. Only those willing to use Facebook could join the project. Parents were able to join the project by contacting the research team through the public Facebook page, following the completion of a project-specific survey, and through contact with RLs.

As a result of the changes in the planned process for stakeholder engagement, the initial recruitment of RAPs was slow. Therefore, the ConnectEpeople survey was developed with RAPs as the first piece of coproduction research. The survey allowed the research team to gather data from a global community of parents of children with CAs and meet the research deadlines for the identification of research priorities.

Communication With Stakeholders

Posting on the Private and Invisible Facebook Groups

Private and invisible Facebook groups were used exclusively to facilitate coproduction research with parents from 7 European countries. Research questions were cocreated, and using an iterative process, the top 10 research priorities were agreed upon [1]. The four private and invisible Facebook groups received the same research questions and information simultaneously. Email was used to communicate information that could not be posted on Facebook, such as large documents. Group posts consisted of research questions, information regarding webinars, updates on the research project, and research activities. RAPs and moderators could freely post in the private and invisible Facebook groups; however, no publicly available hyperlinks were posted to preserve members' anonymity. Web-based meetings were organized via *Doodle Poll* to meet, discuss, and receive updates on the project, and RAPs could contact the research team directly by email at any time.

Posting on Closed Twitter Accounts

For those who wished to follow any of the four closed Twitter accounts, ConnectEpeople sent them a follower request. Membership requests were reviewed by the administrators to ensure legitimacy before acceptance. Twitter accounts demonstrating some activity in their timeline with the corresponding CA were accepted. ConnectEpeople followed all the followers' accounts. Tweets and retweets were screened to ensure that they were specifically related to research, web-based courses, upcoming events, human interest stories, education, and policy news.

Posting on the Public Facebook Page

One public Facebook page was set up to share information and for discussions [17]. Regular posts began on January 7, 2018. Posts were generated by the research team, reposted from organizations followed by ConnectEpeople on Facebook, or identified by the administrators or stakeholders as valid and relevant. No advertisements or calls for donations were reposted, and resources were added to the Facebook public page, including web-based courses and links to research articles.

Development of the YouTube Channel and Webinars

Following discussion in the private and invisible Facebook groups and via the project survey, parents identified topics on which they wanted to have more information. This led to the development of the project webinars, giving all stakeholders the opportunity to hear from and engage directly with CA experts from academia, research, and health care. Webinars were held using the videoconferencing software Go To Meeting (LogMeIn), Skype (Microsoft), or Zoom (Zoom Video Communications) and were live streamed. The ConnectEpeople YouTube channel [18] was set up in March 2018 to share project webinars and videos. Webinar videos were cut into short accessible videos and are available to the public on the YouTube channel.

Data Collection and Analysis

The team collected a wide range of data to determine the most meaningful and impactful information. Qualitative data and feedback from RAPs and other stakeholders and quantitative data, including the number of responses, the time taken to respond, and preferred mode of communication, were recorded. The research team maintained a detailed log of their research, administrative duties and activities, and experiences. The key quantitative outcome measures for the e-forum were metrics data for each of the public social media platforms, as detailed in Textbox 1. The response rates for research-related posts were calculated for the private and invisible Facebook groups.

"Reach is the total number of people who see your content. Impressions are the number of times your content is displayed no matter if it was clicked or not" [19]. Engagement on Facebook is measured by "likes, reactions, comments, shares, and some clicks on links, photos, or videos. Engagement rates on Facebook are measured by engaged users, not total engagements; if someone likes and comments on the post, that counts as two engagements, but one engaged user" [20]. Interactions on Facebook are measured as "communication between an audience member and your...social profile" [21].

Textbox 1. Data collected for each social media platform used in the ConnectEpeople e-forum.

Social media platform and the metrics collected

- Closed Twitter
  - Followers
- Public Facebook
  - Reach, engagement, views, interactions, and followers
- YouTube
  - Views and impressions

Ethical Considerations

Ethical approval for the study was obtained from the Ulster University, Institute of Nursing and Health Research, Ethics Filter Committee on November 21, 2017.

Only parents who had local social support were recruited to ensure that help was available and accessible should they have become distressed at any point during the project. The project screening process for potential RAPs included completion of the State-Trait Anxiety Inventory (STAI) [22] to limit the risk of any potential emotional burden of taking part in a sensitive research project. Parents provided written informed consent. The use of private and invisible Facebook groups protected the identity and privacy of RAPs and their children.

Posts on the private and invisible and the public Facebook page were reviewed by the administrators before being approved to reduce the risk of inappropriate comments. Any potentially controversial or sensitive comments were discussed among the 3 key research team members for consensus on posting.

Results

Engaging Stakeholders

CA Organizations

In total, 128 nonprofit and parent support organizations were contacted by email (n=77) and Facebook (n=51). Those contacted by email received 2-3 follow-up messages and 21% (16/77) responded, 1 of whom declined to participate. Of the organizations contacted via Facebook, 10% (5/51) responded, 1 of whom declined the invitation. As the project progressed, email introductions were made by gatekeeper organizations, which facilitated the research team to make new contacts. Response times varied considerably, and 4 of those who responded via Facebook did so within 48 hours and a fifth responded in 59 days. Email responders averaged 72 days (7-365 days).

Research Aware Parents

In total, 105 parents were contacted, 54 (51.4%) responded, 38 (36.2%) completed the screening process, and 32 (30.5%) entered the ConnectEpeople private and invisible Facebook groups for CHD (n=4), CLP (n=5), DS (n=13, one RAP dropped out), and SB (n=9). Recruitment was conducted from January 2018 to March 2019 [1].

ConnectEpeople Private and Invisible Facebook Groups

Over a 19-month period, the research team posted one research-related post per week in the private and invisible Facebook groups. The CHD group was the most active in terms of average number of RAP’s responses to these posts with 54 responses per participant, followed by SB (33.4 responses per participant), CLP (27.2 responses per participant), and DS (7.4 responses per participant). A total of 2 web-based group meetings took place with 13 of 28 and 5 of 28 RAPs responding to *Doodle Polls*, and 4 attended the first meeting and 5 attended the second meeting.

ConnectEpeople Closed Twitter Group Posts

In total, the 4 closed Twitter groups had 75 followers and followed 650 individuals and organizations.

Two RAPs agreed to follow the closed Twitter groups (SB and CHD). However, the other RAPs did not wish to engage:

> *I never used Twitter because to me it seems like a spot for weird people with too much time. Sorry but I do not like to test it.* [CLP, Germany]
>
> *No sorry I don’t use any other social media apart from Facebook...spend too much time on here as it is!* [CHD, United Kingdom]

ConnectEpeople Public Facebook Data

To date, the ConnectEpeople public Facebook page [17] has 215 followers. One researcher logged on to the public Facebook page daily and posted or reposted information on the four CAs of interest, such as human interest stories, research, public information, and health. All posts were in English, as this was the first language of the researcher. Reposts were from reputable organizations that ConnectEpeople was following. Reposts in languages other than English were first translated using Google Translate. If the researcher could not determine the content following translation, the post was not reposted.

Facebook Insights was used to analyze public Facebook group metrics. Posts with a reach of 100 or above and an engagement rate of 21 or above (10%) were reviewed. Engagement rate was calculated as total engagement or followers × 100 [23]. There were 22 Facebook posts with an engagement of 21 and above, and 34 posts had a reach of 100 and above.

The posts with the greatest reach were those related to project recruitment and survey, which were pinned to the top of the Facebook page. The post with the highest reach (1974) and highest engagement (306) was reposted on *the Mighty* Facebook page and titled “As the school year begins please talk to your kids about disabilities” [24]. *The Mighty* is an online health community created to empower and connect people facing health challenges and disabilities [25]. The ConnectEpeople project–generated Facebook post with the highest engagement (n=132) was one regarding the “ConnectEpeople Research – Parents Voices World Spina Bifida and Hydrocephalus Day 2018” webinar, and the reach was 1282.

Figure 2 shows the number of people who had sight of the public Facebook page. As for all social media projects, the number of people was small (<100) in the early years (January 2018) and increased as the number of interesting posts increased. The recruitment drive in March 2018 shows initial interest, and as posts became more common, additional people viewed the material. The largest number of views (>3000 people) occurred in September 2018. These views were driven by interesting posts or discussions.

Figure 2. The people for whom any content from the ConnectEpeople public Facebook page entered their screen from January 2018 until December 2019.

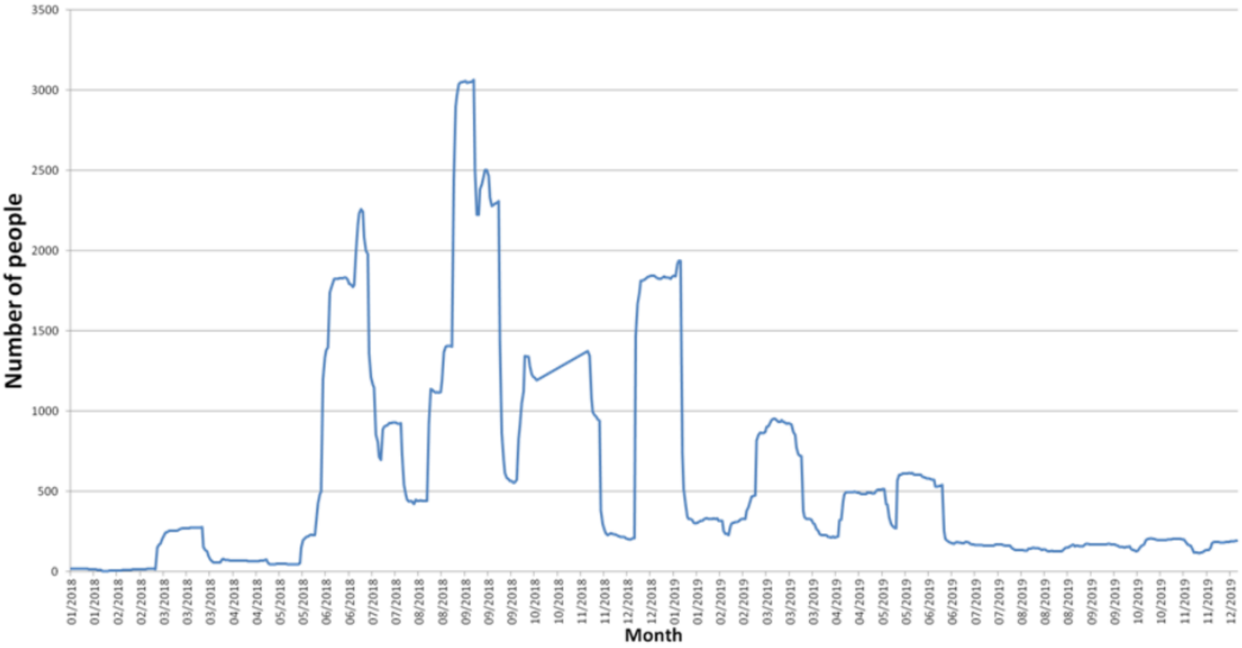
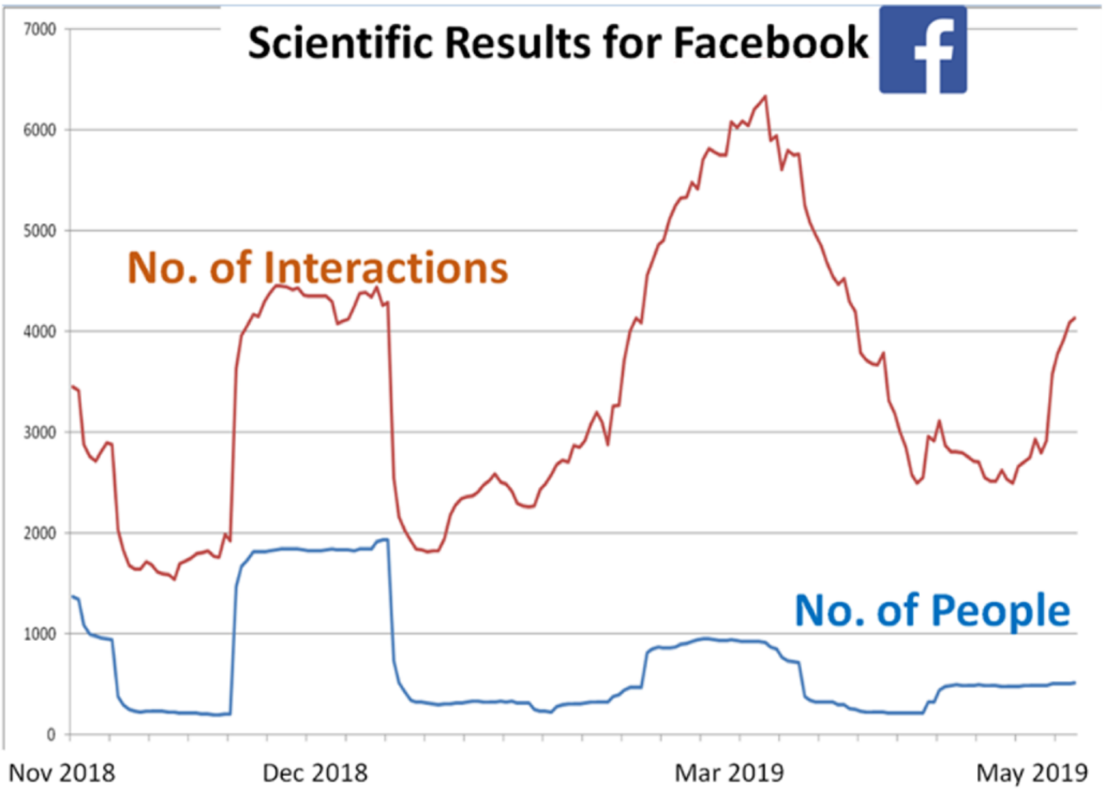


Figure 3 highlights the number of interactions with different posts, compared with the number of people viewing that post. For example, in December 2018, although almost 2000 people viewed the post, there were more than 4000 interactions, giving an average interaction per person of 2:1. In March 2019, although almost 1000 people viewed the post, there were more than 6000 interactions, giving an average interaction per person of 6:1. Thus, although the number of persons viewing was smaller in March 2019 than in December 2018, the March 2019 post attracted many more interactions (>6000) than the December 2018 post (>4000).

Figure 3. Interactions on the ConnectEpeople public Facebook page.



ConnectEpeople YouTube Channel

The ConnectEpeople YouTube channel currently contains 106 videos. To date, there have been 28,708 impressions for YouTube videos. The most viewed video was one from the World Birth Defects Day 2019 webinar titled “Dr Micaela Notarangelo Breastfeeding for cleft babies WBDD 2019” with 5649 views [26].

Development of ConnectEpeople Webinars

Overview

ConnectEpeople parents wanted to hear more regarding research and surgery, and they asked for more information on their child’s everyday needs. Webinars were developed to provide opportunities to hear from and speak to experts in the CA of interest. These included World Down Syndrome Day 2018 with 2509 people engaging, World Spina Bifida and Hydrocephalus Day 2018 with 6164 people engaging, and World Birth Defects Day 2019 with 1419 people engaging. Webinars with experts in the field of CAs, “Supporting families to enhance their child’s development” by Professor Roy McConkey (educationalist) had 2435 people engaging and “Home monitoring for children with complex heart conditions: new horizons of care for parents, clinicians and researchers” with Professor Frank Casey (consultant pediatric cardiologist) had 2998 people engaging. Those who took part included HCPs, support organization representatives, researchers, and parents. The webinars were cut into short topic-specific videos to promote engagement and posted on the project’s YouTube channel.

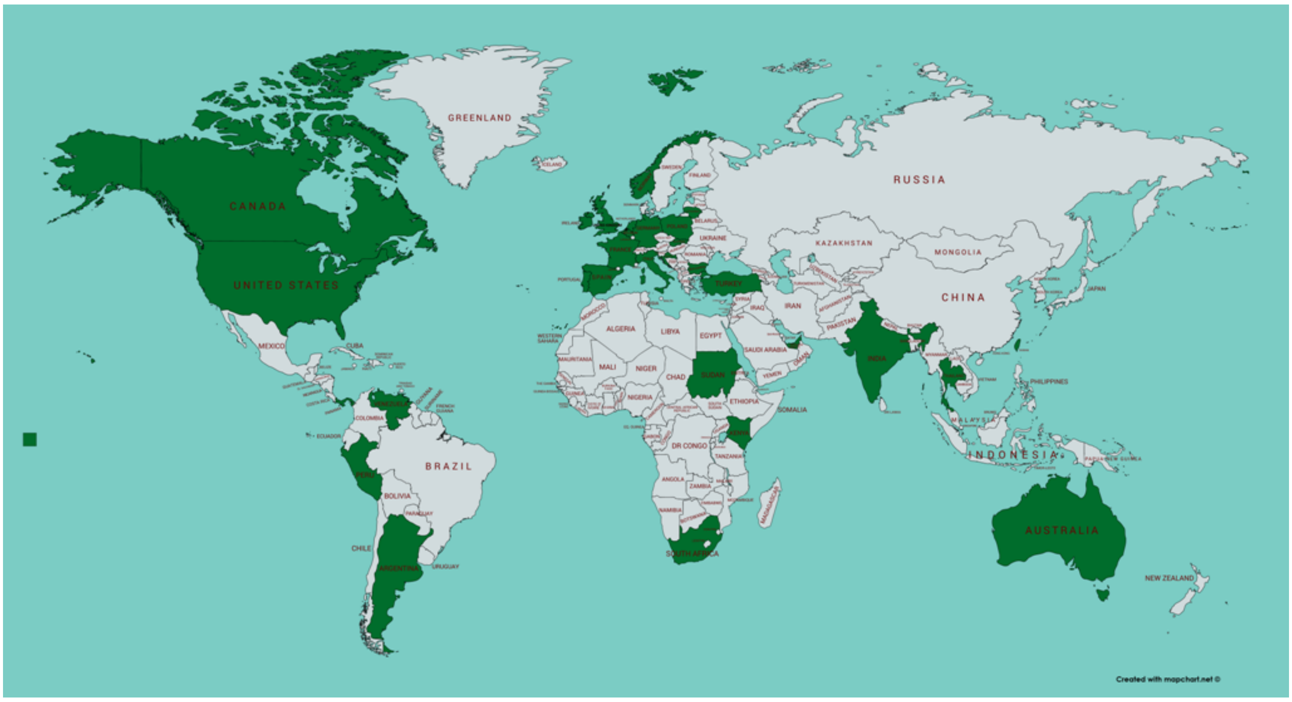
ConnectEpeople Research Team Members Characteristics

The 3 key members of the research team acted as administrators for the four private and invisible Facebook groups. One team member (DE) set up all on Facebook, Twitter, and YouTube accounts; managed webinars; cut and posted videos to the YouTube channel; and managed the Facebook Insights and metrics collection and analysis. DE also managed the technical aspects of Facebook, Twitter, and YouTube, such as changing banners. One researcher (JEMMc) managed the day-to-day running of the private and public Facebook groups and the 4 Twitter accounts, including screening follower requests on Twitter and posting and responding on Facebook and Twitter. JEMMc also managed contacts and recruitment to the ConnectEpeople project and the development of the webinars. The chief investigator (MS) oversaw the ConnectEpeople social media accounts and made final decisions on all private and invisible Facebook posts and webinar programs. The 3 key researchers were fluent in English only. Team members were available on social media daily from 9 AM to 4 PM and from 7 PM to 10 PM. Facebook and Twitter groups were also checked regularly over weekends and holidays.

Additional Findings

Information about ConnectEpeople was accessed by individuals in 35 countries (Figure 4). The most popular time of the day for views on Facebook was in the early hours of the morning with low levels of activity from 2 PM to 11 PM UTC, and on YouTube weekday evenings in line with primetime television. No arguments, negative comments, or inappropriate behaviors were posted on Facebook, Twitter, or YouTube during the project.

Figure 4. The countries in which ConnectEpeople outputs have been accessed.



Discussion

Principal Findings

On the basis of the rapid literature review undertaken and in agreement with Elliott et al [3], there is limited advice for researchers to conduct research based on social media platforms. Building and maintaining the experimental ConnectEpeople e-forum identified a number of interconnected research and technical and ethical learning outcomes for consideration. This may be of particular benefit for teams working with other geographically, culturally, or socially hard to reach groups, such as during the current COVID-19 pandemic. Social media are widely used by stakeholders in children with CAs [4]. Stakeholders were keen to get involved in ConnectEpeople and access new information relating to CHD, CLP, DS, and SB disseminated in a useful, meaningful, and easily accessible way.

Recruitment to the ConnectEpeople coproduction research web-based group was slow because of parents' family and personal needs. In addition, recruiting RAPs and other stakeholders living across Europe was complicated by the unexpectedly limited bilingual assistance and subsequent *cold calling* on organizations. However, the social media metrics and data collected demonstrate that the e-forum format is an effective and engaging communication platform and safe meeting place.

The ConnectEpeople project investigated the use of social media for research activities, including engagement, recruitment, coproduction research, communication and dissemination, quantitative and qualitative data collection, and creating research impact. Social media have broad applications for research, and the authors recommend incorporating a social media strategy into all research projects. Such a strategy must be developed with the flexibility to adapt and incorporate other platforms as they become available and using feedback from stakeholders.

A robust and effective social media strategy requires early financial investment, for while social media are generally free to access and use, considerable time and expertise are necessary to build successful, impactful research communities.

Research, Technical, and Ethical Considerations

Setup of the e-Forum

The ConnectEpeople e-forum was devised as an initial meeting place for geographically distant researchers and stakeholders, and although Elliott et al [3] recommend developing research platforms in collaboration with stakeholders, initial stakeholder input was not possible. Similar to Dyson et al [12], this project was intentionally designed to test multiple social media platforms. Facebook's greatest function is building relationships [5], and Twitter serves to build a web-based brand or identity. Therefore, these platforms were initially chosen for testing, given their popularity based on the scoping review results. The ubiquity of social media makes them ideal platforms to connect quickly and simply, as many people and organizations have their own accounts and are familiar with making connections via the internet. In addition, Facebook, Twitter, and YouTube are free to join and access. Once contact was made with parents and stakeholders, their views and preferences on communication platforms were sought, leading to the development of the webinars and the YouTube channel.

Lovari et al [27] recommend investment in *multichannel* strategies for web-based communication to effectively reach target populations. During the ConnectEpeople project, text, images, videos, and links were cross-posted on Twitter, Facebook, and YouTube, and information was tailored to the target population's needs before dissemination. The project saw limited uptake of Twitter groups by RAPs; however, organizations active on Twitter engaged. RAPs focused on engaging in discussions and sharing of information and a more meaningful web-based experience. As Twitter is more aligned with branding, identity, and limited discussion, this may have been a factor influencing use.

Social media–based studies rely on the digital infrastructure. Crucially, for this project before startup, an information technology readiness survey demonstrated that the aims of the project could not be met with the facilities available, leading to a major review of the project plan. Subsequently, the identified digital infrastructure needs were put in place. Digital infrastructure included data storage, access to apps, such as Facebook, Twitter, and YouTube, and additional apps to present webinars and web-based meetings as the project proceeded, such as Zoom. Digital infrastructure also included devices such as computers and mobile phones to enable the research team to have constant access to Twitter and Facebook, which was more active later in the day. Parents were most likely to connect to the internet via their mobile phones, as reported by Pew Research Center [28]. They were also most likely to connect at home. This was ideal for parents to be able to engage when they had free time but difficult to sustain dialog with the research team within working hours. The constant awareness of the project participants, any potential queries or concerns, or the opportunity to engage in sustained meaningful dialog may have led to an increased burden of responsibility for the researcher. It is important that project mobile phones are separate from the researcher's personal phones and consensus on availability on the web is agreed upon.

Recruitment and Engagement With Stakeholders

In this project, RAPs were key partners in identifying research priorities. The engagement and recruitment of parents was expected to take time, as it was difficult to reach groups with limited time availability due to caring for children with complex needs [29]. The initial task of engaging with organizations to act as gatekeepers was also unexpectedly more time consuming. There were a number of reasons for slow uptake identified during conversations with researchers. Organizations were keen to take part; however, many were led by volunteer parents, and time constraints were a major issue. Some organizations required leadership approval to participate; however, many only met biannually, leading to time delays. The key finding was that parents and other stakeholders were rightfully cautious of connecting to the web with groups reporting to be interested in their children. Ensuring participant safety in research poses additional demands when using social media, and Dol et al [30] stated that health researchers require information on "how to ethically use and engage with social media." Concerns regarding the safety, dignity, and privacy of RAPs and their children led the way for a protracted recruitment process that involved the use of the STAI to check anxiety levels and ensure no additional burden of research on parents. The ConnectEpeople team acknowledged that stakeholders should take the time they needed to ensure they were acting in their child's best interests. Overall, lack of time was the most common reason given for slow and limited responses in this research, and this reflects that parents who have children with complex health needs have additional concerns and demands on their time.

Organizations also experienced difficulty in finding suitable parents. In addition, only 16.4% (21/128) of the organizations responded. However, in agreement with Russell et al [11] and Han et al [15], the recruitment of parents was most successful when facilitated by trusted third parties, namely, parent support organizations and RLs, as they promoted authenticity. The initial positive personal interaction between the researcher and parents built rapport and trust and encouraged engagement with the project. Using private and invisible Facebook for coproduction was welcomed by RAPs.

Communication and Dissemination

The researcher conducting recruitment only spoke English fluently and lived in the United Kingdom and, therefore, relied completely on *cold calling* and strong interpersonal skills to build lasting connections with gatekeepers to facilitate successful recruitment. This also resulted in the necessity of recruiting RAPs who could speak English. The language barrier of pan-European projects and subtleties in language can play a huge role in connecting and communicating successfully on the web. For example, although the translation is available on Facebook, it is only useful for light social discussions and not for those involving technical words and terminology. In addition, cultural aspects and meanings of language can influence the perspectives and understanding of participants.

Good sociability in web-based communities includes the reciprocity and trustworthiness of interactions [31], an important factor in this project. In the ConnectEpeople project, RAPs and stakeholders involved in private and invisible Facebook group discussions were asked to agree to a project-specific social media policy. This was to ensure fair and courteous conduct by members, preserve privacy and confidentiality, and build trust. Clearly defined *rules of engagement* to safeguard individuals have been used for other studies using Facebook [11].

Separate private and invisible Facebook groups were developed for each CA of interest, as research participants trust others with the same life experiences as themselves [32]. However, it was also interesting to find that there were more similarities than differences between the groups. All RAPs wanted up-to-date information; opportunities to talk to experts; and access to appropriate education, health, and social support to enable their children to achieve their maximum potential.

Although clinical concerns play a part of the whole life challenge for children with CAs, they are part of a much wider tableau. Researchers involved in ConnectEpeople were able to connect and discuss with parents directly, which allowed them to learn about the daily life and issues of families who are experts by experience in children with complex health needs. Although the researchers had limited personal experience of CA, they could offer support and information. In a similar way to the web-based community developed by Owens et al [10], "relying on their own humanity and implicit knowledge of what it means to care." The interaction by the research team in the private and invisible Facebook groups enhanced their knowledge and confidence in selecting and developing suitable posts for the ConnectEpeople public Facebook and Twitter. Importantly, during this project, there were no arguments or negative or inappropriate behaviors on any social media account.

Not all RAPs actively communicated within the groups, and there were clear responders and *lurkers* [33]. Many RAPs were absent from private and invisible Facebook groups for extended periods. During their child's sickness was understandably a time when many parents were not available. However, for some, the solidarity within the group offered comfort when children were sick in the hospital and far from friends and family, leading to increased activity in their group. Peer-to-peer support is a key feature of online health communities, even when it is not the intended function of the group [10], and Greenwood et al [14] found that seeing others on the web increased engagement. Shared experiences have been identified [34] by users of diabetes web-based forums as valuable tailored advice that they could not acquire from their HCP.

Social media sites provide a platform for sharing information to a wide and varied audience, and messages should be tailored for target audiences [3]. For example, complex information on CAs can be posted and used by those who have experience and insight, such as parents who have a child with a CA or HCP. Developing and instilling trust early on allows users to discuss difficult issues in a safe environment and be confident in the information shared [35]. In this study, many parents reported that they could not access the appropriate help their child needed from a range of providers, including educational and HCPs. Parents also disclosed their feelings of distrust for some health care providers and shared their concerns about being given misleading, inadequate, or inaccurate information and advice. Brady et al [32] identified that internet forum users were concerned about the accuracy of information available on the web and, to a greater extent, the possibility that other users may believe inaccurate information. Identifying and exposing health misinformation being shared on the web has become a major global concern during the COVID-19 pandemic [36]. The ConnectEpeople RAPs actively worked in partnership to produce accurate, engaging, and impactful outputs. RAPs and other stakeholders were reading and downloading information from the ConnectEpeople e-forum. In addition, they created content, for example, webinar videos.

Data Collection

ConnectEpeople aimed to identify suitable data collection methods for future research on e-forums based on social media. Qualitative data were available in a number of ways, including contemporaneous notes taken by the researcher during conversations with stakeholders, Facebook and Twitter posts, and consent for recordings of web-based meetings with RAPs, which were transcribed and deleted. All data were stored on password-protected computers.

Social media metrics form the basis of quantitative data and are a source of valuable learning in data management. Metrics data must be collated and stored for analysis, as legacy data cannot be maintained within the Facebook Insights function. It is also important for researchers to understand the functionality of social media metrics and how they can be evaluated and analyzed in relation to research outcome measures and data collection. Analysis of metrics provided insight into project reach and impact. Followers alone, although important for increasing brand awareness, will not enhance the reach of posts. Enhancing engagement should be the key goal of Facebook pages to ensure that messages reach the target audience [37,38]. The findings from the public Facebook page (Figure 2) clearly demonstrate that successful posts are not determined by followers or number of people. It remains incumbent on researchers to identify and share posts that are useful and relevant in a format preferred by the target audience. Klassen et al [39] recommend developing posts that elicit positive feelings and are less serious in tone to increase engagement with followers on Facebook. In their study investigating the content and interaction on a Facebook group related to multiple sclerosis, Della-Rosa and Sen [40] identified that the most popular posts were those on support, information, and awareness. Public Facebook posts generated the highest level of reach and engagement related to promoting positive social interactions for children with a disability attending school [24]. This reflects the outcomes of the ConnectEpeople survey findings and those of the previous ConnectEpeople paper, where parents were very concerned about the psychosocial challenges facing their children [1].

The use of private and invisible Facebook and a public Facebook page provided the level of connectedness required for the different needs of stakeholders. However, there was a limited number of organizations and individuals who could see the project's Twitter posts, which is likely the reason for the low uptake on Twitter. The research team would recommend single, open Twitter profiles for research projects, which would also reduce the need for cross-posting on Twitter.

e-Forum Management

The development of a web-based network is expensive, as it requires ongoing administrative support [41]. Coordinating, reviewing, translating, and responding to posts and connecting to the internet requires considerable investment in time and expertise. Social media accounts are typically uncomplicated to set up; however, updating banners and creating and curating accessible, easy-to-understand, usable, and helpful content to meet the needs of the target audience is challenging. This project benefited from the tremendous support of RAPs, gatekeepers, support organizations, and other stakeholders in the development of content, sharing of ConnectEpeople project details, and actively taking part in webinars. Parents want to promote greater understanding and tolerance of children with complex health conditions to ensure a more positive future for all children.

The overall management of the e-forum required skilled time management, digital infrastructure, and creative skills. Experience and knowledge of different social media platforms were essential to maintain safety on the web, set up and invite RAPs to join the private and invisible Facebook, develop and host webinars for a global audience, and use metrics to demonstrate impact. The key skill required was a thorough up-to-date knowledge of CHD, CLP, DS, and SB. The research team was able to access knowledge in the form of research, testimonials, etc. However, parents and families were the most valuable sources of knowledge regarding the challenges of living with a child with complex health needs. Clinical research was important but so too were social and parenting issues.

Developing social media research that respects and values the knowledge of all, and the reciprocal sharing of perspectives and experiences requires skilled researchers and social media experts to build and maintain internet-based relationships. Although the ConnectEpeople project was aimed at a relatively niche audience, outputs traveled to 35 countries across the world in 2 years. This type of research benefits from global access to social media and the valuable opportunity to facilitate research impact. This may be cultural and attitudinal beliefs, social and societal benefits, enhancing capacity, raising understanding and awareness, and promoting health and well-being [42]. Reach and impact are key components of research, and the power of social media to facilitate this should be included in the planning phase.

Other Considerations

The initial project plan to connect with organizations and parents in their country via RLs would still be strongly recommended by the authors to future researchers wishing to replicate our approach. A 2015 Greek study [43] suggested that HCPs and organizations were lagging behind *customers* in their use of social media for health communication, and many researchers are uncertain about using social media for professional activities [44,45]. However, due to the COVID-19 pandemic, support for families has become even more important with the need for strict social distancing, particularly for sick children. This has prompted support for the rapid uptake of social media by support organizations, researchers, and medics [46]. Furthermore, Kemp [47] reported that due to COVID-19, more than 40% of internet users spend more time on social media to help them manage everyday life, and most parents increased their use of social media for information and social support [48]. Many international organizations now use social media to publicize their work and disseminate information, for example, the World Health Organization, United Nations Children’s Fund, Centers for Disease Control and Prevention, European Commission, and the International Clearinghouse for Birth Defects. Social media is evolving as a credible and sustainable choice for engagement and research.

Future Considerations for the e-Forum

The model by Young [49] for the life cycle of web-based communities consists of four stages, namely inception, establishment, maturity, and mitosis. This paper has discussed the ConnectEpeople e-forum up to the establishment stage, where the activities primarily concerned making connections and building a core group of active members. Social media–based researchers must consider how to adapt as groups grow and progress through maturity and mitosis and how changes or increase in user shared content, disengagement, or potential splinter groups should be managed and the likely impact of this on their research.

As research e-forums are developed, understanding the life cycle of such web-based communities is important to guide and direct research endeavors and facilitate continued engagement. Meeting the future needs of members may include the use of different web-based activities, such as blogs and podcasts, to promote the transfer of knowledge and practice and encourage a diversity of membership. Furthermore, other research teams have reported parents and experts by experience can successfully take ownership and become leaders and drivers of the e-forum they have helped to build [10,11].

The COVID-19 pandemic has resulted in new global health needs, including those of children with CAs and their families. Researchers can efficiently and effectively learn from active research e-forums to codevelop research, engage in timely patient and public involvement in research, and be leaders in time-sensitive research. This ensures that the e-forum continues to meet the evolving needs of members and is relevant long term. In addition, the social media use of the target audience should continually be reviewed as new social media platforms become popular.

Limitations

There were only 2 administrators managing public Facebook, four private and invisible Facebook groups, and 4 closed Twitter groups content. The administrators’ first language was English, limiting the availability of multilingual posts on social media and connecting with individuals across Europe. A number of videos posted on the public Facebook page did not have available organic video metrics due to an issue experienced by Facebook from October 25 to 28, 2019, which may have had an impact on the calculated reach and engagement with some posts. Challenges exist with drawing conclusions surrounding the potential impact on families and children’s health, as it is difficult to track the use and implementation of messages shared on social media. In addition, the impact of technology poverty or limited access to digital infrastructure on recruitment and engagement has not been investigated.

Conclusions

Effective use of social media by researchers and relevant key stakeholders requires an understanding of their unique functions and careful planning in design, management, and evaluation strategies. Social media as a research tool has enormous potential to connect and empower people and reach new audiences while providing valuable data. COVID-19 has been a catalyst in the rapid and likely enduring uptake of social media for health information provision by members of the scientific and medical communities [46]. When social distancing measures due to COVID-19 are reduced, hybrid models of research are likely to become commonplace, combining web-based and in-person social connections. Therefore, developing web-based research skills and techniques to harness the versatility of social media has become an essential tool for researchers. The development of a framework for social media research recommended by Elliott et al [3] would require flexibility and ongoing re-evaluation to facilitate the life cycles of social media groups.

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Authors' Contributions

MS conceptualized this study. MS and JEMMc led to the collection of social media data. All authors developed the survey tool. JEMMc analyzed the data. MS and JEMMc drafted the manuscript. All named authors contributed to the improvements and critical revisions and approved the final version for publication.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Systematic literature search.
[DOCX File , 12 KB - pediatrics_v4i4e18483_app1.docx]

Multimedia Appendix 2
PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analyses) diagram for systematic literature search for research articles investigating the design and establishment of a web-based communication platform for patient, parent, or public and professional communication.
[PNG File , 35 KB - pediatrics_v4i4e18483_app2.png]

Multimedia Appendix 3
Ten most important research questions of ConnectEpeople participants with children who have Down syndrome, spina bifida, cleft lip with or without cleft palate, and congenital heart defects.
[DOCX File , 16 KB - pediatrics_v4i4e18483_app3.docx]

Multimedia Appendix 4
Original engagement plan for the ConnectEpeople project.
[PNG File , 309 KB - pediatrics_v4i4e18483_app4.png]

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Abbreviations

CA: congenital anomaly
CHD: congenital heart defect
CLP: cleft lip with or without cleft palate
DS: Down syndrome
HCP: health care professional
RAP: research aware parent
RL: registry leader
SB: spina bifida

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Original Paper

Infant Safe Sleep Practices as Portrayed on Instagram: Observational Study

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Abstract

Background: Parenting practices are highly influenced by perceived social norms. Social norms and American Academy of Pediatrics (AAP) guidelines for infant safe sleep practices are often inconsistent. Instagram has become one of the most popular social media websites among young adults (including many expectant and new parents). We hypothesized that the majority of Instagram images of infant sleep and sleep environments are inconsistent with AAP guidelines, and that the number of "likes" for each image would not correlate with adherence of the image to these guidelines.

Objective: The objective of this study was to determine the extent of adherence of Instagram images of infant sleep and sleep environments to safe infant sleep guidelines.

Methods: We searched Instagram using hashtags that were relevant to infant sleeping practices and environments. We then used an open-source web scraper to collect images and the number of "likes" for each image from 27 hashtags. Images were analyzed for adherence to AAP safe sleep guidelines.

Results: A total of 1563 images (1134 of sleeping infant; 429 of infant sleep environment without sleeping infant) met inclusion criteria and were analyzed. Only 117 (7.49%) of the 1563 images were consistent with AAP guidelines. The most common reasons for inconsistency with AAP guidelines were presence of bedding (1173/1563, 75.05%) and nonrecommended sleep position (479/1134, 42.24%). The number of "likes" was not correlated with adherence of the image to AAP guidelines.

Conclusions: Although individuals who use Instagram and post pictures of sleeping infants or infant sleep environments may not actually use these practices regularly, the consistent portrayal of images inconsistent with AAP guidelines reinforces that these practices are normative and may influence the practice of young parents.

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KEYWORDS

sleep position; bed-sharing; social norms; social media; safe sleep; bedding

Introduction

Studies have investigated the effect that personal social networks (ie, individuals with whom one has personal relationships, social interactions, or both) can have on certain adult health behaviors, such as diet, nutrition, smoking, and obesity [1-3]. These social networks, which traditionally have been largely face-to-face, can also influence parenting practices, such as breastfeeding initiation and continuation [4-8] and vaccination [9]. Data suggest that online social networks, such as Facebook, Instagram, and others, are increasingly important influences on parental practice, including parental smoking cessation [10] and child nutrition [11,12].

It is likely that much of the influence from social networks (face-to-face or online) is derived from the network members providing their opinions about what behaviors and practices are expected and acceptable [13,14]. One then perceives these behaviors and practices to be normative behavior (everyone does this) and strives to adhere to these social norms to avoid judgment and reproach [2,3,15-22]. These social norms can be very powerful. Studies have found social norms to be a key variable mediating the association between maternal education and certain infant care practices [23] and the association between maternal country of birth and breastfeeding [24]. When social norms are contrary to evidence-based guidelines, they can negatively impact health.

One area in which there is often much discrepancy between social norms and evidence-based guidelines is the area of infant safe sleep practices [25]. Certain sleep practices, including nonsupine sleep position, use of soft bedding, soft sleep surfaces, and bed-sharing, are associated with increased risk for sudden unexpected infant death (SUID) [26] and the American Academy of Pediatrics (AAP) has published evidence-based guidelines for infant safe sleep [27] to reduce the risk of SUID. However, although there may be ample public health guidelines and education in the health care professional's office before and after birth, other influences outside the health care setting may have an even stronger impact on sleep practices [28-31], and inconsistent messages about where and how the infant should sleep are associated with nonadherence to safe sleep guidelines [32].

Given that SUID rates in the United States have not declined since 2000 [33], and rates of nonsupine positioning [34], bed-sharing [35,36], and use of soft bedding [37] have not decreased, increased attention has been paid to the importance of changing social norms surrounding these practices. One randomized controlled trial of safe sleep video messages sent to new mothers by SMS text message or email resulted in improvements in safe sleep practices, and demonstrated that these improvements were mediated in part by changes in the mothers' perceptions of the social norms surrounding the particular practices [38].

Media has traditionally been very one of the most influential factors in establishing societal and perceived social norms [39,40]. One qualitative study of new mothers found that images of sleeping infants and infant sleep environments, as found in photographs, books, television, and the internet, were one of the most consistent influences on their decisions about how infants slept at home [41]. However, these images are often inconsistent with safe infant sleep guidelines [42-44]. The power of these images may be increasing as marketing and social networking have come together synergistically to more effectively reach and influence target audiences. Today, nearly anyone can share personal experiences by writing reviews or commenting on and rating experiences. These interactions are highly influential in decisions regarding product purchases [45]. While the effect of these images on decisions regarding product purchases and parenting practices may differ, product purchases (eg, cribs, soft bedding) directly impact on infant sleep practices. Because many products marketed or used for infant sleep do not in fact meet federal safety standards [46] and are not safe for infant sleep, product selection and thus marketing are relevant to increasing safe sleep practices. Parents may be persuaded to purchase these products because they infer from social media that these products are not risky [47] and that use of these products is normative and acceptable infant care practice [48]. Additionally, the structure of social media allows one to selectively view specific advertisers or personalities by "following" them. Similar products or persons are then suggested based on algorithms utilizing one's past online searches. While "following" specific advertisers or personalities creates some self-selection and selection bias regarding what is seen, an algorithm can be triggered by an online search that merely suggests that one is pregnant or has a new infant. This reinforcing nature of social media [49] can potentially make any exposure to certain practices or ideas even more powerful.

Instagram, which is mainly a photo-sharing application (app), has become one of the most popular social media apps/websites among young adults (including many expectant and new parents); among the >1 billion monthly active users [50], 56.3% of users are women, and those aged 25-34 years comprise the largest user group [51]. Further, Instagram is the most popular social media platform for teenagers, with 72% of them being active users [52]. This app, like many others, is designed so that users spend time on the app, and there has been growing concern about the phenomenon of Instagram "addiction." One study found that 2 major needs may contribute to Instagram addiction: recognition (need for admiration from others through Instagram posts) and social (use of Instagram to share views and maintain contact with others) [53]. However, the vast majority of Instagram users do not have high levels of Instagram addiction [54].

Instagram users post photos or videos of content, often with a hashtag (a word or phrase preceded by the # symbol) frequently attached. Tagging with a hashtag allows others to easily find other messages or images that have a similar theme or content. Instagram users can also indicate that they "like" a photo by clicking on a heart icon. The number of "likes" for a photo implies the degree of social endorsement [55]. One small study found that adolescents who viewed photos were more likely to "like" photos with many "likes." This study also found, using functional magnetic resonance imaging, that viewing photos with many "likes" stimulated neural regions associated with social cognition, reward learning, imitation, and attention [55]. Thus, "likes" can act as a form of peer influence and create the perception of normative behavior.

According to surveys conducted by Instagram's parent company (Facebook), 78% and 74% of surveyed Instagram users, respectively, state that they perceive products or product brands viewed on Instagram to be popular and relevant, and 81% use Instagram to help them discover or research products or services [56]. Nearly half reported having made a purchase after seeing a product or service on Instagram. Largely because of Instagram's popularity among potential consumers, nearly half of businesses are active on Instagram [56].

Although Instagram images provide only a snapshot of a single point in time, and although we acknowledge that these images may not accurately reflect how and where the infants portrayed in the images actually sleep, we aimed in this study to determine what proportion of images of sleeping infants and infant sleep environments were consistent with infant safe sleep guidelines.

Because hashtags may be used to search for specific content, we wanted to simulate the search of a typical user looking for images of infant sleep environments (eg, an expectant parent searching for nursery ideas) by using hashtags. Because images in magazines, advertisements, and the internet are often inconsistent with these guidelines [42-44], we hypothesized that the majority of images on Instagram for infant sleep–related hashtags, extracted through a web scraper (which uses automated processes to gather specific data from a website [57]), would also be inconsistent with infant safe sleep guidelines, as published by the AAP [27], and that the number of "likes" for each image would not correlate with adherence of the image to these guidelines.

Methods

We conducted a search for images on Instagram using hashtags that were relevant to infant sleeping practices and environments (as might be done by someone looking for ideas for nursery products). These hashtags were determined by conducting an initial cursory search on Instagram; the hashtags that yielded the greatest frequency of relevant searches were used. Images had to contain a sleeping infant or a sleep environment that appeared to be intended for an infant. Sleep locations not solely intended for infant use (eg, beds, sofas) were included only if a sleeping infant was present. The data were collected via an open-source web scraper (provided by user jaroslavejhlek) on the data scraping website Apify [58].

The first 200 images from each hashtag were utilized for this analysis, as we believed it to be unlikely that users would look beyond the first 200 images in a typical search. All images were either photographs or video thumbnails (still images that preview videos) and were preliminarily sorted into groups that either depicted a sleeping infant or a sleep environment without an infant. Afterward, they were analyzed more thoroughly for adherence to AAP safe sleep guidelines. Table 1 presents the scoring criteria.

Table 1. Criteria for images.

Category	Consistent with AAP[a] guidelines	Inconsistent with AAP guidelines
Sleep position	Supine, held by an awake adult	Side, prone, sitting or upright, held by a sleeping adult
Sleep location	Crib, portable crib, play yard, bassinet, Moses basket, bedside co-sleeper, ground; sleep surface horizontal; no cushioning of sides	Bed (any size); sitting device (car seat, swing); couch, sofa, armchair; in-bed co-sleeper, positioner, or infant "dock" (eg, DockATot); sleep surface not horizontal; sides of sleep product (if applicable) are cushioned
Bedding	No bedding in the sleep area	Presence of unswaddled blanket, pillow, bumper, plush toys, or other soft bedding
Bed-sharing	Infant is not on the same sleep surface as another person or animal	Infant is on the same sleep surface as another person or animal
Head covering	No head covering	Head covering of infant
Strangulation risk	No strangulation risks	Strangulation risks (eg, long ties, drapes)

[a] AAP: American Academy of Pediatrics.

Each image was analyzed by 2 authors, and any discrepancies were reconciled by a third. Images were categorized as consistent with AAP safe sleep guidelines if the sleep surface appeared to be firm and flat (horizontal), without any soft bedding or strangulation risks; if a sleeping infant was visible, the infant had to be supine or held by an awake adult and could not be wearing a head covering.

The number of "likes" associated with each picture at the time of scraping was also collected. Statistical analysis included descriptive statistics. Unpaired *t*-tests, assuming unequal variances, were conducted to determine whether the number of likes was associated with whether the image depicted a safe sleep environment. Because this study involved the collection and study of publicly available data, it was considered exempt by the Institutional Review Board of the University of Virginia.

Results

Overview

Data from 27 hashtags were collected in June 2020. Of the 5400 Instagram images scraped (first 200 images from 27 hashtags), a total of 1563 met inclusion criteria. Of those, nearly three-quarters (1134, 72.55%) had a sleeping infant, and 429 (27.45%) portrayed a sleep environment without a sleeping infant (Table 2). Of the 1563 images, 117 (7.49%) were consistent with AAP safe sleep guidelines. For another 93 (5.95%) images, the sleep location (eg, crib, bed) of the sleeping infant could not be determined, but these images otherwise were consistent with AAP safe sleep guidelines.

Table 3 provides details about the images. The percentages in Table 3 are row percentages, which indicate the number of images in the particular cell, divided by the total number of images in the same row.

Table 2. Instagram hashtags included in analysis.

Hashtag	Total images (N=1563), n	Images consistent with AAP[a] guidelines, n (%)
#baby	11	0 (0)
#babynursery	33	2 (6)
#babynurserydecor	22	4 (18)
#babyshowergiftideas	7	0 (0)
#babysleep	49	2 (4)
#babysleeping	59	4 (7)
#bassinet	83	29 (35)
#crib	61	21 (34)
#cutebabiesofinstagram	23	0 (0)
#infantphotography	22	0 (0)
#infantsleep	43	1 (2)
#naptime	13	0 (0)
#newborn	67	1 (1)
#newbornbaby	74	1 (1)
#nursery	22	2 (9)
#nurserydesign	36	3 (8)
#nurseryinspiration	63	8 (13)
#nurseryinspo	33	0 (0)
#projectnursery	123	28 (23)
#safebaby	25	0 (0)
#sleepbaby	52	2 (4)
#sleepingbabyboy	123	0 (0)
#sleepingbabygirl	129	0 (0)
#sleepingbabyphotography	115	0 (0)
#sleepinginfant	125	3 (2)
#Sleepybaby	76	0 (0)
#twoweeksold	74	4 (5)

[a] AAP: American Academy of Pediatrics.

Table 3. Characteristics of images.

Category	Total (n=1563), n	Bedding present, n (%)[a]	Bed-sharing, n (%)	Posed[b], n (%)	No baby present, n (%)	Location unknown, n (%)
Images consistent with AAP[c] guidelines	117	0 (0)	0 (0)	0 (0)	95 (81.20)	0 (0)
Images inconsistent with AAP guidelines	1446	1173 (81.12)	66 (4.56)	167 (11.55)	332 (22.96)	572 (39.56)
Images with sleeping infant present	1134	845 (74.51)	66 (5.82)	174 (15.34)	0 (0)	662 (58.38)
Images with no sleeping infant present	429	328 (76.46)	0 (0)	0 (0)	429 (100)	1 (0.23)
Images with infant in sleep position inconsistent with AAP guidelines	479	387 (80.79)	28 (5.85)	122 (25.47)	0 (0)	254 (53.03)
Supine	488	406 (83.20)	31 (6.35)	45 (9.22)	0 (0)	299 (61.27)
Side	222	192 (86.49)	16 (7.21)	36 (16.22)	0 (0)	127 (57.21)
Prone	156	131 (83.97)	10 (6.41)	52 (33.33)	0 (0)	27 (17.31)
Sitting/upright	101	64 (63.37)	2 (1.98)	34 (33.66)	0 (0)	27 (26.73)
Held by an awake adult	169	54 (31.95)	7 (4.14)	7 (4.14)	0 (0)	110 (65.09)
Images of an infant sleep location inconsistent with AAP guidelines	162	103 (63.58)	12 (7.41)	18 (11.11)	1 (0.62)	0 (0)
Crib	422	326 (77.25)	2 (0.47)	5 (1.18)	333 (78.91)	0 (0)
Bassinet/Moses basket	150	113 (75.33)	1 (0.67)	5 (3.33)	82 (54.67)	0 (0)
Bed (any size)	128	116 (90.63)	31 (24.22)	18 (14.06)	0 (0)	0 (0)
Sitting device	90	47 (52.22)	1 (1.11)	14 (15.56)	0 (0)	0 (0)
Ground	31	20 (64.52)	2 (6.45)	4 (12.90)	1 (3.23)	0 (0)
Couch/sofa/cushioned armchair	55	40 (72.73)	11 (20.00)	4 (7.27)	0 (0)	0 (0)
In-bed co-sleeper, positioner, or dock	17	16 (94.12)	0 (0)	0 (0)	1 (5.88)	0 (0)
Location unidentifiable	670	491 (73.28)	18 (2.69)	124 (18.51)	1 (0.15)	670 (100)
Images of sleeping infant on the same surface as another sleeping person or animal	65	60 (92.31)	65 (100)	4 (6.15)	0 (0)	18 (27.69)
Sharing with adult	37	33 (89.19)	37 (100)	1 (2.70)	0 (0)	6 (16.22)
Sharing with child	21	20 (95.24)	21 (100)	3 (14.29)	0 (0)	8 (38.10)
Sharing with animal	7	7 (100.00)	7 (100)	0 (0)	0 (0)	3 (42.86)
Images with bedding present	1173	1173 (100)	61 (5.20)	139 (11.85)	319 (27.20)	491 (41.86)
Unswaddled blankets	832	832 (100)	45 (5.41)	95 (11.42)	177 (21.27)	376 (45.19)
Bumpers	146	146 (100)	2 (1.37)	7 (4.79)	82 (56.16)	15 (10.27)
Pillows	536	536 (100)	34 (6.34)	62 (11.57)	185 (34.51)	187 (34.89)
Other bedding	331	331 (100)	9 (2.72)	54 (16.31)	114 (34.44)	126 (38.07)
Images with infant head covered	191	156 (81.68)	6 (3.14)	55 (28.80)	0 (0)	12 (6.28)
Images with potential strangulation risk	196	162 (82.65)	8 (4.08)	80 (40.82)	0 (0)	140 (71.43)
Images with swaddled infant	116	94 (81.03)	9 (7.76)	41 (35.34)	0 (0)	75 (64.66)
Images with posed infant[b]	174	139 (79.89)	4 (2.30)	174 (100)	0 (0)	123 (70.69)
Images with pacifier	98	69 (70.41)	7 (7.14)	3 (3.06)	0 (0)	52 (53.06)

[a] All percentages are row percentages, with the total images in that category as the denominator.

[b] Images with posed infant refer to images of infants that were obviously posed and did not represent true sleep environments (eg, flowerpots).

[c] AAP: American Academy of Pediatrics.

Position

Of the 1134 images that portrayed a sleeping infant, 488 (43.03%) showed the infant sleeping supine, and 169 (14.90%) showed a sleeping infant held by an awake adult. There were 479 (42.24%) images that were inconsistent with AAP recommendation to place infants supine on a firm and flat surface, including 222 (19.58%) images with an infant sleeping on the side, 156 (13.76%) with an infant sleeping prone, and 101 (8.91%) with a sleeping infant that was in the sitting position.

Bedding

In the 1563 images of infant sleep environments, the presence of bedding was the most common reason that the image was inconsistent with safe sleep guidelines; of all images, 1173 (75.05%) contained some form of soft or loose bedding. The most commonly observed bedding type was an unswaddled blanket, which was present in 836 images (71.27% of 1173 images with bedding, 53.49% of all 1563 images). The next most common was a pillow, found in 536 images (45.69% of 1173 images with bedding, 34.29% of all 1563 images). Bumpers were found in 146 images (12.45% of 1173 images with bedding, 9.34% of all 1563 images), and a stuffed animal or other soft bedding was found in 331 images (28.22% of 1173 images with bedding, 21.18% of all 1563 images).

Location

A crib, bassinet, play yard, or bedside co-sleeper was the most commonly observed sleep location (422/1563, 27.00%). Other sleep locations included a Moses basket (150/1563, 9.60%); adult or child bed (128/1563, 8.19%); sitting device such as a car seat or stroller (90/1563, 5.76%); a couch or sofa (55/1563, 3.52%); the ground or floor (31/1563, 1.98%); and an in-bed co-sleeper, positioner, or infant “dock” (eg, DockATot; 17/1563, 1.09%). The largest proportion (670/1563, 42.87%) of images portrayed an infant in a location that could not be definitively identified. Of the images with an unidentified location, 577/670 (86.1%) demonstrated other aspects of the sleep environment that were inconsistent with AAP safe sleep guidelines.

Bed-sharing

Bed-sharing was seen in 65 (5.73%) of all 1134 images with an infant present. An adult bed-sharer was the most common (n=37; 22.4% [37/165] of bed-sharing images, 3.26% [37/1134] of images with an infant present) followed by a child (n=21; 12.7% [21/165] of bed-sharing images, 1.85% [21/1134] of images with an infant present) and an animal (n=7; 4.24% [7/165] of bed-sharing images, 0.62% [7/1134] of images with an infant present).

Posed Images

We separately analyzed images in which the infant was obviously posed and did not represent a true infant sleep environment (eg, flowerpot). This category does not include other images for which the infant may have been posed but were potential infant sleep environments (eg, infant posed on a sofa). There were 174 such images (15.34% of 1134 images with an infant present). Of these, 167 (96.0%) images had elements that were inconsistent with AAP guidelines. The other 7 images (4.0%) were consistent with AAP guidelines with the possible exception of the sleep location, which could not be determined. In the 174 posed images, the infant was prone in 52 (29.9%), supine in 45 (25.9%), on the side in 36 (20.7%), sitting upright in 34 (19.5%), and held by an adult in 7 (4.0%). Infants in posed images, when compared with those in unposed images, were 19.7 percentage points more likely to be portrayed in a nonsupine or upright position (*P*<.001), and were overall more likely to be portrayed in a sleep environment that was inconsistent with AAP guidelines (*P*<.01).

Likes

Images adhering to AAP safe sleep guidelines had a mean 127.8 likes (SD 370.5); if the images with undetermined location were excluded, the mean like count was 181.7 (SD 461.0). Images with elements inconsistent with AAP guidelines had a mean of 128.4 likes (SD 509.9). There was no significant difference in the mean like count between nonadherent images and total adherent images (*P*=.99). When images with undetermined location were excluded, images adhering to AAP guidelines had a higher mean like count than nonadherent images (*P*=.001).

Discussion

Principal Findings

Of the 1563 Instagram images analyzed, only 117 (7.49%) were clearly consistent with AAP safe sleep guidelines. Another 93 (5.95%) were possibly consistent, but were taken in such a way that the sleep environment could not be fully visualized. This means that, even when these images with incomplete information are included, an overwhelming majority (1353/1563, 87%) of Instagram images portrayed unsafe infant sleep environments, as defined by the AAP.

Nearly half of businesses are active on Instagram [56]. As with any marketing strategy, businesses use Instagram to increase sales of their product(s). Businesses are guided to post aesthetically pleasing photos of their products, liberally use hashtags, and facilitate purchases from the website [59]. Company statistics indicate that these strategies are successful in promoting sales of products, as nearly half of surveyed Instagram users stated that they have purchased a product after seeing it on Instagram [56]. While Instagram’s Community Guidelines prohibit content with “the potential to contribute to real-world harm” [60] and the Commerce Policies prohibit sale of “medical and healthcare products and services, including medical devices” [61], there are no rules that specifically address posting of photos that demonstrate unsafe sleep practices.

Although many prospective and new parents purchase products from traditional stores that sell products in person (and in some stores, employees may provide guidance regarding safe sleep guidance), there has been a steady increase over the past decade in the proportion of products sold online [62]. Thus, images posted online, particularly on websites that are viewed by a large proportion of the population, can be extremely influential [63]. Many companies, especially those that advertise on Instagram, utilize a “brand ambassador” program in which parents themselves are sponsored to post pictures promoting a certain product. A direct potential consequence of peers consistently modeling and posting images of specific, unsafe sleep environments is the misconception among new parents that these practices are safe, when physician advice is to the contrary. With regard to infant sleep practices, mothers are more likely to change from safe to unsafe sleep practice if their network members substantially espouse unsafe practices [64], and this may be true for virtual network members as well. The ability for social media to influence the behavior of a large proportion of the population is a well-known phenomenon [47]; indeed, there are now "influencers," who are especially prominent on Instagram. These individuals are paid for their posts because their use of products results in increased sales [65]. Not only do they influence certain practices, but they may create completely new ones as well [66,67].

The Theory of Planned Behavior states that one's behavior is shaped by social norms, and that these norms directly impact one's attitudes about the specific behavior [68]. One's practices and rationalizations for these practices are learned from and reinforced by others [69,70], so that one's behavior becomes increasingly similar to that of network members [2,3,15-22]. Infant sleep practices, especially sleep environments, are not immune from these forces. Images of cribs and bassinets littered with toys, blankets and pillows, infants sleeping nonsupine, or infants wearing warm head coverings or hats with long strings (that pose a strangulation hazard) are displayed, often unopposed, on social media sites. The images, which are usually well produced and chosen because they appear "authentic," come to represent "desirable" environments one wants to emulate [71]. With no regulations relevant to safe infant sleep practices inherent to Instagram, the proxy for acceptability may become how popular or common a sleep environment is. Even though not all of the nonadherent images were posted by individuals, and many (174/1134, 15.3%) were very obviously posed for a photographer, our findings demonstrate that the culture of infant sleep on Instagram is one that does not promote infant safety as a priority.

Nearly half (479/1134; 42.24%) of sleeping infants were portrayed in the nonsupine position; while some may think it encouraging that the majority were in recommended positions (supine or held by an awake adult), the sizeable proportion of infants sleeping nonsupine suggests that supine positioning is not the social norm for many. More concerning is the majority (1173/1563; 75.05%) of images demonstrating the presence of soft bedding. This proportion is similar to national data on bedding use reported by Shapiro-Mendoza and colleagues [37]. Important reasons for such widespread use of soft bedding by parents or guardians include concerns about comfort and warmth [72]. On a social media platform such as Instagram, the use of bedding could also be for purely aesthetic purposes [72], or to signify the status or creativity of the person posting the image.

Cribs were found in 77.62% (333/429) of the images with no baby present, but in only 27.00% (422/1563) of images overall. Many of these images were posted by marketers or decorators (eg, #nurseryinspirations) who aim to establish images of expected or normative practice for parents decorating a new nursery. While cribs are consistent with AAP safe sleep recommendations, many of the other products shown in these marketing images are not. Three-quarters (1173/1563; 75.05%) of these images had soft bedding, including loose blankets, pillows, and bumpers, present.

There is a common assumption that if an object is being sold, then it is safe to use [44]. On social media platforms, the safety assumption can be taken one step further because there is a scoring mechanism to see how popular a practice is: likes. Pictures with more likes may be viewed as more acceptable and thus safe. With regard to the number of likes for images that were consistent or inconsistent with AAP safe sleep guidelines, the mean was similar for these 2 categories. However, it should be noted that there were approximately 12 times fewer images that were consistent with safe sleep guidelines, potentially creating a bias.

Limitations

This study, as is any study involving social media as its data source, is limited by the fact that the sample is inherently biased. Individuals who use Instagram and post pictures of sleeping infants or infant sleep environments may not actually use these practices regularly. For example, a large proportion of images included bedding. Blankets, stuffed animals, and pillows can all be used to make the image more aesthetically pleasing, but may not be in the infant's actual sleep environment. However, the purpose of this study was not to analyze actual practices, but to look at the culture of what is considered desirable to display and be propagated on the platform. We also did not analyze image captions, which may alter the viewer's perception of the image. However, Tiggemann et al [73] found that the effect of a "positive" caption did not significantly change someone's perception of an image that would otherwise make them feel dissatisfied with their body. Further study into the types of captions associated with certain hashtags, as well as the content of captions in safe versus unsafe pictures is necessary to more fully understand the landscape of safe infant sleep on Instagram.

Conclusions

In conclusion, the vast majority of images pertaining to infant sleep are inconsistent with AAP safe sleep guidelines. It is imperative that health care providers at least know and understand the landscape of normative practices on social media so they can best tailor either specific patient advice or public health approaches [74]. Additionally, campaigns to promote safe sleep may require health care professionals and officials to work with influencers and social media companies to promote up-to-date, evidence-based information about current recommendations that is trustworthy and engaging.

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Authors' Contributions

SC contributed to study design, data acquisition, data analysis, and data interpretation. He drafted and critically revised the manuscript. RC and RM contributed to study conception and design, data analysis and interpretation, and critically revised the manuscript. AM contributed to data analysis and interpretation and critically revised the manuscript. All authors have approved the final draft of the manuscript and agree to be accountable for all aspects of the work.

Conflicts of Interest

None declared.

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Abbreviations

AAP: American Academy of Pediatrics
SUID: sudden unexpected infant death

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Original Paper

Clinical Characteristics of Children With COVID-19 in the United Arab Emirates: Cross-sectional Multicenter Study

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Abstract

Background: COVID-19 has infected over 123 million people globally. The first confirmed case in the United Arab Emirates (UAE) was reported on January 29, 2020. According to studies conducted in the early epicenters of the pandemic, COVID-19 has fared mildly in the pediatric population. To date, there is a lack of published data about COVID-19 infection among children in the Arabian region.

Objective: This study aims to investigate the clinical characteristics, laboratory findings, treatment, and outcomes of children with COVID-19.

Methods: This cross-sectional, multicenter study included children with confirmed COVID-19 infection admitted to 3 large hospitals in Dubai, UAE, between March 1 and June 15, 2020. Serial COVID-19 polymerase chain reaction (PCR) testing data were collected, and patients' demographics, premorbid clinical characteristics, and inpatient hospital courses were examined.

Results: In all, 111 children were included in our study and represented 22 nationalities. Of these, 59 (53.2%) were boys. The mean age of the participants was 7 (SD 5.3) years. About 15.3% of children were younger than 1 year. Only 4 (3.6%) of them had pre-existing asthma, all of whom had uneventful courses. At presentation, of the 111 children, 43 (38.7%) were asymptomatic, 68 (61.2%) had mild or moderate symptoms, and none (0%) had severe illness requiring intensive care. Fever (23/111, 20.7%), cough (22/111, 19.8%), and rhinorrhea (17/111, 15.3%) were the most common presenting symptoms, and most reported symptoms resolved by day 5 of hospitalization. Most patients had no abnormality on chest x-ray. The most common laboratory abnormalities on admission included variations in neutrophil count (22/111, 24.7%), aspartate transaminase (18/111, 22.5%), alkaline phosphatase (29/111, 36.7%), and lactate dehydrogenase (31/111, 42.5%). Children were infrequently prescribed targeted medications, with only 4 (3.6%) receiving antibiotics. None of the 52 patients tested for viral coinfections were positive. COVID-19 PCR testing turned negative at a median of 10 days (IQR: 6-14) after the first positive test. Overall, there was no significant difference of time to negative PCR results between symptomatic and asymptomatic children.

Conclusions: This study of COVID-19 presentations and characteristics presents a first look into the burden of COVID-19 infection in the pediatric population in the UAE. We conclude that a large percentage of children experienced no symptoms and that severe COVID-19 disease is uncommon in the UAE. Various laboratory abnormalities were observed despite clinical stability. Ongoing surveillance, contact tracing, and public health measures will be important to contain future outbreaks.

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KEYWORDS

pediatrics; children; COVID-19; SARS-CoV-2; United Arab Emirates; viral shedding; pandemic; treatment; outcomes; clinical; public heath

Introduction

The COVID-19 pandemic has created a global health care crisis, with over 123 million infections reported in more than 185 countries [1]. The death toll from the ongoing pandemic has crossed the 2-million mark and continues to rise [2]. Early studies reported a predominance of respiratory symptoms in adults and increased fatality among older individuals. As infection trends evolved, reports highlighted that other organ systems were also affected by COVID-19 infection. Pediatric COVID-19 studies from China [3], the United States [4], and Europe [5] have demonstrated similarities in disease prevalence, clinical characteristics, and outcomes. Although COVID-19 has fared mildly in the pediatric population, ongoing research is crucial to improve our understanding of this disease in various parts of the world and the role played by children in community-based viral transmission.

As is now widely known, the SARS-CoV-2 outbreak was first identified in December 2019 in Wuhan, China [6]. In contrast, the first confirmed case in the United Arab Emirates (UAE) was reported on January 29, 2020. Our study was conducted in the emirate of Dubai in the UAE, with a population of 3.35 million people from over 200 countries [7]. Dubai has a young population demographic, with 18% of its population aged 19 years or younger. In this study, we sought to determine whether pediatric COVID-19 infection in Dubai, with its unique population demographic, was similar to that reported in other parts of the world. UAE's proactive public health approach, including early school closures from March 8, 2020, the suspension of public transport, mandatory mask-wearing in public, restrictions on family gatherings, 2-week sterilization campaigns, strict lockdown for containment of the virus, robust testing, and contact tracing played an important role in limiting the spread of COVID-19 infection in the UAE, especially among children. Our findings of COVID-19 infection among children in Dubai will provide a global perspective of disease trends caused by the novel coronavirus and help shape public health policies in the future.

Methods

Study Design and Recruitment

This cross-sectional, multicenter study was conducted across 3 large tertiary-care hospitals in Dubai, UAE. Our study population included a total of 111 consecutive pediatric patients admitted to the participating hospitals between March 1 and June 15, 2020. Children 18 years or younger with a confirmed diagnosis of COVID-19 were enrolled in the study. This study was reviewed and approved by the Mediclinic Middle East Institutional Review Board and the Dubai Health Authority's Dubai Scientific Research Ethics Committee. The requirements for written consent were waived by the boards.

Infection was confirmed by qualitative detection of SARS-CoV-2 RNA using real-time reverse-transcription polymerase chain reaction (RT-PCR) through a simultaneous examination of ORF1ab and N-gene from nasopharyngeal swab samples. Patients were tested as a result of clinical symptoms suggestive of COVID-19 infection or a history of close contact with an individual with confirmed COVID-19 infection.

Participants and Data Collection

Data on patient demographics and epidemiology; comorbidities; clinical characteristics; laboratory results, including COVID-19 PCR tests and radiographic findings; and hospital course, including treatment modalities and outcomes, were collected for all patients. BMI for age percentiles were based on calculators adapted from the Centers for Disease Control and Prevention (CDC) population standards for children and adolescents [8]. Classification of disease severity on admission was based on the most recent UAE National Guidelines for Clinical Management and Treatment of COVID-19 at the time [9]. Disease severity was classified into 4 types, as described below. First, *asymptomatic* cases were those with no clinical symptoms, normal inflammatory markers, and normal chest x-ray (CXR). Second, *mild* cases were those with any clinical symptoms (eg, sore throat, nasal congestion, cough, fatigue, myalgia, and fever), normal chest auscultation, normal inflammatory markers, and a normal CXR. Third, moderate cases were those including any of the following: CXR with infiltrates in <50% of lung fields, oxygen saturation (SpO_2) <95% in room air, mild to moderate tachypnea, or elevated inflammatory markers (eg, lactate dehydrogenase [LDH] >245 IU/L, ferritin >300 ng/mL, lymphopenia $<0.8 \times 10^9$/L , c-reactive protein [CRP] >100 mg/L. Fourth, severe cases were those with CXR with infiltrates in >50% of lung fields, SpO_2 <92% in room air or requiring >4 L/min of supplemental oxygen to maintain SpO_2 >94%, tachypnea, respiratory alkalosis, respiratory acidosis, metabolic acidosis, the ratio of arterial oxygen partial pressure (PaO_2 in mmHg) to fractional inspired oxygen (PaO_2/FiO_2) <300 or SpO_2/FiO_2 ratio <264, or any of the following complications: severe pneumonia, acute respiratory failure and acute respiratory distress syndrome , acute renal failure, disseminated intravascular coagulation, sepsis or septic shock.

Statistical Analysis

Data were collected from the patients' electronic medical records and paper charts, entered into Microsoft Excel, and independently reviewed by 4 coinvestigators to verify data accuracy. Data were analyzed using the Statistical Package for Social Sciences (SPSS) software (version 25.0; IBM Corp). Frequencies with proportions were reported for categorical variables, and means with SDs were reported for continuous variables. Association between categorical variables was tested by the chi-square and Fischer Exact test when appropriate.

Mann-Whitney *U* test was used to compare means between 2 groups, and the Kruskal-Wallis H test was used to compare means between more than 2 groups. A *P* value <.05 was considered statistically significant.

Results

Overview

A total of 111 children, aged 18 years or below, were hospitalized with COVID-19 at one of the participating hospitals during the study period between March 1 and June 15, 2020. Over the same period, 1422 adults with COVID-19 were admitted at the 3 study hospitals. Children constituted 7.8% of the total COVID-19 hospital admissions during the study period. Their mean age was 7 years (range: 17 days to 17.2 years). Our analysis showed that significantly more children aged 6 years or below had COVID-19–related symptoms compared to older children (who were more likely to be asymptomatic). Boys were slightly overrepresented in our sample, with a boy:girl ratio of 1.13. Information regarding BMI was available for only 42 of the 111 (37.8%) children, and about half of them (22/42, 52.3%) had BMI measurements within the normal range for age. Underlying chronic health conditions were infrequently reported. Our patient population comprised a total of 22 different nationalities, with the top 5 nationalities being India (35/111, 31.5%), UAE nationals (27/111, 24.3%), Filipinos (15/111, 13.5%), Egyptians (6/111, 5.4%) and Pakistanis (5/111, 4.5%). The vast majority of our patients had a history of household or family exposure to an adult with confirmed COVID-19 diagnosis, and travel outside the UAE in the preceding 2 weeks was an infrequent risk factor for exposure (Table 1).

Table 1. Demographic and epidemiological characteristics of children with COVID-19.

Characteristics	Total participants, n (%) (N=111)	Asymptomatic, n (%) (n=43)	Symptomatic, n (%) (n=68)	*P* value
Age (years)				.02
≤1	17 (15.3)	6 (14)	11 (16.2)	
1-6	36 (32.4)	8 (18.6)	28 (41.2)	
6-12	32 (28.8)	19 (44.2)	13 (19.1)	
≥12	26 (23.4)	10 (23.3)	16 (23.5)	
Gender				.15
Boy	59 (53.2)	26	33	
Girl	52 (46.8)	17	35	
BMI[a]				.37
Underweight	7 (16.7)	1 (6.3)	6 (23.1)	
Normal	22 (52.3)	8 (50)	14 (53.8)	
Overweight	7 (16.7)	4 (25)	3 (11.5)	
Obese	6 (14.3)	3 (18.8)	3 (11.5)	
Nationality				.18
Emirati	27 (24.3)	13 (30.2)	14 (20.6)	
Expatriates	84 (75.7)	30 (69.8)	54 (79.4)	
Pre-existing medical conditions				
Asthma	4 (3.6)	1(2.3)	3 (4.4)	.50
Prematurity[b]	2 (1.8)	1 (2.3)	1 (1.5)	.63
Diabetes mellitus (type 1)	2 (1.8)	2 (4.7)	0	.15
Epidemiological history				
Close contact[c]	104 (93.7)	41 (95.3)	63 (92.6)	.44
Travel outside the UAE	4 (3.6)	0	4 (5.9)	.14

[a] BMI was calculated for 42 children ≥2 years for whom height and weight data were available. It was defined as percentiles for age as per the Centers for Disease Control and Prevention guidelines for children, as follows: underweight <5th percentile; normal ≥5th to <85th percentile; overweight ≥85th to <95th percentile; and obese ≥95th percentile.

[b] Prematurity per the World Health Organization subcategory of very preterm babies (28-32 weeks).

[c] Close contact was defined as being in contact with someone with confirmed COVID-19 for over 15 minutes.

Spectrum of Clinical Symptoms

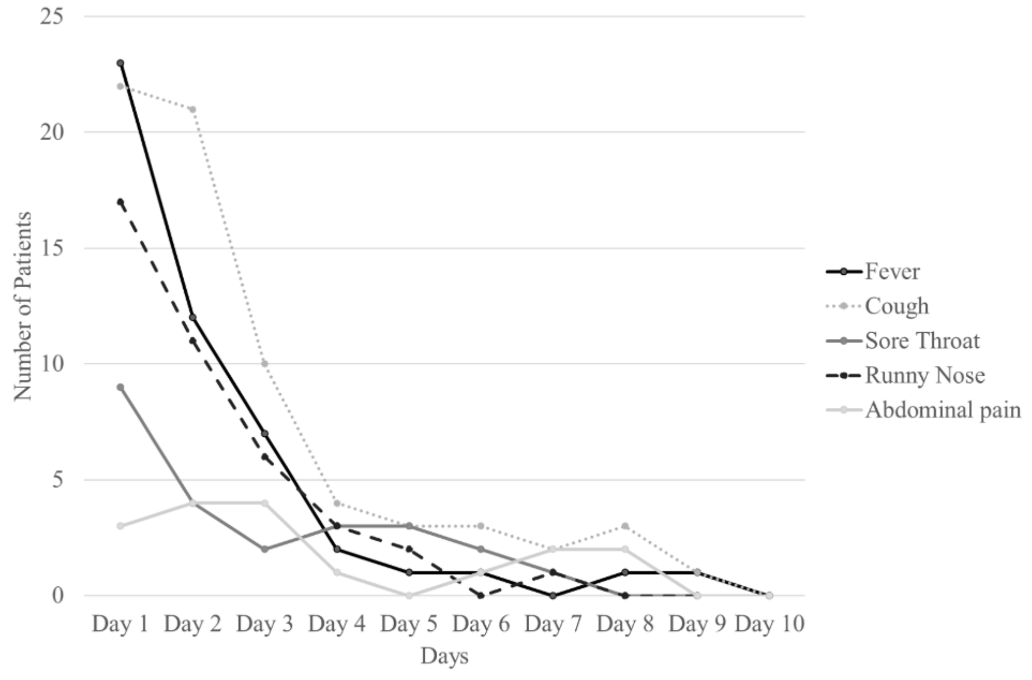
A total of 61.2% (68/111) children presented with mild or moderate symptoms. There were no children admitted with severe symptoms during our study. Fever, cough, and rhinorrhea were the most common presenting symptoms among our patients (Table 2). Anosmia, rash, and gastrointestinal symptoms were infrequently reported on admission. Most of these symptoms had resolved by day 5 of hospitalization (Figure 1). None of the children presented with signs or symptoms suggestive of neurological, cardiac, or renal dysfunction.

Table 2. Clinical symptoms and severity classification on admission.

	Participants, n (%)
Clinical symptoms	
Fever	23 (20.7)
Cough	22 (19.8)
Rhinorrhea	17 (15.3)
Myalgia or fatigue	9 (8.1)
Sore throat	9 (8.1)
Headache	6 (5.4)
Anosmia	5 (4.5)
Abdominal Pain	3 (2.7)
Nausea or vomiting	3 (2.7)
Diarrhea	2 (1.8)
Rash	1 (0.9)
Dyspnea	0 (0)
Classification of clinical severity[a]	
Asymptomatic	43 (38.7)
Mild	32 (28.8)
Moderate	36 (32.4)
Severe	0 (0)

[a] Classification was based on the United Arab Emirates National Guidelines for Clinical Management and Treatment of COVID-19, April 2020.

Figure 1. Trends in clinical symptoms during hospitalization.



Radiologic and Laboratory Findings

Overall, 94 (84.7%) children had chest imaging performed during their hospitalization; the vast majority of which was CXR. Only 2 (1.8%) children had chest computerized tomography (CT) scans, of which 1 child had both CXR and chest CT scans performed. In all, 12 (10.8%) children had 2 CXRs performed over the course of hospitalization. Prominent bronchovascular markings were the most frequently reported CXR findings. Interstitial infiltrates were noted for 7 children (7.5%), 4 of whom had bilateral infiltrates; 4 (3.6%) had bronchial thickening, and only 1 (0.9%) child had ground-glass appearance on CXR. Consolidation or nodular changes on CXR were not reported for any children.

Elevated aspartate transaminases (AST), alkaline phosphatase (ALP), and LDH levels were the most encountered abnormal tests on admission (Table 3). Subgroup analysis of laboratory findings showed that symptomatic patients had significantly higher CRP and LDH and lower hemoglobin when compared to asymptomatic patients.

Table 3. Laboratory parameters on hospital admission.

Laboratory parameter	Value, median (range)			*P* value	Abnormal results[a], n (%)
	Total (N=111)	Asymptomatic (n=43)	Symptomatic (n=68)		
Total WBC[b] in $\times 10^9$/L (n=89)	7.0 (3.0-17.5)	6.6 (3.9-13.1)	7.2 (3.0-17.5)	.85	11 (12.4)
Neutrophils in $\times 10^9$/L (n=89)	2.3 (0.2-8.11)	2.5 (0.2-8.1)	2.2 (0.3-6.1)	.22	22 (24.7)
Lymphocytes in $\times 10^9$/L (n=89)	3.43 (1.1-12.8)	3.0 (2.03-11)	3.7 (1.1L (n=89)-12.8)	.22	7 (7.9)
Hemoglobin in g/dL (n=89)	12.8 (9.5-18.8)	13 (11-18.8)	12.3 (9.5-16.7)	.006	9 (10.1)
Platelets in $\times 10^9$/L (n=89)	283 (133-562)	280 (133-510)	283.5 (182-562)	.89	8 (9.9)
Sodium in mmol/L (n=81)	140 (130-144)	140 (131-144)	140 (130-144)	.28	2 (2.5)
Potassium in mmol/L (n=81)	4.3 (3.4-5.8)	4.1 (3.4-5.8)	4.4 (3.5-5.3)	.16	6 (7.5)
Calcium in mmol/L (n=46)	2.42 (2.22-2.73)	2.42 (2.23-2.73)	2.42 (2.22-2.67)	.96	0 (0)
Magnesium in mmol/L (n=27)	0.86 (0.79-1.01)	0.86 (0.79-0.98)	0.89 (0.81-1.01)	.37	0 (0)
Creatinine in mmol/L (n=23)	51 (35-84)	54 (35-84)	50 (39-73)	.98	5 (21.7)
AST[c] in IU/L (n=80)	25 (12-114)	24 (14-59)	26 (12-114)	.10	18 (22.5)
ALT[d] in IU/L (n=80)	15 (8-76)	15.5 (9-49)	15 (8-76)	.51	1 (1.3)
ALP IU/L (n=79)	211 (37-430)	191 (55-372)	218 (37-430)	.29	29 (36.7)
Albumin in g/dL (n=80)	43 (35.3-49.1)	43.6 (36.5-48)	42.5 (35.3-49.1)	.10	3 (3.7)
Amylase in IU/L (n=35)	66 (23-136)	65 (23-136)	69.5 (31-131)	.33	3 (8.6)
Lipase in IU/L (n=34)	18 (7-64)	17 (13-45)	19.5 (7-64)	.96	1 (2.9)
INR[e] (n=52)	1.04 (0.10-1.34)	1.04 (0.88-1.34)	1.02 (0.10-1.3)	.72	3 (5.8)
PT[f] in seconds (n=52)	13.1 (10.9-15.7)	13.1 (10.9-15.7)	13.1 (11-15.3)	.69	1 (1.9)
aPTT[g] in seconds (n=54)	34.25 (26.9-60.6)	33.4 (27.7-43.2)	34.6 (26.9-60.6)	.25	3 (5.8)
Fibrinogen in mg/dL (n=34)	299 (228-986)	282.5 (228-465)	305.5 (246-986)	.14	2 (3.7)
CRP[h] in mg/dL (n=85)	1.0 (0.10-183.6)	0.9 (0.10-19.5)	1.0 (0.10-183.6)	.047	11 (12.9)
LDH[i] in IU/L (n=73)	232 (134-493)	204.5 (134-245)	258 (142-493)	<.001	31 (42.5)
Procalcitonin in ng/mL (n=61)	0.05 (0.02-0.45)	0.05 (0.02-0.07)	0.05 (0.02-0.45)	.28	0 (0)
D-dimer in ng/mL (n=55)	270 (18-3232)	229.5 (56-3232)	300 (10-1140)	.22	10 (18.2)
Ferritin in ng/mL (n=74)	39.6 (6.66-1276.6)	39.7 (17.7-97.7)	39.4 (6.7-127.8)	.89	5 (6.8)
Creatine kinase IU/L (n=41)	96 (4.3-221)	99.5 (42-163)	76 (4.3-221)	.38	2 (4.9)

[a] Abnormal values based on our laboratory age-specific ranges.

[b] WBC: white blood cells.

[c] AST: aspartate transaminase.

[d] ALT: alanine transaminase.

[e] INR: international normalized ratio.

[f] PT: prothrombin time.

[g] aPTT: activated partial thromboplastin time.

[h] CRP: C-reactive protein.

[i] LDH: lactate dehydrogenase.

Treatment, Clinical Course, and Virologic Outcomes

Children received treatment for COVID-19 according to the UAE National Guidelines published at the time [9]. Hydroxychloroquine was given for a mean of 4.9 days and azithromycin for a mean of 4.8 days. Overall, these medications were well tolerated, and only 1 (5.8%) child reported adverse reactions to hydroxychloroquine (nausea and vomiting) and 1 (25%) to azithromycin (vomiting). One child received both lopinavir-ritonavir and systemic corticosteroids. Patients in our study were infrequently treated for bacterial coinfections, and there was no significant difference in treatment between symptomatic and asymptomatic groups (Table 4).

Table 4. Treatments and complications during hospital stay.

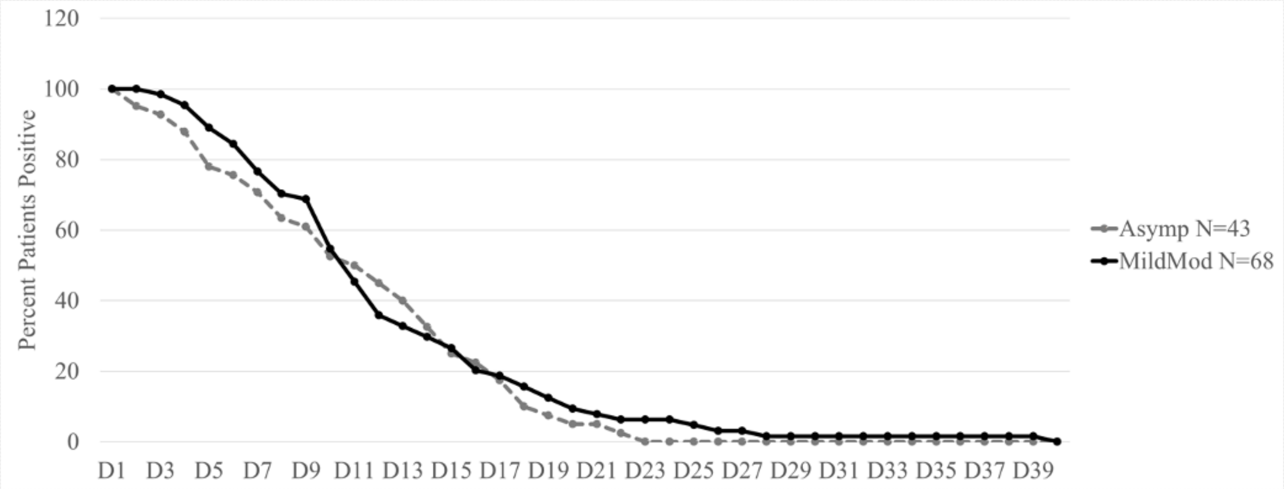
	Total cohort (N=111)	Asymptomatic (n=43)	Symptomatic (n=68)	*P* value
Treatment, n (%)				
Hydroxychloroquine	17 (15.3)	5 (11.6)	12 (17.6)	.28
Azithromycin	4 (3.6)	2 (4.7)	2 (2.9)	.50
Antibiotics	6 (5.4)	3 (7)	3 (4.4)	.16
Lopinavir-ritonavir	1 (0.9)	0 (0)	1 (1.5)	.61
Steroids	1 (0.9)	0 (0)	1 (1.5)	.61
Complications				
Pneumonia, n (%)	3 (2.7)	0 (0)	3 (100)	N/A
Duration of hospitalization days, median (range)	8 (0-30)	7 (1-25)	9 (0-30)	.19
Outcome, n (%)				
Discharge	111 (100)	43	68	N/A[a]
Deaths	0 (0)	0 (0)	0 (0)	N/A

[a] N/A: not applicable

Children were discharged when clinically stable, and COVID-19 PCR test appeared negative as per the UAE National Guidelines for Clinical Management and Treatment of COVID-19 [9]. There were no deaths among our study patients. Among the 68 symptomatic patients in our study, 52 (76.4%) had their nasal samples sent for a respiratory viral PCR panel, and no viral coinfections were detected. Among our total study sample, COVID-19 PCR test results appeared negative after a median of 10 days (IQR 6-14) after the first positive test. There was no significant difference in the median duration of COVID-19 PCR positivity between symptomatic and asymptomatic patients (Figure 2).

D0 signifies the day of first positive COVID-19 PCR test. A positive PCR test result reverted to negative after a median of 10 days in both asymptomatic and symptomatic patients.

Figure 2. Positivity rate of polymerase chain reaction testing for COVID-19 during hospitalization. Asymp: asymptotic patients; MildMod: mild to moderate cases.



Discussion

Principal Findings

In this inaugural pediatric COVID-19 study from the UAE, we shared a comprehensive description of pediatric presentations of COVID-19 during the first wave in Dubai, UAE. This included providing a clear picture of the various ways in which children with COVID-19 can present, monitoring their clinical course, and assessing the total duration of the viral shedding period.

Our findings revealed that the majority of children in our sample size were either asymptomatic or had only mild to moderate symptoms. No cases of severe disease were reported in our sample. COVID-19 PCR turned negative at a median of 10 days after the first positive test. Overall, there was no significant difference in viral shedding duration between asymptomatic and symptomatic children.

A consideration to emphasize is the prevalence of COVID-19 testing in the UAE, which was among the highest reported globally [10], with comprehensive contact tracing that identifies a sizable number of asymptomatic individuals. The UAE National Guidelines followed during the study period required all COVID-19–positive individuals to be admitted to hospitals for the duration of their COVID-19 PCR positivity. This provided a valuable opportunity to study affected children, including asymptomatic and mildly symptomatic ones, who were typically not hospitalized in other countries.

Characteristics of Pediatric Patients with COVID-19

Among our patients, using a strict definition of "asymptomatic"—defined as lack of clinical symptoms, radiographic findings and laboratory abnormalities—43 (38.7%) children were truly asymptomatic; an additional 19 children showed no symptoms but at had least one abnormal inflammatory marker, reflecting a systemic proinflammatory state. Hence, when only clinical symptoms were used to categorize our patients, 62 (55.8%) were asymptomatic compared to the 14.9% to 28% reported in the current pediatric COVID-19 literature [11-14].

Our study cohort spanned 22 nationalities. This mirrored the UAE's diverse population, encompassing an expatriate population of 88% [15]. The vast majority of our patients acquired COVID-19 infection from close family contacts. In our study, we reported 93.7% family clustering, which was higher than the 75% to 90% rate previously reported among children [11,12,16,17]. We theorize this may be due to the strict quarantine measures imposed by local authorities and pre-emptive closure of schools and nurseries at the start of the outbreak, hence limiting wider community transmission. Pre-existing medical conditions were reported in up to 25% of children with COVID-19 in a European multicenter study. Most of our patients were previously healthy, and only 3.6% had a history of asthma; this was lower than expected, given the prevalence of asthma in the UAE was reported at 13% [18,19]. It was thought that asthma predisposes children to increased susceptibility and severity for COVID-19 infection. A few other studies similarly reported low asthma comorbidities among patients with COVID-19 infection [20,21]. Early results from the literature suggest that one of the inhaled corticosteroids (ciclesonide) exhibited antiviral efficacy and inhibited SARS-CoV-2 replication [22,23].

Fever and cough remained the most common presenting symptoms for COVID-19 infection among children in various studies, including ours. Published pediatric studies reported fever in 47% to 59% of patients and cough in 37% to 55% [12,14]. This rate was much higher than our observation, reflecting the high number of asymptomatic and mildly symptomatic children in our study. None of our patients had dyspnea or tachypnea at any point of their stay. Anosmia had been reported more frequently in adults than in children, and it was more prevalent in our study (4.5%) than previously reported (1%) in children [24]. Gastrointestinal symptoms, including vomiting, diarrhea, and abdominal pain, were infrequently presented both in our study and in other pediatric COVID-19 studies [12,13]. None of our patients presented with symptoms of multisystem inflammatory syndrome, although 1 child had a nonspecific rash.

Fewer children with COVID-19 had laboratory abnormalities compared to adults. A meta-analysis of pediatric patients with COVID-19 reported leukopenia or lymphopenia in 28.9% and increased creatine kinase levels in 20.1% as the most common laboratory abnormality [13]. Elevated LDH levels were the most common laboratory abnormality reported in our study, and it was more frequent than that reported in a meta-analysis by Ding et al (42.5% vs 8.3%) [13]. Increased LDH levels have been associated with severe COVID-19 infection [25]. Consistent with this finding, we reported higher LDH in symptomatic children.

Although most studies of COVID-19 infection report lymphopenia and neutrophilia, none of our patients had lymphopenia; however, 12.4% were neutropenic at presentation. It was likely that lymphopenia was a marker of severity of COVID-19 infection; however, since none of our patients had severe disease, coupled with immature immune systems in children, further studies are needed.

Chest CT scans were frequently used during the early phase of the pandemic. A systematic review of imaging findings in children with COVID-19 reported that up to 60% of asymptomatic children had abnormal CT scan findings, including ground-glass opacification and consolidation. However, only 2 children who had progressive symptoms underwent chest CT scans in our study to reduce unnecessary radiation exposure. Follow-up studies often demonstrate resolution of earlier abnormal chest imaging findings, suggesting that long-term pulmonary damage was unlikely [26,27].

Several adult and pediatric studies have shown high rates of concurrent antibiotic use in managing COVID-19 infection [12]. Antibiotic use for bacterial coinfection in our study was extremely low since most of our patients were clinically well.

Duration of Viral Shedding in Asymptomatic and Symptomatic Patients

Very few studies have evaluated the duration of viral shedding in patients with COVID-19 infection. One study in asymptomatic adults reported a median duration of nasal COVID-19 shedding of 19 days (range: 15-26 days), with asymptomatic group patients shedding for a significantly longer duration than those with symptoms [28]. Studies in children suggested a mean duration of viral shedding of 10 days, with prolonged shedding occurring in children with moderate symptoms compared to those with mild symptoms [11]. Among our study population, viral shedding continued for a median of 10 days (range: 1-39 days), without any significant difference between symptomatic and asymptomatic children.

Several challenges have emerged during the COVID-19 pandemic for children and youth including heightened anxiety, disrupted routines, academic and social stresses associated with school closure, and increased risk of domestic violence and abuse [29]. Hospital admission of our studied subjects despite a lack of clinical need for most of them (as per the national COVID-19 guidelines at that time), would most likely have mounted the level of already existing COVID-19 pandemic stress regarding health and well-being, in addition to developing separation anxiety (school-age children isolated from parents), reduced access to psychosocial support, and boredom.

Digital approaches including telemedicine are rapidly established during the current COVID-19 pandemic. They played a major role as a reliable resource to overcome restrictions and challenges, and increased access to effective, accessible, and consumer-friendly care to more patients and families [30].

Currently, children with confirmed or suspected COVID-19 can be isolated at home, assessed, and managed by telemedicine consultation rather unless there is a clinical need for face-to-face consultation or hospital admission.

Study Limitations

Our study's primary limitations were related to the relatively small study population and to the limitations inherent to a retrospective chart review. The changing treatment guidelines by local recommendations precluded any evaluation of treatment efficacy among our patients who received treatment.

Conclusions

Based on our analysis of pediatric patients with COVID-19 from a highly diverse population in the Middle East, we found that many of our demographic and epidemiological findings were similar to those previously reported for COVID-19 infection in children worldwide. However, we observed a higher frequency of asymptomatic and mildly symptomatic children with COVID-19 and some differences in laboratory abnormalities compared to other pediatric studies. Our findings of a similar duration of viral shedding in symptomatic and asymptomatic children highlight the possibility of virus transmission by asymptomatic children, hence reinforcing the importance of continued social distancing, universal mask use and comprehensive contact tracing to control COVID-19 outbreaks once children return to schools.

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Authors' Contributions

All individuals who meet authorship criteria are listed as co-authors and have participated adequately in this work to take public responsibility for the generated results and content, including participation in the idea, design, data analysis, writing of the manuscript, or revision. Furthermore, each author listed certifies that this material or similar material has not been and will not be submitted to or published in any other publication before its appearance in JMIR Pediatrics and Parenting.
FE, ME, EK and HT have collectively designed a customized data collection form, worked on data entry and analysis, wrote the methods section of the manuscript, and extensively contributed to the manuscript revision. BD, KH, DC and HE performed data collection in the participating hospitals. AH has contributed significantly to study design and data analysis. RP has written the background section in the manuscript and provided guidance with the direction of the paper. ZM has written the results section of the manuscript and has helped significantly with study design, data analysis, manuscript writing, and revision. SH has provided immense guidance throughout the project and has contributed to study design, data analysis, and manuscript revision. KS has revised the final manuscript. RA has initiated the project and contributed to study design, format, and discussion section of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

ALP: alkaline phosphatase
ARDS: acute respiratory distress syndrome
AST: aspartate transaminase
CDC: Center of Disease Control and Prevention
CRP: C-reactive protein
CT: computed tomography
CXR: chest x-ray
FiO$_2$: fraction of inspired oxygen
LDH: lactate dehydrogenase
ORF: open reading frame
PCR: polymerase chain reaction
RT-PCR: real-time reverse-transcriptase polymerase chain reaction
SARS-COV-2: severe acute respiratory syndrome coronavirus-2
SpO$_2$: oxygen saturation
UAE: United Arab Emirates

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Original Paper

Youths' and Parents' Experiences and Perceived Effects of Internet-Based Cognitive Behavioral Therapy for Anxiety Disorders in Primary Care: Mixed Methods Study

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Abstract

Background: Anxiety is common among youths in primary care. Face-to-face treatment has been the first choice for clinicians, but during the COVID-19 pandemic, digital psychological interventions have substantially increased. Few studies have examined young people's interest in internet treatment or the attitudes they and their parents have toward it.

Objective: This study aims to investigate adolescents' and parents' attitudes toward and experiences of internet-based cognitive behavioral anxiety treatment in primary care and its presumptive effects.

Methods: The study used mixed methods, analyzing qualitative data thematically and quantitative data with nonparametric analysis. Participants were 14 adolescents and 14 parents recruited in adolescent primary health care clinics. The adolescents and their parents filled out mental health questionnaires before and after treatment, and were interviewed during ongoing treatment.

Results: The quantitative data indicated that the internet-delivered cognitive behavioral therapy program used in this study was successful in reducing symptoms (χ^2_2=8.333; *P*=.02) and that adolescents' motivation is essential to the treatment outcome (*r*=0.58; *P*=.03). The qualitative results show that youths highly value their independence and freedom to organize treatment work on their own terms. The parents expressed uncertainty about their role and how to support their child in treatment. It was important for parents to respect the youths' need for autonomy while also engaging with them in the treatment work.

Conclusions: Internet treatment in primary care is accepted by both youths and their parents, who need clarification about the difference between their role and the therapist's role. Patient motivation should be considered before treatment, and therapists need to continue to develop the virtual alliance. Finally, primary care should be clearer in informing adolescents and their parents about the possibility of internet treatment.

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KEYWORDS

internet; CBT; cognitive behavioral therapy; adolescents; parents; anxiety; primary care; mixed methods; experiences; youths; digital health

Introduction

Cognitive behavioral therapy (CBT) is a well-documented and effective method for various states of anxiety and is considered the treatment of choice [1]. Furthermore, the Swedish National Board of Health and Welfare's updated guidelines for depression and anxiety [2] recommend CBT before or at the same time as drug treatment for diagnosed conditions. However, access to CBT is limited for adults and children, and the COVID-19 pandemic has prompted a worldwide explosion in digital health interventions. The rapid adoption of digital psychological interventions such as internet CBT (iCBT) and video formats for therapy will certainly continue into the recovery from the pandemic and beyond. However, the recommendations for children and youth do not include iCBT [2] and few studies have examined young people's interest in internet treatment or the attitudes they and their parents have toward it. This study aims to investigate adolescents' and parents' attitudes toward and experiences of internet-based anxiety treatment in primary care.

The effectiveness of internet treatment is comparable to that of in-person CBT [3] but with the advantages of greater accessibility, lower costs, and the potential for rapid dissemination and reaching patients who would otherwise not seek psychiatric care for fear of stigmatization [4,5]. Acceptance and commitment therapy (ACT) is considered a treatment method within the "third wave" of CBT. ACT aims to influence core processes maintaining various anxiety problems and is considered a transdiagnostic treatment. Internet-delivered ACT has been investigated in a systematic review that shows efficacy for anxiety disorders among adults [6], and a recent published study showed that acceptance-based iCBT was effective for adolescents with chronic pain [7].

There is a fast-growing research area examining iCBT for adolescents. There are studies on iCBT for children aged 8-12 years [8] and iCBT for those aged 13-19 years diagnosed with anxiety disorder [9,10]. However, in these studies the participants are recruited in response to website postings or local recommendations from health care centers, and none of them are conducted in the clinical context of routine primary care. Studies in clinical care are important to assess patients' experiences and acceptance of treatment delivery.

Few studies have examined young people's attitudes toward internet treatment. When Stallard et al [11] asked children and adolescents aged 8-17 years seeking help at a mental health clinic about their attitudes toward the internet or computer-based mental health programs, 25% of the answers were positive, 25% were negative, and 50% were indecisive.

Qualitative research on young people's experiences of iCBT is also limited. Lenhard et al [12] interviewed 8 adolescents about their experiences of iCBT for obsessive-compulsive disorder (OCD) after treatment completion. Participants were recruited through advertisements in local newspapers, schools, and health care units in a metropolitan area. Results showed that young people appreciated being able to work independently; have control over the therapy process; have flexibility about time and space; be honest about their difficulties; and have the support of therapists, parents, and the content of the program [12]. Jones et al [13] found that caring adults constitute the most contributing factor when adolescents begin to seek help for their mental illness. After treatment begins, young people place more importance on the feeling of having control over their choices, which is associated with staying in treatment. The same study showed that youth's perception of transparency in the therapeutic relationship is important for the treatment work itself. Getting suggestions as opposed to being told what to do contributed to their feeling of control, which in turn affected patients' work with their symptoms [13]. Few studies have been conducted into young people's experiences of provider contact in internet therapy. In their study of college students' experiences of iCBT for generalized anxiety, Walsh and Richards [14] concluded that the development of "virtual alliance" is vital for client's motivation to continue with iCBT.

Qualitative research into parents' role, participation, and experience of internet treatment with their children is limited, and the field needs to be expanded. Spence et al [15] argue that if public health care aims to make internet treatment comparable to clinical treatment for children and adolescents, it needs to be accepted and approved by the parents, who usually initiate health care contacts for their children. The authors measured how satisfied young people and their parents were with internet treatment compared with clinical treatment. Both types of treatment were generally perceived as satisfactory by both groups. However, although there were no differences in the adolescents' satisfaction, the parents were somewhat more satisfied with clinical treatment than with internet treatment [15].

According to Lundkvist-Houndoumadi et al [16], parental participation in CBT can vary based on two conditions. In one condition, parents are seen as cotherapists, who can facilitate generalized therapeutic learning through rewards, encouragement, praise, and other positive reinforcement. In the other, parents are more actively involved as copatients. They work simultaneously on their own feelings and behaviors as their children go into therapy, which can be an opportunity for both to work on the family dynamics that may contribute to adolescents' anxiety problems [16].

In summary, little is known about how adolescents and their parents experience iCBT. The use of self-report instruments in previous studies may have limited their findings since their results might have too narrow a focus. For this reason, we aimed to gain a broader view of adolescents' experiences of iCBT treatment for anxiety in primary care. To enable this broader understanding, youths' and parents' experiences were examined though their own stories in conjunction with self-reports on their well-being.

Methods

This study was conducted in three Swedish primary health clinics, one in an urban area and two in suburbs. The implementation of iCBT was part of a research project conducted in 2017-2020 (Swedish National Research Register, FoU, ID 240221), approved by the Regional Ethics Committee in Gothenburg (Dnr 703-17).

Study Design

This study used a mixed method convergent parallel design to examine an 8-week transdiagnostic iCBT program for adolescents with anxiety disorders treated in primary care. We used two methods to capture participants' views of how the treatment had affected them, with the aim of grasping a deeper understanding of patients' experiences than would be possible through only self-report or only interviews. The study thus used a convergent design, in which qualitative and quantitative data are intended to complement each other and elicit a richer understanding of the research problem [17]. In convergent designs the two types of data are collected during the same time frame and then compared. The quantitative and qualitative data in this study were thus collected during the same intervention period, with the intention to capture different dimensions of the experience. This is called the data diffraction approach [18]. Qualitative and quantitative data were analyzed separately, and we then integrated the analyses of the results to shed light on different aspects of the central phenomena through discussion. The qualitative data examined young people's and their parents' attitudes toward and experiences of iCBT. The study had a phenomenological approach (ie, initial analysis focusing on thorough descriptions, thereafter emphasis on interpretation being inherent in experience) and described the participants' experiences of working with the treatment method [19,20]. The research approach was inductive, and the themes described were extracted from the data. In inductive analysis, data are encoded with no effort to fit them into an existing framework or according to the researcher's analytical knowledge [19].

Participants

Participants were 14 youths and one of their parents. The participants were recruited from three primary health clinics in the Västra Götaland Region on the west coast of Sweden. The inclusion criteria were mild to moderate anxiety problems such as social phobia, generalized anxiety disorder (GAD), panic syndrome, and unspecified anxiety syndrome. Exclusion criteria were severe or ongoing depressive episode, ongoing psychotherapeutic treatment or intervention study, alcohol or drug addiction, severe psychiatric symptoms requiring psychiatric care, risk of suicide, and neuropsychiatric disorder. Out of 14 participating youths, 9 (64%) were aged 13-15 years and 5 (36%) were aged 16-18 years (see Table 1 for demographic variables). The group was broadly representative of the economic and geographic diversity of the local population. Of the 14 child-parent pairs, all parents agreed to be interviewed. One female participant declined to be interviewed since she had not completed the assigned modules. Written informed consent to participate was obtained from all participating youths and parents.

Table 1. Demographic variables.

Variable	Participants (N=14), n (%)
Age (years)	
13-15	9 (64)
16-18	5 (36)
Gender	
Boy	1 (7)
Girl	13 (93)
Other	0 (0)
Country of birth	
Sweden	14 (100)
Other	0 (0)
Parent's country of birth	
Sweden	13 (93)
Other	1 (7)
Parent's highest completed education	
Primary school	0 (0)
High school	3 (21)
University	11 (79)
Parent's living situation	
Cohabitants	1 (7)
Married	11 (79)
Divorced/separated	1 (7)
Parent's occupation	
Sick leave	1 (7)
Studying	1 (7)
Working	12 (86)
Years of current problem	
Less than a year	3 (21)
As long as I can remember	4 (29)
Other alternative	7 (50)
Previous psychological treatment	
No	3 (21)
Yes	11 (79)
Psychopharmacological medication	
Yes, current	0 (0)
Yes, terminated	0 (0)
No, never	14 (100)

Intervention

All participating youths received treatment through the iCBT program "Anxiety Help for Adolescents," a guided internet-delivered self-help treatment program developed by Psykologpartners W&W AB. The intended treatment period is 8 to 12 weeks. "Anxiety Help for Adolescents" is a transdiagnostic program based on the principles of CBT for anxiety. Treatment interventions rely heavily on exposure therapy as described in a treatment manual developed by Hayes, Strosahl, and Wilson [21] and Hayes and Ciarrochi [22].

The iCBT program is aimed at young people between the ages of 13 and 19 with different anxiety diagnoses and is designed for the age and maturity of the targeted group. Theoretical concepts, clinical examples, and the overall structure of the digital treatment program have been exemplified and adapted for the target group through short videos, animations, and linguistic adaptation. The material is divided into eight different chapters/modules, with most participants expected to complete it in 10 weeks. Patients gradually learn new tools through exercises they can do independently, but the therapist is on hand to ask and answer questions and to follow up on the exercises through a messaging system within the program.

The therapists in the study were practicing in primary care in Västra Götaland in Sweden, working with psychological treatment of mental health problems in children and adolescents. The therapists were either licensed psychologists or psychologists under supervision before becoming licensed psychologists and had all been trained in the iCBT program “Anxiety Help for Adolescents.”

Procedures

Young people (aged 13-18 years) seeking help at the primary health clinic for suspected anxiety issues and their accompanying parents were asked to participate in the study. A parent was present at assessment/inclusion and at follow-up talks. All patients were assessed in a clinical interview, and the structured interview MINI-KID (Mini International Neuropsychiatric Interview for Children) [23] was used at pre- and postassessment. The assessment interview was conducted by participating therapists, and the child-parent pairs completed all self-assessment scales for the premeasurements. The measurements used to assess treatment effects are listed in the following sections. All participants provided verbal and written consent prior to participation. Participants meeting the inclusion criteria were directed to iCBT treatment. After treatment, child-parent pairs met the treating psychologist for a final session to evaluate the outcome of therapy. In addition, re-evaluations were carried out according to MINI-KID, and the participants and parents completed all self-assessment scales for the postmeasurements.

Qualitative interviews were conducted continuously from spring and to autumn of 2019. Data were collected by clinical psychologists. The interviews lasted 30 minutes, were recorded using a digital voice recorder, and were transcribed verbatim. The qualitative interviews were conducted with patients and their parents when youths had completed a minimum of 6 modules. The patient group was to some extent homogeneous because they were recruited at the same type of clinics, sought help for anxiety problems, and underwent the same treatment. As the interviews were conducted and transcribed, response patterns began to repeat. The qualitative information was considered saturated and intake on the qualitative part stopped at 23 completed and transcribed interviews, 11 with young people, and 12 with one of their parents.

Measurements for Youths

Self-assessment was performed upon inclusion (pretreatment), after the patients had completed two-thirds of the program (middle), and post treatment.

Symptoms of anxiety and depression in adolescents were measured with the Revised Children’s Anxiety and Depression Scale (RCADS) designed to assess clinical syndromes. The RCADS provides two total scores (anxiety and depression) and six subscales for separation anxiety disorder, social phobia, OCD, panic disorder, GAD, and major depressive disorder. The internal consistency of the RCADS subscales is high, with Cronbach α ranging from .78 to .88 [24,25].

General disability in young people was measured with the youth scale of the Education, Work and Social Adjustment Scale (EWSAS). The EWSAS measures adolescents’ general experienced level of functioning in school and social life [26,27]. It has an internally consistent construct across time with a near acceptable test-retest. The EWSAS also seems to relate to, though not directly measure, severity of illness and psychiatric disorder, and preliminary results support it as a sensitive measure of change for use among children and adolescents. The EWSAS is a valid and reliable assessment of functional impairment that is easy and quick to administer in both research and clinical settings [27].

Global functioning was measured with Children’s Global Assessment Scale. The interviewer assesses the patients’ level of functioning on a scale of 1 to 100, with a higher score indicating a better or higher level of life functioning [28].

Acceptance/psychological flexibility in young people was measured with the Avoidance and Fusion Questionnaire Youth (AFQ-Y8). AFQ-Y8 may be a valuable clinical tool in reflecting changes in psychological flexibility among adolescents aged 12-18 years [29].

Motivation for treatment was measured with the Nijmegen Motivation List 2 (NML-2) [30]. The instrument was designed to measure patient motivation for CBT. The NML-2 consists of three factors: preparedness, distress, and doubt. Preparedness expresses the patient’s preparedness to actively invest in treatment and to make sacrifices. Distress expresses how the patients’ health negatively affects others and themselves. Doubt expresses the patient’s uncertainty about their investment in treatment, the treatment itself, and the possibility of gaining from it. The NML-2 total scores were associated with proximal-treatment helpfulness and with treatment dropout. Higher scores on the NML-2 (range 0-30) reflect higher motivation for treatment. Internal consistency and retest reliability of the factors have been shown to be reasonable [30].

Measurements for Parents

Symptoms of anxiety and depression in adolescents were measured with the Revised Child Anxiety and Depression Scale-Parent (RCADS-P), which assesses parents’ reports of youths’ symptoms of anxiety and depression across the same six subscales as the RCADS previously described. The RCADS-P can be used to track symptoms and provide additional information for assessment [24,25].

General disability in young people was measured with the EWSAS-parent scale. The EWSAS-parent assesses parental reports of youths’ levels of general disability.

Perceived parental stress was measured with the Hospital Anxiety and Depression Scale (HADS). The HADS [31,32] consists of 14 statements (7 on depression and 7 on anxiety) with four response alternatives (0-3). The HADS has been shown to be a reliable and valid instrument for the detection of anxiety and depression in individuals from 16 to 65 years of age [26]. Its reliability was shown by Herrmann [33] with Cronbach α on HASD-A at .80 and on HADS-D at .81. The maximum score on each subscale is 21, and 11 points is the cutoff level for a diagnosis of anxiety or depression. Values of 0 to 6 indicate no or normal anxiety or depression [31].

Motivation for treatment was measured with the NML-2 parent. The NML parent assesses parental reports of youths' motivation to engage in CBT.

Interviews

Semistructured interview guides consisted of questions about experiences and expectations of the treatment before it began and during the treatment, of the treatment interventions themselves, the contact with the therapist, and thoughts about the future after the treatment was completed. Two interview templates were used, one for adolescents and one for parents. The questions were open-ended to facilitate reflection, and probing questions were asked to elicit further exploration [34].

Data Analysis

Quantitative Data Analysis

Quantitative data analysis was performed using SPSS Statistics 25 (IBM Corp). The quantitative premeasurement, middle, and postmeasurement data for the youths were analyzed using a nonparametric statistical method for repeated measures, Friedman analysis of variance (ANOVA) [35,36]. The nonparametric Friedman ANOVA was used because of the small sample size and the assumption of nonnormality of data. The nonparametric test Wilcoxon signed rank test for related samples was used for posthoc analysis. In the last step, Pearson correlation coefficient was used to assess the relationship between motivation for treatment (scored by NML-2; N=14) and changes in symptoms of anxiety and depression (assessed by RCADS-Total and RCADS-Anxiety) between pre- and postintervention. Wilcoxon signed rank test for related samples were used to analyze the parents' pre- and postintervention scores.

Qualitative Data Analysis

Data, in this case transcripts of interviews, were analyzed using thematic analysis. Thematic analysis, as defined by Braun and Clarke [19], is a method for identifying, analyzing, and reporting patterns or themes in data as an aid to their organization and description. Thematic analysis is argued to be a flexible and useful research tool because of its theoretical freedom [19].

The data were thematically analyzed using the six steps proposed by Braun and Clarke [19]. In the first step, the material was read carefully and repeatedly to help researchers become familiar with the content as a whole. In the second step, data were coded according to their interesting aspects in relation to the research questions. Examples of codes include "time" or "difficulties with the internet." In the third step, all code names were collected under common subthemes that described repeated patterns in the responses, such as "treatment work" or "the therapist via the network." In the fourth step, a few themes were developed and analyzed against the entire database. In the fifth step, a concrete thematic map was created with four main themes and several subthemes. In the sixth and final stage, themes were linked both to research questions about attitudes toward and experiences of iCBT treatment and to relevant research on these issues. The first and second authors (JLL and MRL) interpreted the data dialectically, moving between their preunderstandings and the data, and these interpretations were discussed until a consensus was reached on the formulation of the themes presented here. The analysis was repeated by the second and last authors (MRL and SW) to ensure reliability/trustworthiness. Disagreements were resolved through discussion and consensus. The NVivio12 (QSR International) computer program was used as support in data processing.

During the analysis, we considered and reflected upon the ethical aspects raised by Malterud [37]: reflexivity around our preunderstandings and meta-positions, transferability of the data from the selected sample, for whom or what the results are relevant, and the interpretation and analysis of the date, including theoretical preferences and transparency of the procedures. The authors' considered their preunderstandings, and upon ethical reflection, only the third author (LN) had a small clinical experience of working with patients in the treatment program Anxiety Help for Adolescents. We believe our approach to the data, interpretation, and analysis were neutral, as we had no expectations or preunderstandings of the participants' answers to questions about the method or their participation in internet treatment. At the same time, for the past 3 to 8 years, all authors have used CBT with adolescents and adults in primary and psychiatric health care. This professional experience has created an in-depth knowledge and positive attitude toward CBT and its clinical application, which could have influenced the analysis.

Results

Quantitative Results

The quantitative results are based on the 7 adolescents and 9 parents that completed the pre-, middle, and postmeasurement. Tables 2 and 3 show the results for the participating adolescents and parents.

Table 2. Results for participating youths on outcome variables RCADS, AFQ-Y8, EWSAS, and NML-2.

Variable	Mean (SD)	Participants
RCADS[a] total score		
Pre	70.21 (7.6)	14
Middle	66.00 (7.3)	11
Post	59.00 (11.8)	8
RCADS-Anxiety		
Pre	69.93 (7.9)	14
Middle	64.73 (6.3)	11
Post	57.88 (11.0)	8
AFQ-Y8[b]		
Pre	18.79 (5.8)	14
Middle	17.09 (5.0)	11
Post	16.25 (8.4)	8
EWSAS[c]		
Pre	16.79 (6.0)	14
Post	18.25 (6.5)	8
NML-2[d]		
Pre	87.29 (6.5)	14

[a] RCADS: Revised Children’s Anxiety and Depression Scale.

[b] AFQ-Y8: Avoidance and Fusion Questionnaire Youth.

[c] EWSAS: Education, Work and Social Adjustment Scale.

[d] NML-2: Nijmegen Motivation List 2.

Table 3. Result for participating parents on outcome variables RCADS, EWSAS, and HADS.

Variable	Mean (SD)	Participants, n
RCADS[a] total score		
Pre	73.14 (7.4)	14
Post	61.44 (9.7)	9
RCADS-Anxiety		
Pre	71.43 (8.6)	14
Post	60.44 (9.8)	9
EWSAS[b]		
Pre	10.93 (6.0)	14
Post	5.22 (5.0)	9
HADS[c] total score		
Pre	10.57 (5.2)	14
Post	10.67 (5.9)	9
HADS-Anxiety		
Pre	7.57 (3.0)	14
Post	6.67 (3.6)	9
HADS-Depression		
Pre	3.00 (2.8)	14
Post	4.00 (2.6)	9

[a] RCADS: Revised Children's Anxiety and Depression Scale.

[b] EWSAS: Education, Work and Social Adjustment Scale.

[c] HADS: Hospital Anxiety and Depression Scale.

Participating Youths With Complete Data (n=7)

RCADS Total

The results from the Friedman test for the RCADS Total score showed that there was a statistically significant difference between measurement points (χ^2_2=8333; *P*=.02). Post hoc analysis with the Wilcoxon signed rank test for related samples showed a statistically significant reduction in the 7 youths' total scores on anxiety and depression symptoms from pre- to postintervention (*Z*=−2.201; *P*=.03; *r*=0.83).

RCADS-Anxiety

The results from Friedman test for RCADS Total Anxiety score showed a statistically significant difference between measurement points (χ^2_2=9.652; *P*=.008). Post hoc analysis with the Wilcoxon signed rank test for related samples showed a statistically significant reduction in the 7 youths' total anxiety symptoms from pre- to postintervention (*Z*=−2.207; *P*=.03; *r*=0.83).

EWSAS

The results from the Wilcoxon signed rank test for related samples on the EWSAS showed no statistically significant difference between pre- and postintervention (*Z*=−0.677; *P*=.50; *r*=0.26).

AFQ-8

The results from the Friedman test for the AFQ-8 showed no statistically significant difference between measurement points (χ^2_2=0.560; *P*=.76). No post hoc analysis was performed.

Perceived Parental Stress: Parents With Complete Data (n=9) and Their Scoring of Their Children's Symptoms

RCADS Total

The results from the Wilcoxon signed rank test for related samples for the RCADS Total score for the parents showed a statistically significant difference on the parents scoring of their children's symptoms on anxiety and depressive symptoms between pre- and postmeasurement (*Z*=−2.521; *P*=.01; *r*=0.84).

RCADS-Anxiety

The results from the Wilcoxon signed rank test for related samples for the RCADS Total Anxiety score for the parents showed that there was a statistically significant reduction in how the parents scored the children's total anxiety symptoms between pre- and postintervention (*Z*=−2.668; *P*=.008; *r*=0.89).

EWSAS

The results from the Wilcoxon signed rank test for related samples on the parents scoring on the EWSAS showed a statistically significant improvement of the children's general functioning between pre- and postintervention (*Z*=−2.077; *P*=.04; *r*=0.69).

Perceived Parental Stress: Parents With Complete Data (n=9)

HADS

The results from the Wilcoxon signed rank test for related samples on the parents scoring of their symptoms on the HADS (total score) showed no statistically significant difference between pre- and postintervention (*Z*=−0.535; *P*=.59; *r*=0.18).

HADS-A

The results from the Wilcoxon signed rank test for related samples on the parent’s symptoms on anxiety showed no statistically significant difference between pre- and postintervention (*Z*=−1.786; *P*=.07; *r*=0.60).

HADS-D

The results from the Wilcoxon signed rank test for related samples on the parents scoring of their symptoms of depression showed no statistically significant difference between pre- and postintervention (*Z*=−0.948; *P*=.34; *r*=0.32).

Relationship Between Motivation and Changes in Symptoms of Anxiety and Depression

The results of the analysis with the Pearson correlation coefficient showed a statistically significant relationship between motivation for treatment, assessed by NML-2 and scored by the participating adolescents before the start of the treatment, and changes in the RCADS-Total score for anxiety and depression (*r*=0.58; *P*=.03) between pre- and posttreatment. Moreover, there was a statistically significant strong relationship between motivation for treatment, assessed by NML-2 scored by the participating adolescents, and changes in scores for RCADS subscale Anxiety between pre- and postintervention (*r*=0.63; *P*=.02).

The analyses using the Pearson correlation coefficient between the participating parents’ scoring of their children’s motivation for treatment, as assessed by the NML-2 before the start of treatment, and their scoring of their adolescents’ changes on RCADS between pre- and posttreatment showed no statistically significant results for either the RCADS-Total (*r*=0.52; *P*=.06) or the subscale for anxiety (*r*=0.49; *P*=.07). Moreover, there was no statistically significant relationship between the parents’ scores of their adolescents’ motivation for treatment and changes of RCADS when scored by the adolescents themselves between pre- and posttreatment for either the total scale (*r*=0.37; *P*=.19) or the subscale for anxiety (*r*=0.43; *P*=.12).

Qualitative Analysis

Thematic analysis of the 11 interviews with adolescents and 12 interviews with parents resulted in four overarching themes and several subthemes. The results are presented in Textbox 1 and illustrated in the text with quotations.

Textbox 1. Presentation of overarching themes and subthemes.

1. Breaking new grounds
1.1. Adolescents: positive yet uncertain attitudes
1.2. Parents: an ambivalent attitude
2. The adolescent behind the wheel
2.1. Adolescents: needs to be individualized
2.2. Adolescents: an independent task
2.3. Adolescents: a varied relationship with the therapist
2.4. Parents: program requires the youths’ independence
3. The role and function of parents
3.1. Adolescents: parents have a reminding and supportive function
3.2. Parents: limited insight into treatment
4. The effects of treatment
4.1. Adolescents: increased knowledge
4.2. Parents: increased understanding and changed behaviors in the youths
4.3. Parents: concerns about the future

Breaking New Ground

Adolescents: Positive Yet Uncertain Attitudes

All adolescents in the study, regardless of their previous experience with psychological treatment, described being offered treatment on the internet as something new. Most young people described feeling uncertain about what it would mean to work with their mental health via the internet. Several said they were offered internet treatment at their health unit as an alternative and that they saw it as an opportunity to get help faster, which contributed to a more neutral and positive attitude:

> *I was a little hesitant. It felt strange to think that a programme on the net could help me like [...]. Then it felt good because I, ah, I had come so far that I had, like, sought help.* [Youth 3]

Parents: An Ambivalent Attitude

Most parents in the study had not known about the possibility of treatment via the internet, but all of them said they saw it as an opportunity to at least start to get help for their child. However, most expressed skepticism about whether the treatment would work since there would be no in-person, face-to-face contact with the therapist. Some parents wondered whether and how the treatment would work if the child had to complete it alone, but all were positive about trying it:

> *It could also be something that maybe you should think about. Do I fix this via the Internet or set the goals on my own? For some it may work better if you have a personal contact, and you get a task to solve for the next time. I think that is a little bit...you should probably check how I work in such a context. Am I fixing to do this myself or is it good to have this personal contact?* [Parent 1]

The Adolescent Behind the Wheel

Adolescents: Need to Be Individualized

The young people in the study were consistently positive about the treatment program and would recommend it to others. They described various components, tools, and metaphors from the program that they had been thinking about or had worked with. Adolescents appreciated how the program alternated between text, pictures, and films, and that several people with different anxiety problems were presented in the program. However, several young people said they wanted the program to be even more individualized. Some experienced the program as time limited, while others believed that more log-ins would have helped to keep their work with the program more consistent:

> *It's great that it's not all text on one page, but that you browse and that it's new text. I have thought about that. That's really good. Because otherwise, it would be much more boring, I think. It's a lot of pictures and so on, and a lot of videos. It's good.* [Youth 6]

Adolescents: An Independent Task

An important aspect that all young people in the study raised was the independence of the treatment work. They appreciated this partly because they did not need to involve their parents and partly because it was just their own. Most highlighted their ability to keep the treatment work to themselves as an important positive experience. Another advantage of this independence was the opportunity to work when and how it suited them. The young people described how they worked on the treatment on their own and that it was up to them to formulate goals and implement changes at their own pace. Several described how they adapted their time or work with the treatment to fit in with other demands in their life. Being able to pause the treatment or adjust when they worked with it to continue to meet their school's requirements was an important benefit for most young people. However, most young people also described the disadvantages of working via the internet. In many cases, they lacked confidence in their own ability to work therapeutically via the internet:

> *There are still those kinds of things that I – like the programme is not doing it. It helps help me, so that I can see everything, how I should do it, but I am still the one who has to do everything.* [Youth 9]

Adolescents: A Varied Relationship With the Therapist

In general, the adolescents in the study said they were satisfied with their contact with the therapist, even those who did not have much contact. Some youth had contact on a regular basis, while some had no interest in having contact even if they were aware of the opportunity. Those who were in contact with the therapist described receiving help to individualize their goals or support regarding the program itself. Some young people said they did not know what kind of support they could get from the therapist:

> *It is not as good contact as when you had...as if you had talked to them in person, but it is still a very good contact.* [Youth 1]

Parents: Program Requires the Youths' Independence

Most parents in the study had limited insight into their child's treatment work, although most knew that the child was doing that work. Most also knew that there was contact with the therapist during the treatment. At the same time, few parents knew much about how their child arranged the treatment work or what the contact with the therapist looked like. Parents generally expressed respect for the children's treatment work, and many described their children as competent, dutiful, and capable individuals. Parents consistently appreciated their children for their commitment and participation in the treatment:

> *Since she did not want me to sit beside her when she did it, I had to accept it because she is so big that, yes, yes, she has to choose for herself whether I should participate or not, I feel.* [Parent 5]

The Role and Function of Parents

Adolescents: Parents Have a Reminding and Supportive Function

The adolescents in the study described how their parents were a welcome support when they initially sought help, contacted health care, and awaited treatment but became less involved during treatment. The youth described feeling supported by their parents, who they perceived would be available if they needed help:

> *So, it was maybe that my mom kind of tried to talk about it with me. But it was more like I felt it was not a good idea to talk about it.* [Youth 7]

Parents: Limited Insight Into Treatment

The parents in the study reflected on their parental role, not only in their child's treatment but also in general. All parents had a clear appreciation of their children, their characteristics, their anxiety problems and how they developed, and their bravery in seeking help. The parents saw the treatment as aimed toward the child but were unclear about expectations around their own participation. All parents in the study said that they left control over the level of their own participation in the treatment work to their child. Several saw themselves as supporters even though they felt outside the treatment itself, which contributed to their uncertainty about their own role. Some parents wondered whether learning more about the content of the treatment would help them to support their child. Most parents had reflected on the dilemma of how to relate to and support youths expressing their independence while also meeting their needs for support and assistance in treatment. All parents in the study discussed having reflected on the balances between proximity and distance, nagging or stepping back, and staying close but not too involved:

> *I mean I would also like to keep track of things, but I had to...I mean it's like no toddler I have to deal with. She's about to grow up and somehow has to know, and [I have] to show that "I believe in you fixing this". So, I'm worried I can't directly say. I'd say I'm rather a bit more curious about what she has done.* [Parent 3]

The Effects of Treatment

Adolescents: Increased Knowledge

The young people reflected on what they had learned in the treatment about their problems and how they could handle them in the future. Everyone described a process of change from the time they had been offered the treatment until the interviewer called them. On whether the therapy led to improvement or whether their anxiety was still perceived as problematic, all said that they had learned more about their anxiety and how they could handle it differently in the future:

> *Like, if it's something I really don't want to do, then maybe I'm thinking about something I've learned there, that it's better to do it, otherwise you get long-term problems and then, it gets easier. Then you do it.* [Youth 5]

Parents: Increased Understanding and Changed Behaviors in the Youths

All parents in the study noticed changes in how their children handled anxiety. Most described how their children's own understanding of their problems increased over the course of the treatment, and some also saw changes in their behaviors:

> *So, she's gone out to do things I couldn't dream of her doing.* [Parent 4]

Parents: Concerns About the Future

The parents expressed uncertainty about whether the changes they noticed could be attributed to the treatment or to the children's natural development and maturation. Some also expressed concern about what might happen in the future if the child got worse and highlighted the importance of their being able to return to the program to keep the knowledge alive:

> *No, but I really think that as long as the programme continues, then it's going to...then you are reminded if you forget it, and so there is probably no worry. But what I think of, what I started with, is what is there left once you've finished it?* [Parent 6]

Discussion

Principal Findings

The purpose of the study was to investigate in adolescents and their parents their attitudes to and experiences of working with iCBT for anxiety problems. We chose a mixed-methods design to enable a deeper understanding of patients' experiences than would be possible through only one method. The study focused mainly on participants' experiences during the treatment but also highlighted their expectations of iCBT and its presumptive effects.

The quantitative data showed that the youths' symptoms of anxiety and depression improved after completing treatment. These results indicate that the iCBT program was successful in reducing symptoms, which aligns with prior research showing that iCBT is an effective treatment method for adolescents [8,38]. These quantitative results also align with the qualitative results of this study, in which the participating adolescents described how the treatment increased their knowledge and contributed to altering views about their own anxiety problems.

The parents also assessed their children's general functioning as better post treatment, which aligns with the qualitative results in which the parents perceived how their children managed their anxiety problems in a different way. At the same time, parents also expressed concerns that the changes might be short-lived.

The quantitative results further showed a strong relationship between the participants' initial motivation to treatment and outcome. It is possible that youths with higher motivation for treatment before starting treatment also engaged more fully in the iCBT program, which most likely would have affected their treatment outcomes. Several studies on attitudes to internet-delivered psychological treatments highlight the benefits of such treatment (eg, increased ability to work independently and control over the therapy process) [12,39,40], but findings suggest that iCBT treatment might also place more responsibility, and hence a burden that could exacerbate anxiety, on the patients. It is possible that higher initial motivation for treatment increases the ability to structure one's own time and create favorable conditions for engaging in the treatment program. Initial motivation for iCBT treatment might thus be an important factor for the clinician to explore before initiating iCBT treatment with patients in primary care.

The results showed no statistically significant relationship between how parents assessed their adolescents' motivation for treatment and any changes in their symptoms of depression and anxiety as rated by both patients and parents on the RCADS-Total and RCADS-Anxiety. Because of the limited sample size, no major conclusions should be drawn from this, but it is an interesting finding from a clinical perspective. For a clinician, it may be more important to explore and consider the child's motivation, rather than the parent's perception, before deciding to initiate an iCBT treatment. Parents often have opinions about appropriate and preferable treatments for their children, but the results of this study indicate that parents' perceptions of their child's motivation for a particular treatment might have little to do with the child's outcome in therapy. The child's own motivation for treatment seems to be more important than their parents' assumptions and to have a greater association with the treatment outcome.

Both adolescents and their parents described a generally positive attitude toward help with mental health problems via the internet and saw iCBT as an acceptable treatment alternative. The study's results are comparable to those of previous studies that have shown a variation from neutral to positive attitudes to iCBT among youths [15]. The youths in our study expressed a positive attitude to the treatment and would recommend it to other young people with anxiety problems. They described having learned about their own anxiety no matter how successful they felt the treatment had been for them. Contact with the therapist during treatment was perceived as small but sufficient in this study, and the therapist was described as friendly and supportive. Similar to other features of the internet treatment, even contact with the therapist was perceived as having been conducted on the young people's terms.

Parents described positive changes in their adolescents' knowledge and management of anxiety, but they also had concerns that these effects might be short-lived and disappear after treatment completion. The parents' insights into their children's treatment work and contact with the therapist were limited. Parents saw their children as working independently and in not much need of parental support when working with iCBT. The parents tried to respect and acknowledge their growing children's need for independence and autonomy, but also wanted to be supportive of the treatment work and were uncertain about how to help without being intrusive.

Previous research on parental involvement in adolescents' internet therapy has shown the importance of the role of parents in introducing internet therapy to patients younger than 18 years while recognizing that their importance decreases as treatment continues [13,15,16]. However, previous research did not include parents' perceptions of their own participation and role during their children's participation in iCBT. This study's results show that parents vary in how much and in what way they wish, or are able, to be involved in their children's internet treatment. On the one hand, they want to know more about the content of the treatment program to be able to better support their children; on the other hand, they want to let the young people themselves control their treatment work. Despite this contradiction, parents described how they reminded, nagged, and asked about the treatment program, consistent with the role of the therapist in adult iCBT who reminds, motivates, and helps with structures [8].

The study's findings on youths' and their parents' experiences of treatment and the youths' experiences of contact with the therapist could contribute to answering the question raised by Vigerland et al [8] about how a division of roles between parents and caregivers could function in youth therapy via the internet. Through their role as someone who supports, reminds, and is on hand in everyday life, parents could take on the role of cotherapists and thus take over part of the therapist role. The virtual alliance with the therapist could then focus more on increasing compliance and individualizing the internet treatment, and less on motivating the youth to remain in treatment. As noted by Badawy and Radovic [41], a number of challenges and further research is needed to improve telemedicine and iCBT that is offered to young people. Optimizing digital approaches to health care delivery and integrating them into the public health will continue during the current COVID-19 outbreak and other future worldwide crises. In this, it will be important to analyze quality of care with feedback from patients and health care providers as well as cost-effectiveness, degree of improvement of mental health, and balance in use.

In summary, this study's results support the importance of parents' involvement as an important part of iCBT work with young people. This applies not only at the start of treatment as found by Jones et al [13], but also throughout the treatment. Informing and introducing parents to iCBT and the expectations of their participation, and supporting their collaboration with therapists can create even better conditions for the young people undertaking iCBT treatment.

Limitations

The sample in the study was restricted to a gender-biased and small sample of young people and adults, which limit the generalizability of the results but challenges future research to investigate other experiences of internet treatment. The gender bias is important to address in future research and clinical work. We need more generalized data and improved ways to reach boys in early stages of mental illness in primary care. The interviews in the study were conducted during treatment, which could affect the results, as participants may feel compelled to express more positive attitudes than would be the case if the interviews were conducted after completion of treatment or at a later date.

Conclusions

This study's unique contribution about the practical benefits of iCBT for youths is its implementation in a primary care context. The results provide further support for offering internet treatment as a firsthand option to youth seeking mental health care at primary care units. Internet treatment should primarily be offered to motivated young people who have expressed a need to control their own time and those who want to work with psychological treatment independently and without eye-to-eye contact with their therapist.

The take-home messages for clinicians and health care organizations in primary care can be summarized as follows:

- Youths prefer a therapist who they perceive as one who can both give "support" and provide shared reflective opportunities. This finding speaks to maintaining a fundamental emphasis on a relational approach; in other words, for a therapeutic relationship that places the experience of human contact and response in the forefront, whether that experience be digital or physical.
- Youths and parents treated in primary care generally have a positive attitude and experience of iCBT during treatment.
- The participant's motivation should be considered before initiating treatment.
- The parent's role and involvement in iCBT throughout therapy needs clarification when initiating treatment.

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Conflicts of Interest

None declared.

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Abbreviations

ACT: acceptance and commitment therapy
AFQ-Y8: Avoidance and Fusion Questionnaire Youth
ANOVA: analysis of variance
CBT: cognitive behavioral therapy
EWSAS: Education, Work and Social Adjustment Scale
GAD: generalized anxiety disorder
HADS: Hospital Anxiety and Depression Scale
iCBT: internet cognitive behavioral therapy
MINI-KID: Mini International Neuropsychiatric Interview for Children
NML-2: Nijmegen Motivation List 2
OCD: obsessive-compulsive disorder
RCADS: Revised Children's Anxiety and Depression Scale
RCADS-P: Revised Child Anxiety and Depression Scale-Parent

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Original Paper

A Smartphone App for Supporting the Self-management of Daytime Urinary Incontinence in Adolescents: Development and Formative Evaluation Study of URApp

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Abstract

Background: Daytime urinary incontinence (UI) is common in childhood and often persists into adolescence. UI in adolescence is associated with a range of adverse outcomes, including depressive symptoms, peer victimization, poor self-image, and problems with peer relationships. The first-line conservative treatment for UI is bladder training (standard urotherapy) that aims to establish a regular fluid intake and a timed schedule for toilet visits. The success of bladder training is strongly dependent on good concordance, which can be challenging for young people.

Objective: This paper aims to describe the development of a smartphone app (URApp) that aims to improve concordance with bladder training in young people aged 11 to 19 years.

Methods: URApp was designed by using participatory co-design methods and was guided by the person-based approach to intervention design. The core app functions were based on clinical guidance and included setting a daily drinking goal that records fluid intake and toilet visits, setting reminders to drink fluids and go to the toilet, and recording progress toward drinking goals. The development of URApp comprised the following four stages: a review of current smartphone apps for UI, participatory co-design workshops with young people with UI for gathering user requirements and developing wireframes, the development of a URApp prototype, and the user testing of the prototype through qualitative interviews with 23 young people with UI or urgency aged 10 to 19 years and 8 clinicians. The app functions and additional functionalities for supporting concordance and behavior change were iteratively optimized throughout the app development process.

Results: Young people who tested URApp judged it to be a helpful way of supporting their concordance with a timed schedule for toilet visits and drinking. They reported high levels of acceptability and engagement. Preliminary findings indicated that some young people experienced improvements in their bladder symptoms, including a reduction in UI. Clinicians reported that URApp was clinically appropriate and aligned with the best practice guidelines for bladder training. URApp was deemed age appropriate, with all clinicians reporting that they would use it within their own clinics. Clinicians felt URApp would be of particular benefit to patients whose symptoms were not improving or those who were not engaging with their treatment plans.

Conclusions: The next stage is to evaluate URApp in a range of settings, including pediatric continence clinics, primary care, and schools. This research is needed to test whether URApp is an effective (and cost-effective) solution for improving concordance with bladder training, reducing bladder symptoms, and improving the quality of life.

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KEYWORDS

incontinence; urinary incontinence; digital intervention; child health; pediatric; pediatric incontinence; smartphone; intervention development; mobile phone

Introduction

Background

Daytime urinary incontinence (UI), which is the involuntary leakage of urine during the day, is common in childhood and is generally assumed to resolve with age. However, there is evidence from epidemiological studies that childhood UI often persists into adolescence [1-5]. For example, in a UK-based cohort study, 4.2% of females and 1.3% of males reported experiencing daytime UI at 14 years [6].

UI in adolescence is associated with a range of adverse outcomes, including depressive symptoms, peer victimization, poor self-image, and problems with peer relationships [7]. Key concerns of young people with continence problems include the perceived stigma of incontinence, fear of bullying and social isolation, adverse impacts on academic achievement, and difficulties in self-managing their continence problems at school (eg, restricted access to toilets during lessons) [8].

Most cases of UI in children and adolescents are functional (ie, with no underlying neurological, structural, or anatomical cause [9]), and the first-line conservative treatment is bladder training (standard urotherapy) [10,11]. Bladder training is a behavior modification intervention that aims to promote regular fluid intake throughout the day, establish a timed schedule for toilet visits (emptying the bladder every 2-3 hours), educate patients on how the bladder works and the causes of UI, and provide guidance on establishing optimal voiding behavior (eg, optimal toilet posture and relaxing the pelvic floor).

Bladder training can be an effective treatment for UI [12,13]; however, success is strongly dependent on good concordance with the timed schedule of toileting and drinking [14]. Concordance is challenging for many young people, strongly depending on their level of maturity, self-motivation, and ongoing support from clinicians [15]. Suboptimal clinical care experiences in young people with incontinence (eg, poor continuity in care, high rates of relapse, and treatment failure) diminish their belief in the success of treatments and add to their distress [15]. There is evidence that young people with UI have a strong desire to be involved in decisions about their treatment and to feel supported in self-managing their bladder symptoms [15]. Promoting the acceptance of chronic health conditions and the need for ongoing active management is linked to more positive coping strategies and greater treatment concordance [16-19]. There is some evidence that supplementing bladder training with a timer watch might aid concordance in children [11,20]; however, these watches can attract unwanted attention from peers. Our research with young people has highlighted the need to provide an age-appropriate self-management solution to help them manage their bladder symptoms [8,15]. This is further supported by the literature on self-management of other health conditions and the growing use of smartphone technology [21,22].

Objectives

This paper describes the development of a smartphone app (URApp [23]) for young people, which aims to improve their concordance with bladder training. URApp was co-designed with young people and clinicians and incorporates theoretically underpinned behavior change techniques (BCTs) [24]. The development of URApp was informed by the Medical Research Council guidance for developing and evaluating digital interventions [25], which recommends the use of theory to inform intervention design and delivery [26,27]. There is evidence that embedding behavior change theory in health interventions increases their effectiveness, and interventions that incorporate more BCTs are more effective [28]. The development of URApp was also guided by the person-based approach (PBA) for developing behavioral health interventions [29]. The PBA involves in-depth qualitative research with the target user population at every stage of the development process to understand and accommodate their needs. The interventions are iteratively optimized to improve their acceptability and feasibility and make them engaging for users. The paper aims to provide an overview of the development of URApp, including its design, prototype development, and usability testing.

Methods

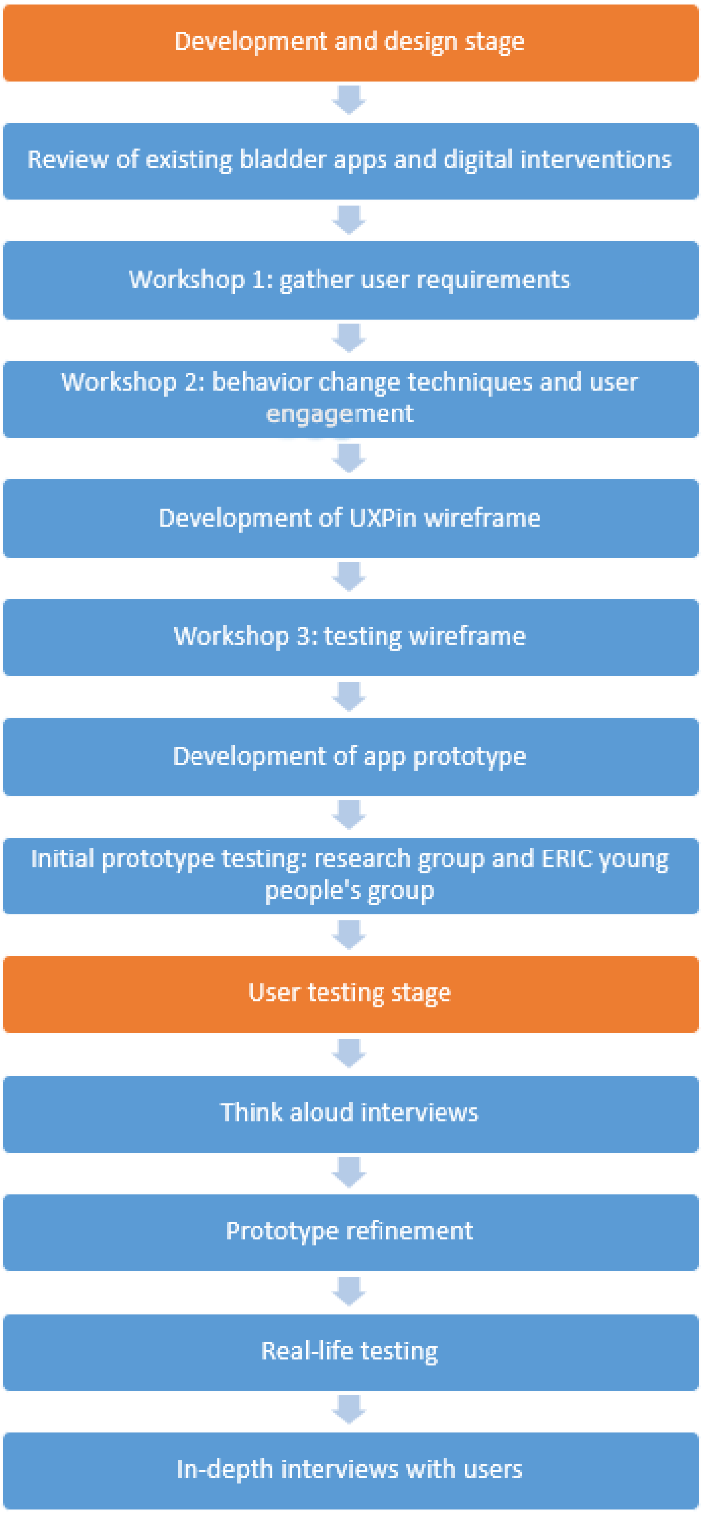
Overview

The development of URApp comprised 4 stages, as follows:

1. Review of current smartphone apps for UI
2. Participatory co-design workshops with young people with UI to gather user requirements for the app and to develop the wireframes
3. Development of the app prototype
4. User testing of the app prototype comprising in-depth qualitative research with young people and clinicians to explore their views of URApp

The methods and results for each stage have been presented together to aid the understanding of the app development process. A flow diagram of the method sequence is shown in Figure 1.

Figure 1. Flow diagram of the methods sequence.



Ethical Approval

Ethical approval for all stages of the development process was granted by the University of Bristol research ethics committee.

Clinical Input

Input from expert clinicians was obtained throughout the app development process to ensure that URApp was compatible with clinical advice given to young people receiving treatment for UI. Clinical input was obtained from (1) stakeholders in the study steering group, including a lead consultant pediatrician in charge of a specialist bladder clinic and a specialist bladder and bowel care nurse; (2) a clinical advisory group comprising 2 specialist nurses and a nephrologist; and (3) interviews with clinicians involved in continence care as part of the user testing stage.

Inclusion Criteria

Participants were aged between 10 and 19 years, with current (or previous) experience of functional UI or urgency, able to provide informed consent (aged 16-19 years) or assent (aged 10-15 years), and able to speak and understand English. Young people taking part in user testing were also required to have an Android or iOS smartphone.

Recruitment

Young people who took part in the participatory co-design workshops and user testing were recruited through advertisements on the website of ERIC, The Children's Bowel and Bladder Charity [30], and the ERIC Facebook and Twitter pages. The advertisements provided an overview of the study and included links to allow potential participants (and their parents) to download the study information sheets.

Clinicians were recruited through an extensive network of clinical contacts established by ERIC and the Paediatric Continence Forum [31]. Purposive sampling was used to gain views of clinicians from a range of backgrounds, including continence nurses, pediatricians, urologists, and general practitioners.

Consent and Assent

Written informed consent was obtained from all the participants. Parent consent and child assent were obtained from participants aged <16 years.

Patient and Public Involvement and Advisory Groups

Patient and Public Involvement (PPI) in research is the research carried out *with* or *by* members of the public rather than *to*, *about*, or *for* them [32]. It can include patients, carers, and people who use health and social care services. A total of 2 PPI groups were formed to provide input for the running of the study and comprised 3 young people from the ERIC Young People's Advisory Group and 3 clinicians (general practitioner, bowel and bladder nurse, and nephrologist). The clinician PPI group also provided feedback on the support pages in URApp to ensure that the information was consistent with clinical advice.

Participants

The participants included 23 young people with current or previous UI or urgency. Table 1 provides a summary of participant characteristics and the phase of the development process in which they were involved. A total of 8 clinicians provided feedback about URApp in the qualitative interviews (Table 2).

Table 1. Demographic characteristics of the young people involved in the app development.

Participant ID	Age (years)	Gender	App development stage
W1	13	Female	Workshops 1, 2, and 3
W2	10	Female	Workshops 1, 2, and 3
W3	12	Male	Workshop 2
W4	10	Male	Workshop 3
W5	17	Male	Workshops 2 and 3
W6	12	Female	Workshop 1
W7	17	Female	Workshop 1
W8	15	Female	Workshops 2 and 3
W9	14	Male	Workshop 2
W10	12	Female	Workshops 1, 2, and 3
W11	11	Female	Workshop 3
P2	18	Female	TA[a], RLT[b], and IDI[c]
P5	11	Male	TA
P6	13	Male	TA, RLT, IDI
P8	19	Female	TA
P10	11	Male	TA, RLT, IDI
P11	18	Male	TA, RLT, IDI
P13	12	Female	TA, RLT
P14	14	Female	TA, RLT, IDI
P22	12	Female	TA, RLT
P23	11	Female	RLT, IDI
P26	12	Female	RLT, IDI
P27	11	Female	TA, RLT

[a] TA: think aloud.

[b] RLT: real-life testing.

[c] IDI: In-depth interview.

Table 2. Description of the professional background of the clinicians.

Participant	Role
Clinician 1	Clinical nurse specialist
Clinician 2	GP[a]
Clinician 3	Clinical nurse specialist
Clinician 4	School nurse
Clinician 5	Children’s specialist nurse
Clinician 6	Pediatric bowel and bladder care service clinical and professional lead
Clinician 7	Consultant urologist
Clinician 8	Clinical nurse specialist

[a] GP: general practitioner.

Results

Stage 1: Review of Current Digital Interventions to Support Young People With Daytime Wetting

Overview

In March 2017, we conducted a review of existing apps to ensure that none were specifically aimed at supporting self-management of bladder problems in young people. Existing apps were designed for young children and their parents to manage bedwetting, for pregnant or postpartum women (mainly for stress incontinence), and for older people with UI. Most apps provided only a bladder diary or reminders for pelvic floor exercises, and few were evidence-based or coproduced with stakeholders. This search was updated in April 2021, and no relevant apps were identified. A list of the reviewed apps is available on request.

Identifying the Core App Functions

We identified the core functions needed to support bladder training based on clinical guidance. Core app functions included setting a daily drinking goal, recording fluid intake and toilet visits, setting reminders to drink fluids and go to the toilet, and recording progress toward drinking goals. Clinicians advised that the app should also allow users to record stool frequency and consistency because of the comorbidity of constipation and UI [33]. A table outlining the key components of bladder training and target behavior change is included in Multimedia Appendix 1.

Stage 2: Participatory Co-Design Workshops

Stage 2 Methods

Stage 2 focused on designing an app that supported the core features of bladder training. We invited young people to take part in 3 participatory co-design workshops at the University of Bristol to identify user requirements for the app (workshop 1), to explore which BCTs to use in the app to improve concordance (workshop 2), and to test an interactive wireframe created in UXPin (workshop 3) [34]. Wireframes provide a 2D blueprint of the app interface that allows testing of the app's navigation and user journey and gain feedback on its content and layout.

The workshops were facilitated by researchers with expertise in health and developmental psychology, behavior change, qualitative research, participatory co-design, and user experience. All workshops had a lead facilitator and were guided by a detailed schedule of the content and structure for each activity. We used a range of tools to elicit the views of young people, for example, large (A3) phone templates for sketching ideas for app functions and screen layout and sticky notes with different colors and shapes to annotate the designs (see Figure 1 for example).

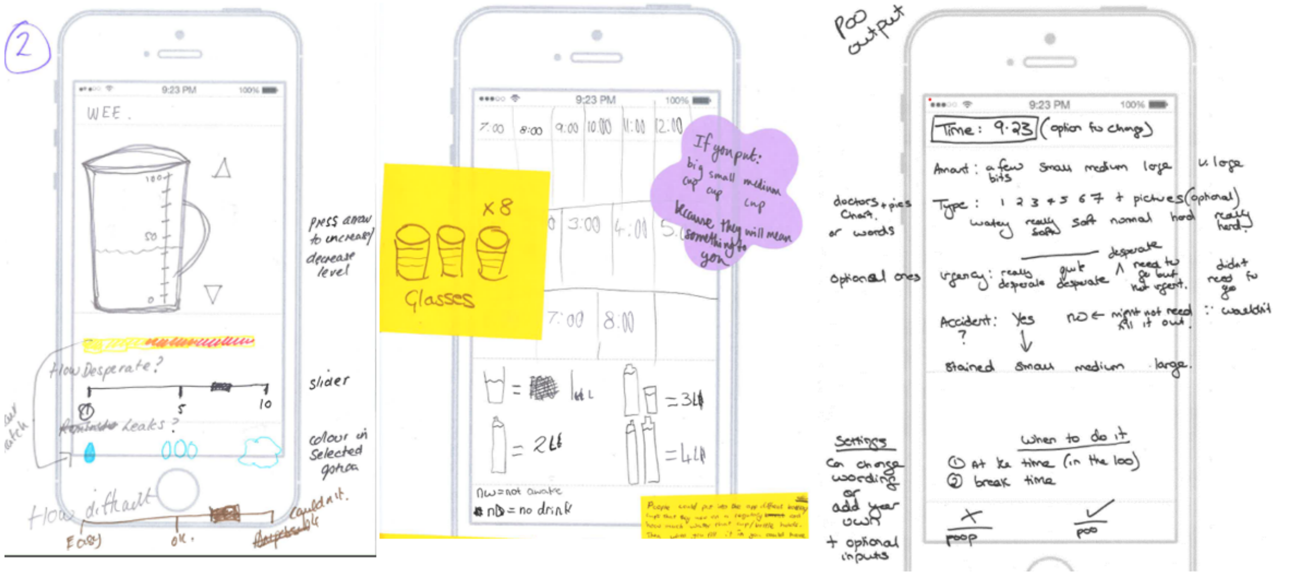
Before commencing the workshops, the research team had an initial meeting with the app development team (Natural Apptitude [35]) to discuss the purpose of the app and its core functions. The findings from each workshop were discussed with the app developers to ensure that the user requirements were feasible in terms of time and cost.

Stage 2 Results

Workshop 1: Identification of User Requirements and Implementation of Core Functions

This workshop was led by a participatory co-design expert (LM) and a health psychologist (KW). The plan for the session was presented to the participants, and they were given a brief explanation of the key elements of bladder training. We asked the participants about their mobile phone use at home and at school or college, their preferred methods of recording toilet visits (wees and poos were their preferred terms) and drinking in the app, the potential ways to receive reminders for drinking and toilet visits, and information that would be useful to record in a daily diary (eg, mood, medications, and life events). Young people were also asked to provide feedback on the existing apps we had reviewed, and they reported that those apps did not meet their user requirements and were not age appropriate. Example results from workshop 1 are shown in Figure 2.

Figure 2. Workshop 1 example.



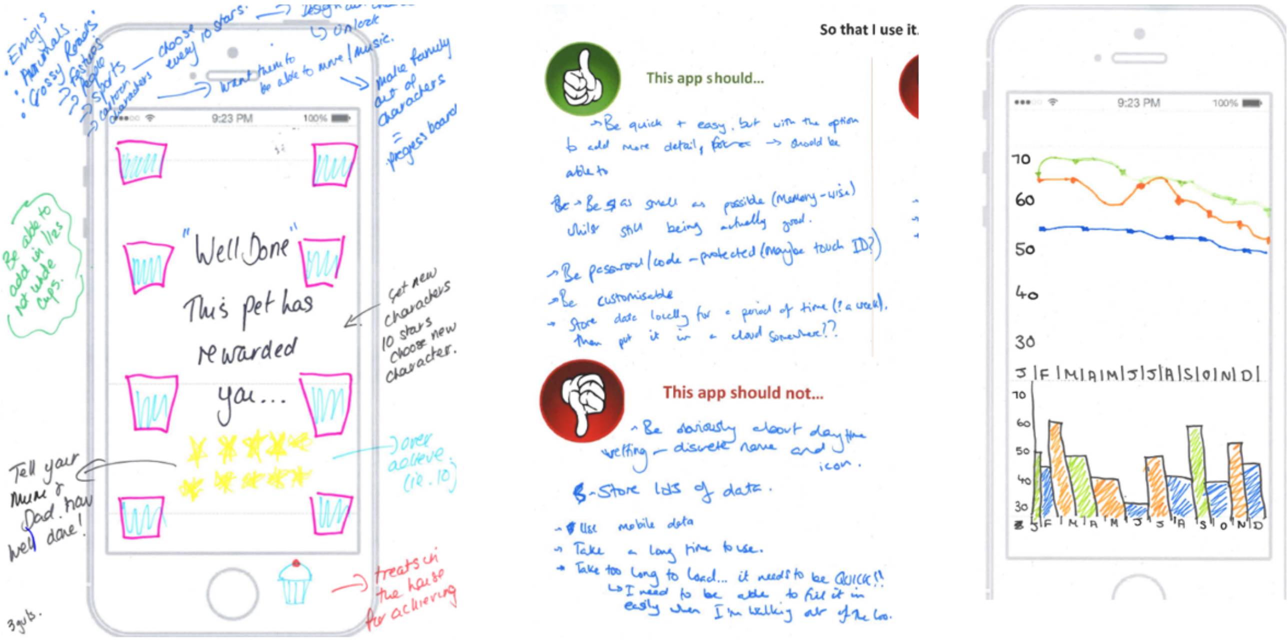
Workshop 2: User Engagement and Behavior Change

This workshop was led by a behavior change expert (LW). The first aim of this workshop was to identify how to maximize user engagement with the app. Activities included identifying apps that were popular among young people, discussing why they liked these apps, and examining the app functions that motivated their continued use.

The second aim was to obtain views on BCTs that could be implemented in the app to support self-management and improve concordance with bladder training. It was established that the app should provide rewards for changes in behavior within the young person's control, that is, for recording their drinks and toilet visits and achieving daily drinking goals (recommended daily amount is 6-8 glasses of water or dilute squash regularly spaced throughout the day). The app would not provide rewards for fewer *wetting accidents* and *leaks*, as this could undermine motivation because of a perceived lack of personal control and competence [36].

Participants provided ideas for daily rewards (eg, collecting stars and trophies) and *streak rewards* (for continuous daily use of the app, eg, used in Snapchat) that could help motivate them to keep using the app. They sketched ideas for recording progress toward daily drinking goals in the app (eg, progress bars and charts) and other data they wished to record (eg, number and type of daily toilet visits and number of wetting accidents). Figure 3 shows examples of workshop 2's outputs.

Figure 3. Workshop 2 example.



The workshop findings relating to BCTs were reviewed against the Behavior Change Taxonomy [24]. Optimal BCTs were identified as *graded goal setting and reviewing* (modifying goals to make them more achievable), *action planning* (ie, setting goals for daily drinking and incrementally increasing fluid intake), *prompts and cues* (ie, reminders to drink fluids and use the toilet), *rewards* (ie, for achieving drinking goals), and *self-monitoring* (ie, charts and a daily diary to review progress). The BCTs that were chosen in the app align with the self-determination theory [36] and are aimed at supporting users' feelings of autonomy, competence, and relatedness, all of which have been shown to promote intrinsic motivation [37]. The *rewards* BCT further aligns with the theories of gamification [38,39]. Further input on the BCTs was gained from a digital intervention and behavior change expert (LY). The PBA to intervention design highlights the importance of responding to the user engaging with the app by providing personalized feedback [29]; therefore, this BCT was added to the URApp design. A full breakdown of the BCTs in URApp and how they are implemented is included in Multimedia Appendix 2. Following the first 2 workshops, an interactive wireframe was designed using UXPin. This is an essential stage in the design process and provides a visual guide for app layout, navigation between screens, and basic functionality.

Workshop 3: Feedback on the Wireframe

This workshop was led by an expert in user experience and prototyping (SC). The aim of workshop 3 was to review the interactive wireframe, design the app setup instructions and the drinks and reminders functions, and identify what information resources to include in the app. The wireframe was demonstrated (Figure 4) on a large screen. Participants were provided with smartphones and tablets to test the wireframe using a set of tasks aimed at navigating through the app screens and testing specific app functions (eg, adding a new drink). After completion of the workshop, adjustments were made to the wireframe based on user feedback (eg, changing *loo visits* to *visits* for more privacy, storing and reopening unfinished drinks, and a library of recent drink containers).

Figure 4. Wireframe example.

Stage 3: Development of the App Prototype

Stage 3 Methods

Following completion of the workshops and adjustments to the wireframe, the research team collaborated with the app developers to produce the app prototype. A matrix was produced containing all the app functions, the purpose of each function, and how they should work. The priority of each function was defined using the MSCW (must have, should have, could have, would have) framework. Decisions were based on whether the function was deemed to be core or additional; participants' and clinicians' rating of importance; and the feasibility, technical difficulty, and cost of implementing each function in the app.

The developers shared regular videos to demonstrate their progress with the app build and designs for each screen and had regular meetings with the research team to review each stage of the build.

The initial app prototype was tested at a workshop attended by the ERIC Young People's Advisory Group. They were asked to provide feedback on the app's design, navigation, and functionality. This feedback was discussed within the research team, and the proposed changes were sent to the developers. Updated versions of the app were then made available to the research team for review through a closed (beta) testing group, and this iterative process continued throughout the app development process.

Stage 3 Results: Design and Content of Prototype

A prototype of the app was produced with the following functions:

- Passcode for security
- Daily drinking goal set by the user and based on clinical guidance
- Customizable reminders for drinking and toilet visits
- An interactive homepage to record drinks and view daily drinking progress
- A range of standard drink containers
- Option to add a customized container and use a picture of the user's own container
- Toilet visit recording
- Progress charts, daily diary, and summary
- Rewards for reaching drinking goals
- Personalized feedback linked to the support and advice pages
- Task center for viewing notifications and completing tasks (eg, viewing daily feedback and completing weekly evaluations)

Example screenshots of the drink recording page, range of drinking containers, and toilet visit recording page are shown in Multimedia Appendix 3.

Stage 4: User Testing

Stage 4 Methods

Think Aloud Interviews

Young people participated in *think aloud* interviews to provide their immediate reactions to every element of the app. This phase was key to optimizing the design and function of the app before real-life testing. Feedback from young people was logged in a *table of changes*, and the coding framework described in Table 3 was applied [29]. The table included positive and negative feedback on all functions of the URApp, suggested changes, reason for changes, and MSCW priority. Potential changes were discussed with stakeholders, and the decisions were communicated to the developers who implemented them before the real-life user testing.

Table 3. Table of changes for the coding framework.

Code	Full form	Meaning
IMP	Important for behavior change	This is an important change that is likely to affect behavior change or a precursor to behavior change (eg, acceptability, feasibility, persuasiveness, motivation, and engagement) or is in line with the logic model or with the guiding principles. For example, participants appear unconvinced by an aspect of the intervention, so you decide to add motivational examples.
EAS	Easy and uncontroversial	An easy and feasible change that does not involve any major design changes; for example, a participant was unsure of a technical term, so you add a definition.
REP	Repeatedly	This was said repeatedly by >1 participant.
EXP	Experience	This is supported by experience. Please specify what kind of experience; for example, patient and public involvement members agree this would be an appropriate change, and experts (eg, clinicians on your development team) agree that this would be an appropriate change. This is supported by evidence in the literature.
NCON	Does not contradict	This does not contradict experience (eg, evidence) or the logic model or the guiding principles.
NC	Not changed	It was decided not to make this change. Please explain why (eg, it would not be feasible or only one person said this).

Real-life User Testing

In the real-life testing phase, young people were provided with the updated app prototype to use for a period of 4 to 6 weeks. This is the minimum time needed to see improvements in bladder symptoms as a result of bladder training. At the end of the testing period, participants were invited to take part in an in-depth interview (on Skype) about their experiences of using URApp. The in-depth interviews were guided by a semistructured topic guide, which included sections on using URApp (general usability and function), BCTs included in the app, barriers to app use, health beliefs (understanding of bladder training and views on whether changes in drinking and toileting have affected symptoms), and views on using the app in consultations with clinicians (eg, specialist nurses and urologists). A deductive framework approach was used to analyze the interviews [40].

Interviews With Clinicians

We conducted semistructured interviews with clinicians involved in continence care to gain their feedback on the app design and function, clinical use and appropriateness, and potential implementation within clinical care. Clinicians were guided through the initial app setup and functionality of the app. Specific feedback was sought on whether the app functions aligned with the best practices in bladder training guidelines. Interviews were conducted by phone because of clinician location and availability.

Stage 4 Results

User Feedback

Of the 23 young people, 10 (43%) took part in the think aloud interviews, and 10 (43%) took part in the real-life testing (see Table 1 for full details). Young people reported that they liked URApp's appearance and functions and thought that it could be helpful for self-managing their bladder symptoms:

> *It's easy to use, it's not confusing, the setup, the layout...I think I would use it. [P22]Much better than paper diaries...I never got around to filling them out, whereas this would be on my phone, which I would have on me, so I think that's a lot handier.* [P8]

App Design

Participants found the design of the app pleasing and suitable for a wide range of ages. Younger participants said that they would like to have the option to customize the app and make it more personalized to them:

> *It looks good, they're [the design graphics] simple, you don't want them too flashy because it might take away from the actual purpose. [P2]I think it needs more personalisation, because it's something you're going to go on quite a lot so you want it to be personal...so you could change the colours, or add photos, pictures.* [P15]

Core Functions

The core function of the app, recording drinks and toilet visits, worked well. Users liked how quick it was to record toilet visits and the interactive nature of recording drinks by pulling down the fluid level with their fingers. However, some participants felt that this function needed to be made clearer:

> *You can drag by moving the water...Maybe make it a bit more obvious, I only knew because I accidentally touched it and it moved...maybe when you first download the App have a walk through. [P2]Oh yeah you just drag it...Oh that's cool! You drink it yourself! You do a virtual drinking, that's so cool! And you get stars! This is a brilliant app!* [P10]

Feedback highlighted that the ability to add drinks retrospectively should be made clearer:

> *It wasn't obvious how to change the time of the drink...maybe you could make it bigger?* [P14]

Young people liked the toilet visit options and found the choices clear and with nice graphics. Two areas for improvement were highlighted: first, including *wee leak* options for incontinence pad wearers (ie, wet pad), and second, more information on how to judge stool consistency.

Data Display

Data collected in URApp are displayed in 3 ways—a progress chart (line and bar graph), a daily diary, and a summary providing an overview for the chosen period (eg, wees have mostly been large). Feedback on how the data were displayed varied between participants; for example, older participants tended to like the progress charts and found them helpful in identifying patterns and tracking changes over time:

> *It's easier to spot patterns, you don't have to work it out for yourself. [P8]You can change what data is shown, it's another nice way of being able to see. [P2]I think it's a good idea, you can see how much you've improved, if the app is helping you.* [P22]

Other participants preferred the summary and daily diary, as they provided a simpler overview of the data. The key feedback was that users wanted a space to record events, their mood, and any factors that might affect their symptoms, such as stressful events, changes in medication, or certain drinks:

> *Being able to track things using your own words as well and maybe being able to track your mood, because it's something that's closely linked to having a bladder or bowel condition.* [P2]

Rewards and Feedback

Feedback on the rewards was very positive, with young people reporting that they liked all the streaks, stars, and trophies. Younger participants particularly liked the star and trophy rewards and thought this would encourage them to use the app and keep them motivated:

> *It makes you feel more committed to achieving your goals...You achieve stuff...It makes you feel good about yourself. You have something to tell you that you've done it good.* [P14]

Young people also liked how similar the streak rewards were to those in other apps that they used:

> *The language ("streaks") makes it easy for kids to understand because it's like other apps like Snapchat.* [P8]

Young people found the daily feedback on their drinking goals easy to understand and liked the large graphics. The feedback indicates the achieved percentage of daily drinking goals and provides an appropriate, encouraging message based on the percentage. A few participants reported that they would like to be able to see if they went over their daily drinking goal, for example, 110%.

There was less engagement with the weekly feedback among some young people who did not use this feature. A small number reported that the notification to complete the feedback was not obvious enough, and they did not see the prompt. Those that did use the weekly feedback found the personalized feedback messages and linked support pages interesting but reported that they were too text heavy and long:

> *There could be a few pictures in it, stick figures. [P15]More pictures would be useful, because how your body works is quite difficult anyway, showing the bladder has muscles that contract too much.* [P2]

Clinician Feedback

A total of 8 clinicians provided feedback on the app (see Table 2 for full details). Clinician feedback focused on the consistency of the app with the best practice guidelines for bladder training, how the app aligned with their own practice, data use and integration with medical records, and using the app as part of clinical care.

Clinical Use and Appropriateness

The app design and content aligned with the best practice guidelines for bladder training. Clinicians were positive about app functions and customizability:

> *I think that looks good, particularly being set up with a clinician. I think it's really easy to use, I mean I've used it and I'm not tech savvy...They can set whatever reminder they want themselves. [Clinician 5]I think that's really good. I like the fact [the reminders are] every two hours, you've got the days of the week on there, they can do their own things with it. That's what I'd say, you need to drink regular, these are the times you need to drink, with your breakfast, on your way to school.* [Clinician 4]

The range and size of the drinking containers were appropriate and fitted with the estimates used in clinics. A small number of clinicians recommended adding a container for small bottles used by younger children; however, they all agreed that a custom container could be made if needed:

> *Oh that's good! That's quite good because it's visual isn't it, especially the water bottle and the can. The majority of children I see, the lunch time drop in, they've always got those plastic bottles.* [Clinician 4]

Clinicians liked the functionality of recording drinks by pulling the fluid level down. They felt that this interactive nature would appeal to young people:

> *That's clever [pull down to drink] because you say I've got this glass and I only drank half of it then it is a way of reflecting that, yeah that's nice...yeah that's really neat, I like the dragging down.* [Clinician 7]

Overall, clinicians felt the app fitted very well with their clinical practice and the information they needed during appointments. Some reported that being able to record the type of drinks, such as fizzy drinks, caffeine, or milk, as well as their amount would be useful, as this could affect UI symptoms:

> *My only comment is I would like to know what the child has had to drink...[for example] caffeine or fizz...Because I say to the kids avoid fizzy, avoid caffeine, milk doesn't count as a drink.* [Clinician 5]

During the discussion about the app functions, it was decided that the option to record this in a free text diary would meet the clinicians' needs, as plotting this information on the charts would be highly complicated.

Data Use and Integration With Medical Records

All clinicians said that the URApp data would be of clinical use and relevance. Clinicians reported that it was challenging for patients to provide an accurate log of their drinking and toileting since their previous clinic visit and felt that an app would have more appeal to young people:

> *It's difficult to get young people to engage with recording diary information, including frequency/volume charts, with something a bit more modern you'd get more engagement and more data.* [Clinician 7]*Some of them are very easily distracted and don't do their diaries and things. Especially the bigger ones they got no excuses because they've got phones on them all the time haven't they. So they've got no excuse for not recording it.* [Clinician 3]

Views on how best to integrate the data with medical records varied. Some clinicians said that being able to download the data would be the best option for them, whereas others said they would use the data for discussions in their clinic and take written notes. The most acceptable solution for all clinicians was a screenshot of the data that could be shared with the user's permission during a clinic session:

> *We have to document everything anyway, I'd use it all. Would be good if you could have it on a printout because you could put it in your records... I'd like a picture of it, it can be scanned into the records.* [Clinician 4]

Patient Engagement

The feedback on anticipated patient engagement was optimistic. Clinicians felt that the interactive nature of URApp would appeal to young people, particularly the customizability and reward systems:

> *I think we would use it on every single child that came to our clinic, anyone that came to bladder training, we would direct them all to it and say this is part of it, download this app we're not going to give you an appointment until you've got some data on it.* [Clinician 7]

Clinicians felt it would be especially beneficial to use with patients who were not making progress with their treatment or were not engaging with their treatment plans:

> *I'm already thinking of kids I could use this with. I'm just going through a load of telephone reviews, and nothing has changed for these kids. It's just exhausting really.* [Clinician 6]*It's sustainable and it's something that will get their concentration. They like these sorts of things. Sitting in front of someone being nagged at all the time, if they can actually do the app themselves and tap in all the stuff, and hopefully there's obviously research to show it does motivate people and keep them going.* [Clinician 6]

Final App Modifications

Findings from the user testing phase were inputted into the table of changes and synthesized to identify the key areas for modification. All potential changes were discussed within the research team and coded using the MSCW framework with an additional *no change* code. Decisions were made based on repetition of feedback, importance for app functioning, importance for behavior change, consistency with clinical treatment guidelines, and cost of the change. A total of 9 key modifications were identified. Table 4 provides a summary of the identified changes and the app function areas.

Table 4. Summary of the final app modifications.

App function area	App modification
Recording new drinks	Pop-up message to explain how to pull down the fluid level on first use
Adding new drinks	Making the option to change the time of drink more obvious
Daily diary	Free text option for recording notes
Settings/about	Add a PDF link to instruction manual
Background and information pages	Reformat and reduce amount of text
Wees	Change leak text to include incontinence pad users
Poos	Pop-up with more information on stool consistency
Task center	Pulsing red button on home page to make this more obvious
Drinking goal feedback	Show goal completion over 100% if the user has exceeded their daily drinking goal

Discussion

Principal Findings

URApp is the first smartphone app specifically designed to support young people with UI. User testing among young people with UI demonstrated that URApp is acceptable, usable, engaging, and potentially effective in supporting concordance with bladder training. Young people liked the design and style of URApp and felt that it was age appropriate. Younger participants expressed a desire to be able to personalize the design of URApp to a greater extent, for example, by changing the theme colors or having seasonal backgrounds. Young people found the app quick and easy to use and liked the interactive nature of recording drinks.

All participants found URApp to be helpful in managing their drinking and toilet schedules, with many requesting to continue using the app beyond the study. Several participants reported that they had been able to increase their drinking or maintain more regular drinking as a result of using URApp. These findings are encouraging and provide preliminary evidence that URApp could be a potentially effective solution for providing personalized support to young people to self-manage their bladder symptoms.

URApp was designed to be discreet, and the mandatory passcode ensures privacy, a feature that was highly valued by the young people who tested the app. Previous research had found that timer watches prompt unwanted attention from peers, creating a barrier to their use [8,15]. URApp provides discreet prompts through the phone user's SMS text message notification sound and allows users to customize their reminder text.

Young people were positive about the reward functions in URApp and felt this would motivate them to keep using the app. This is important, as continued concordance with the timed drinking and toileting schedule is crucial for successful bladder training [13].

Clinicians thought that URApp could provide an age-appropriate solution to aid concordance with bladder training in young people and, therefore, could be used as an adjunct to treatment. The option to customize the reminder time and text was particularly commended, as this could be tailored to each individual patient. Clinicians also reported that being able to record the type of drink was beneficial, as certain types of drinks (eg, fizzy and caffeinated drinks) might have an adverse impact on bladder function in some patients.

Strengths and Limitations

URApp was developed using a rigorous approach to intervention and app design, which is underpinned by the behavior change theory. Development methods were guided by Medical Research Council recommendations for the development and evaluation of digital interventions [27] and informed by the PBA to intervention development [29]. This is the optimal approach for developing digital health interventions to ensure their usability and acceptability [41].

The end user population was included throughout the development process. This means that URApp was centrally designed around user needs and feedback. Engaging with the app development team from the project's outset ensured that the proposed design and functions of the app were feasible in terms of cost and delivery within the project timeline.

Although our results are encouraging, this work does have limitations. User testing was restricted to young people with English as a first language and with predominantly high levels of educational ability. Further testing and refinement of URApp is needed with young people from a range of educational, socioeconomic, and ethnic backgrounds.

In addition, young people included in the study had already engaged in treatment for UI, either through primary or secondary care. It is not clear if URApp would offer the same level of acceptability and utility to young people who had not yet engaged in treatment. This is an important area for further research, as the stigma of continence problems prevents many young people from seeking treatment.

Conclusions

This study provides initial support for the acceptability and usability of URApp. The next stage is to test whether URApp is effective in aiding concordance with bladder training, and therefore, improve bladder symptoms and enhance well-being. URApp should be tested across a range of settings, including pediatric continence clinics, primary care, and schools (via school nurses). The cost-effectiveness of using URApp to support bladder training in primary and secondary care settings and in the community also needs to be examined. An interactive website [23] has been developed where users can download URApp at no cost (available for iOS and Android devices) and access resources to support young people with UI.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Core app functions to support bladder training and target behavioral change.
[DOCX File , 14 KB - pediatrics_v4i4e26212_app1.docx]

Multimedia Appendix 2

Behavior change techniques used in URApp.
[DOCX File , 17 KB - pediatrics_v4i4e26212_app2.docx]

Multimedia Appendix 3
Example of final prototype.
[DOCX File , 664 KB - pediatrics_v4i4e26212_app3.docx]

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Abbreviations

BCT: behavior change technique
MSCW: must have, should have, could have, would have

NIHR: National Institute for Health Research
PBA: person-based approach
PPI: patient and public involvement UI: urinary incontinence

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Original Paper

Promoting Safe Sleep, Tobacco Cessation, and Breastfeeding to Rural Women During the COVID-19 Pandemic: Quasi-Experimental Study

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Abstract

Background: Safe Sleep Community Baby Showers address strategies to prevent sleep-related infant deaths. Due to the COVID-19 pandemic, these events transitioned from in-person to virtual.

Objective: This study describes outcomes of transitioning Safe Sleep Community Baby Showers to a virtual format and compares outcomes to previous in-person events.

Methods: Participants from four rural Kansas counties were emailed the presurvey, provided educational materials (videos, livestream, or digital documents), and completed a postsurvey. Those who completed both surveys received a portable crib and wearable blanket. Within-group comparisons were assessed between pre- and postsurveys; between-group comparisons (virtual vs in-person) were assessed by postsurveys.

Results: Based on data from 145 in-person and 74 virtual participants, virtual participants were more likely to be married ($P<.001$) and have private insurance ($P<.001$), and were less likely to report tobacco use ($P<.001$). Both event formats significantly increased knowledge and intentions regarding safe sleep and avoidance of secondhand smoke (all $P\leq.001$). Breastfeeding intentions did not change. Differences were observed between in-person and virtual meetings regarding confidence in the ability to avoid secondhand smoke (in-person: 121/144, 84% vs virtual: 53/74, 72%; $P=.03$), intention to breastfeed ≥6 months (in-person: 79/128, 62% vs virtual: 52/66, 79%; $P=.008$), and confidence in the ability to breastfeed ≥6 months (in-person: 58/123, 47% vs virtual: 44/69, 64%; $P=.02$).

Conclusions: Although both event formats demonstrated increased knowledge/intentions to follow safe sleep recommendations, virtual events may further marginalize groups who are at high risk for poor birth outcomes. Strategies to increase technology access, recruit priority populations, and ensure disparities are not exacerbated will be critical for the implementation of future virtual events.

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KEYWORDS

COVID-19; SIDS; sudden infant death syndrome; safe sleep; tobacco cessation; breastfeeding; virtual education

Introduction

The impact of SARS-CoV-2 on maternal and perinatal outcomes appears to be less severe than initially thought, though infection is still a cause for concern [1-4]. However, impacts appear to go beyond the physiologic reactions to direct infection [1]. Pregnant and postpartum women have reported changes in employment and financial status, mental health, social support, and for some even access to care [5]. Women also reported changes in infant care practices, such as breastfeeding and infant sleep strategies, specifically attributed to the pandemic, though changes did not always reach statistical significance [5].

Although empirical data are not yet available, personal communication with emergency and support services indicate there may be an increase of sleep-related infant deaths during the pandemic. Sleep-related infant deaths, including sudden infant death syndrome (SIDS), accidental suffocation or strangulation in bed, and other undetermined deaths, are the primary cause of death for infants from 28 days to 1 year of life despite risk reduction strategies promoted by the American Academy of Pediatrics (AAP; eg, supine position) [6]. Programs such as Safe Sleep Community Baby Showers [7-9] are a recognized strategy to promote infant safe sleep [10] where women and their support persons are brought together at a community venue to celebrate their pregnancy and receive education. Topics address risk reduction strategies to prevent sleep-related infant deaths, including safe sleep position and surface, breastfeeding, and tobacco-free environments. Tools needed to create a safe sleep environment (eg, portable crib or wearable blanket) are often provided to attendees [7-9].

During the COVID-19 pandemic, many programs that support maternal and infant health, including education on the AAP safe sleep recommendations, had to redirect resources and reduce or even halt support services. New delivery strategies were needed to accommodate stay-at-home orders and gathering size restrictions when services were available. One such strategy was virtual education; however, the impact of transitioning Safe Sleep Community Baby Showers from in-person to virtual is unknown. As such, the purpose of this study is to describe the outcomes of virtual Safe Sleep Community Baby Showers and compare the results to previous in-person events.

Methods

Settings

The Kansas Infant Death and SIDS (KIDS) Network has created a statewide infrastructure of certified safe sleep instructors [8,11] who facilitate in-person Safe Sleep Community Baby Showers. With the support of the KIDS Network, safe sleep instructors in four rural counties (Geary, Cloud, Harvey, and Shawnee) held virtual Safe Sleep Community Baby Showers in 2020. Outcomes from these events were compared to previous in-person Safe Sleep Community Baby Showers held in 2019.

Participants

Participants were pregnant or postpartum women. For in-person events, participants were recruited via social media, radio ads, and fliers, and through health care providers and maternal and child health programs. Presurveys were completed on paper at the event prior to the education. Postsurveys were completed immediately following the education. Participants for virtual events were recruited through local outreach including social media and referral by partner programs and events. Potential participants were emailed a link and instructions to complete the presurvey. Once completed, educational materials and links were distributed. The postsurvey link with instructions was emailed following completion of the education. Participants at all events who completed both pre- and postsurveys received a portable crib and wearable blanket.

Instruments

A 22-item presurvey, including demographics; knowledge; intention; and practice questions on safe sleep, tobacco use/avoidance, and breastfeeding, was completed by participants prior to receiving education. Due to skip logic, not all participants completed all items. At the end of the event, 13 of the same knowledge and intention items from the presurvey and an additional 9 items related to confidence and satisfaction with the event were collected. Deidentified survey data were collected and managed using REDCap, a secure web-based data capture application hosted at the University of Kansas Medical Center [12,13].

Education

Safe sleep, breastfeeding, and tobacco cessation/avoidance education was provided to participants regardless of education format. In-person events were interactive by nature, using presentation and demonstration, but also included video components. For virtual events, Geary and Cloud counties chose to provide educational videos and prerecorded presentations to participants (passive). Harvey and Shawnee counties held real-time interactive education over a virtual platform (interactive).

Statistical Analysis

Descriptive statistics, confidence items, and satisfaction are summarized using frequencies (percentages). Comparisons between pre- and postsurveys were made using McNemar test for paired dichotomous variables (safe vs unsafe responses), Friedman test, and chi-square likelihood ratio test. Data from previous in-person Safe Sleep Community Baby Showers for three of the four counties were used to assess potential differences in postintervention outcomes. One was omitted due to using a previous version of the survey. The Mann-Whitney Wilcoxon test for independent samples was used for comparison between virtual and in-person events. Due to different education formats (interactive and passive) for virtual Safe Sleep Community Baby Showers, a secondary data analysis was completed. Alpha was set a priori at .05. Statistical analyses were performed using SPSS for Windows, Version 23.0 (IBM Corp). This project involved secondary analysis of deidentified program data and was reviewed by the University of Kansas Medical Center Human Subjects Committee who determined it to not be human participant research.

Results

Participants

Between August 2020 and November 2020, four virtual Safe Sleep Community Baby Showers were held in rural Kansas counties: Harvey, Geary, Cloud, and Shawnee. A total of 97 individuals engaged in the virtual events; 22 completed only the presurvey, and 1 completed only the postsurvey. Therefore, 74 participants were included in the analysis. Due to similarity in results between events, data is reported in aggregate on the tables. In 2019, one in-person Safe Sleep Community Baby Shower was held in each of the following counties Geary, Cloud, and Shawnee counties with a total of 145 attendees across all events. All completed both pre- and postsurveys.

Demographics

Full demographics are in Table 1. Differences in marital status and insurance status were observed between virtual and in-person participants. Virtual participants were significantly more likely to be married ($P<.001$) and have private insurance ($P<.001$).

Table 1. Participant characteristics.[a]

	In-person CBS[b] (n=145), n (%)	Virtual CBS (n=74), n (%)	Between group difference, *P* value[c]
County of residence			<.001
Harvey	0 (0.0)	15 (20.3)	
Geary	54 (37.2)	42 (56.8)	
Cloud	20 (13.8)	11 (14.9)	
Shawnee	71 (49.0)	6 (8.1)	
Race/ethnicity			.44
Non-Hispanic White	87 (60.4)	51 (68.9)	
Non-Hispanic Black	30 (20.8)	10 (13.5)	
Hispanic	15 (10.4)	9 (12.2)	
Other[d]	12 (8.3)	4 (5.4)	
Marital status			<.001
Single	58 (40.3)	8 (10.8)	
Married	59 (41.0)	51 (68.9)	
Other[e]	27 (18.8)	15 (20.3)	
Partner race/ethnicity			.64
Non-Hispanic White	74 (51.0)	46 (62.2)	
Non-Hispanic Black	27 (18.6)	11 (14.9)	
Hispanic	17 (11.7)	7 (9.5)	
Other[d]	14 (9.7)	5 (6.8)	
Not applicable/choose not to answer	13 (9.0)	5 (6.8)	
Mother's education			.05
Some high school	23 (16.0)	5 (6.8)	
High school graduate or GED[f]	79 (54.9)	32 (43.2)	
2-year community college graduate	12 (8.3)	13 (17.6)	
4-year college graduate	15 (10.4)	13 (17.6)	
Graduate school	9 (6.3)	7 (9.5)	
Other	6 (4.2)	4 (5.4)	
Insurance status			.001
Private insurance	27 (18.8)	26 (35.1)	
KanCare/Medicaid	84 (58.3)	23 (31.1)	
Military	24 (16.7)	20 (27.0)	
Other[g]	9 (6.3)	5 (6.8)	
Prenatal care provider			.11
Private provider's office	54 (37.8)	34 (46.6)	
Hospital clinic	66 (46.2)	30 (40.5)	
Community health clinic	16 (11.2)	4 (5.4)	
Clinic at work or school	0 (0.0)	2 (2.7)	
County health department	2 (1.4)	0 (0.0)	
Other	5 (3.5)	3 (4.1)	

[a] Missing data: in-person: race/ethnicity (n=1), marital status (n=1), mother's education (n=1), insurance status (n=1), prenatal care provider (n=2); virtual: prenatal care provider (n=1).

[b] CBS: Community Baby Showers.

[c] *P* value <.05 indicates a statistically significant difference between pre- and postsurvey responses.

[d] Race/ethnicity: other includes multiracial and other.

[e] Marital status: other includes partnered, separated, and divorced.

[f] GED: General Educational Development.

[g] Insurance status: other includes self-pay, managed care organization/marketplace, and other.

Changes in Safe Sleep Knowledge and Intentions

Following the Safe Sleep Community Baby Showers, in-person participants demonstrated a positive increase from pre- to postsurvey in intention to follow safe sleep practices related to anticipated sleep position (pre: 128/144, 89% vs post: 142/144, 99%; *P*<.001), anticipated sleep surfaces (pre: 126/145, 87% vs post: 140/145, 97%; *P*=.001), anticipated crib items (pre: 86/130, 66% vs post: 123/130, 95%; *P*<.001), and discussing safe sleep with others (pre: 90/138, 65% vs post: 132/138, 96%; *P*<.001; Table 2). On the postsurvey, the majority (123/125, 98%) reported knowing at least one person who would support safe sleep. Virtual participants also demonstrated a positive increase from pre- to postsurvey in intention to follow safe sleep practices related to only placing their baby on the back to sleep (pre: 63/74, 85% vs post: 74/74, 100%; *P*=.001), safe sleep surfaces (pre: 60/73, 82% vs post: 71/73, 97%; *P*=.001), inclusion of only safe items in the crib (pre: 58/73, 80% vs post: 71/73, 97%; *P*<.001), and discussing safe sleep with others (pre: 53/73, 73% vs post: 73/73 100%; *P*<.001). In addition, all virtual participants (74/74, 100%) reported knowing at least one person who would support safe sleep. No differences in anticipated safe sleep practices were observed between those who attended an in-person event compared to those who attended a virtual event.

Table 2. Changes in intended safe sleep practices.[a]

	In-person CBS[b] (n=145)			Virtual CBS (n=74)			Between-group differences, *P* value[c]
	Presurvey, n (%)	Postsurvey, n (%)	Within-group difference, *P* value	Presurvey, n (%)	Postsurvey, n (%)	Within-group difference, *P* value	
Safe sleep position (back only)	128 (88.9)	142 (98.6)	<.001	63 (85.1)	74 (100)	.001	.31
Safe sleep surface (crib, portable crib, or bassinet only)	126 (86.9)	140 (96.6)	.001	60 (82.2)	71 (97.3)	.001	.78
Safe crib items (firm mattress, fitted sheet, or wearable blanket only)	86 (66.2)	123 (94.6)	<.001	58 (79.5)	71 (97.3)	<.001	.33
Have or plan to discuss safe sleep with others	90 (65.2)	132 (95.7)	<.001	53 (72.6)	73 (100)	<.001	.07

[a] Missing data: in-person: sleep position (n=1), crib items (n=15), talk to others about safe sleep (n=7); virtual: sleep surface (n=1), crib items (n=1), talk to others about safe sleep (n=1).

[b] CBS: Community Baby Showers.

[c] *P* value <.05 indicates statistically significant difference between pre- and postsurvey responses.

Changes in Readiness to Quit and Knowledge of a Tobacco-Free Environment

The majority of in-person participants (n=100, 69%) and virtual participants (n=72, 97%) reported not using tobacco products in the 6 months prior to the Safe Sleep Community Baby Showers; however, this number was significantly lower for in-person participants (*P*<.001). Of in-person participants reporting tobacco use (n=44/144), the majority (n=27/44, 61%) reported daily use, while 5% (n=2/44) reported weekly and 34% (n=15/44) were not currently using. Of virtual participants who reported using (n=2/74), one was not currently using and the other reported daily use. No significant changes in readiness to quit were observed between pre- and postsurvey for either group.

Positive changes were observed for in-person participants from pre- to postsurvey regarding plans to not allow tobacco use in the home or car (pre: 123/142, 87% vs post: 132/142, 93%; *P*=.04), knowledge of three ways to avoid secondhand exposure (pre: 107/140, 76% vs post: 135/140, 96%; *P*<.001), and knowledge of at least three local resources for tobacco cessation (pre: 24/133, 18% vs post: 55/133, 41%; *P*<.001; Table 3). Following the events, virtual participants also reported positive changes from pre- to postsurvey in plans to not allow tobacco use inside their home or car (pre: 67/74, 91% vs post: 73/74, 99%; *P*=.01), knowledge of three ways to avoid secondhand exposure (pre: 52/74, 70% vs post: 74/74, 100%; *P*<.001), and knowledge of at least three local resources for tobacco cessation (pre: 7/73, 10% vs post: 38/73, 52%; *P*<.001). No differences were observed between virtual and in-person participants.

Table 3. Smoking exposure, cessation, resources, and intent to quit.[a]

	In-person CBS[b] (n=145)			Virtual CBS (n=74)			Between-group differences, *P* value[c]
	Presurvey, n (%)	Postsurvey, n (%)	Within-group difference, *P* value	Presurvey, n (%)	Postsurvey, n (%)	Within-group difference, *P* value	
Secondhand exposure in home or car[d]			.04			.01	.05
Never	123 (86.6)	132 (93.0)		67 (90.5)	73 (98.6)		
Daily	18 (12.7)	9 (6.3)		5 (6.8)	1 (1.4)		
Weekly	1 (0.7)	1 (0.7)		2 (2.7)	0 (0.0)		
Know ≥3 ways to avoid secondhand exposure			<.001			<.001	.10
Yes	107 (76.4)	135 (96.4)		52 (70.3)	74 (100)		
No	33 (23.6)	5 (3.6)		22 (29.7)	0 (0.0)		
Know ≥3 local resources for tobacco cessation			<.001			<.001	.12
Yes	24 (18.0)	55 (41.4)		7 (9.6)	38 (52.1)		
No	109 (82.0)	78 (58.6)		66 (90.4)	35 (47.9)		

[a] Missing data: in-person: secondhand exposure in home or car (n=3), know >3 ways to avoid secondhand exposure (n=5), know >3 local resources (n=12); virtual: know >3 local resources (n=1).

[b] CBS: Community Baby Showers.

[c] *P* value <.05 indicates statistically significant difference between pre- and postsurvey responses.

[d] Presurvey indicates actual behavior; postsurvey represents future intention.

Changes in Breastfeeding Intentions

In-person participants planned to breastfeed their baby with no change observed from pre- to postsurvey (pre: 130/138, 94% vs post: 132/138, 96%; *P*=.53; Table 4). Differences were also not observed in intention to breastfeed longer than 6 months (pre: 77/128, 60% vs post: 79/128, 62%; *P*=.63). However, following the events, more in-person participants reported being confident in their ability to breastfeed for longer than 6 months (pre: 50/123, 41% vs post: 58/123, 47%; *P*=.008), and knowledge of at least three local breastfeeding resources (pre: 45/138, 33% vs post: 81/138, 59%; *P*<.001). Virtual participants planned to breastfeed their baby with no change observed pre- to postsurvey (pre: 69/74, 93% vs post: 69/74, 93%; *P*=.56). No differences were reported in intention to breastfeed longer than 6 months (pre: 52/66, 79% vs post: 52/66, 79%; *P*>.99) or confidence in ability to breastfeed longer than 6 months (pre: 41/69, 59% vs post: 44/69, 64%; *P*=.38). A statistically significant difference was observed in knowledge of at least three local breastfeeding resources (pre: 13/74, 18% vs post: 41/74, 55%; *P*<.001) following the virtual events. Differences were observed between in-person and virtual participants in their intention to breastfeed longer than 6 months (post: 79/128, 62% vs post: 58/66, 79%; *P*=.008) and confidence in ability to breastfeed for longer than 6 months (post: 58/123, 47% vs post: 44/69, 64%; *P*=.02).

Table 4. Breastfeeding intent, confidence, and knowledge of resources.[a]

	In-person CBS[b] (n=145)			Virtual CBS (n=74)			Between-group differences, *P* value[c]
	Presurvey, n (%)	Postsurvey, n (%)	Within-group difference, *P* value	Presurvey, n (%)	Postsurvey, n (%)	Within-group difference, *P* value	
Likelihood of breastfeeding			.53			.56	.80
Don't plan to breastfeed	4 (2.9)	5 (3.6)		5 (6.8)	5 (6.8)		
Not likely	4 (2.9)	1 (0.07)		0 (0.0)	0 (0.0)		
Somewhat likely	25 (18.1)	24 (17.4)		10 (13.5)	11 (14.9)		
Very likely	105 (76.1)	108 (78.3)		59 (79.7)	58 (78.4)		
Intend to breastfeed >6 months			.63			>.99	.008
Yes	77 (60.2)	79 (61.7)		52 (78.8)	52 (78.8)		
No	51 (39.8)	49 (38.3)		14 (21.2)	14 (21.2)		
Confident in ability to breastfeed for >6 months			.008			.38	.02
Yes	50 (40.7)	58 (47.2)		41 (59.4)	44 (63.8)		
No	73 (59.3)	65 (52.8)		28 (40.6)	25 (36.2)		
Knowledge of ≥3 local breastfeeding resources			<.001			<.001	.65
Yes	45 (32.6)	81 (58.7)		13 (17.6)	41 (55.4)		
No	93 (67.4)	57 (41.3)		61 (82.4)	33 (44.6)		

[a] Missing data: in-person: likelihood (n=7), duration (n=6), confidence (n=11), knowledge of local resources (n=7); virtual: duration (n=8), confidence (n=5).

[b] CBS: Community Baby Showers.

[c] *P* value <.05 indicates statistically significant difference between pre- and postsurvey responses.

Confidence Change

On the postsurvey, participants were asked to rate their confidence based on education received (Table 5). Significant differences were only observed between the two groups in confidence to avoid secondhand smoke (*P*=.03).

Table 5. Confidence in ability to engage in risk reduction strategies following Safe Sleep Community Baby Showers.[a]

	In-person CBS[b] (n=145)	Virtual CBS (n=74)	Between-group difference, *P* value[c]
Get baby to sleep on their back			.22
Less confident	1 (0.7)	0 (0.0)	
No change	24 (16.6)	18 (24.3)	
More confident	120 (82.8)	56 (75.7)	
Have baby sleep in my room, but separate crib, portable crib, or bassinet			.18
Less confident	1 (0.7)	0 (0.0)	
No change	23 (15.9)	18 (24.3)	
More confident	121 (83.4)	56 (75.7)	
Keep loose blankets out of the crib			.60
Less confident	3 (2.1)	0 (0.0)	
No change	25 (17.4)	17 (23.0)	
More confident	116 (80.6)	57 (77.0)	
Follow safe sleep recommendations even when people give different advice			.50
No change	17 (15.2)	14 (18.9)	
More confident	95 (84.8)	60 (81.1)	
Avoid secondhand smoke			.03
No change	23 (16.0)	21 (28.4)	
More confident	121 (84.0)	53 (71.6)	
Breastfeed			.14
No change	36 (25.5)	26 (35.1)	
More confident	105 (74.5)	48 (64.9)	

[a] Missing data: in-person: loose blankets (n=1), follow recommendations (n=33), secondhand smoke (n=1), breastfeeding (n=4).

[b] CBS: Community Baby Showers.

[c] *P* value <.05 indicates statistically significant difference between pre- and postsurvey responses.

Participant Satisfaction

Satisfaction with events was high. In-person participants were very satisfied (120/144, 83%), satisfied (22/144, 15%), or neutral (2/144, 1%). The majority of virtual participants reported being very satisfied (57/74, 77%). The remainder were satisfied (16/74, 22%) or neutral (1/74, 1%). Several comments specifically addressed the virtual nature of the training. One woman stated:

> *Thank you for the opportunity to participate in the community baby shower over zoom! It's a great way to keep promoting safe sleep for babies while keeping up with the strange times we are living in today.*

No significant differences in event satisfaction were observed between in-person and virtual participants (*P*=.27).

Secondary Analysis of Virtual Education Formats

Two different education formats were used at the virtual Safe Sleep Community Baby Showers. A total of 53 (71.6%) participants received passive education and 21 (28.4%) attended an interactive virtual event. Participants who attended passive virtual events were significantly more likely to have received a high school diploma or General Educational Development (GED; *P*=.01) and have military insurance (*P*=.01), whereas participants who attended interactive events were more likely to receive prenatal care at a private provider's office (*P*=.01). No differences in anticipated safe sleep practices, smoking exposure or cessation, breastfeeding intention or confidence, or confidence on engagement in risk reduction strategies were observed between those who attended a passive virtual event compared to those who attended an interactive virtual event. Differences between the two groups were observed regarding knowledge of resources following the events. Specifically, participants who attended interactive events were more likely to know three or more local resources for tobacco cessation (*P*<.001) and three or more local breastfeeding resources (*P*<.001).

Discussion

Impact of Virtual Format

Safe Sleep Community Baby Showers held as virtual events in rural counties due to the COVID-19 pandemic had significantly more participants who reported being married and on private insurance than in-person events. These characteristics are frequently associated with positive perinatal outcomes (eg, [14,15]). In addition, though it did not cross the threshold for significance, virtual attendees were less likely to report low education levels (37/74, 50% high school diploma/GED or less) than in-person attendees (102/144, 71%).

Women of higher socioeconomic status may have been more likely to participate in Safe Sleep Community Baby Showers for a variety of reasons. Rural communities are highly susceptible to COVID-19 due to vulnerable populations, fewer physicians, and lack of related services [16]. However, impacts may be especially dire for socially vulnerable populations [16], and concerns for immediate needs (eg, food, housing, or employment) impacted by the pandemic may have resulted in lower participation in educational events by low-income women. Further, during the pandemic, many health departments and health care providers had to modify or suspend services such as prenatal home visits, which may have promoted Safe Sleep Community Baby Showers to hard-to-reach families.

Differences in participants between the two event formats may also highlight access disparities that are exacerbated with the use of technology [17]. To reduce unintended negative impacts, future events could use Crawford and Serhal's [18] digital health equity framework, an expansion of Dover and Belon's [19] theories of health equity. Dover and Belon's [19] model suggests that the interplay of social determinants of health and health system use impact health equity. Within the model, impacts of socioeconomic, cultural, and political context, and their influence on the social stratification process, health policy context, environment, health-related behaviors and health beliefs, and social circumstances are explored [19]. Crawford and Serhal [18] expand this framework by considering the impacts of digital health resources and digital health literacy in enhancing health equity. For example, an individual's use of technology and capacity to access and interpret digital content is shaped by their social, cultural, and economic position, which should be considered in the development of health care and education and, even more importantly, in the development of policy [18].

As COVID-19 transmission risks are reduced through increased vaccine availability, it may be important to consider ways to safely hold in-person events, as data suggests these events serve individuals reporting more sociodemographic and behavioral risk factors associated with infant mortality [20]. If COVID-19 risks persist, identifying outreach strategies and partnerships to increase access to technology may be critical to ensure high-risk families have access to virtual events and to prevent further marginalizing disparate groups. Event dissemination and recruitment strategies may also need to be shifted to better promote virtual events to disadvantaged groups, such as through health care providers, other maternal child health programs, or trusted community members.

Despite demographic differences in attendees, both event formats were successful at promoting the AAP Safe Sleep Recommendations, with participants showing significant increases regarding intentions to use safe sleep practices following the baby showers. Postevent rates reflected those from previously published studies [7-9]. Similarly, positive improvements were observed within events for tobacco cessation/avoidance items, though self-reported tobacco use was significantly higher for in-person participants. This could further reflect in-person participation by a higher risk group or may suggest a higher likelihood to truthfully report tobacco use in person. Fewer improvements were observed for breastfeeding intention and duration, though knowledge of breastfeeding support resources increased. In addition, only the in-person events increased participant confidence in the ability to breastfeed for greater than 6 months, which has been linked to benefits for both mother and infant, including reduced infant mortality [21].

To further assess impacts of the virtual education, a secondary analysis was performed to compare passive versus active education strategies. Participants differed in terms of demographic variables such as insurance type, but this is likely a reflection of the community at large and not the educational format. For example, Geary County, which used a passive education format, had high rates of military insurance but is the home of a military base. In terms of knowledge outcomes, the most prominent difference appeared in recognition of tobacco cessation and breastfeeding support resources. This may have resulted from additional discussion by participants and presenters in the interactive format. If the passive format will be used in the future, special care should be taken to provide additional information on resources available to support desired behaviors.

Limitations

This study is limited as events took place in rural counties in a Midwest state and may not be generalizable to urban areas or other regions. These rural communities had been engaged in safe sleep promotion through the Safe Sleep Instructor [8,11] project over a number of years, which may have impacted baseline data and openness to safe sleep education. The proportions of participants by county differed between in-person and virtual formats, which may have contributed to demographic differences. However, poverty rates for the counties were comparable: Harvey 9.6%, Cloud 11.4%, Shawnee 11.4%, and Geary 13%; state range 3.3% to 22.4% [22]. Data were self-reported, which could result in social desirability response bias. In addition, behavioral data following the event could not be collected, as it was outside the scope of this project. Future studies should assess parent behaviors related to infant safe sleep following educational events. The authors would like to note there were fewer missing data with the virtual trainings. This may indicate a benefit of allowing participants to complete data forms at their leisure prior to the event. Future research should assess attitudes and comfort around completing surveys online compared to in-person.

Conclusions

Although both event formats demonstrated the ability to increase knowledge/intentions in most areas measured, virtual events may further marginalize groups who are at high risk for poor birth outcomes. These findings have implications beyond safe sleep promotion, especially as the COVID-19 pandemic continues to accelerate the use of telemedicine and virtual platforms for public health education. Strategies to increase technology access, recruit priority populations, and ensure disparities are not enhanced will be critical for implementation of future virtual events.

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Conflicts of Interest

None declared.

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Abbreviations

AAP: American Academy of Pediatrics
GED: General Educational Development
KIDS: Kansas Infant Death and SIDS
SIDS: sudden infant death syndrome

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Original Paper

Toward a Behavior Theory–Informed and User-Centered Mobile App for Parents to Prevent Infant Falls: Development and Usability Study

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Abstract

Background: Falls account for approximately 50% of infant injury hospitalizations, and caretaker behavior is central to preventing infant falls. Behavior theory–informed interventions for injury prevention have been suggested, but to date, few have been reported. The potential of using smartphones for injury prevention intervention delivery is also underexploited.

Objective: This study aims to develop a behavior theory– and evidence-based as well as user-centered digital intervention as a mobile app for parents to prevent infant falls following agile development practices.

Methods: Infant falls while feeding was selected as the fall mechanism to demonstrate the approach being taken to develop this intervention. In phase 1, the Behaviour Change Wheel was used as a theoretical framework supported by a literature review to define intervention components that were then implemented as a mobile app. In phase 2, after the person-based approach, user testing through think-aloud interviews and comprehension assessments were used to refine the content and implementation of the intervention.

Results: The target behaviors identified in phase 1 were adequate rest for the newborn’s mother and safe feeding practices defined as prepare, position, and place. From behavioral determinants and the Behaviour Change Wheel, the behavior change functions selected to achieve these target behaviors were psychological capability, social opportunity, and reflective motivation. The selected behavior change techniques aligned with these functions were providing information on health consequences, using a credible source, instruction on performing each behavior, and social support. The defined intervention was implemented in a draft Android app. In phase 2, 4 rounds of user testing were required to achieve the predefined target comprehension level. The results from the think-aloud interviews were used to refine the intervention content and app features. Overall, the results from phase 2 revealed that users found the information provided to be helpful. Features such as self-tracking and inclusion of the social and environmental aspects of falls prevention were liked by the participants. Important feedback for the successful implementation of the digital intervention was also obtained from the user testing.

Conclusions: To our knowledge, this is the first study to apply the Behaviour Change Wheel to develop a digital intervention for child injury prevention. This study provides a detailed example of evidence-based development of a behavior theory–informed mobile intervention for injury prevention refined using the person-based approach.

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KEYWORDS

child injury; Behaviour Change Wheel; mobile app; mobile phone

Introduction

Background

Falls account for almost half of all injury-related hospitalizations in infants aged <1 year [1], with potential lifelong consequences. Infant falls are often explained by the characteristics of natural development (rolling, exploring, and natural curiosity), which occurs rapidly over the first year of life. Falls frequently happen when caretakers are underprepared for risks associated with this rapid motor development and environments are inappropriate or not well matched to the developmental level. The latter includes misuse of nursery furniture. Age-appropriate injury prevention education for caretakers and home safety assessments have therefore been suggested as potential interventions for infant fall prevention in previous studies [2,3], and there is good evidence that parenting interventions can be effective for reducing child injury generally [4]. Although many falls prevention programs target children aged <5 years and there are a few proven interventions effective for preventing child injury in the home generally, there is currently a paucity of proven theory-driven fall prevention interventions specifically targeting caretaker behavior and environmental risks to reduce falls in children aged <1 year [5]. We intend to fill this gap by developing an intervention targeting caretaker behavior and attention to environmental risks to reduce the risk of falls in children aged <1 year.

As fall mechanisms change with the age of the infant [6], any type of intervention needs to account for the different contexts or scenarios related to falls throughout the first year of life. It is well understood that educational interventions alone may not lead people to act on the information they receive; therefore, it is important that the intervention be firmly grounded in behavior change theory such as the one underpinning the Behaviour Change Wheel [7]. This is a commonly used theoretical framework in the design of behavior change interventions targeting a broad array of public health problems [8-11].

Smartphones are an ideal delivery channel for child injury prevention interventions, with new parents increasingly using technology to access health information, especially in countries with high smartphone use [12]. Smartphones and digital technologies and apps also provide a mechanism for delivering a greater array of behavior change techniques targeting behavior change than paper-based or person-to-person intervention delivery methods. They also provide an opportunity for remote engagement with specific sectors of the community when one-to-one engagement is difficult, such as in a pandemic [13,14] or geographically isolated locations. A behavior change intervention combined with mobile technology is known as a digital behavior change intervention (DBCI). Given the flexibility of this delivery mechanism and the growing evidence for the effectiveness of DBCIs in other areas of public health, particularly those DBCIs grounded in behavior theory [15], we plan to develop our intervention as a DBCI.

As usability is critical to the success of DBCIs [16], user testing is an important part of the intervention development process, and think-aloud studies are commonly used for this purpose [17]. Coupled with the Behaviour Change Wheel methodology, this can be used to understand both the hedonic or utilitarian aspects of the DBCI and the appropriateness and anticipated challenges in adherence to embedded behavior change techniques [17]. Information comprehension is another important aspect of usability likely to affect DBCI effectiveness. Although this does not seem to be something routinely assessed in user testing of DBCIs, the need to make sure that the intervention is suitable for users of different levels of literacy has been noted previously [18], and a systematic assessment of comprehension is common in the development of written health information [19].

Objective

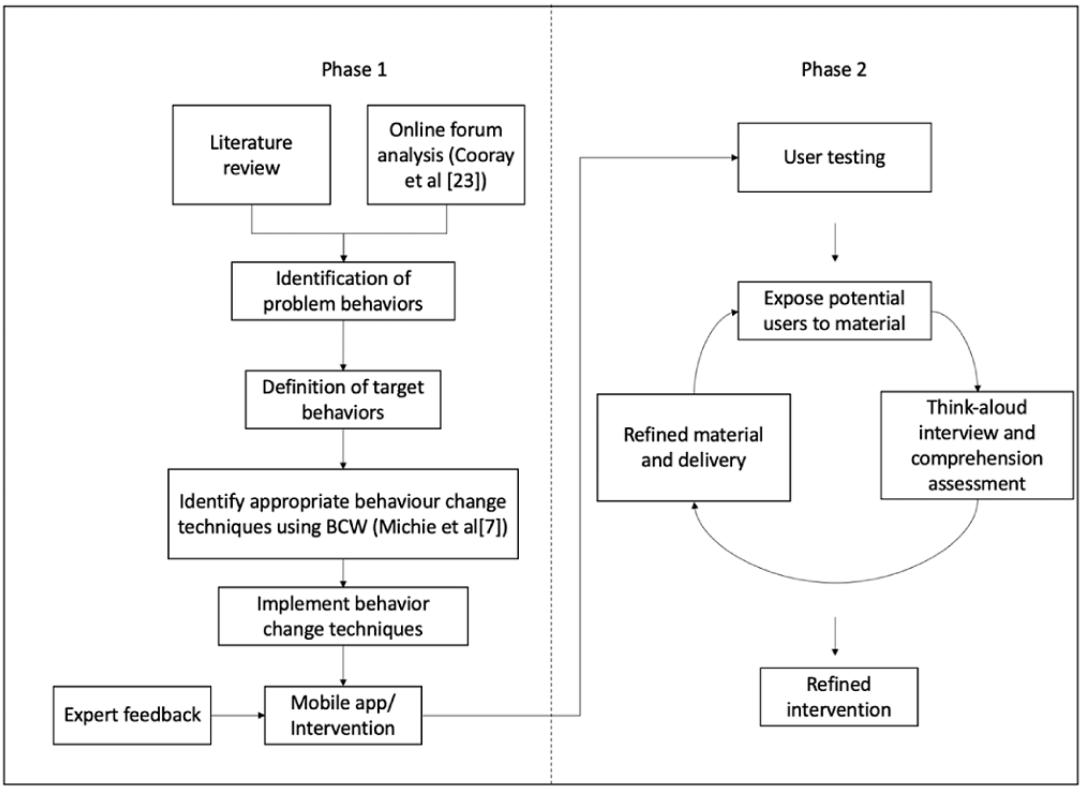
The aim of this study is to develop an intervention using the Behaviour Change Wheel, supported by empirical data and expert feedback, to systematically identify behavior change techniques and implement them digitally (phase 1) and to optimize the digital intervention modules through user feedback and assessment of comprehension of information (phase 2). In previous work, we have identified key fall mechanism priorities [20,21], and following agile development practices [22], we are developing this intervention in a modular way. The key infant fall mechanisms we are targeting in this intervention are falls from furniture, falls when being carried or supported by someone, and falls from baby products. Our approach to developing this multitarget intervention involves the development of 4 distinct modules that address (1) falls from furniture, (2) falls that occur when the baby is feeding, (3) other aspects of home environments where falls occur when the infant is being carried (eg, steps and stairs), and (4) falls from baby products. The same development and user-testing approach is being applied in the development of each of these 4 modules. To allow our development process to be described in detail in a single paper, we have chosen the module targeting infant falls related to feeding as a case study to describe this process.

Methods

Two-Phased Approach

Figure 1 depicts the two-phased approach used in developing the intervention module. Phase 1 involved the development and digital implementation of the intervention material, whereas in phase 2, the digital information and delivery method were optimized after think-aloud interviews and comprehension assessment with the target audience.

Figure 1. Two-phased development of the intervention. BCW: Behaviour Change Wheel.



Phase 1: Intervention Content Design and Development

The aim of phase 1 is to identify problem and target behaviors to inform and then develop the intervention content for the DBCI. The Behaviour Change Wheel framework [7], a literature review, and a qualitative analysis of infant fall events from a web-based parenting forum [23] were used to identify problem behaviors and target behaviors to inform the intervention strategy. Specifically, problem behaviors were behaviors that would need to change for falls to be prevented. Target behaviors were then chosen if assessed as likely to modify or prevent the *problem behaviors*. The target behaviors were then used in a behavior analysis to identify intervention functions and behavior change techniques following the Behaviour Change Wheel [7] process. In summary, this includes (1) understanding the capability, opportunity, and motivation factors underpinning the target behavior; (2) identifying intervention functions; (3) identifying behavior change techniques to be included; and (4) implementing the selected behavior change techniques in the intervention [7].

The intervention content was then drafted and reviewed by a team of health care professionals, including injury experts, a pediatric surgeon, and content area specialists. They included breastfeeding specialists and midwives. The final draft content was then included in a purpose-built digital intervention module in the form of a mini-app. App feature selection was informed by previous studies reporting common characteristics of health apps to change and manage behaviors [18]. NC conducted the literature review. NC, CH, SA, and JB applied the Behaviour Change Wheel, created the intervention strategy, and developed the intervention content. NC developed the app.

Phase 2: User Testing and Intervention Optimization

Phase 2 objectives are to ensure usability of the intervention, including comprehension of the intervention content. This was achieved by exposing potential users to the draft intervention content through the mini-app. Ethical approval was granted by the human research ethics committee of South Eastern Sydney Local Health District (2019/ETH00298). Participation involved an initial demographics and falls perception questionnaire, followed by a think-aloud interview as well as a comprehension assessment.

Participants were recruited in sequential rounds of 5 from a single tertiary maternity hospital antenatal ward and day-stay unit. Adult expectant parents were identified as the key user group because the intervention targets fall prevention in infants from birth to 12 months of age and the intention is to ultimately deliver the intervention to this group of the population. To be included, the expectant parents had to be conversant in English and could be first-time or experienced parents. This recruitment method prioritized mothers over fathers; however, this was deemed acceptable for the purposes of this study because mothers are commonly the primary caretakers of infants [24]. Written informed consent was obtained from willing participants.

Participants were individually presented with the mini-app on a study smartphone and asked to provide feedback through a *think-aloud* interview (Multimedia Appendix 1). This interview was audiotaped and analyzed later. The interview involved asking the participants to verbalize their thoughts while they used the digital intervention, after which we administered a set of questions to explore what the participants liked or disliked about the intervention content, along with any suggested improvements. Once completed, the participants were allowed to use the mini-app again, and a structured questionnaire (Multimedia Appendix 2) was used to assess their comprehension of the information provided. This approach has been used in previous studies testing comprehension of medical information [25], as well as by researchers developing consumer materials for child restraint installation [26]. To ensure that all participants were provided with falls prevention information regardless of the state of the mini-app, on completion, they were provided a widely available factsheet detailing advice on childhood falls prevention [27].

The results from the think-aloud interviews and comprehension assessments were analyzed as described in the next section and used to refine the intervention content and mini-app design before the process was repeated on the next round of 5 participants. Iterative rounds of 5 participants with the intervention content and mini-app refinement continued until 80% of the participants demonstrated at least 90% comprehension, which was defined as 4 out of 5 participants in each round achieving a score of at least 11 out of 12 in the comprehension assessment [19].

Analysis and Refinement

The comments collated from the think-aloud interviews were used in a systematic process of making person-based changes as outlined in Morrison et al [28]. The steps in this process were as follows:

1. Conduct and transcribe the interview
2. Extract negative and positive verbatim comments
3. Tabulate and code comments in a table of potential changes
4. Determine and implement modifications

All discussions were first transcribed verbatim by SLS. The researcher then worked line by line through each transcript to tabulate aspects of the data that showed positive and negative perceptions of the intervention, as well as any suggested modifications. For app refinement, members of the research team considered whether a modification to the intervention program would suitably address the concern expressed in each comment listed in the table. The criteria for making modifications were likely positive impact on drivers of behavior change (capability, opportunity, and motivation) or acceptability and feasibility. If the changes were uncontroversial and feasible to apply, they were implemented immediately. In other cases, more data were collected from another round of testing to seek more opinions before implementing the change. Finally, modifications requiring further tailoring and major changes to the app were discussed with the broad research team and if agreed upon were noted for later implementation in the final integrated app. For analysis of the comprehension questionnaire, comprehension scores were calculated for each user per round of testing, and percentages were tabulated.

Results

Phase 1: Intervention Planning and Development

Problem Formulation

Table 1 presents a summary of the key themes identified from the literature review and the qualitative analysis of web-based forum discussions [23]. From these themes, the problem behaviors were defined as follows: (1) tired mother falling asleep while feeding her baby (on a chair or on a bed) intentionally or unintentionally and (2) baby left alone on the bed to feed (bottle-feeding) or baby left alone on the bed before or after a feed.

Table 1. Key themes identified from the literature review and the qualitative analysis of web-based forum discussions.

Key themes	Support from literature	Scenarios (from web-based parenting forum analysis)
Possibility of sleeping while holding the baby	The possibility of mothers falling asleep while they are feeding their babies [29-33]	"I used to fall asleep while breastfeeding and after nearly dropping Tilly onto a metal table leg I gave up actually breastfeeding at night"
Exhausted mother	During the postpartum period, mothers are often exhausted and tend to fall asleep while feeding their babies [31,34]	"She was about 6 weeks old and I was totally sleep deprived. Sat down on the couch to nurse her, dozed off with her snuggled low in my arms (basically in my lap)...DD rolled down my legs and into the coffee table"
Importance of support and mother calling for help	Interventions should target reducing maternal exhaustion such as implementing mothers' nap time in the study by Hodges and Gilbert [34]. In addition, mothers need to call for assistance when tired [32]	"...my ex-h had left and I had 3 other children. I was beyond exhausted. More than once I fell asleep while feeding on the couch, only to be woken by my baby crying after she had rolled off me"
Postpartum depression and risk of injury	The evidence of postpartum depression and fall injury relationship [35] and importance of better social support for prevention	—[a]
Parents' awareness of risk of falls	Parents not aware of the risk of infant falls [34]	"...I fell asleep while feeding and it happened again...but a post on...revealed that it happens to lots of people"
Feeding place and position	Wallace [36] looked at redesigning bed rails of hospital beds. Thus, the target behavior was selected as lying in the middle of the bed when feeding the baby	"...I was breastfeeding him in bed and fell asleep with him on the outside. I woke up when I heard a thud and DS cry"
Risks of cosleeping and always placing the baby in the cot after a feed	Keeping the baby in a separate sleeping place; the best place has been identified as a cot by the mother's bedside [32,33]	—

[a] Not available.

After further review of the emerging themes listed in Table 1 and discussion with the team of experts, the following target behaviors for intervention development were selected:

1. Getting sufficient rest with the newborn (get help from others, sleep when the baby sleeps, use a breast pump to express milk, and plan sleep)
2. Preparing before the feed
3. Safe positioning during the feed
4. Safe placement of the infant after the feed

Table 2 presents the results of the application of the Behaviour Change Wheel to the identified target behaviors.

Table 2. Applying the Behaviour Change Wheel to the identified target behaviors.

COM-B[a] analysis	Intervention functions	Intervention strategy with BCTs[b]
Getting enough rest with a newborn		
• Psychological capability: Knowing ways and techniques to get sufficient rest with a newborn • Social opportunity: Getting help from others • Reflective motivation: Believing in the importance of getting enough rest for the sake of personal health and baby's health • Automatic motivation: Having the habit of sleeping when the baby sleeps	• Education • Persuasion • Environmental restructuring • Enablement	• Provide information on the importance of mother getting enough rest for the sake of personal and infant health (BCT: information on health consequences) • Provide information on ways to get enough rest with a newborn (BCT: instruction on how to perform the behavior) • Inform to discuss sleep arrangements with a support person (BCT: action planning) • Inform to use support groups to get better rest (BCT: social support unspecified) • All the information is from a credible source (BCT: credible source) • Provide reminders to informing to get enough rest (BCT: prompt and cues)
Preparing before the feed		
• Psychological capability: Knowing what is needed for a feed, why it is important to prepare and to prepare before a feed • Physical opportunity: Having a feeding basket with prepared items • Reflective motivation: Believing in the importance of preparing and understanding the possibility of leaving the infant alone, if unprepared • Automatic motivation: Having the habit of preparing before a feed	• Education • Persuasion • Environmental restructuring	• Provide information on the importance of preparing and the possibility of leaving the infant alone when unprepared and the risks (BCT: health consequences) • Provide information on what is usually needed for a feed and how to prepare before a feed (BCT: instruction on how to perform the behavior) • Provide information to prepare a feeding basket and place near the usual feeding position (BCT: adding objects to the environment) • Provide a mechanism to ensure self-monitoring behavior (BCT: self-monitoring)
Safe positioning during a feed		
• Psychological capability: Know the consequences and possibility of baby falls while feeding and the common scenarios; know the safe places to feed depending on the situation • Reflective motivation: Believing the importance of safe positioning to prevent falls and SUDI[c]	• Education • Persuasion • Training	• Provide information on the risk of infant falls when feeding, especially if it involves a risky place or posture, for example, falling asleep while feeding the baby in a chair (BCT: information on health consequences) • Provide information on safe feeding places and posture depending on the situation and ways to feed safely (BCT: information on how to perform the behavior)
Safe placement of the infant after a feed		
• Psychological capability: Know the risk of cosleeping, including risk of falls and other fatal sleep accidents; know the possibility of mother falling asleep during or after a feed; know that the cot in the parents' room is the safe place for the infant to sleep • Physical opportunity: Having a good quality cot • Reflective motivation: Intentions to put the infant in the cot	• Education • Persuasion • Training • Environment restructuring • Enablement	• Provide information on the adverse outcomes of cosleeping and why the cot is the safest place for the infant to sleep (BCT: information on health consequences) • Provide information about cot standards in Australia and why the cot in the parents' room is the best place for the infant to sleep (BCT: restructuring the physical environment) • Inform to put the baby in the cot after a feed (BCT: information on how to perform the behavior)

[a] COM-B: capability, opportunity, motivation-behavior.

[b] BCT: behavior change technique.

[c] SUDI: sudden unexpected death in infancy.

Implementation of the Planned Intervention Strategy (App Development)

To implement the planned intervention strategy, a minimum viable product mini-app was developed for use on the Android platform. The mini-app had 3 main sections. The *Learn* section included information articles with an interlinked *Action* section that provided a self-monitoring mechanism, including one-time and multitime actions. Multitime actions were intended to support behaviors that require repetition. The *Engage* section included a group chat where users could get social support. This feature was also intended to enhance user engagement with the app. In addition, there was an onboarding section to introduce the app to the users. Users were informed about the option of setting up reminders for the *Actions* without fully implementing this feature in the mini-app for testing. The *Learn*, *Action*, and *Engage* categories were devised to allow appropriate implementation of selected behavior change techniques and align with approaches commonly used in other digital behavior change apps.

Phase 2: Intervention Optimization Results

Participants

A total of 23 women were recruited for the user-testing exercise; 13% (3/23) withdrew because of time constraints. Of the 20 participants, 15 (75%) were aged 26-35 years, 14 (70%) were nulliparous (70%), 10 (50%) were Australian-born, 12 (60%) were in de facto relationships, 13 (65%) were employed full time, and 15 (75%) were living in apartment buildings. Of the 20 participants, 16 (80%) had attained either a university or Technical and Further Education graduate degree or a postgraduate degree and 9 (45%) had high household income (earning more than Aus $150,000 [US $109,500]; Table 3). Target comprehension levels were achieved in 4 rounds (Table 4).

Table 3. Participants' demographics (N=20).

Demographics	Values, n (%)
Gender (female)	20 (100)
Age (years)	
26-35	15 (75)
36-45	5 (25)
Parity	
Multiparous	6 (30)
Nulliparous	14 (70)
Nationality (Australian)	10 (50)
Language spoken at home (English)	20 (100)
Household income (Aus $; US $)	
20,001-100,000 (14,601.30-73,000)	4 (20)
100,001-150,000 (73,001.30-109,500)	4 (20)
>150,000 (109,500)	9 (45)
Decline to answer	3 (15)
Marital status	
Married	7 (35)
Divorced	0 (0)
Separated	0 (0)
Single parent	1 (5)
In a de facto relationship	12 (60)
Education level	
Primary school, secondary school, some university, or TAFE[a] diploma	4 (20)
University or TAFE graduate	9 (45)
Postgraduate degree	7 (35)
Employment status	
Unemployed	2 (10)
Seasonal or casual employment	0 (0)
Part-time employment	3 (15)
Full-time employment	13 (65)
Student (full time, part time, or correspondence)	0 (0)
Not applicable or decline to answer	2 (10)
Primary residence	
A stand-alone house	2 (10)
A semidetached town house or duplex	1 (5)
A townhouse complex	2 (10)
An apartment building	15 (75)

[a] TAFE: Technical and Further Education.

Table 4. Results of comprehension assessment in each user-testing round (5 participants per round).[a]

	Score (%), mean (SD)	Score (%), range	Participants scoring 90%, n (%)
Round 1 participants' comprehension scores	84.8 (12.7)	66-100	2 (40)
Round 2 participants' comprehension scores	80 (19.2)	50-100	2 (40)
Round 3 participants' comprehension scores	81.6 (21.8)	58-100	3 (60)
Round 4 participants' comprehension scores	88.4 (17.5)	58-100	4 (80)

[a] Score is percentage of correct answers out of 12 questions.

Feedback on Target Behaviors and Intervention Content

Overall, the participants reported that they found the information useful and easy to understand. They commonly reported already knowing recommended behaviors or that they found the recommended behaviors *common sense* but identified the importance of having the information provided at the right time. They also acknowledged the value of credible sources:

> *A lot of it seems like common sense...but I suppose, well, now, but maybe in the moment it's good reminder to have.*
>
> *I think it's helpful to have it written as you know, from the doctor's perspective and I guess it's quite confronting to hear that so many admissions...are from I guess, avoidable things.*

The participants particularly liked that the intervention targeted social and environmental aspects, for example, the importance of rest for the infant's well-being and the importance of support from family and friends to get enough rest. However, there were some concerns with support not being available for everyone:

> *It's telling me that my rest is really important...and um that it's actually like a safety issue for the baby that I have enough sleep and I just don't think that that information is out there enough...*

Some participants felt that the information is targeted more toward new mothers with 1 baby and pointed out the importance of information being suitable for the broader audience. In addition, they pointed out some information that they believed may not be practical and requested didactic information:

> *So I guess this app is more targeted towards new mums rather than mums who have already had another baby as well?...if baby is sleeping, we'll probably be looking after the other one and not really looking after ourselves...*

Views Toward the App

In general, the participants liked the concept of the app but felt that the delivery of information could be more graphical. They commonly liked the *self-tracking* actions and the idea of receiving reminders and felt that this made the intervention more *app*-like. However, some were confused with the expected use of tracking, that is, as a checklist rather than using it while attending to the baby:

> *I quite like, and maybe this is just my personality, but I quite like that you can mark as done.*

The participants commonly requested additional information related to childcare, which was beyond the scope of the intervention, and some felt that the app scope may be too narrow. They also expressed the importance of the delivery channel if they are to use such an app:

> *I guess it would be how you would get this app, how much it would cost, is it free or not?...*
>
> *...scope is too narrow, if you want women to use it. It should be much larger than this. It's not just about falling and placing, its about why they scream, what the signs are...just like if you want somebody for real to use the app.*

Mixed feedback was received about the chat feature, with some having concerns about moderation, bullying, and unsound advice being provided on social media platforms. Others felt that it might be a good place to open up about issues that they cannot raise with their immediate family and requested a professional moderator for the chat. Overall, it was clear that they saw this feature as a place to raise all infant-related questions rather than questions relevant to the intervention:

> *Yea, I don't know, I just find it hard to...yea, cos of like Facebook and stuff and there's a lot of bullying and judgement and what not...I don't want mums to feel like bullied or that like they're doing the wrong thing, they're already so vulnerable.*
>
> *...you've got heaps of apps like that out there already but to have access to someone with medical advice would be amazing.*

Key Intervention Modifications After User Testing

After review of the feedback, the modifications, as summarized in Textbox 1, will be taken into future app development.

Screenshots of the app are available in Multimedia Appendix 3.

Textbox 1. Feedback, key takeaways, and app modifications.

App scope may be too narrow or niche

- When testing future modules, users will be given a version that will look visually similar to the final app consisting of multiple modules

Importance of timed information or reminders

- A feature where users can set up local reminders for actions will be implemented in future modules. The final intervention will include timed push notifications to further support adherence with the actions

Importance of providing practical advice

- Special consideration was given to ensuring the practicality of the information and the app features

Perceived complications with a group chat feature

- Group chat feature requires modification. A feature to submit questions to a professional has been suggested as a replacement for this feature, and the practicality of this is being investigated

Discussion

Principal Findings

This paper describes a behavior theory and user-centered approach to developing a DBCI, an intervention to target the problem of infant falls. In this paper, we have outlined the entire development and user-testing process undertaken to construct an intervention module targeting falls that occur while the infant is feeding. The same process is being applied to 3 more modules targeting the remaining common fall mechanisms: (1) *falls from furniture*, (2) *falls from baby products*, and (3) *falls related to risky home environments (eg, steps and stairs)*; the module used as the case study in this paper was arbitrarily chosen. The decision to present just 1 module as a case study was made to ensure that the full detail of the systematic intervention development method could be presented.

The systematic exploration of the problem from a behavior perspective and the identification of intervention content to specifically target behavior using the strong theoretical base of the Behaviour Change Wheel [7] is a strength of this development process. The need to ground injury prevention interventions targeting behavior in behavior theory has been clearly acknowledged [37], and the Behaviour Change Wheel and the COM-B Model—which proposes that there are 3 components to any behavior (B): capability (C), opportunity (O), and motivation (M)—are increasingly being used for this purpose in other contexts [38,39]. However, there is a relative paucity of studies in the literature describing processes for achieving this, particularly in the context of injury prevention. Similarly, although person-centered approaches to developing DBCIs have been used extensively in other areas of health to produce effective digital interventions [40,41], there seems to be limited application of this type of systematic approach to injury prevention digital intervention development. The work described in this paper fills both gaps.

In our behavior theory–driven approach using the COM-B Model and Behaviour Change Wheel we used a literature review and qualitative analysis of infant fall events from a web-based parenting forum [23] to identify the problem behaviors targeted in this intervention. The research team in consultation with a broader group of experts then selected behavior change functions and techniques. In other contexts, different approaches have been used. For example, others have used stakeholder meetings and interviews with the target audience [39] or surveys [38] to identify target behaviors. The critical similarity in the different approaches is reliance on data collected directly from the target population rather than assumptions from research teams on what behaviors need to change and what might be driving these behaviors.

Another strength is the inclusion of a comprehension assessment in the user-testing component. This is not a common feature of person-centered approaches to behavior change and DBCIs; yet, in other areas of health communication, ensuring comprehension is recognized as critical [25]. This also somewhat addresses the call to pay greater attention to eHealth literacy made in a recent systematic review of digital health interventions for injury prevention [42]. However, in addition to understanding the content of the digital intervention, there is also a need to ensure that users can adequately navigate to *seek and find* information [43]. We intend to assess this in the next phase of development, which will combine the intervention modules within an integrated app and undergo longitudinal testing.

In addition to describing the intervention development process, this paper also demonstrates the benefit of the user-testing process in behavior change app development. Several important insights from user perspectives have been identified that may be important for encouraging the use of the app in parents of infants, and we will attempt to incorporate these strategies in the final integrated app. Of particular interest is the feedback centered around integrating the injury prevention intervention into an app with broader scope and incorporating noninjury prevention advice to mothers and caregivers of infants. Although there is emerging interest in the integration of injury prevention with more general pediatric health care [44,45], to our knowledge there has been little formal investigation of the efficacy of embedding targeting child injury prevention interventions within the context of child and family health care, including general parenting advice. In other contexts, researchers have noted that motivation and engagement with interventions delivered digitally through mobile technologies may be increased by providing features that the user sees as beneficial

[46]. This may be a worthy area of further exploration regarding increasing parental engagement in digital injury prevention interventions and, as noted by Issom et al [46], highlights the need for participatory approaches to digital intervention development.

The intervention development process we have described increases the likelihood that the intervention will be effective in promoting desired parental behaviors for preventing infant falls. The process should also increase acceptability and usability of the end product among the target audience. However, the work to date does not yet demonstrate this. Once the intervention modules have been integrated into the app, there will be a need to robustly establish the effectiveness of the intervention. This is particularly important because despite reports of the promise of mobile behavior change interventions for reducing childhood injury [42,47], there are relatively few trials reporting effectiveness of DBCIs targeting childhood injury prevention.

More broadly, our user-centered approach to intervention development and intention to robustly evaluate the effectiveness of the intervention responds to research needs in the digital health care space generally [13,14]. The intervention development process we have described could be applied to many other settings where there is a need for theory- or evidence-informed intervention that relies on user acceptance and engagement.

A limitation observed in the user-testing phase of the study is the homogeneity of the mothers recruited. All were relatively highly educated and from high-income sectors of the community. This is problematic, given that the target audience for this intervention includes the complete demographic range of parents of infants, particularly because it is recognized that there is an increased risk of injury among children from the lower socioeconomic sectors of communities [48]. Previous work has identified that >95% of women in a high-income country setting own a smartphone regardless of individual sociodemographic factors [49], indicating that the bias in our sample reflects a limitation of the study rather than a limitation in the intention of our intervention, that is, using a smartphone digital delivery method. This study limitation highlights the need to use broader recruitment strategies to ensure that women from a wider variety of backgrounds are invited to participate. A potential strategy for achieving this would be to conduct user testing over a broader geographic area that incorporates wider sociodemographic diversity. Similarly, for other injury types, it will be useful to recruit other common carers such as fathers, coparents, and grandparents.

Conclusions

The work presented in this paper provides a detailed description of a behavior theory–driven and person-centered approach to designing, developing, and optimizing a DBCI targeting a significant childhood injury problem. The process described and the intervention being developed address important gaps in the literature regarding the development of digital child injury prevention interventions. Ultimately, this work represents the first stage in the development of a unique intervention targeting the widespread problem of falls in children aged <1 year. This will be the first intervention of its kind, and as demonstrated in this paper, it is being developed in a unique, systematic, and robust manner.

Authors' Contributions

NC conceptualized and designed the study, created the intervention content and developed the mobile app, carried out the analysis, drafted the initial manuscript, and reviewed and revised the manuscript. SLS created the intervention content, conducted the interviews, analyzed the data, drafted the initial manuscript, and reviewed and revised the manuscript. CH created the intervention content, drafted the initial manuscript, and reviewed and revised the manuscript. SA created the intervention content, coordinated and supervised study activities, and critically reviewed the manuscript for important intellectual content. LK and NN conceptualized and designed the study, coordinated and supervised study activities, and critically reviewed the manuscript for important intellectual content. JB conceptualized and designed the study, coordinated and supervised study activities, drafted the initial manuscript, reviewed and revised the manuscript, and critically reviewed the manuscript for important intellectual content. 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
Think-aloud interview protocol.
[PDF File (Adobe PDF File), 81 KB - pediatrics_v4i4e29731_app1.pdf]

Multimedia Appendix 2
Comprehension-assessment questionnaire.
[PDF File (Adobe PDF File), 61 KB - pediatrics_v4i4e29731_app2.pdf]

Multimedia Appendix 3
Screenshots of the app.
[PDF File (Adobe PDF File), 4156 KB - pediatrics_v4i4e29731_app3.pdf]

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Abbreviations

DBCI: digital behavior change intervention

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Original Paper

The Role of Education, Monitoring, and Symptom Perception in Internet-Based Self-management Among Adolescents With Asthma: Secondary Analysis of a Randomized Controlled Trial

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Abstract

Background: Internet-based self-management programs improve asthma control and the asthma-related quality of life in adults and adolescents. The components of self-management programs include education and the web-based self-monitoring of symptoms; the latter requires adequate perception in order to timely adjust lifestyle or medication or to contact a care provider.

Objective: We aimed to test the hypothesis that adherence to education and web-based monitoring and adequate symptom perception are important determinants for the improvement of asthma control in self-management programs.

Methods: We conducted a subgroup analysis of the intervention group of a randomized controlled trial, which included adolescents who participated in the internet-based self-management arm. We assessed the impacts that attendance in education sessions, the frequency of web-based monitoring, and the level of perception had on changes in asthma control (Asthma Control Questionnaire [ACQ]) and asthma-related quality of life (Pediatric Asthma Quality of Life Questionnaire) from baseline to 12 months after intervention.

Results: Adolescents who attended education sessions had significant and clinically relevant improvements in asthma control (ACQ score difference: −0.6; *P*=.03) and exhibited a nonsignificant trend of improvement in asthma-related quality of life (Pediatric Asthma Quality of Life Questionnaire score difference: −0.45; *P*=.15) when compared to those who did not adhere to education. Frequent monitoring alone did not improve asthma control (*P*=.07) and quality of life (*P*=.44) significantly, but its combination with education did result in improved ACQ scores (difference: −0.88; *P*=.02). There were no significant differences in outcomes between normoperceivers and hypoperceivers.

Conclusions: Education, especially in combination with frequent web-based monitoring, is an important determinant for the 1-year outcomes of asthma control in internet-based self-management programs for adolescents with partly controlled and uncontrolled asthma; however, we could not establish the effect of symptom perception. This study provides important knowledge on the effects of asthma education and monitoring in daily life.

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KEYWORDS

web-based monitoring; internet self-management; adolescents; asthma; education; perception

Introduction

Asthma control is the goal in long-term asthma management, but despite the availability of effective therapies, this goal is not reached in three-quarters of patients with persistent asthma [1-3]. Adolescents form a vulnerable subgroup of patients with asthma that is characterized by a high prevalence of poor outcomes and high rates of morbidity and mortality. A lack of knowledge and perception of symptoms, especially when combined with a desire for independence and high-risk behaviors, interferes with adherence to asthma medication [4-6].

Asthma control and asthma-related quality of life can be improved in adults and adolescents, and the number of outpatient visits can be reduced by participating in an internet-based self-management (IBSM) support program [7-10]. In a previous randomized controlled trial, we assessed whether IBSM improved asthma control, asthma-related quality of life, and lung function in adolescents with partially controlled and uncontrolled asthma [11]. Adolescents allocated to the IBSM group of the trial showed improved asthma-related quality of life and asthma control within 3 months. However, these effects were not sustained during a longer period of time in a part of the intervention group. In the original paper, we did not assess which factors predicted favorable outcomes among the intervention group after the 12-month follow-up. These adolescents had access to education and self-monitored their asthma control, which are important components of self-management [7,11,12]. Adequately self-monitoring asthma control perceptions of airway obstruction symptoms seems crucial. Therefore, adherence to self-monitoring and education and the perception of airway obstruction might be important determinants of long-term outcomes in asthma self-management. This study is a secondary analysis of the Self-Management in Asthma Supported by Hospitals, Internet, Nurses and General Practitioners (SMASHING) trial [11], which we conducted in order to assess whether (1) adherence to education, (2) the amount of symptom monitoring, and (3) the level of symptom perception are related to improvements in asthma control and asthma-related quality of life in adolescents with partly controlled and uncontrolled asthma. We hypothesized that adherence to education sessions, frequent web-based monitoring, and an adequate perception of dyspnea are prerequisites to improving asthma control, asthma-related quality of life, and lung function after 12 months.

Methods

Patients

A detailed description of the methodology and patient recruitment process has been published before [11]. In short, adolescents aged between 12 and 18 years with a doctor's diagnosis of persistent asthma were recruited from 35 general practices and the pediatric departments of 8 hospitals throughout the Netherlands. Patients requiring oral steroids for maintenance or patients with relevant comorbidities were excluded [11]. Only patients with partly controlled and uncontrolled asthma, as determined by having an Asthma Control Questionnaire (ACQ) score of >0.75 or an Asthma Therapy Assessment Questionnaire score of >1.0, were enrolled in the trial [13,14]. Patients were randomized via block randomization by a study coordinator who had no contact with the participants. After randomization, the baseline characteristics of the participants in the intervention arm and the control arm were similar [11]. In total, 11 of the 46 participants in the intervention group and 4 of the 44 participants in the usual care group dropped out. Furthermore, 9 of the remaining participants in the intervention group did not report secondary outcome measure (asthma control) results at 12 months after intervention [11].

Design

To assess possible predictors of favorable outcomes in an IBSM support program, this study conducted an analysis of adolescents who participated in the intervention group of a randomized parallel trial (the SMASHING trial), which had a 1-year follow-up with 2-week evaluation periods at baseline and at 12 months [11]. In addition to usual care, adolescents in the IBSM intervention group received protocolized education in sessions that only involved small groups of participants. Furthermore, participants were asked to monitor their asthma control by using the ACQ weekly, and they received instant therapeutic advice according to a personal web-based treatment plan [11,13]. Participants could always report their daily symptoms and lung function by using a diary card (via the internet or short text messages) or by contacting the asthma nurse by phone or via the web. Apart from web-based information and interactive communication with the asthma nurse, education consisted of 2 asthma self-management education group sessions that were conducted within 6 weeks before participants entered the trial. Patient-tailored information about asthma self-management was provided in response to participants' questions and individual concerns. Patients were asked to record asthma control outcomes by filling out the 7-item ACQ weekly. These included lung function (forced expiratory volume in 1 second [FEV_1]), which was measured with a handheld electronic spirometer (Piko-1; nSpire Health Inc) and recorded in a personal page on a secure web application. They received instant feedback (based on a specific algorithm) on their levels of asthma control, including advice on how to adjust their medication according to a predefined personal treatment plan. At 0, 3, and 12 months, all participants monitored symptoms and lung function daily for 2 weeks, filled out the ACQ twice during those 2 weeks, and completed the Pediatric Asthma Quality of Life Questionnaire (PAQLQ) [15-18] once. To assess levels of symptom perception, participants were asked to visit the lung function laboratory to perform a bronchial challenge inhalation test involving methacholine at 12 months after intervention. If this visit could not be planned within 8 weeks from the 12-month evaluation period, the participants monitored symptoms, lung function, and ACQ entries for an additional 2 weeks before the methacholine challenge test. The studied group consisted of the patients in the intervention arm of the SMASHING study. Monitoring and education were only accessible to the intervention arm; hence, there are no such data for the participants in the control arm of the study.

Measurements

Adherence to Education

Patients were defined as being adherent to education if they attended at least 1 of the 2 education sessions and as being nonadherent if they did not follow any education session.

Adherence to Monitoring

Adherence to monitoring was based on the frequency of monitoring ACQ entries during the follow-up period. Adolescents were asked to monitor ACQ entries weekly. We presumed that at the start of the trial, all participants would be motivated to perform monitoring, whereas during the follow-up of the program, only dedicated participants would continue to perform monitoring. We assumed that a monitoring frequency of at least 30 records in 12 months (full compliance in the first month and 50% compliance in the remaining period) would reflect adequate adherence to the intervention. Therefore, participants were divided into subgroups based on whether they adhered to ACQ monitoring (adherent subgroup: ≥30 ACQ entries; nonadherent subgroup: <30 ACQ entries).

Perception of Dyspnea

Perceptions of dyspnea were assessed in 2 ways, and patients were categorized as normoperceivers or hypoperceivers of dyspnea. First, perceptions of dyspnea were assessed during the methacholine inhalation challenge test. Methacholine was administered in doubling concentrations (range 0.15-640 μmol/mL). The challenge test was discontinued if the FEV_1 decreased by more than 20% of the baseline value. All subjects were asked to assess the severity of their breathlessness before the first measurement of lung function, after the inhalation of a placebo (saline), and after receiving each incremental dose of methacholine. Patients rated the severity of the breathlessness that they experienced during the challenge test on a revised Borg scale [19]. The Borg scale is a category scale with ratio properties in which words describing increasing degrees of breathlessness are anchored to numbers ranging between 0 and 10, with 10 indicating the most severe degree of breathlessness. Perceptions of dyspnea were analyzed by using individual plots (Borg scores vs the percentage fall in FEV_1) and expressed as slopes of the regression line (Borg slope). Based on the median of the Borg slope, patients were categorized as normoperceivers (≥median) or hypoperceivers (<median). Second, because the Borg slope was assessed at 12 months after intervention, to gain a longitudinal impression of perception, we also assessed a symptom slope by plotting the slope of the individual regression lines of daily symptom scores against the prebronchodilator-predicted FEV_1 percentages during the follow-up. Based on the symptom slope, 2 independent observers (JKS and TB) categorized the adolescents as normoperceivers, hypoperceivers, hyperperceivers, or undefinable participants. Discordance was settled by consensus. Interobserver agreement was estimated by using the Cohen κ.

Outcomes

The outcome parameters consisted of the difference between the baseline and 1-year outcomes of the PAQLQ and the individual averages of ACQ scores and FEV_1 measurements from the 2-week diary cards. The minimal important change for both PAQLQ scores and ACQ scores was a difference of 0.5 points on their respective scales [20,21].

Statistical Analysis

To assess the effect that education has on outcomes, we compared improvements in asthma-related quality of life and asthma control among adherent participants who had followed at least 1 of the 2 education sessions to those improvements in participants who did not follow any education session (the nonadherent participants), by using the Student 2-tailed *t* test.

We assessed whether adolescents who performed frequent monitoring (≥30 entries) clinically improved at 12 months after intervention in terms of asthma control (ΔACQ score≤−0.5) or quality of life (ΔPAQLQ score≥0.5) by using the Student *t* test. We constructed a linear effects model to assess asthma control, quality of life, and lung function for the following three participant categories: no adherence to education and monitoring, only adherence to education, and adherence to both education and monitoring.

We also assessed whether normoperceivers clinically improved (ie, in terms of asthma control [ΔACQ score≤−0.5] or quality of life [ΔPAQLQ score≥0.5]) more than hypoperceivers at 12 months after intervention by using the Student *t* test.

All analyses were performed with the Stata 11.0 (StataCorp LLC) statistical software package.

Results

Summary of Patient Characteristics

In the SMASHING study, 46 patients were randomized to the intervention arm. Of these participants, 11 dropped out during follow-up. Of the remaining 35 participants, 9 did not submit the final 12-month questionnaire. In an attempt to obtain at least the primary outcomes of the original study, we asked participants to fill out the PAQLQ. Hence, only 9 participants submitted this PAQLQ at the 12-month follow-up (Figure 1). The patient characteristics of the 35 adolescents in the IBSM group who completed the PAQLQ are presented in Table 1.

Figure 1. Study flow diagram. ACQ: Asthma Control Questionnaire; PAQLQ: Pediatric Asthma Quality of Life Questionnaire; SMASHING: Self-Management in Asthma Supported by Hospitals, Internet, Nurses and General Practitioners.

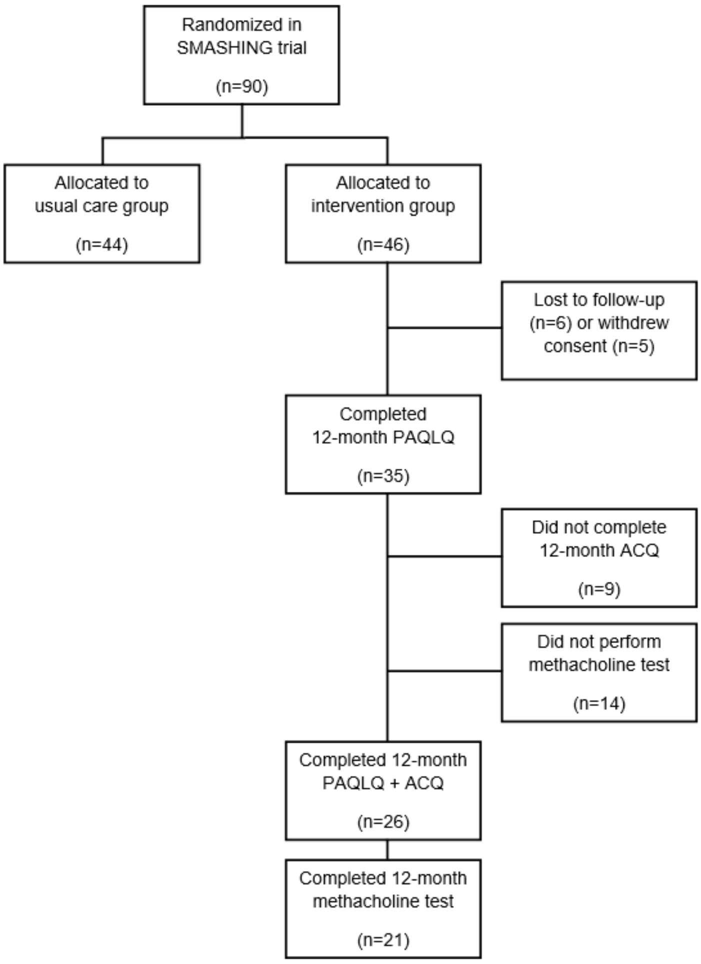

Table 1. Patient characteristics.

Characteristics	Internet-based self-management group (SMASHING[a] study; n=35)	Nonadherence to education (n=13)	Adherence to education[b] (n=22)
Males, n (%)	14 (40)	6 (46)	9 (36)
Age (years), mean (range)	14.1 (12-17)	13.7 (12-16)	14.1 (12-17)
Care provider, n (%)			
General practitioner	12 (34)	2 (15)	10 (45)
Pediatrician	23 (66)	11 (85)	12 (55)
FEV_1[c] (L), mean (range)	2.86 (1.74-4.31)	3.08 (1.99-4.30)	2.74 (1.74-4.26)
FEV_1 (prebronchodilator; %), mean (range)	93 (65-125)	93.6 (73.2-117.7)	91.8 (64.5-125.9)
Daily inhaled corticosteroid dose (µg), mean (range)	353 (0-1000)	335 (100-1000)	402 (0-1000)
Pediatric Asthma Quality of Life Questionnaire score, mean (range)	5.78 (3.51-6.97)	5.84 (4.47-6.63)	5.75 (3.51-6.97)
Asthma Control Questionnaire score, mean (range)	1.22 (0.22-2.91)	1.03 (0.22-2.30)	1.33 (0.29-2.91)

[a] SMASHING: Self-Management in Asthma Supported by Hospitals, Internet, Nurses and General Practitioners.

[b] Adherence is defined as having attended at least 1 of the 2 education sessions.

[c] FEV_1: forced expiratory volume in 1 second.

Education

Of the 35 participants, 22 (63%) followed at least 1 education session (Table 1). Adolescents who were adherent to education showed significant improvements between 0 and 12 months in terms of asthma control (ΔACQ score: mean −0.60; 95% CI −1.12 to −0.08; *P*=.03) when compared to those who were not adherent to education (Table 2). This difference was clinically relevant. No statistically significant difference was found for asthma-related quality of life (ΔPAQLQ score: mean 0.45; 95% CI −0.17 to 1.07; *P*=.15) between these two groups (Table 3).

Table 2. Asthma control improvement dichotomized by education, monitoring, and perception. A lower (negative) score represents a more favorable outcome.

Categories	ACQ6[a] score (n=26), mean (95% CI)	*P* value
Education		
Nonadherence (n=7)	−0.015 (−0.68 to 0.65)	N/A[b]
Adherence (n=19)	−0.62 (−0.86 to −0.37)	N/A
Difference	−0.60 (−1.12 to −0.08)	.03
Monitoring		
<30 entries (n=16)	−0.28 (−0.56 to 0)	N/A
≥30 entries (n=10)	−0.73 (−1.23 to −0.24)	N/A
Difference	−0.45 (0.94 to 0.05)	.07
Education and monitoring		
Comparison 1		
Education nonadherence and <30 monitoring entries (n=5)	−0.05 (−0.92 to 0.82)	N/A
Education adherence and ≥30 monitoring entries (n=8)	−0.93 (−1.32 to −0.53)	N/A
Difference	−0.88 (−1.59 to −0.17)	.02
Comparison 2		
Education adherence and <30 monitoring entries (n=11)	−0.39 (−0.67 to −0.11)	N/A
Education adherence and ≥30 monitoring entries (n=8)	−0.93 (−1.33 to −0.53)	N/A
Difference	−0.54 (−0.98 to −0.11)	.02
Borg score		
Hypoperceiver (n=8)	−0.18 (−0.72 to 0.36)	N/A
Normoperceiver (n=6)	−0.66 (−1.25 to −0.07)	N/A
Difference	−0.48 (−1.20 to 0.24)	.17
Symptom slope		
Hypoperceiver (n=15)	−0.49 (−0.91 to −0.07)	N/A
Normoperceiver (n=7)	−0.49 (−0.86 to −0.13)	N/A
Difference	0 (−0.26 to 0.26)	.99

[a] ACQ6: 6-item Asthma Control Questionnaire.

[b] N/A: not applicable.

Table 3. Asthma-related quality of life improvement dichotomized by education, monitoring, and perception. A higher (positive) score represents a more favorable outcome.

Categories	PAQLQ[a] score (n=35), mean (95% CI)	*P* value
Education		
Nonadherence (n=13)	−0.094 (−0.65 to 0.47)	N/A[b]
Adherence (n=22)	0.36 (−0.01 to 0.73)	N/A
Difference	0.45 (−0.17 to 1.07)	.15
Monitoring		
<30 entries (n=24)	0.11 (−0.20 to 0.42)	N/A
≥30 entries (n=11)	0.36 (−0.42 to 1.15)	N/A
Difference	0.25 (0.41 to 0.91)	.44
Education and monitoring		
Comparison 1		
Education nonadherence and <30 monitoring entries (n=11)	0.07 (−0.42 to 0.55)	N/A
Education adherence and ≥30 monitoring entries (n=9)	0.66 (0.01 to 1.32)	N/A
Difference	0.60 (−0.15 to 1.34)	.11
Comparison 2		
Education adherence and <30 monitoring entries (n=13)	0.14 (−0.32 to 0.61)	N/A
Education adherence and ≥30 monitoring entries (n=9)	0.66 (0.01 to 1.32)	N/A
Difference	0.52 (−0.21 to 1.25)	.15
Borg score		
Hypoperceiver (n=8)	−0.02 (−0.60 to 0.57)	N/A
Normoperceiver (n=10)	0.09 (−0.46 to 0.63)	N/A
Difference	0.10 (−0.64 to 0.84)	.77
Symptom slope		
Hypoperceiver (n=16)	0.25 (−0.33 to 0.83)	N/A
Normoperceiver (n=7)	0.17 (−0.39 to 0.74)	N/A
Difference	0.079 (−0.84 to 1.00)	.86

[a] PAQLQ: Pediatric Asthma Quality of Life Questionnaire.

[b] N/A: not applicable.

Monitoring of Asthma Control

We found no statistically significant difference in improvements in ACQ scores between adolescents who had more than 30 monitoring entries compared to those who conducted monitoring less frequently (ΔACQ score: mean −0.45; 95% CI −0.94 to 0.045; *P*=.07) or in improvements in asthma-related quality of life (ΔPAQLQ score: mean 0.25; −0.41 to 0.91; *P*=.44; Table 2 and 3). However, in adolescents who were adherent to both education and the frequent monitoring of ACQ entries (≥30 entries), there was a significant and clinically relevant improvement in asthma control (ΔACQ score: mean −0.88; 95% CI −1.59 to −0.17; *P*=.02) when compared to such improvements in adolescents who were not adherent to education and conducted monitoring less frequently (Table 2). The group of patients who were adherent to both education and monitoring also showed better asthma control compared to that of adolescents who adhered to education but had less than 30 monitoring entries (ΔACQ score: mean −0.54; 95% CI −0.98 to −0.11; *P*=.02; Table 2). The same trend was found for the difference in PAQLQ scores, but this did not reach significance, as shown in Table 3 (*P*=.15). A linear effects model for assessing the impacts of no adherence, only education, and adherence to both education and monitoring showed that adherence to education and frequent monitoring had a favorable effect on asthma control (ACQ score: mean −0.45; 95% CI −0.74 to −0.16; *P*=.004). However, their effects on quality of life (PAQLQ score: mean 0.29; 95% CI −0.07 to −0.64; *P*=.11) and lung function (FEV$_1$ score: mean 0.08; 95% CI −0.16 to 0.33; *P*=.49) were not significant (Table 4).

Table 4. Lung function improvement dichotomized by education, monitoring, and perception. A higher (positive) value represents a more favorable outcome.

Categories	FEV_1[a] value (n=29), mean (95% CI)	*P* value
Education		
Nonadherence (n=9)	0.12 (−0.10 to 0.33)	N/A[b]
Adherence (n=20)	0.31 (0.061 to 0.56)	N/A
Difference	0.19 (−0.41 to 0.58)	.32
Monitoring		
<30 entries (n=18)	0.24 (−0.04 to 0.52)	N/A
≥30 entries (n=11)	0.27 (0.01 to 0.44)	N/A
Difference	0.03 (−0.40 to 0.35)	.89
Education and monitoring		
Comparison 1		
Education nonadherence and <30 monitoring entries (n=7)	0.16 (−0.08 to 0.39)	N/A
Education adherence and ≥30 monitoring entries (n=9)	0.33 (0.19 to 0.46)	N/A
Difference	0.17 (−0.06 to 0.40)	.13
Comparison 2		
Education adherence and <30 monitoring entries (n=11)	0.29 (−0.18 to 0.77)	N/A
Education adherence and ≥30 monitoring entries (n=9)	0.33 (0.19 to 0.46)	N/A
Difference	0.04 (−0.47 to 0.55)	.88
Borg score		
Hypoperceiver (n=8)	0.44 (−0.13 to 1.00)	N/A
Normoperceiver (n=8)	0.12 (−0.20 to 0.43)	N/A
Difference	0.32 (−0.26 to 0.91)	.26
Symptom slope		
Hypoperceiver (n=16)	0.19 (0.01 to 0.38)	N/A
Normoperceiver (n=7)	0.10 (−0.18 to 0.39)	N/A
Difference	0.09 (−0.23 to 0.41)	.57

[a] FEV_1: forced expiratory volume in 1 second.

[b] N/A: not applicable.

Perception

A total of 21 participants in the IBSM group performed the methacholine test and had Borg scores (Table 5). They were categorized as normoperceivers (n=11) and hypoperceivers (n=10). Based on the symptom slope, participants in the IBSM group were categorized as normoperceivers (n=17), hypoperceivers (n=10), hyperperceivers (n=1), and undefinable participants (n=18; interobserver agreement: κ=0.67). There was no strong relationship between the Borg slope and symptom slope (Spearman correlation coefficient [R_s]: −0.29). There were no statistically significant differences in outcomes between normoperceivers and hypoperceivers based on the Borg slopes for asthma control (ΔACQ score: mean 0.48; *P*=.17) and asthma-related quality of life (ΔPAQLQ score: mean −0.10; *P*=.77; Table 5). Similarly, no significant differences in outcomes were found if perception was based on the symptom slope (Table 5).

Table 5. Outcomes in normoperceivers and hypoperceivers based on Borg and symptom slopes.

Slopes and outcomes	Value (number of normoperceivers)	Value (number of hypoperceivers)	Difference (95% CI)	*P* value
Borg slope				
$\Delta mACQ_{0-12}$[a]	−0.66 (6)	−0.18 (8)	0.48 (−0.24 to 1.2)	.17
$\Delta PAQLQ_{0-12}$[b]	0.09 (10)	0.02 (8)	−0.10 (−0.84 to 0.63)	.77
$\Delta mFEV_{1,0-12}$[c]	0.12 (8)	0.44 (8)	0.32 (−0.26 to 0.90)	.26
Symptom slope				
$\Delta mACQ_{0-12}$	−0.49 (15)	−0.49 (7)	0 (0.65 to 0.78)	>.99
$\Delta PAQLQ_{0-12}$	0.25 (16)	0.17 (7)	0.08 (−0.84 to 0.10)	.86
$\Delta mFEV_{1,0-12}$	0.19 (16)	0.10 (7)	0.09 (−0.23 to 0.41)	.57

[a] $\Delta mACQ_{0-12}$: change in mean Asthma Control Questionnaire scores from 0 months to 12 months after intervention.

[b] $\Delta PAQLQ_{0-12}$: change in mean Pediatric Asthma Quality of Life Questionnaire scores from 0 months to 12 months after intervention.

[c] $\Delta mFEV_{1,0-12}$: change in mean forced expiratory volume in 1 second values from 0 to 12 months after intervention.

Discussion

This study showed that participation in education sessions, especially in combination with frequent monitoring, is an important determinant for the 1-year outcomes of asthma control in IBSM programs for adolescents with partly controlled and uncontrolled asthma.

Attending at least 1 education session was a predictor of significant improvement in asthma control during the follow-up when compared to not attending any education session. Frequent monitoring alone was not a predictor of significant improvement in asthma control. However, for the group of education-adhering adolescents, frequent monitoring was a predictor of even further improved asthma control when compared to frequent monitoring in the nonadherent group. We did not observe important improvements in asthma-related quality of life in these groups. Differences in quality of life and asthma control were found between the subgroup that was nonadherent to both education and monitoring and the subgroup that was adherent to both education and monitoring. However, these subgroups were too small for establishing a solid conclusion. Our linear effects model showed the favorable effect that education and monitoring have on asthma control. No significant differences in asthma control or quality of life were observed between the small groups of normoperceivers and hypoperceivers, as determined by the Borg score (asthma control: *P*=.17; quality of life: *P*=.77) and by the constructed “real-life” symptom slope (asthma control: *P*=.99; quality of life: *P*=.86).

Although no causal relationship could be established due to the design of this study, the findings contribute to previous literature reporting that education and monitoring are generally associated with improved asthma control; however, results have been mixed for improvements in quality of life [22,23]. A recent study showed that thorough education, especially in peer groups, can have a sustainable beneficial effect [23]. Further, a large cohort study established that education should be an integral part of effective asthma treatment, as it can result in fewer asthma exacerbations [24]. Our study highlights both the importance and the challenge of adherence to asthma therapy in adolescents [25].

Several limitations need to be addressed. High dropout rates are a common challenge in studies with adolescent populations. Consequently, our small sample size could have contributed to a loss of statistical power and an increase in uncertainty for several outcomes. Nonetheless, several significant and clinically relevant predictors of improved asthma control were established in this study. Enrolling a higher percentage of the eligible population of 688 patients would have been desirable for increasing statistical power. We note that in the randomized controlled trial, monitoring was performed by using short text messages, and this was a more laborious process compared to other easy-to-use methods, such as using mobile phone apps, that can be implemented by using modern mobile communication technology. We believe that a simple web application and the absence of long questionnaires (eg, the questionnaires to which adolescents had to commit themselves in order to be enrolled in the trial) would help with increasing adolescent participation in self-management interventions in clinical practice.

With respect to possible selection bias, one could argue that the improvement in asthma control in patients who adhered to education and monitoring might not have been due to adherence to the intervention itself but, instead, might have been due to the selection of a cooperative and adherent patient population that can be expected to exhibit better health statuses. However, even within a potentially adherent patient group, we observed further improvements in asthma control among patients who attended education sessions.

Unfortunately, not all participants completed the methacholine inhalation challenge test. Therefore, we constructed a “real-life” measure for perceptions of symptom severity (ie, the symptom slope). Although we found good interobserver agreement for this novel measure, there were no important differences among comparison groups. Therefore, the absence of differences in symptom perceptions did not seem to depend on our chosen methodology or a lack of statistical power.

With regard to external validity, one could argue that only highly motivated adolescents participate in extensive studies such as ours. Therefore, our results might not apply to the entire population of adolescents with asthma. We however argue that the problems of adolescent chronic health care do not lend themselves well to a one-size-fits-all approach. Although we might not reach all adolescents, promoting health in motivated groups is desirable in itself, and effective self-management in motivated adolescents might increase motivation among youth. Therefore, we believe that our results provide useful insights for supporting self-management in adolescents with asthma.

Our results imply that following at least 1 educational group session results in a significant and clinically relevant improvement in asthma control when compared to following no education at all. This emphasizes and supports the importance of educating adolescents with asthma, which is in line with several other studies [22,26,27]. Our results show that adolescents who follow education and conduct frequent monitoring during a study exhibit significantly better and clinically relevant changes in asthma control after 12 months. The same trend was seen with regard to asthma-related quality of life, but this trend was not statistically significant (*P*=.15). Therefore, in adolescents with asthma who follow an IBSM program, both education and monitoring seem to be important factors in achieving better asthma control and asthma-related quality of life.

In our study, we could not find a significant difference in the results of adolescents who were normoperceivers and those who were hypoperceivers. It can be argued that the assessment of the perception of airway obstruction during a methacholine challenge does not reflect real-life symptom perception. However, this perception, which was assessed based on the relationship between symptoms and lung function, was not related to improvements in asthma control and quality of life. This suggests that the role of symptom perception in self-management is complex, and this illustrates that the concept of perception is difficult to capture with indices based on the relationship between symptom scores and lung function.

We conclude that the results of our study emphasize the importance of education adherence and frequent monitoring in improving asthma control among adolescents with partly controlled and uncontrolled asthma. No significant association between improvements in asthma control and perceptions of asthma control was found.

Conflicts of Interest

None declared.

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Abbreviations

ACQ: Asthma Control Questionnaire
FEV$_1$: forced expiratory volume in 1 second
IBSM: internet-based self-management
PAQLQ: Pediatric Asthma Quality of Life Questionnaire
SMASHING: Self-Management in Asthma Supported by Hospitals, Internet, Nurses and General Practitioners

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Original Paper

Videos With the Hashtag #vaping on TikTok and Implications for Informed Decision-making by Adolescents: Descriptive Study

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Abstract

Background: Despite the public health importance of vaping and the widespread use of TikTok by adolescents and young adults, research is lacking on the nature and scope of vaping content on this networking service.

Objective: The purpose of this study is to describe the content of TikTok videos related to vaping.

Methods: By searching the hashtag #vaping in the discover feature, ~478.4 million views were seen during the time of data collection. The first 100 relevant videos under that hashtag were used in this study. Relevance was determined by simply noting if the video was related in any way to vaping. Coding consisted of several categories directly related to vaping and additional categories, including the number of likes, comments, and views, and if the video involved music, humor, or dance.

Results: The 100 videos included in the sample garnered 156,331,347 views; 20,335,800 likes; and 296,460 comments. The majority of the videos (n=59) used music and over one-third (n=37) used humor. The only content category observed in the majority of the videos sampled was the promotion of vaping, which was included in 57 videos that garnered over 74 million views (47.5% of cumulative views). A total of 42% (n=42) of the 100 videos sampled featured someone vaping or in the presence of vape pens, and these videos garnered over 22% (>35 million) of the total views.

Conclusions: It is necessary for public health agencies to improve understanding of the nature and content of videos that attract viewers’ attention and harness the strength of this communication channel to promote informed decision-making about vaping.

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KEYWORDS

vaping; TikTok; social media; misinformation; decision-making; adolescents; young adults; e-cigarettes; public health; informed decision-making

Introduction

Use of e-cigarettes or “vaping” functions by producing an aerosol when liquid nicotine is heated [1]. Liquid nicotine contains chemicals (eg, heavy metals such as nickel, tin, and lead; volatile organic compounds like benzene; the carcinogens acetaldehyde and formaldehyde; cadmium, a toxic metal; and ultrafine particles that can be inhaled deeply) and flavorings (eg, diacetyl, a chemical linked to the condition bronchiolitis obliterans, and diketone, also known to cause lung damage), which are inhaled into the lungs [2]. “E-cigarettes are not safe for youth, young adults, pregnant adults, as well as adults who do not currently use tobacco products, according the United States Centers for Disease Control and Prevention (CDC)” [1]. Additionally, “while e-cigarettes may have the potential to benefit some people and harm others, scientists still have a lot to learn about whether e-cigarettes are effective in helping adults quit smoking” [1]. Evidence suggests that vaping has negative health effects [3]. Current (2020) estimates indicate that 19.6% of high school students and 4.7% of middle school students in the United States reported present use of e-cigarettes [4]. A survey of adolescents in the United States revealed a positive association between frequency of social media use and exposure to e-cigarette messages across four different social media platforms [5]. Further, in a recent study of adolescents aged 13-18 years, an association was found between increased daily social media use and intent to use e-cigarettes, and that those who used social media more daily had a more positive outlook about e-cigarettes and sensed that e-cigarettes were less dangerous [6]. There have been studies of vaping on several social media websites. Researchers on Instagram found that e-cigarettes were promoted among youth [7] and that provaping content is prevalent [8]. Similar sentiment was noted on YouTube [9,10], with researchers noting the presence of beneficial health claims [11] and minimal Food and Drug Administration warnings [12]. In concert, studies of vaping content on Twitter determined that there was a high level of endorsement of vaping [13], and these were dominant forces [14].

TikTok, a social media platform, has had an exponential increase in popularity, with roughly 100 million monthly users in the United States and 689 million monthly users worldwide [15]. This platform allows for the uploading of short video segments, which often tend to be entertainment based. In the United States, the age groups that most commonly use TikTok are those aged 10-19 years (32.5%), followed by those 20-29 years of age (29.5%) [16]. Despite the public health importance of vaping and the widespread use of TikTok by adolescents and young adults, at the time this study was conducted (March 2021), we did not identify any published studies on the nature or scope of vaping on TikTok, thus identifying a gap in the literature. The purpose of this study is, therefore, to describe the content of posts on TikTok related to vaping.

Methods

In March 2021, a cross-sectional, descriptive study was conducted. By searching the hashtag #vaping in the discover feature, ~478.4 million views were seen during the time of data collection. The first 100 relevant videos under that hashtag were used in this study. The coding sheet was based on a prior study of e-cigarettes conducted on a different social media platform [9], and the methods mirrored those of another TikTok study with a different focus [17]. Relevance was determined by simply noting if the video was related in any way to vaping. The coding categories included showing someone vaping or in the presence of vape pens, mentioned danger, mentioned/suggested long-term health effects, mentioned specific products, demonstrated how to make homemade vaping products, showed vape stores and/or purchasing vape products, showed vaping tricks (blowing smoke rings), contained information from medical professionals, mentioned safety, and contained misinformation. Additional categories included if the video involved music, humor, or dance. In addition to the number of videos associated with each category, the number of likes and comments were also documented. One individual (author AP) coded all videos, while a second individual (author CHB) coded a 10% random sample. Out of 380 total data points, the two reviewers differed in only 3, demonstrating high interrater reliability (κ=0.98). Descriptive statistics were calculated using Excel (Microsoft Corporation). Human participants were not included in this research, which was not reviewed by the Institutional Review Board (IRB) at William Paterson University; the study was deemed exempt by the IRB at Teachers College, Columbia University.

Results

The 100 videos included in the sample garnered 156,331,347 views; 20,335,800 likes; and 296,460 comments (Table 1). The majority of the videos (n=59) used music and over one-third (n=37) used humor. The only content categories observed in the majority of the sample was “promoted vaping,” which was included in 57 videos that garnered over 74 million views (47.5% of cumulative views). Independent 1-tailed *t* tests (=.05) confirmed that using music or promoting vaping alone did not have a statistically significant association with whether a video was viewed, liked, or commented on. Even though the videos covering “mentioned danger” and “mentioned long-term health effects” were only covered in 38 and 30 videos, respectively, videos covering each of these categories garnered ~54% of the cumulative views (over 84 million). Although 42 of the videos featured someone vaping or in the presence of vape pens, these videos only garnered 22.67% (n=35,447,500) of the total views.

The following remaining characteristics were present in fewer than half but still over one-quarter (>25%) of the videos sampled: showing someone vaping or vape pens (n=42), mentioned dangers (n=38), used humor (n=37), and mentioned long-term effects (n=30). In these cases, too, independent 1-tailed *t* tests (α=.05) were performed to determine if the presence of this content was statistically associated with views, likes, or comments received. Only one test returned significant results (P<.05). Showing someone vaping or vape pens returned a statistically significant result (P=.02) with respect to video views.

Table 1. Observed content, views, likes, and comments of 100 TikTok videos related to vaping.

	Videos (N=100), n	Views (N=156,331,347), n (%)	Likes (N=20,335,800), n (%)	Comments (N=296,460), n (%)
Used music	59	69,398,247 (44.39)	7,450,600 (36.64)	72,004 (24.29)
Used humor	37	75,969,247 (48.60)	12,129,900 (59.65)	195,854 (66.06)
Used dance	2	3,700,000 (2.37)	601,800 (2.96)	8663 (2.92)
Provaping content				
Promoted vaping	57	74,256,900 (47.50)	7,410,900 (36.44)	75,397 (25.43)
Showed someone vaping or in the presence of vape pens	42	35,447,500 (22.67)	4,182,600 (20.57)	39,682 (13.39)
Mentioned specific products	18	27,208,600 (17.40)	2,313,900 (11.38)	13,399 (4.52)
Demonstrated how to make home-made vaping products	15	25,059,200 (16.03)	1,327,700 (6.53)	3983 (1.34)
Contained misinformation	6	17,984,900 (11.50)	1,621,300 (7.97)	32,753 (11.05)
Antivaping content				
Mentioned dangers	38	84,911,247 (54.31)	12,684,700 (62.38)	228,753 (77.16)
Mentioned long-term health effects	30	84,316,147 (53.93)	12,208,700 (60.04)	219,399 (74.01)
Contained information from medical professionals	11	48,035,700 (30.73)	9,147,500 (44.98)	166,336 (56.11)
Mentioned safety	9	15,903,800 (10.17)	1,963,000 (9.65)	14,669 (4.95)

Discussion

This study demonstrates that the portrayal of vaping content is prevalent on TikTok. This is exemplified by the fact that 42 of the 100 videos in our sample showed someone vaping or in the presence of vape pens, and these videos garnered over 35 million views. Additionally troubling was the fact that more than half of the videos in the sample, which garnered over 74 million views, "promoted vaping." On a positive note, 38 of the 100 videos mentioned the dangers of vaping, and 30 of the videos mentioned long-term health consequences; videos covering these topics attracted over 84 million views, the highest proportion of cumulative views of any coding category. Although there were 6 videos containing misinformation, there were 11 containing information from medical professionals.

Although the conclusions that can be drawn from this study are limited by the cross-sectional design, small and selective sample, and limited scope of information coded, the data show that a variety of information about vaping is being communicated and widely viewed on TikTok. This is particularly important since the majority of TikTok users are within an age range that makes them susceptible to both the influence of social media and experimentation with vaping. It is important to note that user agreements prohibit content that depicts use of alcohol, tobacco, or drugs by a minor [18]. However, the age of the person featured in each video was not estimated to avoid introducing the potential for error. This study fills a research gap by investigating a public health issue on an emerging video-sharing networking service. The necessity to learn more about coverage of vaping content on this platform is confirmed by the age of users and the popularity of the site. Public health agencies not only should be aware of and address provaping communications on TikTok and other social media but also should find ways to communicate effectively and help adolescents and young adults make informed decisions about vaping based on accurate and up-to-date scientific understanding. The widespread reach of videos addressing the dangers and long-term health effects of vaping suggests that TikTok users are interested in this content.

Social media may be viewed as a source of entertainment for users, and this is clearly one of its benefits. At the same time, TikTok and other social media have become a dominant communication channel through which people learn about health, form health-related beliefs, and connect with others who may reinforce health-compromising behaviors. It is, therefore, necessary for public health agencies to improve understanding of the nature and content of videos that attract viewers' attention and to harness the strength of the platform to promote informed decision-making about vaping.

Authors' Contributions

CHB and CEB conceptualized the study. AP collected the data, and JF conducted the data analysis. All authors contributed to the manuscript production.

Conflicts of Interest

None declared.

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Abbreviations

IRB: Institutional Review Board

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Original Paper

Gender-Based Differences and Associated Factors Surrounding Excessive Smartphone Use Among Adolescents: Cross-sectional Study

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Abstract

Background: Excessive smartphone use is a new and debated phenomenon frequently mentioned in the context of behavioral addiction, showing both shared and distinct traits when compared to pathological gaming and gambling.

Objective: The aim of this study is to describe excessive smartphone use and associated factors among adolescents, focusing on comparisons between boys and girls.

Methods: This study was based on data collected through a large-scale public health survey distributed in 2016 to pupils in the 9th grade of primary school and those in the 2nd grade of secondary school. Bayesian binomial regression models, with weakly informative priors, were used to examine whether the frequency of associated factors differed between those who reported excessive smartphone use and those who did not.

Results: The overall response rate was 77% (9143/11,868) among 9th grade pupils and 73.4% (7949/10,832) among 2nd grade pupils, resulting in a total of 17,092 responses. Based on the estimated median absolute percentage differences, along with associated odds ratios, we found that excessive smartphone use was associated with the use of cigarettes, alcohol, and other substances. The reporting of anxiety and worry along with feeling low more than once a week consistently increased the odds of excessive smartphone use among girls, whereas anxiety and worry elevated the odds of excessive smartphone use among boys. The reporting of less than 7 hours of sleep per night was associated with excessive smartphone use in all 4 study groups.

Conclusions: The results varied across gender and grade in terms of robustness and the size of estimated difference. However, excessive smartphone use was associated with a higher frequency of multiple suspected associated factors, including ever having tried smoking, alcohol, or other substances; poor sleep; and often feeling low and feeling anxious. This study sheds light on some features and distinctions of a potentially problematic behavior among adolescents.

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KEYWORDS

smartphone; cell phone; adolescent; sleep; anxiety; substance use; nicotine; alcohol drinking; smartphone use; addiction; behavioral addiction; worry; pathology; internet

Introduction

Smartphones are the preferred tools for web-based activity, and regardless of age, almost every person possesses a smartphone [1,2]. Adolescence is a very sensitive period, wherein many physiological, psychological, and social changes occur, making this age group vulnerable to potential adverse effects of cellphone use, including depressive symptoms, anxiety, and low self-esteem [1,2]. Smartphone use is a new and debated phenomenon frequently mentioned in the context of behavioral addiction, demonstrating both common and distinct traits when compared to pathological gaming and gambling among adolescents [3-5].

Research on problematic or addictive smartphone use has expanded during the last decade, as the proportion of smartphone users has steadily increased [6-9]. Excessive smartphone use is characterized by maladaptive smartphone use with functional impairment. Excessive smartphone use may lead to symptoms commonly observed in substance use disorders, such as tolerance, withdrawal after periods of nonuse, continued use despite adverse effects, and difficulty controlling use [10,11]. Moreover, overuse of smartphones has been associated with increased anxiety, depression, poor sleep quality, low self-esteem, and higher perceived stress, as well as other addictions such as addiction to alcohol tobacco and illicit drugs [12-14].

Unlike both gaming and gambling, excessive use of smartphones appear to be more common among girls, and the motives for smartphone use seemingly show gender-based differences [15,16]. Boys are more likely to use their phones for gaming, media sharing, and internet searches, whereas girls are more likely to use their phones for social reasons—social media or texting [15,16]. Researchers have suggested different problems correlating to different motives for smartphone use [17].

Given the increasing interest of behavioral addictions and alarming reports on the consequences of screen time and adolescents increasing psychological complaints [3,5,6], this study aims to address knowledge gaps concerning the frequency of excessive smartphone use among Swedish adolescents, and whether the prevalence of suspected associated factors differed between those who reported excessive smartphone use and those who did not. Specifically, we used a large sample of Swedish pupils from primary and secondary schools to investigate whether differences existed between the two groups in terms of the following outcomes: (1) often feeling low; (2) often feeling anxious; (3) self-reported attention deficit hyperactive disorder (ADHD); (4) self-reported autism spectrum disorder (ASD); (5) being satisfied with one’s own general health; (6) poor sleep; (7) loneliness; and having tried (8) smoking, (9) alcohol, and (10) other substances.

Methods

Participants and Procedures

Data were collected from a public health survey distributed in 2016 to pupils in the 9th grade of primary school and 2nd grade of secondary school. The survey distribution covered all 33 municipalities in Skåne, a region in southern Sweden. The overall response rate was 77% (9143/11,868) among 9th grade pupils and 73.4% (7949/10,832) among 2nd grade pupils, resulting in a total of 17,092 responses. The main purpose of the survey was to investigate health and various social factors among Swedish adolescents. Previous school surveys in Skåne were primarily focused on alcohol, drug, and tobacco use. In contrast, the public health school survey of 2016 included a broad spectrum of public health questions regarding demographics and family characteristics (section A); general self-perceived health (section B); accidents and injuries (section C); leisure-time activities and habits (section D); dietary habits (section E); alcohol (section F); tobacco smoking and snuff use (section G); narcotic drugs (section H); sex and life together (section I); school context (section J); security and exposure (section K); gambling (section L); and general health, life satisfaction, and beliefs concerning the future (section M).

The survey was provided by the regional council of Scania County (Region Skåne) in cooperation with the municipal association of Skåne, and it was answered anonymously in classroom settings. Participation was voluntary; all questions were described as optional, and all measures were based on self-reports (see Multimedia Appendix 1).

Measures

Excessive Smartphone Use

The survey contained a 6-item questionnaire about mobile phone habits that has been previously used in a large-scale European study called “Net Children Go Mobile” [18]. The questionnaire begins with asking the respondents “in the past 12 months, how often have these things happened to you?” and then proceeds to list the following 6 statements: (1) “I have felt bothered when I could not check my mobile phone”; (2) “I have caught myself doing things on my mobile phone that I was not really interested in”; (3) “I have felt a strong need to check my mobile phone to see if anything new has happened”; (4) “I have spent less time than I should with either family, friends or doing schoolwork”; (5) “I find myself using my mobile phone even in places/situations where it is not appropriate”; and (6) “I have tried unsuccessfully to spend less time using my mobile phone.” Respondents were asked to state the degree to which they agreed with each statement using a 5-point scale (“very often,” “fairly often,” “not very often,” “almost never,” or “never”). We created a new binary variable labeled “Excessive smartphone use.” Respondents who answered “often” or “very often” to 2 or more of the 6 statements were categorized as “yes,” and all others were categorized as “no” [18].

Associated Factors

Based on previous research outlined in the Introduction, combined with clinical experience, we chose to investigate a broad range of suspected associated factors. These factors were related to overall well-being, mental health, and various risk-taking or adverse behaviors. Using the available survey data, we created 9 new, binary variables in order to examine the frequency of each factor: (1) often feeling low, (2) often feeling anxious, (3) ADHD, (4) ASD, (5) loneliness, (6) poor sleep, (7) tried smoking, (8) tried alcohol, and (9) tried other substances.

Respondents' psychological health was assessed using 2 questions from the Health Behaviour in School-Aged Children Symptom Checklist, both with separately verified and satisfactory test-retest reliability [19]. Specifically, respondents rated, on a 5-point scale ("about every day," "more than once a week," "about every week," "about every month," or "rarely or never"), how often they had felt low and felt anxious or worried during the past 6 months. We created 2 new binary variables, labeled "often feeling low" and "often feeling anxious," where those who answered "about every day" or "more than once a week" were categorized as "yes," and all others were categorized as "no."

Questions about long-term somatic or psychiatric disorders were also included in the survey. Respondents were asked whether they had ADHD or attention deficit disorder (ADD) and autism or Asperger syndrome, and based on their answers (ie, "yes" or "no"), 2 new binary variables—labeled "ADHD" and "ASD"—were created. Respondents who affirmed ADHD/ADD or ASD were categorized as "yes," and all others were categorized as "no."

Further, respondents rated, on a 4-point scale ("have no close friend," "have one close friend," "have two close friends," or "have several close friends"), whether they presently have a close friend with whom they could talk in confidence about almost any personal matter. We created a new binary variable, labeled "loneliness," with those answering "have no close friend" classified as "yes," and all others classified as "no."

Next, respondents were asked, "How would you describe your health in general?" with 5 possible response options ("very good," "good," "fairly good," "bad," or "very bad"). A new binary variable, labeled "satisfied with your own geneal health," was created, with the answers "very good" and "good" categorized as "yes," and all other answers categorized as "no."

Thereafter, respondents rated, on a 3-point scale, how many hours a night they usually sleep on weekdays ("less than 7 hours," "7-9 hours," or "more than 9 hours"). Based on their responses, we created a new binary variable, labeled "poor sleep," with those answering "less than 7 hours" classified as "yes," and all others classified as "no".

The survey also included questions about smoking, alcohol consumption, and other substance use. For smoking, respondents were asked whether they smoke cigarettes, and their answers were recorded on a 7-point scale ("no, I have never smoked"; "no, but I have tried"; "no, I have smoked but have since quit"; "yes, when I'm on a party"; "yes, sometimes"; "yes, almost every day"; or "yes, every day"). A new binary variable labeled "tried smoking" was created, with those answering "no, I have never smoked" classified as "no," and all other responses classified as "yes."

For alcohol habits, respondents were asked whether they had ever drunk alcohol, with possible answers being "yes" or "no." A new binary variable labeled "tried alcohol" was created, with those answering "yes" classified as "yes," and those answering "no" classified as "no."

Finally, for other substance use, respondents were asked to rate, on a 4-point scale ("no"; "yes, more than 12 months ago"; "yes, during the last 12 months"; or "yes, during the last 30 days"), whether they ever had used other substances (eg, narcotics). A new binary variable labeled "tried other substances" was created, with those answering "no" classified as "no," and all other responses classified as "yes."

Statistical Analysis

The R statistical programming language (version 4.0.4) [20], along with several functions from the tidyverse package [21], was used for intermediate data processing and statistical analysis. We opted for a fully Bayesian approach, and all Bayesian models were specified using the R package brms [22]. The brms package interfaces R with the Stan probabilistic programming language [23], which is a state-of-the-art language for specifying and estimating Bayesian models. Bayesian binomial regression models were used to examine whether the frequency of the associated factors outlined above differed between adolescents reporting excessive smartphone use and those who did not. All models used weakly informative priors centered around zero, which should provide moderate regularization while still having minimal impact on obtained estimates [24]. Finally, the R package emmeans [25] was used for postprocessing results.

We present group differences as estimated median absolute percentage differences along with the associated odds ratio (OR), reported with 95% highest density intervals (HDIs). In contrast to a frequentist CI, the 95% HDI may be interpreted such that it has a 95% probability of actually containing the values inside it [26]. Furthermore, the region of practical equivalence (ROPE) approach was used to determine whether an estimated difference was of practical and/or clinical importance [26]. Specifically, we considered an estimated difference of at least 5% (in either direction) as the minimal difference for "practical equivalence." If the 95% HDI was not beyond this cutoff value, we deemed the results as *uncertain* in terms of practical and clinical importance.

Results

Prevalence of Excessive Smartphone Use

Information about gender was missing for 86 respondents, bringing the total sample size available for group-based analysis to 17,006. Furthermore, there were varying levels of missing data for smartphone use as well as for the associated factors, as indicated in the tables below. Excessive smartphone use was more prevalent among girls (approximately 60%) than among boys (approximately 35%) in both grades (see Table 1 for details). Although results varied across gender and grade in terms of robustness and size of the estimated differences, overall, we found that excessive smartphone use was associated with a higher frequency of multiple suspected associated factors such as ever having tried smoking, alcohol, and other substances; poor sleep; and often feeling low and often feeling anxious. Several of these findings were both robust, with differences exceeding the ROPE with 95% probability by a large margin, and substantial, with some estimated differences reaching as high as 15%. In addition, for several other variables where the differences, with 95% probability, did not exceed the ROPE, the differences nonetheless robustly exceeded zero.

Table 1. Frequency of excessive smartphone use among school pupils in southern Sweden, based on data collected in 2016.

Study group	Total respondents, n	Valid responses, n (%)	Excessive smartphone use, n (%)	Non-excessive smartphone use, n (%)
Boys in 9th grade of primary school	4609	4187 (90.8)	1492 (35.6)	2695 (64.4)
Girls in 9th grade of primary school	4497	4232 (94.1)	2515 (59.4)	1717 (40.6)
Boys in 2nd grade of secondary school	3945	3605 (91.4)	1342 (37.2)	2263 (62.8)
Girls in 2nd grade of secondary school	3955	3749 (94.8)	2233 (59.6)	1516 (40.4)

Boys in the 9th Grade of Primary School

A total of 33.6% (499/1484) of the boys in the 9th grade of primary school who reported excessive smartphone use were categorized as self-reporting poor sleep compared to 25.1% (674/2682) of those who did not report excessive smartphone use, with an estimated difference of 8.5% (95% HDI 6.1%, 10.9%) and an associated OR of 1.51 (95% HDI 1.33, 1.68). Furthermore, participants who reported excessive smartphone use had a higher frequency of having tried smoking (575/1435, 40.1%) and alcohol (939/1453, 64.6%) than those who did not report excessive smartphone use (smoking: 685/2609, 26.3%; alcohol: 1378/2646, 52.1%), with an estimated difference of 13.8% (95% HDI 11.3%, 16.5%) and OR of 1.88 (95% HDI 1.66, 2.1) for smoking and an estimated difference of 12.5% (95% HDI 9.9%, 15.1%) and OR of 1.68 (95% HDI 1.5, 1.87) for alcohol use. Furthermore, boys who reported excessive smartphone use had higher frequencies of often feeling low, often feeling anxious, ASD, and having tried other substances, as well as a lower frequency of being satisfied with their own health, although these differences did not reliably exceed the ROPE.

In summary, excessive smartphone use among boys in the 9th grade of primary school was robustly associated with a higher frequency of poor sleep and having tried smoking and alcohol. Details are presented in Table 2 and Figure 1.

Table 2. Excessive smartphone use and associated factors among boys in the 9th grade of primary school, based on data collected in southern Sweden in 2016.

Factor[a]	Excessive smartphone use		Non-excessive smartphone use		Estimated difference (%) (95% HDI[b])	OR[c] (95% HDI)
	Total respondents, n	Value, n (%)	Total respondents, n	Value, n (%)		
Often feeling low (n=4053)	1442	162 (11.2)	2611	184 (7)	4.2 (2.6, 5.8)	1.67 (1.37, 1.99)
Often feeling anxious (n=4039)	1438	143 (9.9)	2601	150 (5.8)	4.2 (2.7, 5.7)	1.8 (1.45, 2.18)
Satisfied with health (n=3799)	1328	1228 (92.5)	2471	2326 (94.1)	–1.7 (–3.1, –0.2)	0.77 (0.6, 0.94)
ADHD[d] (n=4056)	1436	43 (3)	2620	68 (2.6)	0.4 (–0.5, 1.3)	1.15 (0.8, 1.55)
ASD[e] (n=4053)	1437	43 (3)	2616	43 (1.6)	1.3 (0.5, 2.2)	1.85 (1.21, 2.54)
Poor sleep (n=4166)	1484	499 (33.6)	2682	674 (25.1)	*8.5 (6.1, 10.9)*[f]	1.51 (1.33, 1.68)
Loneliness (n=4154)	1486	126 (8.5)	2668	233 (8.7)	–0.3 (–1.8, 1.2)	0.97 (0.79, 1.16)
Tried smoking (n=4044)	1435	575 (40.1)	2609	685 (26.3)	*13.8 (11.3, 16.5)*[f]	1.88 (1.66, 2.1)
Tried alcohol (n=4099)	1453	939 (64.6)	2646	1378 (52.1)	*12.5 (9.9, 15.1)*[f]	1.68 (1.5, 1.87)
Tried other substances (n=4004)	1408	124 (8.8)	2596	130 (5)	3.8 (2.4, 5.3)	1.83 (1.45, 2.24)

[a] Note that the total number of respondents for each factor differs due to missing data.

[b] HDI: highest density interval.

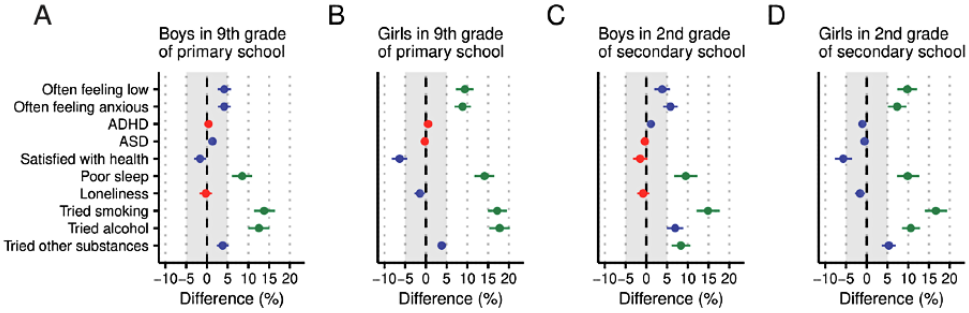
[c] OR: odds ratio.

[d] ADHD: attention deficit hyperactivity disorder.

[e] ASD: autism spectrum disorder.

[f] Estimated differences that, with 95% probability, are above the prespecified cutoff for practical equivalence are italicized.

Figure 1. . Estimated differences in the frequency of associated factors between respondents who reported excessive smartphone use and those who did not. Dots represent posterior medians, and lines represent 95% highest density intervals. The shaded area shows the region of practical equivalence (ROPE) of ±5%. Estimated differences that, with 95% probability, are larger than the ROPE are represented in green, whereas estimated differences that, with 95% probability, are larger than zero but smaller than the ROPE are represented in blue. Differences, with 95% probability, not larger than zero are represented in red. Estimates are based on data collected among school pupils in southern Sweden in 2016.



Girls in the 9th Grade of Primary School

Of the girls who reported excessive smartphone use, 27.4% (678/2475) reported often feeling low and 22.9% (565/2469) reported often feeling anxious, as compared to 18% (303/1684) and 14% (236/1682), respectively, of the girls who did not report excessive smartphone use. The estimated difference and OR for often feeling low were 9.4% (95% HDI 7.2%, 11.5%) and 1.72 (95% HDI 1.5, 1.94), respectively, and the corresponding values for often feeling anxious were 8.9% (95% HDI 6.9%, 10.9%) and 1.82 (95% HDI 1.57, 2.08), respectively. In addition, 41.9% (1052/2509) of those reporting excessive smartphone use were classified as having poor sleep, compared to 27.8% (473/1702) of those not who did not report excessive smartphone use, with an estimated difference of 14.1% (95% HDI 11.7%, 16.5%) and an associated OR of 1.88 (95% HDI 1.67, 2.08).

Girls who reported excessive smartphone use also reported higher frequencies of having tried smoking (985/2478, 39.7%) and alcohol (1568/2494, 62.9%) compared to those not who did not (381/1689, 22.6% for smoking and 768/1703, 45.1%, for alcohol use), with an estimated difference of 17.2% (95% HDI 14.9%, 19.6%) and OR of 2.27 (95% HDI 2, 2.53) for smoking, and an estimated difference of 17.8% (95% HDI 15.2%, 20.3%) and OR of 2.06 (95% HDI 1.85, 2.29) for alcohol use. Moreover, girls with excessive smartphone use had lower frequencies of being satisfied with their own health as well as loneliness, and a higher frequency of having tried other substances, but these differences did not reliably exceed the ROPE.

In summary, excessive smartphone use among girls in the 9th grade of primary school was robustly associated with a higher frequency of often feeling low, often feeling anxious, poor sleep, and having tried smoking and alcohol. Details are presented in Table 3 and Figure 1.

Table 3. Excessive smartphone use and associated factors among girls in the 9th grade of primary school, based on data collected in southern Sweden in 2016.

Factor[a]	Excessive smartphone use		Non excessive smartphone use		Estimated difference (%) (95% HDI[b])	OR[c] (95% HDI)
	Total respondents, n	Value, n (%)	Total respondents, n	Value, n (%)		
Often feeling low (n=4159)	2475	678 (27.4)	1684	303 (18)	*9.4 (7.2, 11.5)* [d]	1.72 (1.5, 1.94)
Often feeling anxious (n=4151)	2469	565 (22.9)	1682	236 (14)	*8.9 (6.9, 10.9)* [d]	1.82 (1.57, 2.08)
Satisfied with health (n=3998)	2363	1940 (82.1)	1635	1446 (88.4)	–6.3 (–8.2, –4.5)	0.6 (0.5, 0.69)
ADHD[e] (n=4121)	2444	80 (3.3)	1677	46 (2.7)	0.5 (–0.4, 1.4)	1.2 (0.85, 1.6)
ASD[f] (n=4108)	2436	24 (1)	1672	21 (1.3)	–0.3 (–0.8, 0.3)	0.78 (0.43, 1.21)
Poor sleep (n=4211)	2509	1052 (41.9)	1702	473 (27.8)	*14.1 (11.7, 16.5)* [d]	1.88 (1.67, 2.08)
Loneliness (n=4210)	2507	139 (5.5)	1703	119 (7)	–1.4 (–2.7, –0.2)	0.78 (0.62, 0.95)
Tried smoking (n=4167)	2478	985 (39.7)	1689	381 (22.6)	*17.2 (14.9, 19.6)* [d]	2.27 (2, 2.53)
Tried alcohol (n=4197)	2494	1568 (62.9)	1703	768 (45.1)	*17.8 (15.2, 20.3)* [d]	2.06 (1.85, 2.29)
Tried other substances (n=4146)	2454	150 (6.1)	1692	39 (2.3)	3.8 (2.8, 4.8)	2.78 (1.99, 3.65)

[a] Note that the total number of respondents for each factor differs due to missing data.

[b] HDI: highest density interval.

[c] OR: odds ratio.

[d] Estimated differences that, with 95% probability, are above the prespecified cutoff for practical equivalence are italicized.

[e] ADHD: attention deficit hyperactivity disorder.

[f] ASD: autism spectrum disorder.

Boys in the 2nd Grade of Secondary School

Boys who reported excessive smartphone use had higher frequencies of poor sleep (636/1336, 47.6% vs 858/2253, 38.1%), having tried smoking (851/1292, 65.9% vs 1120/2195, 51%), and having tried other substances (280/1267, 22.1% vs 300/2181, 13.8%) compared to those who did not report excessive smartphone use, with estimated differences of 9.5% (95% HDI 6.7%, 12.4%) and OR 1.48 (95% HDI 1.31, 1.65) for poor sleep, 14.9% (95% HDI 12.1%, 17.7%) and OR 1.85 (95% HDI 1.64, 2.08) for having tried smoking, and 8.3% (95% HDI 6.1%, 10.6%) and OR 1.78 (95% HDI 1.52, 2.06) for having tried other substances. Boys who reported excessive smartphone use also had higher frequencies of often feeling low, often feeling anxious, ASD, and having tried alcohol, although these differences did not reliably exceed the ROPE.

In summary, excessive smartphone use among boys in the 2nd grade of secondary school was robustly associated with a higher frequency of poor sleep and having tried smoking and other substances. Details are presented in Table 4 and Figure 1.

Table 4. Excessive smartphone use and associated factors among boys in the 2nd grade of secondary school, based on data collected in southern Sweden in 2016.

Factor[a]	Excessive smartphone use		Non excessive smartphone use		Estimated difference (95% HDI[b])	OR[c] (95% HDI)
	Total respondents, n	Value, n (%)	Total respondents, n	Value, n (%)		
Often feeling low (n=3519)	1312	183 (13.9)	2207	223 (10.1)	3.8 (2, 5.7)	1.44 (1.2, 1.7)
Often feeling anxious (n=3521)	1312	172 (13.1)	2209	161 (7.3)	5.8 (4.1, 7.6)	1.92 (1.56, 2.29)
Satisfied with health (n=3278)	1190	1069 (89.8)	2088	1907 (91.3)	–1.5 (–3.2, 0.3)	0.84 (0.68, 1.01)
ADHD[d] (n=3519)	1305	44 (3.4)	2214	50 (2.3)	1.1 (0.2, 2.1)	1.51 (1.01, 2.06)
ASD[e] (n=3516)	1308	28 (2.1)	2208	55 (2.5)	–0.4 (–1.2, 0.5)	0.85 (0.54, 1.2)
Poor sleep (n=3589)	1336	636 (47.6)	2253	858 (38.1)	*9.5 (6.7, 12.4)* [f]	1.48 (1.31, 1.65)
Loneliness (n=3582)	1334	95 (7.1)	2248	177 (7.9)	–0.8 (–2.2, 0.8)	0.9 (0.71, 1.1)
Tried smoking (n=3487)	1292	851 (65.9)	2195	1120 (51)	*14.9 (12.1, 17.7)* [f]	1.85 (1.64, 2.08)
Tried alcohol (n=3535)	1312	1149 (87.6)	2223	1792 (80.6)	7 (4.9, 9)	1.7 (1.43, 1.99)
Tried other substances (n=3448)	1267	280 (22.1)	2181	300 (13.8)	*8.3 (6.1, 10.6)* [f]	1.78 (1.52, 2.06)

[a] Note that the total number of respondents for each factor differs due to missing data.

[b] HDI: highest density interval.

[c] OR: odds ratio.

[d] ADHD: attention deficit hyperactivity disorder.

[e] ASD: autism spectrum disorder.

[f] Estimated differences that, with 95% probability, are above the prespecified cutoff for practical equivalence are italicized.

Girls in the 2nd Grade of Secondary School

Girls who reported excessive smartphone use had had higher frequencies of often feeling low (702/2198, 31.9% vs 332/1499, 22.1%) and often feeling anxious (560/2211, 25.3% vs 269/1493, 18%), with an estimated difference of 9.8% (95% HDI 7.3%, 12.1%) and OR of 1.65 (95% HDI 1.44, 1.86) for often feeling low and an estimated difference of 7.3% (95% HDI 5.1%, 9.5%) and OR of 1.55 (95% HDI 1.34, 1.76) often feeling anxious. In addition, 48.6% (1081/2224) of girls who reported excessive smartphone use were classified as having poor sleep, compared to 38.7% (584/1508) of those who did not report, with an estimated difference of 9.9% (95% HDI 7.3%, 12.7%) and an associated OR of 1.5 (95% HDI 1.33, 1.67).

Furthermore, girls who reported excessive smartphone use had higher frequencies of having tried smoking (1299/2181, 59.6% vs 640/1492, 42.9%) and alcohol (1903/2201, 86.5% vs 1136/1498, 75.8%), with an estimated difference of 16.7% (95% HDI 14%, 19.4%) and OR of 1.96 (95% HDI 1.74, 2.18) for smoking and an estimated difference of 10.6% (95% HDI 8.5%, 12.8%) and OR of 2.04 (95% HDI 1.75, 2.33) for alcohol. Finally, although the differences did not reliably exceed the ROPE, girls who reported excessive smartphone use had a relatively higher frequency of having tried other substances, as well as lower frequencies of ADHD, ASD, being satisfied with one's own health, and loneliness.

In summary, excessive smartphone use among girls in the 2nd grade of secondary school was robustly associated with a higher frequency of often feeling low, often feeling anxious, poor sleep, and having tried smoking and alcohol. Details are presented in Table 5 and Figure 1.

Table 5. Excessive smartphone use and associated factors among girls in the 2nd grade of secondary school, based on data collected in southern Sweden in 2016.

Factor[a]	Excessive smartphone use		Non-excessive smartphone use		Estimated difference (%) (95% HDI[b])	OR[c] (95% HDI)
	Total respondents, n	Value, n (%)	Total respondents, n	Value, n (%)		
Often feeling low (n=3697)	2198	702 (31.9)	1499	332 (22.1)	*9.8 (7.3, 12.1)* [d]	1.65 (1.44, 1.86)
Often feeling anxious (n=3704)	2211	560 (25.3)	1493	269 (18)	*7.3 (5.1, 9.5)* [d]	1.55 (1.34, 1.76)
Satisfied with health (n=3488)	2064	1650 (79.9)	1424	1219 (85.6)	–5.7 (–7.7, –3.5)	0.67 (0.57, 0.78)
ADHD[e] (n=3682)	2185	61 (2.8)	1497	58 (3.9)	–1.1 (–2.1, –0.1)	0.71 (0.5, 0.94)
ASD[f] (n=3679)	2184	13 (0.6)	1495	17 (1.1)	–0.5 (–1.1, 0)	0.52 (0.24, 0.88)
Poor sleep (n=3732)	2224	1081 (48.6)	1508	584 (38.7)	*9.9 (7.3, 12.7)* [d]	1.5 (1.33, 1.67)
Loneliness (n=3741)	2227	98 (4.4)	1514	91 (6)	–1.6 (–2.8, –0.4)	0.72 (0.55, 0.9)
Tried smoking (n=3673)	2181	1299 (59.6)	1492	640 (42.9)	*16.7 (14, 19.4)* [d]	1.96 (1.74, 2.18)
Tried alcohol (n=3699)	2201	1903 (86.5)	1498	1136 (75.8)	*10.6 (8.5, 12.8)* [d]	2.04 (1.75, 2.33)
Tried other substances (n=3633)	2161	294 (13.6)	1472	122 (8.3)	5.3 (3.6, 7)	1.75 (1.44, 2.09)

[a] Note that the total number of respondents for each factor differs due to missing data.

[b] HDI: highest density interval.

[c] OR: odds ratio.

[d] Estimated differences that, with 95% probability, are above the prespecified cutoff for practical equivalence are italicized.

[e] ADHD: attention deficit hyperactivity disorder.

[f] ASD: autism spectrum disorder.

Discussion

Principal Findings

Using a large and representative sample of Swedish adolescent pupils, we found that excessive smartphone use was more prevalent among girls (approximately 60% of all respondents) than among boys (approximately 35% of all respondents). Furthermore, excessive smartphone use was robustly associated with a substantially higher prevalence of poor sleep and, with slight differences between grades and gender, with higher frequencies of having tried smoking, alcohol, and other substances. Among girls, both in the 9th grade of primary school and 2nd grade of secondary school, we found that excessive smartphone use was robustly associated with a higher frequency of often feeling low and feeling anxious. Several other factors differed reliably from zero between the groups, although these differences did not, with 95% probability, exceed the ROPE. Our study adds to the knowledge of excessive smartphone use by investigating the corresponding male and female characteristics and possible associated factors among adolescents in an ordinary Swedish school setting.

Excessive smartphone users of both male and female genders in the 9th grade showed a disproportionate high prevalence of having used cigarettes and alcohol. A similar observation was made for smartphone users of the 2nd grade of secondary school, but in this grade, boys also had a higher probability of experience with illicit drugs. Similar results can be found in the literature; for example, Marmet et al [12] investigated the coexistence of behavioral and substance addiction among adult men and found that individuals with smartphone addiction were more likely to also be addicted to alcohol, tobacco, and illicit drugs. Behavioral and substance addiction have previously been reported as heavily related, and a sharing of a common personality trait has been hypothesized. Our findings warrant for additional research on excessive smartphone use in adolescents in order to implement prevention plans to hinder the development of other forms of addiction [3,27].

The relationship between ADHD and excessive smartphone use has been previously established [1,2,28,29]. The mechanism is thought to act through the lack of social interactions with others, a key characteristic in patients with ADHD, who concordantly feel a stronger need to be assured by and connected to others. Another suggested mechanism is the tendency to be easily bored typically exhibited by individuals with ADHD, resulting in a search for constant stimulation [30-32]. Children with ASD spend significantly more time using screen-based media than any leisure activity, and the correlation between internet addiction and ASD has already been established [15,16,33-37]. In ASD, the mechanism of internet overuse is considered to be due to their autistic traits: restricted, repetitive patterns of behavior, interests, or activities [38]. Some studies prove that children with ASD can learn via smartphone use, especially when the content is responsive to their interests, which makes smartphone use a valuable experience.

In this study, we found a relationship between ADHD and excessive use of smartphone with the strongest probability among boys in the 2nd grade of high school, but it did not exceed the ROPE in any of the groups. We also found increased probability of excessive smartphone use in individuals with ASD, which was the strongest among boys in the 9th grade of primary school but the probability did not exceed the ROPE in any of the groups. One possible explanation is that ADHD and ASD were self-reported; even though the questionnaire was filled in anonymously, one still cannot rule out the tendency to underreport stigmatizing diagnoses as ADHD and ASD.

In none of the groups, loneliness was associated with excessive smartphone use. Previous research suggests a reversed relationship in which close relationships serve as a protective factor against smartphone addiction, when investigating a population comprising both boys and girls [39]. Perhaps our finding could be considered in correspondence with findings that girls, unlike boys, usually use their phones for social reasons such as social media or texting; hence, they may not express a feeling of loneliness [39]. The act of ignoring others in favor of smartphone use at a social setting, also called phone snubbing (or *phubbing*), has become increasingly common. This is associated with poorer relationship satisfaction and lower family well-being and can be supported by other psychological effects in relation to the increased use of electronic devices, such as feeling low or anxious [40-42]—a finding we were able to verify in our study.

In both age groups, we found that girls who reported excessive smartphone use had a higher probability of often feeling low and often feeling anxious. This finding is in line with previous research findings stating excessive smartphone use is significantly associated with depression and anxiety [43,44].

Elhai et al [10] performed a systematic review on problematic smartphone use and reported that both anxiety and depression are related to problematic smartphone use. The female gender is usually described as a risk factor for problematic smartphone use [10], but whether the female gender also increases the negative consequences thereof, such as psychological complaints, is a question for future studies to answer.

Furthermore, the reporting of less than 7 hours of sleep per night (labeled as “poor sleep” in this study) was reported in both sexes and in both grades. Standard sleep recommendations for teenagers (14-17 years) propose 8 to 10 hours of sleep on a daily basis [45,46]. The importance of sleep during adolescence is a key factor for many neurobiological processes, and sleep contributes to physical and mental health [47,48]. Over the past 20 years, sleep patterns among adolescents have changed, and a link to the increasing amount of time adolescents of today spend on the internet has been suggested [47,49,50]. Royant-Parola et al [51] found that smartphone use, in particular, is associated with poor sleep and negative daily functioning, as well as negative mood. The use of screens such as smartphones and sleep patterns have been previously studied, and suggested proposed mechanisms include (1) displacement of time spent sleeping by time spent using screens, (2) psychological stimulation from screen media content, and (3) alerting and circadian effects of exposure to light from screens [52]. Many adolescents use their smartphones just before bedtime, often leaving their phones in bed and repeatedly and frequently checking for notifications. This behavior is thought to increase smartphone use over time, engaging the person in social reassurance from friends and partners and increasing the possibility for excessive smartphone use [53]. Billieux et al [54,55] described this type of behavior is associated with depression and anxiety. This is also in line with our findings, since participants with the highest probability of poor sleep (ie, girls in both age groups) also had the highest probability of feeling low and feeling anxious.

Strengths and Limitations

This study has some limitations. One of the limitations is the cross-sectional design of the study, which does not allow for conclusions to be drawn regarding causation since such this would require a longitudinal investigation. Moreover, all the measures used for this study were based on self-report, which implies a risk for recall bias that could influence the findings. One could also argue for the use of more objective measures, such as electronic registration of smartphone use, as well as more objective indicators of psychological health (eg, cortisol profiles and actual diagnoses).

This study also has considerable strengths. These include the large, representative sample size along with the high response rate, which reduces the risk of selection bias. The survey also included many variables that are not to be found in registers and can only be captured in questionnaires or interviews. Another strength is the Bayesian approach to statistical analysis, which facilitates genuine probabilistic statements about our findings. Furthermore, using the ROPE procedure as a guide to determine the effects that may be of clinical and practical importance offer further robustness to our findings. Future research exploring excessive smartphone use during adolescence should use longitudinal design for an in-depth understanding of the topic.

Conclusions

Although results varied across gender and grade in terms of robustness and size of the estimated difference, overall, we found that excessive smartphone use was associated with a higher frequency of multiple suspected associated factors, including ever having tried smoking, alcohol, and other substances; poor sleep; and often feeling low and often feeling anxious. Moreover, our findings suggest that girls with excessive smartphone use are more prone to experience psychological health concerns than boys—a discrepancy that warrants further investigation. The current study brings light to some features and distinctions of a relevant potentially problematic behavior among adolescents of today.

Conflicts of Interest

AH holds a researcher position at Lund University, which is sponsored by the state-owned gambling company AB Svenska Spel, which had no role in the present work.

Multimedia Appendix 1
Supplementary material.
[DOCX File , 33 KB - pediatrics_v4i4e30889_app1.docx]

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Abbreviations

ADD: attention deficit disorder
ADHD: attention deficit hyperactivity disorder
ASD: autism spectrum disorder
HDI: highest density interval
OR: odds ratio
ROPE: region of practical equivalence

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Original Paper

Caregiver Acceptability of Mobile Phone Use for Pediatric Cancer Care in Tanzania: Cross-sectional Questionnaire Study

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Abstract

Background: There is a 60% survival gap between children diagnosed with cancer in low- and middle-income countries (LMICs) and those in high-income countries. Low caregiver knowledge about childhood cancer and its treatment results in presentation delays and subsequent treatment abandonment in LMICs. However, in-person education to improve caregiver knowledge can be challenging due to health worker shortages and inadequate training. Due to the rapid expansion of mobile phone use worldwide, mobile health (mHealth) technologies offer an alternative to delivering in-person education.

Objective: The aim of this study is to assess patterns of mobile phone ownership and use among Tanzanian caregivers of children diagnosed with cancer as well as their acceptability of an mHealth intervention for cancer education, patient communication, and care coordination.

Methods: In July 2017, caregivers of children <18 years diagnosed with cancer and receiving treatment at Bugando Medical Centre (BMC) were surveyed to determine mobile phone ownership, use patterns, technology literacy, and acceptability of mobile phone use for cancer education, patient communication, and care coordination. Descriptive statistics were generated from the survey data by using mean and SD values for continuous variables and percentages for binary or categorical variables.

Results: All eligible caregivers consented to participate and completed the survey. Of the 40 caregivers who enrolled in the study, most used a mobile phone (n=34, 85%) and expressed high acceptability in using these devices to communicate with a health care provider regarding treatment support (n=39, 98%), receiving laboratory results (n=37, 93%), receiving reminders for upcoming appointments (n=38, 95%), and receiving educational information on cancer (n=35, 88%). Although only 9% (3/34) of mobile phone owners owned phones with smartphone capabilities, about 74% (25/34) self-reported they could view and read SMS text messages.

Conclusions: To our knowledge, this is the first study to assess patterns of mobile phone ownership and use among caregivers of children with cancer in Tanzania. The high rate of mobile phone ownership and caregiver acceptability for a mobile phone–based education and communication strategy suggests that a mobile phone–based intervention, particularly one that utilizes SMS technology, could be feasible in this setting.

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KEYWORDS

mHealth; literacy; smartphone use; developing countries; pediatric cancer; cancer; pediatrics; children; parents; caregivers; mobile health; smartphone; SMS; education; knowledge transfer; communication

Introduction

Each year, low- and middle-income countries (LMICs) account for over 85% of the 400,000 newly diagnosed pediatric cancer cases [1]. Survival rates of these cases range from 5% to 25% in LMICs to over 80% in high-income countries (HICs) [2,3]. Almost one-third of the survival difference can be attributed to treatment abandonment, defined as the failure to initiate or sustain treatment during 4 or more successive weeks [3]. Although health system barriers underlie various causes of treatment abandonment, patient-level barriers also contribute to this phenomenon. For instance, caregiver interviews in LMICs identified limited cancer awareness at the community level and treatment knowledge as critical factors influencing treatment abandonment [4-6]. Hence, in addition to health system strengthening efforts, we need innovative strategies to reduce patient-level barriers and improve survival outcomes for children with cancer in LMICs.

Bugando Medical Centre (BMC) is a tertiary, urban hospital located in Mwanza, Tanzania, and it is one of the three cancer treatment centers in the country. The catchment area comprises 18 million people, and an estimated 1100 new pediatric cases of cancer are diagnosed annually (age <18 years) in this region [7-9]. Of these children, only 20% present for clinical diagnosis and treatment, and over 40% abandon treatment prior to completion. In interviews at BMC, caregivers identified challenges of inadequate care coordination and limited communication between pediatric cancer providers, patients, and themselves as reasons for treatment abandonment [10,11]. Among caregivers of children diagnosed with cancer, fewer than 20% knew their child's diagnosis or that potentially curative treatment was available for childhood cancer [11]. Owing to limited human resources in many LMIC settings, in-person education and individualized patient navigation and follow-up is often neither feasible nor cost effective [12]. Hence, identification and implementation of alternative modalities of patient education and support in LMIC settings may facilitate caregiver education and support for treatment completion.

With increasing global rates of cellular subscriptions, mobile phones may offer an alternative modality of communication for patient-facing interventions to improve cancer education and treatment support. According to the World Bank, mobile phone subscription rates in Tanzania in 2019 were as high as 82%, reflecting an increase compared to previous years [13]. In recognition of this growing digital technology landscape, the Tanzanian Ministry of Health, Community Development, Gender, Elderly and Children established the National Digital Health Strategy 2019–2024 [14]. This national strategy seeks to establish a strong digital health infrastructure within health systems to promote the quality of health service delivery and support improved health outcomes. Moreover, investments in patient-facing mobile health (mHealth) strategies, in parallel, could help reduce gaps in pediatric oncology care in Tanzania and bolster the evidence base for these technologies in reducing treatment abandonment in LMICs.

The recent World Health Organization digital health guidelines encouraged the use of mobile devices for patient-facing interventions and targeted client communication in particular [15]. Underlying this guideline is a key principle for digital development, which highlights the need to understand the existing ecosystem, including "technology infrastructure and other factors that can affect an individual's ability to access and use a technology or to participate in an initiative" [16]. However, mobile phone ownership and use patterns among caregivers of pediatric patients with cancer and their acceptability toward using these devices for communication related to health education and care coordination are not well established. To bridge this gap, we conducted a cross-sectional survey assessing caregiver patterns of mobile phone ownership and use, as well as the acceptability of mobile phone use for improving caregiver education, provider-patient communication, and care coordination at BMC in the context of pediatric cancer care.

Methods

Study Setting

BMC is a 950-bed consultant hospital located in Mwanza, Tanzania. It is one of the three cancer treatment centers in the country, and the only oncology referral center for the Lake Zone of Tanzania. BMC reports more than 200 newly diagnosed pediatric cancer cases each year [8].

Study Design and Participants

In July 2017, a cross-sectional survey was conducted among a purposive sample of caregivers of children aged <18 years who were diagnosed with cancer at BMC. All caregivers who were seen in either the inpatient or outpatient setting during the study period were approached for participation in the study. Only one caregiver per patient completed a survey. Informed consent and survey completion was done in either Swahili or English, based on the participant's language preference. Adult participants provided written informed consent. For participants who self-identified as unable to read, we obtained verbal consent with thumbprint in the presence of a literate witness per institutional standards.

Survey Questions and Administration

A 26-question survey instrument to elicit descriptive data on patterns of mobile phone ownership and use was previously developed, translated into Swahili, and pilot-tested in the Tanzanian population [17]. Survey domains include mobile phone ownership, technology literacy, and perceived acceptability for digital health interventions. In this study, the section on intervention acceptance was further tailored to include specific pediatric cancer use cases. Participants independently completed the survey. For those who self-identified as unable to read, a patient navigator read the questionnaire aloud and recorded the responses from the caregiver. Surveys were completed in a private room to ensure confidentiality of responses. All surveys were completed on paper, and the responses were stored in a secured office at BMC.

Statistical Analysis

Statistical analysis was conducted using Excel (version 16; Microsoft Corporation). Descriptive statistics were generated from the survey data using mean and SD values for continuous variables and percentages for binary or categorical variables.

Ethics Approval

The study was reviewed and approved by the National Institute for Medical Research in Tanzania (NIMR/HQ/R.8a/Vol. IX/3096), the Ethics Committee at BMC (CREC/292/2018), and Duke University Center Institutional Review Board (PRO00094010).

Results

Overview

All eligible caregivers who were approached (N=40) agreed to participate in the study. Survey findings related to mobile phone ownership and use are described in Table 1.

Table 1. Mobile phone ownership and use among caregivers (N=40) of pediatric patients with cancer at Bugando Medical Centre, Tanzania.

Characteristics	Value, n (%)
Do you use a mobile phone?	
Yes	34 (85)
No[a]	6 (15)
What type of mobile phone do you use?	
Basic phone (non–touch screen)	31 (91)
Android Smartphone	3 (9)
Who owns the mobile phone you use?	
Self	33 (97)
Spouse (husband or wife)	1 (3)
Do you share your mobile phone with others?	
Yes	6 (18)
No	28 (82)
With whom do you share your mobile phone?[b]	
Spouse (husband or wife)	2 (33)
Someone in the community	1 (17)
Other	3 (50)
Do you use multiple SIM[c] **cards with your mobile phone?**	
Yes	21 (62)
No	13 (38)
Which of the following mobile networks do you use?[d]	
Airtel	22 (65)
Halotel	6 (18)
TTCL[e]	2 (6)
Tigo	5 (15)
Vodacom	26 (76)
For what purpose do you use a mobile phone?	
Personal use only	13 (38)
Work and personal use	21 (62)

[a] Additional questions only asked of participants who reported using a mobile phone.

[b] Asked only if participants previously answered “Yes” to sharing their phone.

[c] SIM: subscriber identification module.

[d] Can have multiple networks.

[e] TTCL, Tanzania Telecommunications Company Limited.

Mobile Phone Ownership

Of the 40 participating caregivers, the majority (n=34, 85%) reported mobile phone use. Of these, 97% (33/34) owned mobile phones, and 3% (1/34) reported their spouse as the primary owner of the mobile phone. Most caregivers (31/34, 91%) owned mobile phones that did not have smartphone capabilities. Vodacom and Airtel were the two most used cellular networks, reported by 76% (26/34) and 65% (22/34) of respondents, respectively.

Technology Literacy

We assessed survey respondents’ technology literacy pertaining to their mobile devices (Table 2). All caregivers with mobile phones reported being able to receive phone calls. A majority of respondents reported being able to view and read a text message (25/34, 74%), but fewer participants reported being able to compose text messages. About 1 in 2 caregivers (18/34, 53%) knew how to take and send a picture via a cell phone, and 47% (16/34) knew how to watch videos.

Table 2. Technology literacy among caregivers of pediatric patients with cancer who own mobile phones (n=34) at Bugando Medical Centre, Tanzania.

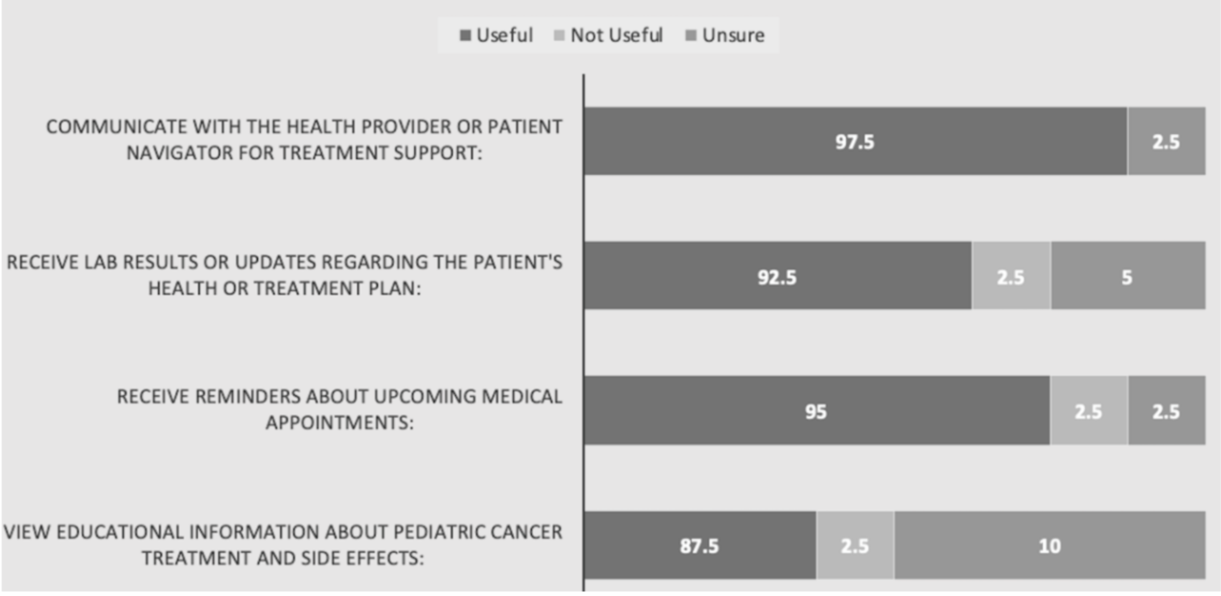
Characteristics	Value, n (%)
Turn phone on or off	
Able	34 (100)
Not able	0 (0)
Charge phone	
Able	30 (88)
Not able	4 (12)
Make phone calls	
Able	33 (97)
Not able	1 (3)
Receive phone calls	
Able	34 (100)
Not able	0 (0)
Type using the mobile phone keyboard (ie, to compose a text message or email)	
Able	16 (47)
Not able	18 (53)
Send a text message	
Able	22 (65)
Not able	12 (35)
Open and read a text message	
Able	25 (74)
Not able	9 (26)
Take pictures	
Able	18 (53)
Not able	16 (47)
Watch video	
Able	16 (47)
Not able	18 (53)
Charging Phone	
Never	22 (67)
Sometimes	3 (9)
Always	8 (24)
Unclear	1 (3)
Network Connectivity (ie, no signal, dropped calls, etc)	
Never	22 (65)
Sometimes	3 (9)
Always	9 (26)
Browse the internet	
Able	4 (12)
Not able	30 (88)
Use an installed app (eg, WhatsApp)	
Able	4 (12)
Not able	30 (88)

Characteristics	Value, n (%)
Download and install apps	
Able	5 (15)
Not able	29 (85)
Make monetary transactions	
Able	16 (47)
Not able	18 (53)
Change phone settings (eg, brightness of screen)	
Able	17 (50)
Not able	17 (50)
Phone theft or loss	
Never	16 (47)
Sometimes	14 (41)
Always	4 (12)

Perceived Needs

Caregiver responses to the utility of implementing mobile technology in the treatment of pediatric cancer therapy at BMC are illustrated in Figure 1. Of the 40 caregivers, 98% (n=39) thought using mobile technology to communicate with providers would be useful, 95% (n=38) wanted to use mobile technology to receive reminders regarding upcoming appointments, and 88% (n=35) wanted to receive education material and information. Over half (23/40, 58%) of all respondents answered an additional open-ended free-text response question asking what other benefits mobile technology could have in the treatment for their child. Of those, the majority (22/23, 96%) of respondents focused their answer on the potential use of mobile technology to communicate with a medical provider in a time of emergency (ie, febrile illness or severe nausea or vomiting).

Figure 1. Caregiver acceptability for mobile phone use in pediatric cancer care.



Discussion

Principal Findings

mHealth interventions have soared in recent history, with over 500 projects implemented in sub-Saharan Africa in the last decade [18-20]. This proliferation of mHealth interventions is due in part to the rapid expansion of mobile phone use and infrastructure worldwide [21]. The majority of caregivers surveyed at BMC owned and used mobile phones and were interested in using these devices to learn and communicate about their child’s cancer treatment. These findings support high feasibility and acceptability for mHealth strategies at BMC to provide targeted information and communication to caregivers of children with cancer, while reducing burden on limited health care resources and personnel. However, additional studies will be needed to confirm the feasibility and acceptability of any future mHealth interventions that are developed for caregivers.

In this study, the proportion of caregivers who reported using a mobile phone (85%) was similar to the national mobile phone subscription rate in Tanzania (82%) [13]. In sub-Saharan Africa, data plans are often inexpensive, and their use is widespread regardless of socioeconomic status [22,23]. Furthermore, investments in mobile phone infrastructure have led to an estimated 93.7% cell tower coverage nationwide, suggesting that an intervention delivered by mobile phone has a high potential reach in Tanzania [24].

Although access to cell coverage is high, many caregivers reported using multiple SIMs with different cellular carriers. Having multiple SIM cards may be a barrier to implementing interventions since other studies have reported challenges with reaching participants when an alternate SIM is in use [25]. However, in Tanzania, mobile phone owners maintain the same telephone number when they switch networks, as part of the Mobile Number Portability Act [26,27]. The high rate of mobile phone ownership and flexibility between networks in Tanzania are important in establishing consistent communication between patients and providers. Our results reveal that the most effective delivery method of content to caregivers in our study setting was via phone calls, as 97% to 100% of respondents that used a mobile phone were capable of making or receiving a phone call.

Although text messaging is a cheaper alternative to voice-based communication in Tanzania, our findings suggest low literacy among caregivers to support a text messaging intervention. We found that text messaging would not be as effective, as only 74% could read a text message and 65% of respondents could send a text message. When faced with the challenges of low literacy rates, *Wazazi Nipendeni*, a text messaging app for pregnant women in Tanzania, added *supporters* and voice-based technology to read the text messages [21,28]. However, in many LMICs, including Tanzania, there is perceived community stigmatization related to pediatric cancer, and having someone other than an immediate family member read or verbalize messages may exacerbate the existing barriers to cancer diagnosis and treatment. Therefore, further research is needed to understand the acceptability of using family or community *supporters* for childhood cancer and whether community-based cancer stigma poses barriers to such a strategy.

In our study, we surveyed caregivers directly to assess their perspectives on the value of a mobile phone–based intervention. Our data suggest high acceptability and desire among caregivers to use mobile phones to communicate with providers, receive lab and appointment reminders, and view educational material related to their child's cancer diagnosis. An important point to note is that almost all respondents who answered the free-text question regarding other uses of a digital case management system requested a hotline number they could contact in the event of an emergency. Currently, there are no systems in place for a caregiver to contact a trained oncology provider at BMC, and this is likely the situation in other LMIC settings as well. Including end-user participants in the creation and implementation of technologies increases adoption of the intervention, and the idea of using patient-centered feedback in mHealth systems has been a diverging point between successful and unsuccessful implementations [29]. Our results support this claim, as our user-centric approach identified the need of a direct pathway for caregivers to access information from medical providers about their child's diagnosis and treatment. Including this information in the implementation of future digital platforms will allow us to better care for patients.

Our study sought to evaluate caregiver acceptability of mobile phone use in the global pediatric oncology setting. Of all the initiatives in the 2014 African Strategies for Health mHealth Compendiums, only one focuses on cancer—mEPOC, an app that provides early detection and prevention of oral cancers. There have not been other reports of mHealth in global pediatric oncology [30]. Therefore, this represents an area of need in LMICs, as supporting caregivers of patients with cancer is known to have a positive impact on parent distress and treatment outcomes in HICs [31,32].

Limitations

This study has several limitations. First, although the survey was previously translated to Swahili and adapted for use in Tanzania, the transcultural adaptation was done for the southern region of Tanzania, whereas our study was completed in the Northeast region of the country, potentially limiting its generalizability [17]. However, the Swahili language used in Tanzania is the same throughout the country, and the domain questions selected used concrete concepts (ie, if the respondent owned a mobile phone), for which regional variations in interpretation would be unlikely. Second, due to the small sample size, we were unable to conduct advanced statistical analyses to assess associations between caregiver characteristics and acceptability. Future planned studies could provide an in-depth assessment of caregiver acceptance by recruiting a larger sample of respondents. Nonetheless, our data suggests that an mHealth intervention at the pediatric cancer department of BMC would be used by caregivers and that it could decrease treatment abandonment via improved communication with providers and patients, clinic reminders, education, and a hotline for emergencies. Given geographical barriers to care in certain parts of Tanzania, especially in rural settings where traveling to health facilities may entail significant time and financial burden, a medical emergency hotline could be of significant benefit for caregivers. Our high rates of population mobile phone use, feasibility, and acceptability of mobile phone intervention delivery are consistent with other chronic disease mHealth research [33]. With cancer being one of the major causes of death from noncommunicable diseases, and with the number of new cases of pediatric cancers rising, it is imperative that we build the evidence base for patient-facing mHealth interventions in this field.

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Conflicts of Interest

LZ received research funding awarded to her institution from Proteus Digital Health and the PhRMA Foundation, as well as consulting from Novartis and Pfizer, all unrelated to the current work. LV receives funding from the National Center for Advancing Translational Sciences of the National Institutes of Health under Award Number KL2TR002554. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Abbreviations

BMC: Bugando Medical Centre
HIC: high-income country
LMIC: low- and middle-income country
mHealth: mobile health

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Original Paper

Acceptability, Feasibility, and Quality of Telehealth for Adolescent Health Care Delivery During the COVID-19 Pandemic: Cross-sectional Study of Patient and Family Experiences

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Abstract

Background: Data regarding the acceptability, feasibility, and quality of telehealth among adolescents and young adults (AYA) and their parents and caregivers (caregivers) are lacking.

Objective: The aim of this study was to assess the noninferiority of telehealth versus in-person visits by comparing acceptability with respect to efficiency, effectiveness, equity, patient-centeredness, and confidentiality.

Methods: Cross-sectional web-based surveys were sent to caregivers and AYA following video visits within an Adolescent Medicine subspecialty clinic in May-July 2020. Proportions of AYA and caregivers who rated telehealth as noninferior were compared using chi-squared tests. Feasibility was assessed via items measuring technical difficulties. Deductive thematic analysis using the Institute of Medicine dimensions of health care quality was used to code open-ended question responses.

Results: Survey response rates were 20.5% (55/268) for AYA and 21.8% (123/563) for caregivers. The majority of the respondents were White cisgender females. Most AYA and caregivers rated telehealth as noninferior to in-person visits with respect to confidentiality, communication, medication management, and mental health care. A higher proportion of AYA compared to caregivers found telehealth inferior with respect to confidentiality (11/51, 22% vs 3/118, 2.5%, $P<.001$). One-quarter (14/55) of the AYA patients and 31.7% (39/123) of the caregivers reported technical difficulties. The dominant themes in the qualitative data included advantages of telehealth for efficiency and equity of health care delivery. However, respondents' concerns included reduced safety and effectiveness of care, particularly for patients with eating disorders, owing to lack of hands-on examinations, collection of vital signs, and laboratory testing.

Conclusions: Telehealth was highly acceptable among AYA and caregivers. Future optimization should include improving privacy, ameliorating technical difficulties, and standardizing at-home methods of obtaining patient data to assure patient safety.

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KEYWORDS

telehealth; telemedicine; adolescent; COVID-19; acceptability; feasibility; young adult; teenager; cross-sectional; patient experience; experience; efficiency; equity; survey

Introduction

With the rapid shift to video visits during the COVID-19 pandemic, adolescents, who are typically digital natives, have been key consumers of technology-delivered health care [1]. Prior to COVID-19, telehealth was seen as a potential tool to increase access to care and reduce health disparities for adolescents, but geographic restrictions and limited reimbursement led to low utilization [2]. Widespread adoption of telehealth was facilitated by emergency waivers issued by the Centers for Medicare and Medicaid Services, which allowed for geographic flexibility and expanded reimbursement, and the proliferation of Health Insurance Portability and Accountability Act compliant videoconferencing platforms [3,4]. Most commercial insurers quickly followed in relaxing telehealth restrictions to keep pace.

With the rapid transition to telehealth during the COVID-19 pandemic, data gathering of end-user acceptability of telehealth has lagged. The crisis conditions of the pandemic resulted in minimal opportunity for stakeholder input and design from adolescents and young adults (AYA) and their families. Even prior to the pandemic, there were limited data on the acceptability of telehealth for adolescents, and existing studies were mostly confined to mental and sexual health care [5-7], thus neglecting other areas of adolescent health care delivery, including gender-affirming care and management of eating disorders. Although recent systematic reviews demonstrate acceptability of telehealth for a variety of pediatric and adult conditions and modest effect sizes for effectiveness for telemedicine management of pediatric conditions, including asthma, attention deficit hyperactivity disorder, and depression, the acceptability of video-delivered care for a broad sample of adolescent health conditions remains unknown [1,8].

Telehealth for adolescent care presents unique use case challenges. Adolescent Medicine service providers navigate additional confidentiality barriers, frequently need to integrate mental health care into visits, and often practice within interdisciplinary care teams, including psychologists, nutritionists, and social workers. Additional protections are needed to maintain confidentiality during adolescent enrollment within electronic health portals and telehealth applications while still allowing for parent and caregiver (caregiver) proxy access to essential health care information [9]. For example, caution is needed to assure that sensitive test results (such as pregnancy testing) are not released to parents through portals without adolescent consent and that confidential telehealth visits for sexual health services are not “visible” to parents. Early analyses have demonstrated successful adoption of telehealth, with high uptake rates for adolescent health care over periods of just days to weeks [9,10]. However, separate from adoption metrics, acceptability and feasibility assessments are essential to assure that telehealth is delivered with equivalent confidentiality protections to in-person care. The importance of confidential care has been amplified by the pandemic, given the rising rates of mental health conditions that necessitate additional privacy protections for both data collection and treatment delivery [11]. Early data from Adolescent Medicine providers demonstrate challenges to ensuring privacy and confidentiality, despite use of headphones, platform chat functions, and yes/no history-taking questions [12]. Providers have also noted that some patients from lower socioeconomic status households experienced greater difficulty securing private space owing to more crowded living arrangements, thereby presenting a potential challenge to equity [12].

Concerns surrounding widespread implementation of telehealth for adolescents remain, including threats to quality of care across the Institute of Medicine (IOM) dimensions of health care quality: safety, effectiveness, timeliness, efficiency, equity, and patient-centeredness [13,14]. Although telehealth has the potential to increase the reach of health care, early data show that it may paradoxically worsen health disparities owing to differential access to wireless internet, private spaces for visits, and mobile devices across race and socioeconomic status [15,16]. An additional area for concern is patient safety, as the lack of hands-on physical examinations and standardized collection of vital signs could lead to errors in diagnosis [17].

The perspectives of both patients and caregivers are critical for assessing the acceptability of telehealth for adolescents. The American Academy of Pediatrics Supporting Pediatric Research in Outcomes and Utilization of Telehealth (SPROUT) research network developed the SPROUT Telehealth Evaluation and Measurement (STEM) framework, a mechanism to evaluate perspectives on telehealth across stakeholders [18]. The Experience branch of the STEM framework emphasizes the need to understand patient and caregiver perspectives on multiple visit aspects, including overall satisfaction, communication quality, and impact on family routines [18]. We therefore sought to examine patient and caregiver attitudes toward telehealth in an Adolescent Medicine subspecialty clinic system. Our primary aim was to determine the acceptability, feasibility, and quality of telehealth for delivery of adolescent health care among patients and caregivers. A secondary aim sought to evaluate the agreement between patient and caregiver responses on acceptability measures.

Methods

We conducted a cross-sectional web-based survey to assess attitudes toward telehealth in AYA and parents and caregivers (caregivers).

Settings and Participants

Participants or their dependents received care within an Adolescent Medicine subspecialty clinic, within a large academic pediatric hospital network in the Philadelphia area. The clinic provides contraceptive and gynecologic services, gender-affirming care, HIV treatment and prevention, and management of eating disorders for AYA. The clinic transitioned from 100% in-person visits to majority synchronous video visits starting March 2020 owing to the COVID-19 pandemic [10]. The telehealth platform allowed for a multiple user interface, and visits were attended by multiple clinical team members, including registered dieticians, social workers, psychologists, and interpreters as needed. Patients aged ≥13 years who completed a video visit from May-July 2020 were eligible for enrollment. Caregivers were eligible if their child <18 years of age completed a video visit during the study period or if they accompanied their child 18 years or older in a video visit (ie, the patient did not attend the visit independently). Patients and caregivers could participate independent of each other, and the data therefore do not represent patient/caregiver dyads. Potential participants were called before their telehealth visit by study staff, had contact information confirmed, and were informed about the survey. After visits were completed, links to research electronic data capture–based surveys were sent via text message or email to the participant and, separately, their caregiver, per inclusion criteria.

Measures

The 32-item (AYA) and 29-item (caregiver) web-based surveys assessed telehealth acceptability and feasibility. Survey items were adapted from previously validated scales, and items were selected using a modified Delphi procedure with experts from Adolescent Medicine, psychology, and informatics [19]. Telehealth acceptability was measured on a 5-point Likert scale comparing telehealth to in-person care with respect to provider-patient communication, convenience, privacy, and achieving goals of care. Feasibility was assessed via questions regarding technical difficulties with visits. Additional independent measures were included for AYA and caregivers, respectively. AYA surveys included items addressing ability to find a private space for the visit and whether there were opportunities to speak with their provider alone. Caregivers provided both their own and their child's demographic information and completed an additional question on their perceptions of how well their child's concerns were addressed at telehealth visits compared to in-person visits. In order to capture additional perspectives on telehealth that may not have been captured in our measures, both surveys contained 3 open-ended questions: (1) what are the disadvantages of telehealth compared to in-person visits? (2) what are the advantages of telehealth compared to in-person visits? and (3) please let us know any additional areas in which you felt telehealth was different from in-person visits.

Quantitative Analysis

Demographic characteristics of patients and caregivers were assessed via descriptive statistics, including means, medians, and standard deviations. For items comparing in-person to telehealth visits, we assessed noninferiority of telehealth to in-person care by dichotomizing responses into 2 categories: telehealth better or the same as in-person and telehealth worse than in-person. As our primary aim was to assess acceptability for both caregivers and adolescents and to identify areas for optimization to assure joint acceptability, we compared proportions of each population rating telehealth as noninferior to in-person care by using chi-squared and Fisher exact test. All analyses were completed in Stata 15 (College Station, TX, StataCorp LP).

Qualitative Analysis

Three independent coders qualitatively analyzed responses to the open-ended questions in the survey regarding telehealth advantages and disadvantages. The primary (AWP) and secondary (PM, HLF) coders reviewed the open-text survey responses by using a semiquantitative spreadsheet approach, which captured the descriptions and frequencies of themes. The patient and, separately, caregiver-specific responses were independently double-coded using deductive thematic analysis to identify themes unique to the patient and caregiver experiences. The coding team developed an initial codebook of themes based on consensus with each coder and then they separately applied the codebook themes to the entirety of the open-text survey data. Any coding discrepancies were resolved by consensus. To ground findings within an existing health care quality framework, the primary coder categorized the final themes according to the IOM dimensions of health care quality: safety, effectiveness, timeliness, efficiency, equity, and patient-centeredness [13,14]. All procedures were reviewed and deemed by the Institutional Review Board to be exempt as quality improvement.

Results

Quantitative Data

In May-June 2020, 268 and 563 surveys were deployed to unique AYA patients and caregivers, respectively, with a response rate of 20.5% (55/268) for AYA and 21.8% (123/563) for caregivers. The majority of the patient and caregiver respondents were White cisgender females (Table 1). The race and sex distributions of patient survey respondents were representative of the patient population seen by the clinic during spring 2019. The most common visit reasons were eating disorders (18/55, 33% patients, 52/123, 42.3% caregivers) and gynecology/reproductive health (18/55, 33% patients, 44/123, 35.8% caregivers).

The majority of the visits were conducted by physician providers (Table 2). Most AYA and caregivers used a smartphone with a Wi-Fi connection for their telehealth visit. With respect to confidentiality, nearly all AYA (54/55, 98%) were able to identify a private space for their visit (Table 2) and 36 out of 55 AYA (65%) spoke to a provider alone during their telehealth visit (Table 2). Of the 19 AYA who did not speak to their provider alone, 3 (16%) wanted to do so (Table 2).

With regards to acceptability (Table 3), the majority of AYA and caregivers rated telehealth as noninferior to in-person visits with respect to privacy, communication, managing medication questions, and discussing test results, mood, and mental health. A significantly higher proportion of AYA compared to caregivers felt telehealth was inferior to in-person care with respect to privacy (11/51, 22% vs 3/118, 2.5%, respectively, $P<.001$). There were no other significant differences between AYA and caregivers in the acceptability ratings across domains.

With respect to feasibility, 39 out of 123 (31.7%) caregivers and 14 out of 55 AYA (25%) reported technical difficulties with telehealth, including difficulty accessing the patient portal. However, 104 out 123 caregivers (84.5%) and 49 out of 55 AYA (89%) reported that the technology system was easy to use, and 97 out of 123 caregivers (78.8%) and 38 out of 55 AYA (69%) reported that video visits improved efficiency of care, including time saved, compared to in-person visits (Table 2).

Table 1. Demographic characteristics of the survey respondents.

Characteristic	Patient survey (n=55)	Caregiver survey (n=123)
Age[a] (years), median (IQR)	18 (17-20)	48 (44-51)
Race[a,b], n (%)		
White	42 (76.4)	104 (86.7)
Black	9 (16.4)	14 (11.7)
Asian	4 (7.3)	1 (0.8)
Native American	1 (1.8)	3 (2.5)
Other	4 (7.3)	2 (1.7)
Latina[a]	7 (12.7)	6 (5)
Sex[a], n (%)		
Male	10 (18.2)	7 (5.8)
Female	45 (81.8)	113 (94.2)
Gender identity[a], n (%)		
Cisgender male	11 (20)	7 (5.8)
Cisgender female	31 (56.4)	113 (94.2)
Transgender male	7 (12.7)	0
Transgender female	2 (3.6)	0
Gender queer/nonconforming/nonbinary	4 (7.3)	0
Visit reason[b], n (%)		
Eating disorder	18 (32.7)	52 (42.3)
Gynecology/contraception	18 (32.7)	44 (35.8)
Gender-affirming care	12 (21.8)	27 (22)
HIV treatment/prevention	3 (5.5)	0
Mental health/substance abuse	3 (5.5)	2 (1.6)
Other	4 (7.3)	4 (3.3)

[a] Data not provided by 3 (2.4%) caregiver survey respondents.

[b] Checkbox question: participants could select more than one category if applicable; therefore, percentages add to >100%.

Table 2. Telehealth visit characteristics.

	Patients (n=55), n (%)	Caregivers (n=123), n (%)
Previous Adolescent Medicine visit	41 (74.6)	98 (79.7)
Visit location		
Home	54 (98.2)	123 (100)
Other	1 (1.8)	0
Able to identify private space	54 (98.2)	N/A[a]
Providers present[b]		
Physician	47 (85.5)	91 (74)
Nurse practitioner/Physician assistant	6 (10.9)	25 (20.3)
Nurse	4 (7.3)	3 (2.4)
Psychologist/licensed professional counsellors	2 (3.6)	12 (9.8)
Social worker	2 (3.6)	2 (1.6)
Physical/occupational therapist	1 (1.8)	2 (1.6)
Dietician	5 (9.1)	6 (4.9)
Other	1 (1.8)	5 (4.1)
Connection type[b]		
Wi-Fi	47 (85.5)	101 (82.1)
Data	13 (23.6)	35 (28.5)
Device used		
Tablet	8 (14.5)	26 (21.1)
Smartphone	40 (72.7)	74 (60.2)
Desktop computer	7 (12.7)	6 (4.9)
Laptop computer	0	17 (13.8)
Difficulty of video visit use		
Difficult	3 (5.5)	10 (8.1)
Neutral	3 (5.5)	9 (7.3)
Easy	49 (89.1)	104 (84.6)
Technical difficulties[b]		
No issues	41 (74.5)	84 (68.3)
Video never worked/stopped working	1 (1.8)	15 (12.2)
Audio never worked/stopped working	5 (9.1)	15 (12.2)
Poor audio/video quality	6 (11)	14 (11.4)
Resorted to telephone call	2 (3.6)	6 (4.9)
Difficulty signing up for or starting the telehealth application	3 (5.5)	11 (8.9)
Would participate in a video visit again		
Disagree	8 (14.5)	15 (12.2)
Neither agree nor disagree	10 (18.2)	8 (6.5)
Agree	37 (67.3)	100 (81.3)
Frequency of talking to health care provider alone during in-person visits[c]		
Never/almost never	6 (14.6)	N/A
Occasionally/sometimes	15 (36.6)	N/A
Almost every time/every time	20 (48.8)	N/A

	Patients (n=55), n (%)	Caregivers (n=123), n (%)
Talked to provider alone in telehealth visit	36 (65.4)	N/A
Wanted to talk to provider alone[d]		
Disagree	7 (36.8)	N/A
Neither agree nor disagree	9 (47.4)	N/A
Agree	3 (15.8)	N/A
Convenience compared to in-person visit		
Telehealth took longer	8 (14.5)	14 (11.4)
No difference	6 (10.9)	7 (5.7)
Telehealth saved time	38 (69)	97 (78.9)
Never had an in-person visit	3 (5.5)	5 (4.1)

[a] N/A: not applicable.

[b] Participants could select more than one category if applicable; therefore, percentages add to >100%.

[c] Answered only by patients who had attended a previous adolescent clinic visit (n=41).

[d] Answered only by patients who did not speak to their provider alone during their clinic visit (n=19).

Table 3. Comparison of patient and caregiver acceptability of telehealth.[a]

Acceptability of telehealth, domain	Telehealth visit noninferior to in-person visit, n (%)		*P* value
	Patients (n=55)	Caregivers (n=123)	
Safety			
I felt comfortable with the privacy of the video visit.[b]	40 (78.4)	114 (96.6)	<.001
Effectiveness			
Obtaining prescription refills[c]	43 (95.6)	82 (98.8)	.28
Managing medication side-effects and questions[d]	43 (93.5)	87 (97.8)	.22
Discussing test results[e]	42 (97.7)	72 (96)	.54
Discussing mental health[f]	39 (78)	99 (89.2)	.05
Receiving referrals to other providers[g]	41 (97.6)	74 (98.7)	.59
Timeliness/efficiency			
The visit was convenient for me[h]	49 (96.1)	117 (99.2)	.22
Equity			
I felt comfortable with the way my provider communicated with me[i]	50 (98)	113 (96.6)	.52
Patient-centeredness			
I felt comfortable discussing private topics alone with my health care provider[j]	45 (86.5)	109 (94)	.11
I felt comfortable communicating with my health care provider[b]	48 (94.1)	112 (94.9)	.55
I felt my provider paid attention to me[b]	49 (96.1)	118 (100)	.09
I felt my provider listened to me[b]	50 (98)	116 (98.3)	.66
I felt my concerns were addressed[b]	50 (98)	115 (97.5)	.65

[a] Chi-squared test was used.

[b] Not applicable or no prior in-person visit for 4 (7.3%) patients and 3 (2.4%) caregivers; data missing for 2 (1.6%) caregivers.

[c] Not applicable or no prior in-person visit for 10 (18.2%) patients and 37 (30.1%) caregivers; data missing for 3 (2.4%) caregivers.

[d] Not applicable or no prior in-person visit for 9 (16.4%) patients and 29 (24.6%) caregivers; data missing for 5 (4.1%) caregivers.

[e] Not applicable or no prior in-person visit for 12 (21.8%) patients and 44 (35.8%) caregivers; data missing for 4 (3.3%) caregivers.

[f] Not applicable or no prior in person visit for 5 (9.1%) patients and 9 (7.3%) caregivers; data missing for 3 (2.4%) caregivers.

[g] Not applicable or no prior in-person visit for 13 (23.6%) patients and 45 (36.7%) caregivers; data missing for 3 (2.4%) caregivers.

[h] Not applicable or no prior in-person visit for 3 (5.5%) patients and 3 (2.4%) caregivers; data missing for 1 (1.8%) patient and 2 (1.6%) caregivers.

[i] Not applicable or no prior in-person visit for 4 (7.3%) patients and 3 (2.4%) caregivers; data missing for 3 (2.4%) caregivers.

[j] Not applicable or no prior in-person visit for 3 (5.5%) patients and 5 (4.1%) caregivers; data missing for 2 (1.6%) caregivers.

Qualitative Data

Nearly half (n=26) of the 55 patients (47%) and 86 of the 123 caregivers (69.9%) completed the open-ended questions. The demographics of the patient and caregiver responses to the open-ended questions were reflective of the total survey population. The sample was largely White (19/26, 73% AYA; 75/86, 87% of caregivers) cisgender females (19/26, 73% AYA; 75/86, 87% of caregivers). Emergent themes within the IOM quality framework and exemplar quotes are shown in Table 4.

The most frequently cited advantage of telehealth compared to in-person visits was within the IOM dimension of *Timeliness*. Both patients and caregivers indicated that time was saved from no commute or in-person waiting room time and reported financial savings from less work missed and no transportation costs. The second most common theme was “Improved access to care for vulnerable populations” within the *Equity* IOM domain. Patients and caregivers described telehealth as expanding access to people who may experience a variety of challenges with attending in-person Adolescent Medicine visits. Patients also discussed how telehealth improved equity in care delivery, including, but not limited to, reducing misgendering patients by clinic staff.

Table 4. Advantages/disadvantages reported in the patient and caregiver open-ended survey responses.

Construct, advantage/disadvantage	Themes	Frequency[a]	Exemplar quotes
Safety: Delivering health care that minimizes risks and harm, including avoiding preventable injuries and reducing medical errors			
Advantage	Improved patient safety	8	*…There's a greater risk of getting COVID-19 when you do in-person visits rather than telehealth visits.* [Patient]
Disadvantage	Increased safety risks due to lack of hands-on data	4	*…I feel that there is potential for parents to miss or overlook clues about teen eating disorders using telemedicine as a primary treatment option.* [Caregiver]
Disadvantage	Decreased visit privacy	10	*…Due to my answer-giving at home, I feel it's not as safe because I have neighbors… and our house is connected to someone else's house.* [Patient]
Effectiveness: Providing services based on scientific knowledge and evidence-based guidelines			
Advantage	Improving adherence to treatment recommendations	4	*…Accountability for seeing the doctor has been a powerful motivator for our family to do the right thing.* [Caregiver]
Disadvantage	Limited scope of practice	47	*…Telehealth is not able to easily address physical problems, can't take blood pressure etc.* [Patient]
Timeliness: Reducing delays in providing and receiving health care			
Advantage	Allowed continuity of care during the pandemic	12	*…I would not prefer [telehealth] as a matter of course but appreciated this visit since there was no other alternative at the moment.* [Caregiver]
Advantage	Reduced delays in care	16	*…I know my child will be seen sooner vs coming in after waiting months for appointments due to heavy schedules.* [Caregiver]
Disadvantage	Disrupted care due to technical issues	14	*…After checking in, and downloading applications, application repeatedly restarted, only worked for audio … cut out 3 different times and required Doctor/us to switch to a phone call* [Caregiver]
Disadvantage	Visit workflow challenges	2	*…I was not made aware that the staff would call my home phone…I specifically asked them not to call, and the call disturbed…my family who were busy with online job interviews and standardized tests.* [Patient]
Efficiency: Delivering health care in a manner that maximizes resource use and avoids waste			
Advantage	Improved convenience for families	102	*…Usually an appointment …takes us 4 hours and this only took 1 hour for the actual appointment.* [Caregiver]
Advantage	Decreased cost to families	9	*…So much cheaper than paying gas tolls and parking plus saves two hours of drive time.* [Caregiver]
Disadvantage	Increased financial burden on families	1	*…My daughter does n't get weighed in or her vitals taken. We have to go to her primary for weight check and [orthostatic vital signs] … which means I pay for a second doc visit.* [Caregiver]
Equity: Delivering health care that does not differ in quality according to personal characteristics			
Advantage	Improved quality of care for vulnerable populations	45	*…The front desk staff cant misgender me because I don't interact with them.* [Patient]
Advantage	Increased access to care vulnerable populations	7	*…For people who are sick or nonmobile. these visits benefits [them] because they could still get the treatment they need right from home…* [Patient]
Disadvantage	Limited resources or technology access impede care	2	*…[Telehealth] may be hard for some people to use or have access to.* [Patient]
Patient-centeredness: Providing care that takes into account the preferences and aspirations of individual service users			
Advantage	Improved person-centered communication	16	*…I loved it! Doctor was engaged and it felt like a regular visit … I felt like it was less intimidating.* [Patient]
Advantage	Strengthened preexisting patient-provider relationships	5	*…We have already met with the doctor and are very comfortable with telehealth appointments.* [Caregiver]

Construct, advantage/disadvantage	Themes	Frequency[a]	Exemplar quotes
Disadvantage	Environmental distractions may impede care	6	*…My family is extremely nosey and it was hard to find a quiet/safe place in my house.* [Patient]
Disadvantage	Diminished clinician-patient communication and rapport	28	*…My daughter [was] able to leave the room if not wanting to engage, where in person visits are more engaging.* [Caregiver]

[a] Frequency of the coded theme among adolescents and young adults and caregivers.

With respect to the disadvantages of telehealth, the most common theme was "Limitations in scope of practice" within the *Effectiveness* IOM domain. Patients and caregivers discussed that the lack of hands-on physical examination and laboratory testing, which were felt to be essential for the delivery of evidence-based care, could lead to decreased quality of care. Patients and caregivers also frequently endorsed challenges to *patient-centeredness*, particularly in communication and building rapport. With respect to *Equity*, one caregiver described the financial burden of telehealth owing to the challenges with a limited scope of practice, where caregivers may be required to pay for separately for both a telehealth visit and an in-person laboratory visit to meet the health needs of their child.

Caregiver responses differed qualitatively from patient open-ended responses in 2 ways. First, caregivers placed greater emphasis on the importance of preexisting provider-patient relationships in successfully creating a comfortable visit environment via telehealth. Second, caregivers more commonly framed telehealth as advantageous with respect to *patient-centeredness*, including comfort, provider-patient communication, and engagement in visits.

Discussion

Principal Findings

Within an Adolescent Medicine clinic, we found high acceptability of telehealth among both patients and caregivers. The majority of the patients and caregivers reported that telehealth visits were easy to use and saved time and they expressed willingness to participate in another telehealth visit. Key areas for optimization in telehealth implementation included improving technical problems, which may limit uptake, and ensuring adequate confidentiality standards for AYA in the video visit setting. Although >85% of respondents found the telehealth system easy to use, a quarter of the patients and nearly a third of caregivers reported experiencing at least one technical issue during their telehealth visit. The most common issue across both groups was malfunctioning of the audio component in the video visit. The analysis of telehealth satisfaction among pediatric neurology service providers during the COVID-19 pandemic similarly revealed high levels of satisfaction, despite nearly 40% encountering technical challenges, and the providers surveyed also reported that audio problems were the most common [16]. In order to optimize telehealth quality, it will be essential to resolve technical issues impacting communication of clinical information and treatment recommendations. As technology continues to rapidly evolve, health systems likely need to "go back to the drawing board" to conduct more extensive usability testing on their systems. The user-centered design process is typically part of scale-up of new mobile health interventions but was bypassed owing to the urgency of the pandemic. Periods of respite between COVID surges may provide an opportunity to refine the user experience. Lastly, as health systems optimize their technology, consideration should be given to integrating remote patient monitoring options such as heart rate monitors, actigraphy, and pulse oximetry to augment video history and examination findings [20-22]. These digital tools also hold promise as health-promoting interventions in their own right. Remote patient monitoring strategies with real-time patient feedback may improve disease self-management and treatment adherence in conditions such as asthma and diabetes for adolescents.

Privacy was the only acceptability measure in which we found divergence between caregivers and adolescents. A significantly higher proportion of patients rated telehealth as inferior to in-person care for privacy. This finding suggests that AYA perceptions of visit privacy may be more complex than the simple ability to identify a private space for the visit, which >98% of patients were able to do. Prior research efforts with Adolescent Medicine providers have identified several strategies for optimizing privacy and confidentiality during telehealth visits. For at-home visits in which patients have access to adequate technology and space for the visit, these include the use of headphones, yes/no history-taking questions, use of chat functions, and using background white noise to lessen the chance that others in the household will overhear [12,23]. In efforts to improve telehealth privacy, special attention should be paid to adolescents who lack stable housing, private space, or consistent access to technology. These include creating dedicated patient telehealth "drop-in" kiosks stocked with computers or tablets and soundproof space at essential locations that may remain open in a public health crisis, such as pharmacies, primary care clinics, or schools. In addition, models from the Veterans Administration have demonstrated that delivery of tablets to unstably housed individuals is a feasible strategy for maintaining access to telehealth for vulnerable populations [12,15,23-25].

The high acceptability and convenience of telehealth reported by AYA patients and caregivers point to potential benefits of integrating telehealth visits in adolescent care in the future years. However, the future of telehealth in the United States remains uncertain. In April 2021 and July 2021, the US Department of Health and Human Services renewed the declaration of the COVID-19 pandemic as a public health emergency for an additional 90 days [26]. Under this renewal, the blanket waivers issued by the Centers for Medicare and Medicaid Services to increase geographic flexibility and expanded reimbursement remained in effect [3]. In the absence of a further renewal, however, many of these waivers may no longer apply, making telehealth far less feasible. Some commercial insurers began withdrawing additional provisions, allowing for expanded telehealth reimbursement in fall 2020, with more following in winter and spring 2021. Given broad state discretion, telehealth policy for Medicaid and Children’s Health Insurance Policy is also in flux across states. High acceptability of telehealth suggests that the integration of telehealth as an additional care delivery mode may be highly beneficial. In addition, given the increasing rates of adolescent mental health diagnoses, suicidal ideation, and suicide attempts during the pandemic [27-29], telemedicine will be an essential means of delivering evidence-based mental health care to youth, given the dearth of available in-person services [1]. Whether our health system can rise to this challenge will depend on the continuation of policies that, by lessening geographic restrictions and achieving parity with in-person visit reimbursement rates, enabled widespread telehealth use.

Our analysis has several limitations. The survey response rate was low, and therefore, may not provide a complete picture of patient and caregiver experiences with telehealth. Surveys were sent to patients attending visits during May-June 2020, when COVID-19 cases were rapidly rising in the United States. Many patients and caregivers were experiencing abrupt changes to their routines and additional stressors during these months, which may have limited the response rate. However, the response rate of the patients compared to that of the caregivers was approximately the same, and the patient race and sex demographic distribution did not differ significantly from patients seen in the clinic for in-person visits during spring 2019. The majority of the respondents were White, non-Hispanic, cisgender females, and therefore, our results may not be generalizable to other populations. Previous analyses of telehealth during COVID-19 in both pediatric and adult populations have demonstrated racial and socioeconomic disparities in telehealth utilization, with non-White patients, Latinx patients, and patients with low median household incomes having both lower overall utilization and utilizing audio only visits more often than audio plus video [16,30-32]. These studies provide an early signal that rapid introduction of telehealth, in many instances, has led to the unintended consequence of widening the equity gap in health care delivery. Our telehealth platform was designed to allow multiple users, including interpreters, to attend visits. This multiuser interface may not be generalizable to less-resourced health systems, and thus, attention should be paid in future research to capture the experiences of populations with limited English proficiency in a diversity of health systems. Understanding and addressing emerging health disparities and evaluating telehealth acceptability among marginalized groups will be crucial in any future implementation of telehealth.

Conclusions

Widespread telehealth adoption in response to the COVID-19 pandemic altered health care delivery during 2020 and 2021. We demonstrate high acceptability of telehealth by AYA and caregivers of AYA, a population for which very little was previously known about the acceptability and feasibility of the use of telehealth. Our data support the importance of maintaining reimbursements for telehealth as a strategy for adolescent health care delivery. Future research addressing telehealth in adolescents should focus on ensuring equity, optimizing the end-user experience, and improving confidentiality protections.

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Authors' Contributions

SMW, JC, KB, ND, and LAS conceived and designed this study. SMW was the primary writer of the manuscript, with DEA as the secondary writer. DP and JP conducted all quantitative statistical analyses. AWP, HLF, and PM conducted all qualitative analysis. All authors revised and reviewed the manuscript and approved the final copy.

Conflicts of Interest

None declared.

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Abbreviations

AYA: adolescents and young adults
IOM: Institute of Medicine
SPROUT: Supporting Pediatric Research in Outcomes and Utilization of Telehealth
STEM: SPROUT Telehealth Evaluation and Measurement

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Short Paper

Delivery Outcomes During the COVID-19 Pandemic as Reported in a Pregnancy Mobile App: Retrospective Cohort Study

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Abstract

Background: The COVID-19 pandemic has presented obstacles for providers and patients in the maternal health care setting, causing changes to many pregnant women's birth plans, as well as abrupt changes in hospital labor and delivery policies and procedures. Few data exist on the effects of the COVID-19 pandemic on the maternal health care landscape at the national level in the United States.

Objective: The aim of this study is to assess the incidence of key obstetrics outcomes (preterm delivery, Cesarean sections, and home births) and length of hospital stay during the COVID-19 pandemic as compared to the 6 months prior.

Methods: We conducted a retrospective cohort study of women aged 18-44 years in the United States who delivered between October 1, 2019, and September 30, 2020, had singleton deliveries, and completed a birth report in the Ovia Pregnancy mobile app. Women were assigned to the prepandemic cohort if they delivered between October 2019 and March 2020, and the pandemic cohort if they delivered between April and September 2020. Gestational age at delivery, delivery method, delivery facility type, and length of hospital stay were compared.

Results: A total of 304,023 birth reports were collected, with 152,832 (50.26%) in the prepandemic cohort and 151,191 (49.73%) in the pandemic cohort. Compared to the prepandemic cohort, principal findings indicate a 5.67% decrease in preterm delivery rates in the pandemic cohort ($P<.001$; odds ratio [OR] 0.94, 95% CI 0.91-0.96), a 30.0% increase in home birth rates ($P<.001$; OR 1.3, 95% CI 1.23-1.4), and a 7.81% decrease in the average hospital length of stay postdelivery (mean 2.48 days, SD 1.35). There were no overall changes in Cesarean section rates between cohorts, but differences were observed between age, race, and ethnicity subgroups.

Conclusions: Results suggest a need for continuous monitoring of maternal health trends as the COVID-19 pandemic progresses and underline the important role of digital data collection, particularly during the pandemic.

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KEYWORDS

digital health; COVID-19; maternal health; obstetrics; COVID; pandemic; pregnant women; birth; hospital; delivery; women's health; Cesarean sections

Introduction

The first confirmed case of COVID-19 in a pregnant woman in the United States was during the week of January 19, 2020. By March 8, there were over 100 confirmed cases in pregnant women per day, increasing to over 2000 cases per day by the first peak in early July [1]. By mid-to-late March 2020, the World Health Organization had declared COVID-19 a pandemic, and shortly thereafter states initiated stay-at-home orders, the Centers for Medicaid and Medicare Services expanded its coverage to include telehealth services, international travel was restricted, clinical trials were stalled, and the health care landscape was changed indefinitely [2]. During the following 16 months, and at the time of this writing, the COVID-19 pandemic presented novel obstacles for patients and providers in the maternal health care setting. For pregnant women, the risk of infection has been a source of fear and anxiety, causing many to rethink birth plans [3]. For hospitals, the virus has forced changes to labor and delivery policies and procedures, including increased restrictions on the number of allowed support persons and visitors, reduced intermediary locations for admitted patients, and expedited postpartum discharges [4].

Several studies have explored the effects of COVID-19 infection in pregnant women and on their birth outcomes, but there remains a lack of data (particularly at the national level) describing the effects of the pandemic itself—including infections and policy and lifestyle adjustments—on birth outcomes. Early studies on potential pandemic effects show decreases in preterm deliveries [5,6], as well as labor and delivery units with reductions in hospital length of stay [7]. The free Ovia Pregnancy (Ovia Health) mobile app, developed to help support women throughout their pregnancies, is uniquely positioned to address this gap by tracking real-time pregnancy and birth outcomes data on a national scale. Annually, the app serves approximately 3 million women and families across 50 states, with 60% of users logging in on iOS devices and 40% on Android.

Using user-reported data from the Ovia Pregnancy mobile app, we assessed key obstetrics outcomes throughout the COVID-19 pandemic and compared them to outcomes in the 6 months prior to the pandemic. This short paper focuses on the incidence of preterm delivery, Cesarean sections, and home births, as well as the length of hospital stays postdelivery during the first 6 months of the pandemic and the preceding 6 months.

Methods

Study Design

We conducted a retrospective cohort study of women aged 18-44 years residing in the United States who had singleton deliveries between October 1, 2019, and September 30, 2020, and completed a birth report in a pregnancy mobile app. The birth report collected delivery date, delivery method, delivery facility type, and hospital admission and discharge dates. We assigned women to the prepandemic cohort if they delivered between October 1, 2019, and March 30, 2020, and to the pandemic cohort if they delivered between April 1, 2020, and September 30, 2020. We compared gestational age at delivery, delivery method, delivery facility type, and hospital length of stay. Preterm delivery was defined as a baby born before 37 weeks of pregnancy. Delivery method options were vaginal, planned and unplanned Cesarean sections, and vaginal birth after Cesarean (VBAC). Delivery facility type options included hospital, birthing center, home birth, or other. Hospital length of stay was equal to the difference in days between hospital admission date and discharge date and was limited to those who reported stays ≤14 days. Demographic data were collected via Ovia Pregnancy app questions delivered to users as part of their app experience. With the exception of age, all demographic questions were optional.

Statistical Analysis

All analyses were conducted in R Studio (version 1.3.959; R Foundation for Statistical Computing). Descriptive statistics were calculated using the *describeBy* function and unadjusted odds ratios for categorical variables were computed using the *odds.ratio* function. Proportions tests were conducted using the *prop.test* function. Means were compared using two-sample *t* tests. Relative change from prepandemic to pandemic was also calculated for all outcomes. This study was granted exemption by an independent review board (Advarra).

Data Privacy

All of the data used in the study were collected from US resident users. All of the personal information collected by Ovia is processed in accordance with Ovia’s Privacy Policy [8] and applicable law.

Results

Sample Cohorts and Demographics

A total of 304,023 pregnant women in the United States between the ages of 18 and 44 years completed a birth report via the Ovia Pregnancy app and were thus eligible for the study. Among those, 152,832 (50.26%) women delivered between October 2019 and March 2020 and were assigned to the prepandemic cohort and 151,191 (49.73%) delivered between April 2020 and September 2020 and were assigned to the pandemic cohort. Women who reported their births represented 30.37% (prepandemic) and 31.10% (pandemic) of all women who used the app and also were expected to deliver during the respective time periods based on their logged last menstrual period date. The sample used in this study represents approximately 8.11% of annual births in the United States [9].

Among all users in the sample, 14.9% (n=45,530) completed questions about their race, 20.4% (n=61,886) completed questions about their education, 58.3% (n=177,359) completed questions about their employment status, and 21.7% (n=65,957) completed questions about their income. The majority identified as White (n=32,477, 71.33%), college-educated (n=23,085, 37.30%), and employed (n=131,420, 74.09%), and had annual household incomes over $100,000 (n=15,997, 24.25%). The average age at delivery was 28.31 years, and users in the pandemic cohort were, on average, slightly older. Demographic stratifications by cohort are shown in Table 1.

Table 1. Sample demographics prepandemic and during the pandemic.

Variables	Prepandemic (October 2019-March 2020; n=152,832)	Pandemic (April-September 2020; n=151,191)
Age at delivery (years), mean (SD)	28.2 (5.28)	28.5 (5.23)
Age group at delivery (years), n (%)		
<20	5775 (3.78)	4848 (3.21)
20-24	36,323 (23.77)	33,658 (22.26)
25-29	48,026 (31.42)	47,258 (31.26)
30-34	43,682 (28.58)	45, 687 (30.22)
35-39	15,474 (10.78)	17,152 (11.34)
40-44	2552 (1.67)	2588 (1.71)
Race, n (%)		
White (non-Hispanic)	16,571 (71.04)	15,906 (71.63)
Black (non-Hispanic)	1584 (6.79)	1467 (6.61)
Asian American/Pacific Islander	415 (1.78)	372 (1.68)
Hispanic/Latinx	1782 (7.64)	1704 (7.67)
Multiracial	2973 (12.75)	2756 (12.41)
Annual household income ($), n (%)		
<25,000	5370 (15.87)	4655 (14.49)
25,000-50,000	8047 (23.78)	7436 (23.15)
50,000-75,000	6311 (18.65)	6181 (19.24)
75,000-100,000	6034 (17.83)	5926 (18.45)
>100,000	8072 (23.86)	7925 (24.67)
Completed education level, n (%)		
Some high school	917 (2.91)	900 (2.96)
High school degree/equivalent	4123 (13.10)	3689 (12.13)
Some college	7711 (24.50)	7331 (24.10)
College degree	11,670 (37.08)	11,415 (37.53)
Some postgraduate studies	1446 (4.59)	1463 (4.81)
Postgraduate degree	5604 (17.81)	5617 (18.47)
Employment status, n (%)		
Employed	65,619 (73.53)	65,801 (74.67)
Not employed	23,619 (26.47)	22,320 (25.33)

Preterm Delivery

A total of 272,686 (89.69%) users in the sample had valid gestational ages at delivery based on the last menstrual period date. Overall preterm delivery rates had a relative decrease of 5.67%, from 8.46% (n=11,192) in the prepandemic cohort to 7.98% (n=11,216) in the pandemic cohort (*P*<.001; odds ratio [OR] 0.94, 95% CI 0.91-0.96; Table 2). When compared to the reference period of October 2019, the overall greatest relative decrease in preterm deliveries was in September 2020 (Figure 1). Those aged 25-29 years had the greatest relative decrease in preterm delivery rates at 9.70%, from 8.36% (n=3422) in the prepandemic cohort to 7.55% (n=3286) in the pandemic cohort (*P*<.001; OR 0.90, 95% CI 0.85-0.94), followed by those aged 30-34 years, who had a 7.24% relative decrease, from 8.10% (n=3036) to 7.52% (n=3223; *P*=.002; OR 0.92, 95% CI 0.87-0.97; Table 3). Compared to other races and ethnicities, White non-Hispanic users had the greatest relative decrease in preterm deliveries at 6.28%, from 7.74% (n=1069) to 7.25% (n=1069; *P*<.001; OR 0.85, 95% CI 0.78-0.94; Table 4).

Table 2. Comparison of birth outcomes prepandemic and during the pandemic.

Birth outcomes	Value, n (%)		Relative change, %	*P* value	Odds ratio (95% CI)
	Prepandemic	During the pandemic			
Reported births, n (%)	152,832 (50.26)	151,191 (49.73)	–1.05	N/A[a]	N/A
Gestational age at delivery, n (%)					
Full-term births	121,113 (91.54)	129,165 (92.01)	0.51	<.001[b]	0.94 (0.91-0.96)
Preterm births (<37 weeks)	11,192 (8.46)	11,216 (7.98)	–5.67	<.001[b]	0.94 (0.91-0.96)
Delivery method, n (%)					
Vaginal	103,808 (67.98)	102,717 (67.95)	–0.04	.79	1 (0.98-1.01)
Cesarean section	46,923 (30.73)	46,381 (30.68)	–0.16	.79	0.99 (0.98-1.01)
Vaginal birth after Cesarean	1981 (1.30)	2072 (1.37)	5.38	.29	0.96 (0.91-1.02)
Delivery facility type, n (%)					
Hospital	141,267 (91.76)	141,173 (90.97)	–0.86	<.001[b]	0.90 (0.87-0.93)
Birthing center	4812 (3.13)	4985 (3.21)	2.56	.11	1 (99.2-1.07)
Home	1535 (1.00)	2019 (1.30)	30.00	<.001[b]	1.3 (1.23-1.4)
Total out-of-hospital (birthing center + home)	6347 (4.12)	7004 (4.51)	9.47	<.001[b]	1.1 (1.06-1.14)
Hospital stay length in days, mean (SD)					
All deliveries	2.69 (1.39)	2.48 (1.35)	–7.81	<.001[b]	N/A
Vaginal + vaginal birth after Cesarean	2.42 (1.19)	2.24 (1.16)	–7.44	<.001[b]	N/A
Cesarean section	3.46 (1.62)	3.17 (1.59)	–8.38	<.001[b]	N/A

[a] N/A: not applicable.

[b] 5% statistical significance cutoff.

Figure 1. Relative change in reported birth outcomes by month, compared to reference period (October 2019).

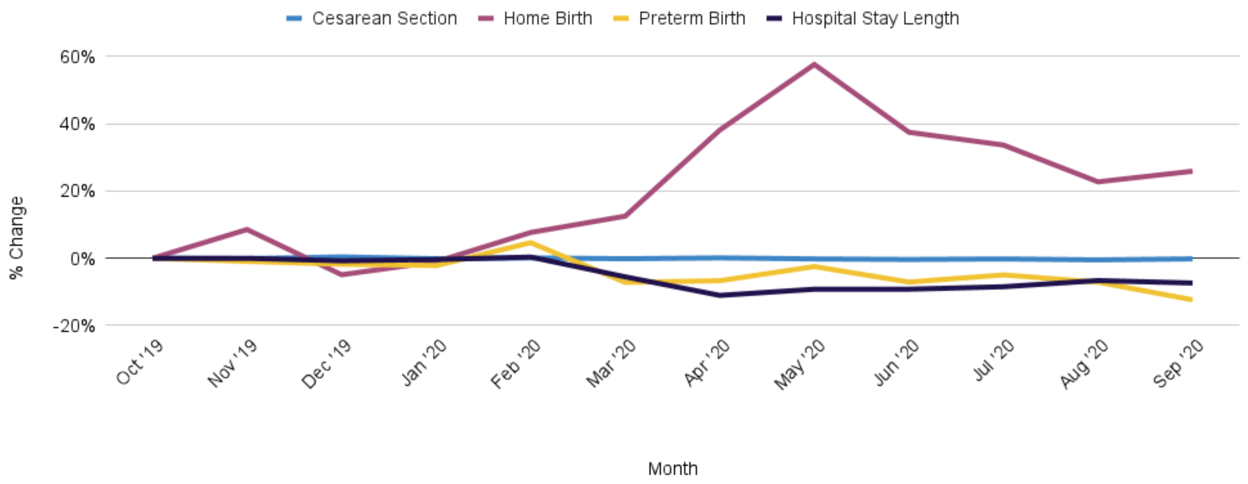

Table 3. Comparison of birth outcomes (preterm or full-term) prepandemic and during the pandemic by age group at delivery.

Age group (years), n (%)	Prepandemic, n (%)		Pandemic, n (%)		Relative change, %	*P* value	Odds ratio (95% CI)
	Preterm	Full-term	Preterm	Full-term	Preterm		
<20	474 (9.25)	4648 (90.75)	411 (9.27)	4022 (90.73)	0.19	1	1 (0.87-1.15)
20-24	2587 (8.15)	29,153 (91.85)	2572 (8.36)	28,190 (91.64)	2.58	.35	1.02 (0.97-1.08)
25-29	3422 (8.36)	37,498 (91.64)	3286 (7.55)	40,231 (92.45)	–9.70	<.001[a]	0.90 (0.85-0.94)
30-34	3036 (8.10)	34,427 (91.90)	3223 (7.52)	39,653 (92.48)	–7.24	.002[a]	0.92 (0.87-0.97)
35-39	1363 (9.29)	13,307 (90.71)	1424 (8.74)	14,873 (91.26)	–5.95	.09	0.93 (0.86-1.01)
40-44	310 (12.97)	2080 (87.03)	300 (12.02)	2196 (87.98)	–7.34	.34	0.91 (0.77-1.09)

[a] 5% statistical significance cutoff.

Table 4. Comparison of birth outcomes (preterm versus full-term) prepandemic and during the pandemic by race and ethnicity.

Race and ethnicity	Prepandemic, n (%)		Pandemic, n (%)		Relative change, %	*P* value	Odds ratio (95% CI)
	Preterm	Full-term	Preterm	Full-term	Preterm		
White (non-Hispanic)	1069 (7.74)	12,751 (92.26)	1069 (7.25)	13,677 (92.75)	–6.28	<.001[a]	0.85 (0.78-0.94)
Black (non-Hispanic)	160 (11.28)	1259 (88.72)	170 (12.59)	1180 (87.41)	0.13	.31	1.13 (0.90-1.43)
Asian American/Pacific Islander	30 (8.19)	336 (91.81)	33 (9.42)	317 (90.58)	15.03	.65	1.16 (0.69-1.97)
Hispanic/Latinx	154 (9.91)	1399 (90.09)	146 (9.24)	1433 (90.76)	–6.76	.85	1.03 (0.81-1.30)
Multiracial	241 (9.62)	2262 (90.38)	237 (9.47)	2265 (90.53)	–1.62	.88	0.98 (0.81-1.18)

[a] 5% statistical significance cutoff.

Cesarean Sections

Among the total sample, 303,882 (99.9%) users completed the delivery method field of the app's birth report form. Overall Cesarean section rates did not change significantly in the pandemic cohort compared to the prepandemic cohort (Table 2); however, there was a 11.68% relative increase in Cesareans in users under 20 years old, from 19.13% (n=1105) to 21.37% (n=1036; *P*=.004; OR 1.15, 95% CI 1.04-1.26; Table 5). Conversely, those aged 30-34 years had a 2.11% relative decrease, from 33.39% (n=14,539) to 32.68% (n=14,930; *P*=.02; OR 0.96, 95% CI 0.94-0.99; Table 5). Compared to other races and ethnicities, Black non-Hispanic users had the greatest difference in Cesarean rates with a 10.22% relative increase, from 36.48% (n=578) to 40.21% (n=590; *P*=.03; OR 1.17, 95% CI 1.01-1.35; Table 6).

Table 5. Comparison of birth outcomes (delivery method) prepandemic and during the pandemic by age group at delivery.

Age group (years), n (%)	Prepandemic, n (%)		Pandemic, n (%)		Relative change, %	*P* value	Odds ratio (95% CI)
	Cesarean section	Vaginal/vaginal birth after Cesarean	Cesarean section	Vaginal/vaginal birth after Cesarean	Cesarean section		
<20	1105 (19.13)	4670 (80.87)	1036 (21.37)	3812 (78.63)	11.68	.004[a]	1.15 (1.04-1.26)
20-24	9124 (25.13)	27,187 (74.87)	8598 (25.55)	25,059 (74.45)	1.67	.20	1.02 (0.98-1.06)
25-29	14,103 (29.38)	33,903 (70.62)	13,664 (28.92)	33,589 (71.08)	–1.57	.12	0.97 (0.95-1.00)
30-34	14,563 (33.39)	29,052 (66.61)	14,930 (32.68)	30,749 (67.32)	–2.11	.025[a]	0.96 (0.94-0.99)
35-39	6774 (41.16)	9684 (58.84)	6899 (40.24)	10,247 (59.76)	–2.24	.08	0.96 (0.92-1.00)
40-44	1254 (49.23)	1293 (50.77)	1254 (48.47)	1333 (51.53)	–1.55	.60	0.97 (0.86-1.08)

[a] 5% statistical significance cutoff.

Table 6. Comparison of birth outcomes (delivery method) prepandemic and during the pandemic by race and ethnicity.

Race and ethnicity	Prepandemic, n (%)		Pandemic, n (%)		Relative change, %	*P* value	Odds ratio (95% CI)
	Cesarean section	Vaginal/vaginal birth after Cesarean	Cesarean section	Vaginal/vaginal birth after Cesarean	Cesarean section		
White (non-Hispanic)	5070 (30.60)	11,494 (69.40)	4849 (30.49)	11,053 (69.51)	–0.38	.83	0.99 (0.94-1.04)
Black (non-Hispanic)	578 (36.48)	1006 (63.52)	590 (40.21)	877 (59.79)	10.22	.03[a]	1.17 (1.01-1.35)
Asian American/Pacific Islander	133 (32.04)	282 (67.96)	124 (33.33)	248 (66.67)	4.01	.75	1.06 (0.78-1.42)
Hispanic/Latinx	578 (32.45)	1203 (67.55)	550 (32.27)	1154 (67.73)	–0.54	.94	0.99 (0.86-1.14)
Multiracial	928 (31.21)	2045 (68.79)	839 (30.44)	1917 (69.56)	–2.47	.54	0.96 (0.86-1.07)

[a] 5% statistical significance cutoff.

Out-of-Hospital Births

Among the sample, 295,791 (97.29%) users provided their birth facility type in the app. Total out-of-hospital birth rates increased by 9.47%, from 4.12% (n=6347) to 4.51% (n=7004; *P*<.001; OR 1.1, 95% CI 1.06-1.14). When assessing home birth rates alone, there was a 30.00% relative increase in pandemic rates from 1.00% (n=1535) to 1.30% (n=2019; *P*<.001; OR 1.3, 95% CI 1.23-1.40; Table 2). The overall relative increase in home birth rates peaked in May 2020 and remained consistently high through the end of the study period (Figure 1). Users aged 35-39 years had the greatest change in home birth rates at 37.18%, increasing to 1.60% (n=270) from 1.17% (n=186; Table 7). There were no statistically significant differences when stratifying by race and ethnicity (Table 8).

Table 7. Comparison of birth outcomes (delivery location) prepandemic and during the pandemic by age group at delivery.

Age group (years), n (%)	Prepandemic, n (%)		Pandemic, n (%)		Relative change, %	*P* value	Odds ratio (95% CI)
	Home birth	Other	Home birth	Other	Home birth		
<20	33 (0.58)	5621 (99.42)	31 (0.65)	4756 (99.35)	10.95	.77	1.11 (0.67-1.82)
20-24	291 (0.83)	34,892 (99.17)	338 (1.02)	32,653 (98.98)	23.87	.007[a]	1.24 (1.06-1.45)
25-29	509 (1.10)	45,885 (98.90)	669 (1.45)	45,587 (98.55)	31.83	<.001[a]	1.32 (1.18-1.49)
30-34	486 (1.16)	41,508 (98.84)	672 (1.50)	44,087 (98.50)	29.73	<.001[a]	1.30 (1.16-1.46)
35-39	186 (1.17)	15,731 (98.83)	270 (1.60)	16,573 (98.40)	37.18	<.001[a]	1.37 (1.14-1.66)
40-44	30 (1.21)	2442 (98.79)	39 (1.53)	2502 (98.47)	26.47	.39	1.26 (0.78-2.06)

[a] 5% statistical significance cutoff.

Table 8. Comparison of birth outcomes (delivery location) prepandemic and during the pandemic by race and ethnicity.

Race and ethnicity	Prepandemic, n (%)		Pandemic, n (%)		Relative change, %	*P* value	Odds ratio (95% CI)
	Home birth	Other	Home birth	Other	Home birth		
White (non-Hispanic)	249 (1.54)	15,824 (98.46)	281 (1.80)	15,319 (98.20)	16.27	.08	1.16 (0.98-1.34)
Black (non-Hispanic)	14 (0.90)	1527 (99.10)	20 (1.38)	1422 (98.62)	52.66	.29	1.52 (0.77-3.11)
Asian American/Pacific Islander	3 (0.75)	396 (99.25)	4 (1.08)	364 (98.92)	44.57	.71	1.44 (0.23-9.96)
Hispanic/Latinx	10 (0.58)	1713 (99.42)	12 (0.71)	1665 (99.29)	23.29	.78	1.23 (0.52-2.95)
Multiracial	52 (1.80)	2822 (98.20)	69 (2.56)	2617 (97.44)	41.98	.06	1.42 (0.99-2.06)

Hospital Length of Stay

A total of 122,613 (40.33%) users who delivered in a hospital provided their admittance and discharge dates in the app. Average hospital length of stay decreased by 7.81% in the pandemic cohort (mean 2.48 days, SD 1.35) as compared to the prepandemic cohort (mean 2.69, SD 1.39; Table 2). The largest overall decrease in hospital length of stay was in April, compared to the reference period of October 2019 (Figure 1). Results were similar when stratified by birth method; mean hospital length of stay decreased by 8.38% for Cesarean sections and mean length of stay decreased by 7.44% for vaginal deliveries (Table 2). Users aged 40-44 years had the greatest decrease in mean hospital length of stay, both overall and for Cesarean deliveries, at 10.06% (mean 2.77, SD 1.65) and 14.84% (mean 3.27, SD 1.78), respectively (Table 9). Among vaginal deliveries, women aged 30-34 years had the greatest decrease in length of stay at 7.92%. Hospital length of stay decreases persisted across race and ethnicity groups. For all deliveries, multiracial users had the greatest decrease in length of stay at 11.41% (Table 10). For Cesarean sections, Asian American/Pacific Islander users had a 9.8% decrease in length of stay. For vaginal and VBAC births, Hispanic and Latinx users had the greatest decrease in length of stay at 7.92%.

Table 9. Comparison of hospital length of stay after delivery prepandemic and during the pandemic, by age group at delivery.

Age groups by delivery type	Hospital length of stay (days), mean (SD)		Relative change, %	*P* value
	Prepandemic	Pandemic		
Age groups for all deliveries (years)				
<20	2.73 (1.32)	2.56 (1.24)	–6.23	<.001[a]
20-24	2.65 (1.33)	2.48(1.33)	–6.42	<.001[a]
25-29	2.66 (1.4)	2.66 (1.32)	0.38	<.001[a]
30-34	2.7 (1.41)	2.48 (1.36)	–6.77	<.001[a]
35-39	2.84 (1.51)	2.58 (1.43)	–9.15	<.001[a]
40-44	3.08 (1.62)	2.77 (1.65)	–10.06	<.001[a]
Age groups for Cesarean sections (years)				
<20	3.47 (1.52)	3.3 (1.42)	–4.90	.05
20-24	3.42 (1.57)	3.19 (1.62)	–6.73	<.001[a]
25-29	3.47 (1.67)	3.13 (1.52)	–9.80	<.001[a]
30-34	3.44 (1.59)	3.18 (1.63)	–7.56	<.001[a]
35-39	3.52 (1.60)	3.19 (1.58)	–9.38	<.001[a]
40-44	3.84 (1.83)	3.27 (1.78)	–14.84	<.001[a]
Age groups for vaginal + vaginal birth after Cesarean deliveries (years)				
<20	2.57 (1.22)	2.38 (1.13)	–7.39	<.001[a]
20-24	2.44 (1.16)	2.28 (1.16)	–6.56	<.001[a]
25-29	2.38 (1.18)	2.21 (1.15)	–7.14	<.001[a]
30-34	2.40 (1.20)	2.21 (1.13)	–7.92	<.001[a]
35-39	2.46 (1.32)	2.27 (1.23)	–7.72	<.001[a]
40-44	2.50 (1.15)	2.41 (1.44)	–3.60	.26

[a] 5% statistical significance cutoff.

Table 10. Comparison of hospital length of stay prepandemic and during the pandemic, by race and ethnicity.

Race/ethnicity by delivery type	Hospital length of stay (days), mean (SD)		Relative change, %	*P* value
	Prepandemic	Pandemic		
Race/ethnicity for all deliveries				
White (non-Hispanic)	2.58 (1.36)	2.32 (1.24)	–10.47	<.001[a]
Black (non-Hispanic)	2.84 (1.45)	2.57 (1.43)	–9.51	<.001[a]
Asian American/Pacific Islander	2.74 (1.57)	2.46 (1.15)	–10.22	<.001[a]
Hispanic/Latinx	2.44 (1.21)	2.33 (1.29)	–4.51	.07
Multiracial	2.63 (1.41)	2.33 (1.24)	–11.41	<.001[a]
Race/ethnicity for Cesarean sections				
White (non-Hispanic)	3.47 (1.52)	3.3 (1.42)	–4.90	.05
Black (non-Hispanic)	3.42 (1.57)	3.19 (1.62)	–6.73	<.001[a]
Asian American/Pacific Islander	3.47 (1.67)	3.13 (1.52)	–9.80	<.001[a]
Hispanic/Latinx	3.44 (1.59)	3.18 (1.63)	–7.56	<.001[a]
Multiracial	3.52 (1.6)	3.19 (1.58)	–9.38	<.001[a]
Race/ethnicity for vaginal + vaginal birth after Cesarean deliveries				
White (non-Hispanic)	2.57 (1.22)	2.38 (1.13)	–7.39	<.001[a]
Black (non-Hispanic)	2.44 (1.16)	2.28 (1.16)	–6.56	<.001[a]
Asian American/Pacific Islander	2.38 (1.18)	2.21 (1.15)	–7.14	<.001[a]
Hispanic/Latinx	2.4 (1.2)	2.21 (1.13)	–7.92	<.001[a]
Multiracial	2.46 (1.32)	2.27 (1.23)	–7.72	<.001[a]

[a] 5% statistical significance cutoff.

Discussion

Principal Findings

This paper describes key birth outcomes during the COVID-19 pandemic. Our results indicate a decline in preterm births, a contrast to recent trends in the United States reflecting data from nonpandemic years [9,10]. These results were most prominent among those aged 25-29 years and 30-34 years, and among White users. The overall declines align with other reports indicating COVID-19–related decreases in preterm deliveries, many of which have suggested several plausible reasons for the decline, including less exposure to infection and other consequences of physical distancing, mask wearing, increased attention to health and exercise, and possible reduction in antenatal surveillance that might lead to medical interventions and early delivery [5,6]. As these studies also suggest, more in-depth research is needed to test the plausibility of any one hypothesis.

Overall results indicated no change in Cesarean section rates between the two cohorts, but age-specific results showed increases in Cesarean section rates among those under 20 years and decreases in those aged 30-34 years. When comparing race and ethnicity, Black non-Hispanic users had a significant increase in Cesareans compared to all other race groups. Special attention and further research should be conducted to address age-specific differences, as well as social determinants of health that disproportionately affect Black pregnant women, particularly during the COVID-19 pandemic.

We also found a significant increase in home births in just 6 months, compared to national reports indicating no change in home birth rates between 2018 and 2019 [9]. This change was especially apparent in users aged 35-39 years. It is important that providers be diligent in informing patients and providing appropriate resources about home birth risks, as planned home births are associated with poorer outcomes for most of the population, as compared to hospital births [11].

Our study also shows a decreased average length of stay after delivery among those who delivered in a hospital, particularly among those aged 40-44 years and those who are multiracial. Reduced hospital length of stay has both positive and negative implications: decreased hospital stay length could lead to increased readmission rates and costs, and poorer postpartum and neonatal outcomes [12]. Conversely, early discharge may reduce SARS-CoV-2 exposure with limited adverse consequences in low-risk patients [7].

Limitations

Our study is limited in that those who choose to report the details of their deliveries in an app may differ from those who do not. We are also reliant on user-reported data, which we recognize can present additional biases. Relatedly, while we do present some demographic data in this paper, we are largely restrained by demographic data completeness for this population, as most demographic fields in the Ovia Pregnancy app are not required or collected in the sign-up process. As such, sample sizes were limited when performing stratified analyses, and in-app questions, such as household income, education level, and employment status may have been completed and unchanged outside of the study time period.

We also know that SARS-CoV-2 infection may play a significant role in the birth outcomes described here [13], and we are limited in that the Ovia Pregnancy app does not collect specific COVID-19 infection data.

Conclusions

As the pandemic progresses, continuous monitoring of these trends and others is necessary to evaluate long-term effects on birth outcomes. The use of digital data collection is paramount to monitoring these trends in real time, particularly during a time when there are increased limitations regarding access to care.

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Conflicts of Interest

None declared.

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Abbreviations

OR: odds ratio
VBAC: vaginal birth after Cesarean

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Corrigenda and Addenda

Correction: Youths' and Parents' Experiences and Perceived Effects of Internet-Based Cognitive Behavioral Therapy for Anxiety Disorders in Primary Care: Mixed Methods Study

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In "Youths' and Parents' Experiences and Perceived Effects of Internet-Based Cognitive Behavioral Therapy for Anxiety Disorders in Primary Care: Mixed Methods Study" (JMIR Pediatr Parent 2021;4(4):e26842) the authors noted one error.

In the originally published manuscript, some affiliations were missing for first author Josefine Lotten Lilja. Only affiliation 1 was listed for this author, but all 3 affiliations on the paper should have been listed for this author.

The full list of authors and affiliations was originally published as follows:

> *Josefine Lotten Lilja[1*], PhD; Mirna Rupcic Ljustina[1], PsyM; Linnea Nissling[1,2,3*], PsyM; Anna Caroline Larsson[1*], PsyM; Sandra Weineland[1,2,3*], PhD*
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The correction will appear in the online version of the paper on the JMIR Publications website on December 2, 2021, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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