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Original Paper

# Proxy Information Seeking by Users of a Parenting Information Website: Quantitative Observational Study

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## Abstract

**Background:** One of the largest groups of consumers who seek health information on the internet are parents of young children, as well as people in their social circle. The concept of proxy seeking (on behalf of others) has been explored in the literature, yet little is known about the outcomes.

**Objective:** The main aim of this study was to describe consumer health information outcomes reported by proxy seekers using a parenting website.

**Methods:** We conducted a 2-year quantitative observational study. Participants were parents of 0- to 8-year-old children and members of their entourage in Canada who had accessed *Naître et Grandir* through the website or through a weekly newsletter. For each *Naître et Grandir* webpage, participants' perceptions regarding the outcomes of seeking and using specific webpages were gathered using a content-validated Information Assessment Method questionnaire. We compared the outcomes reported by parents with those reported by members of their entourage after consulting a parenting information website and explored if the method of accessing the information by the proxy seekers (website or weekly newsletter) changed the outcomes reported. For key primary survey items, the chi-square test was conducted, and differences in relative frequencies of responses were computed along with confidence intervals.

**Results:** A total of 51,325 completed questionnaires were included in the analysis, pertaining to 1079 *Naître et Grandir* webpages (mean 48; range 1-637). Compared to parents, individuals in the entourage are more likely to report using the information in discussion with others (mean difference 0.166, 95% CI 0.155-0.176). Parents, on the other hand, were more likely than the entourage to report using the information to better understand (mean difference 0.084, 95% CI 0.073-0.094), to decide to do something (mean difference 0.156, 95% CI 0.146-0.166), or to do something in a different manner (mean difference 0.052, 95% CI 0.042-0.061). In addition, results suggest that the differences in perceived benefits of parenting information by the entourage depend on how they access the information. Respondents who were actively seeking the information (through the website) were more likely to report that the information would help them be less worried (mean difference 0.047; 95% CI 0.024-0.069), handle a problem (mean difference 0.083; 95% CI 0.062-0.104), and decide what to do with someone else (mean difference 0.040, 95% CI 0.020-0.058). Respondents who passively acquired the information (through the newsletter) were more likely to report that the information would help improve the health or well-being of a child (mean difference 0.090; 95% CI 0.067-0.112).

**Conclusions:** By better understanding how consumers and their entourages use information, information providers can adapt information to meet both individual and group needs, and health care practitioners can target patients' entourages with web-based health information resources for dissemination and use.

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**KEYWORDS**

consumer health information; information seeking behavior; child development; child health; information outcomes; health information; digital health; parenting; online information



## Introduction

### Background

In 2017, almost all (99.0%) Canadian households had fixed broadband internet access [1], and 75% to 96% of Canadians aged 15 to 64 years used the internet on a daily basis [2]. This is in line with other Organization for Economic Cooperation and Development (OECD) countries, in which more than 80% of households have access to high-speed internet [3]. In these countries, the proportion of adults seeking consumer health information on the internet has more than doubled between 2008 and 2017 [4]. The internet is a frequently accessed platform for finding consumer health information, in addition to common health information sources such as health care professionals or members of one's social circle, and other sources such as books and television [5,6]. The use of trustworthy consumer health information from the internet can improve quality of life and is generally associated with increased empowerment of consumers and their families and with improved health outcomes [6-8].

There are, however, still barriers to benefitting from consumer health information from the internet. These include illness challenges, such as someone being too physically or mentally incapacitated to start a search for themselves. A second barrier may be lower eHealth literacy, meaning a consumer's ability to seek, find, understand, and appraise consumer health information from the internet and apply the knowledge gained to addressing health issues. At least one-third of the population of 18 OECD countries may have low health literacy [9]. Moreover, when faced with a stressful situation, consumers may experience transitory low literacy level, as the interdependence between information and emotion is well established in the literature [10]. Finally, there are negative outcomes (or tensions) reported by users seeking consumer health information from the internet and health care practitioners.

Our recent qualitative study [11] described personal tensions, such as increased anxiety and interpersonal tensions between patients and physicians as a result of discussing consumer health information from the internet, and service-related tensions, such as postponing a clinical visit [11]. One strategy to reduce these tensions is discussing the information with someone in one's social circle [11]. Approximately 90% of individuals in OECD countries report having access to social support (eg, relatives or friends) who can help them in times of need [12]. Access to social support is positively linked to internet access and use because these providers of support are internet users themselves and have relevant support and awareness [13]. Proxy consumer health information seeking on the internet is a common phenomenon: almost two-thirds of consumer health information seekers have reported searching on behalf of someone else to provide informational social support [14-16]. This proxy consumer health information seeking on the internet may overcome previously mentioned barriers. This is especially true if the support provider has higher eHealth literacy than the receiver: they are thus better able to explain, contextualize, or validate the information [17,18]. However, while there are several studies [19-21] that explored behavior related to proxy

consumer health information seeking on the internet, few explored how the seeker uses the information with others, and what outcomes they report as a result of this use.

### Parents and Proxy Health Information-Seeking Behavior and Outcomes

One of the largest groups of consumers of web health information consumers is parents of young children. A recent systematic review [22] and empirical studies [23,24] on how parents find, use, and evaluate consumer health information from the internet for their children reported that parents worldwide are heavy users across diverse circumstances. Parents find the information themselves or reach out to their social circle (or entourage) for tailored advice, emotional support, and culturally relevant parenting information [25]. A 2015 survey, conducted in Quebec, of a representative sample of 23,693 parents of preschool children showed that only 1.5% of parents do not know where to find information on the internet about children, either directly or mediated by someone else [26] as a proxy—"seeking information in a nonprofessional or informal capacity on behalf (or because) of others without necessarily being asked to do so [27]."

Previous work [28] shows that the use of high-quality parenting consumer health information from the internet by mothers can lead to benefits such as decreased worries and increased self-confidence in decision-making, regardless of socioeconomic status [28]. However, little is known about proxy information seeking by the entourage of parents. The main objective of this study was to explore these outcomes as reported by users of a parenting information website. A secondary objective was to explore if the method of obtaining the information influences the reported outcomes of proxy information seeking on the internet.

## Methods

### Design

We conducted a 2-year quantitative observational study. Ethical approval was obtained from the institutional review board of the Faculty of Medicine, McGill University, prior to the start of data collection. We used the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) checklist [29].

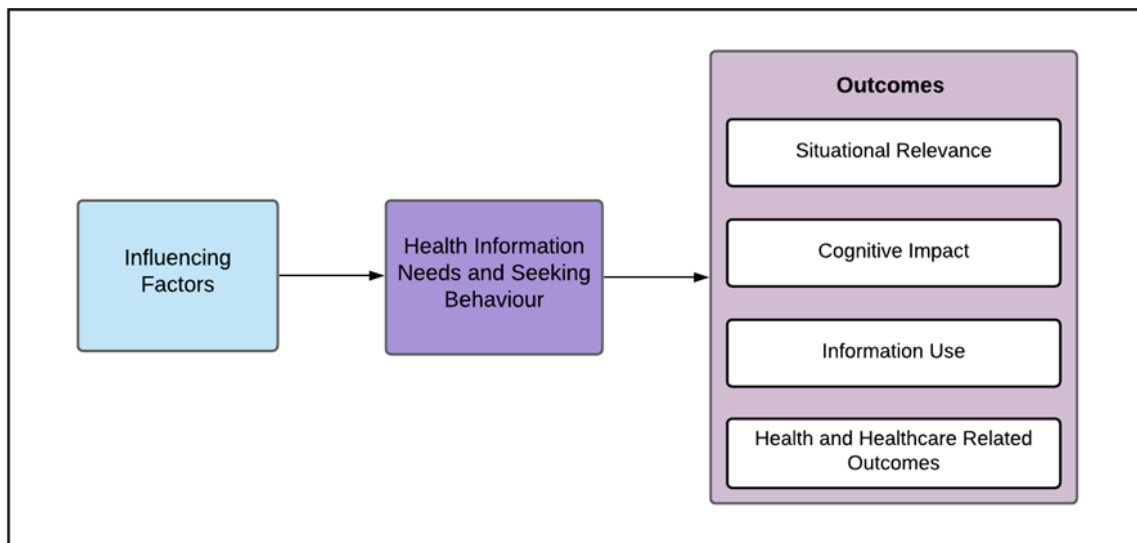
### Consumer Health Information From the Internet Outcomes

A conceptual framework (Figure 1) was adapted from [30]. There are 4 types of influencing factors: individual characteristics (eg, age and income), sociotechnical factors (eg, eHealth literacy and social support), patient-professional relationships, and education-health-social resources. Together, these factors determine the extent to which information is accessed and how it is used by patients. An information need is a condition in which "certain information contributes to the achievement of a genuine or legitimate information purpose [31]." These needs may be explicitly stated or implicitly understood based on an individual's health status or situation [31]. Seeking consumer health information on the internet is

purposive and active searching for information as a consequence of an information need or to satisfy a goal [32]. Finally, there are 4 individual levels of web-based consumer health

information-seeking outcomes: situational relevance, cognitive impact, and use of information, and health and health care-related outcomes.

**Figure 1.** Outcomes framework.



### **Naître et Grandir**

The *Naître et Grandir* website provides parents with support in raising their children, from the time they are conceived until they are 8 years old.

*Naître et Grandir* is funded by the Lucie and André Chagnon Foundation, a philanthropic organization that seeks to contribute to the prevention of poverty through the creation of conditions and environments that are favorable to the educational success of children, specifically, those from socially vulnerable families and communities. Low health literacy levels in parents are detrimental to child health education, healthy behaviors, health, and medication, thus *Naître et Grandir* is an important resource for French-speaking parents and their entourage [33]. In addition to accessing the website directly, *Naître et Grandir* readers can sign up to receive a weekly newsletter containing links to *Naître et Grandir* webpages tailored to their child's age. *Naître et Grandir* provides free parenting information content produced using an expert-based process and an editorial process that caters to lower health literacy levels (Grade 8 reading levels) with additional audio and video formats [28].

Since 2014, our team at McGill University and *Naître et Grandir* have worked in partnership to implement the Information Assessment Method questionnaire for evaluating the pages of parenting information. In addition, *Naître et Grandir* has been able to improve informational content based on the comments provided by Information Assessment Method users, which are coded by 2 editors in a web-based system. This is referred to as 2-way knowledge translation [34].

### **Information Assessment Method**

The framework is operationalized in the Information Assessment Method questionnaire used to evaluate health information outcomes from the viewpoint of information users (clinicians, managers, patients and public) [35]. The Information Assessment Method questionnaire has been content validated for different audiences using participatory mixed methods (integrating quantitative survey data with qualitative insights [36]). It has been implemented by different information providers to allow information users to rate specific health information content on the internet (eg, a webpage), stimulate their reflection, and collect feedback [35]. Consequently, responses and comments can be used by information providers to improve content.

The validity of the Information Assessment Method has been assessed on 2 occasions: It was first validated specifically for parents in 2015 using quantitative data (raters' responses) and qualitative data (raters' comments and qualitative interviews [37]). It was then validated again in 2019 specifically for parents of lower socioeconomic status using qualitative data from interviews with low-socioeconomic status parents used in this study [28] and was validated in French (as it is implemented with *Naître et Grandir*) and underwent a transcultural adaptation into English ([Multimedia Appendix 1](#)). When *Naître et Grandir* readers land on a webpage corresponding to a specific topic (directly or through the newsletter link), a lateral tab appears inviting them to complete a survey ([Figure 2](#)).

Figure 2. Screenshot from a *Naître et Grandir* page.

### Study Participants and Data Collection

Data collection was co-constructed with *Naître et Grandir* in the course of the ongoing partnership. The editors of *Naître et Grandir* provided feedback on the questionnaire; however, they did not influence the data analysis and interpretation.

Participants in this study were *Naître et Grandir* readers in Canada and 4 other OECD countries with francophone populations (France, Belgium, Switzerland, and Luxembourg) that have similar health and social systems and comparable average household incomes, internet access, and reported social support levels [12].

Each participant had arrived at a specific *Naître et Grandir* webpage (either directly through the website), had clicked on the lateral tab, and had completed the Information Assessment Method questionnaire asking them to evaluate that specific *Naître et Grandir* webpage during the study period (April 13, 2019 to March 30, 2021). All completed questionnaires were included in the analysis. Among them, participants were divided into 2 group—self-identified parents of 0- to 8-year-old children or an entourage member (grandparent, family member, friend, neighbor, or professional working with children). A second analysis was conducted in the entourage group between those who had accessed the *Naître et Grandir* webpage and Information Assessment Method questionnaire through the weekly newsletter and those who had landed directly on the *Naître et Grandir* website. Variables included in the analysis correspond to the Information Assessment Method questions. No incentive was provided to participate.

### Statistical Analysis

Comparisons (1) between parents and entourage Information Assessment Method responses and (2) between newsletter and website Information Assessment Method responses from entourage were assessed using frequency analyses. Difference in proportions with 95% confidence intervals were calculated [38,39]. To take multiple comparisons into account and retain a global Type I error level of 5%, confidence levels were corrected using Bonferroni adjustment. In addition, the Pearson chi-square test was used to determine whether the differences between 2 groups of participants were statistically significant. Test results were deemed statistically significant when  $P$  values  $< .001$ . All statistical analyses were completed using SAS software (version 9.4; SAS Institute).

### Hypotheses

Based on our previous work exploring information outcomes, we hypothesized that, when the information is considered relevant and easy to understand, the entourage would be more likely to report discussing the information with others. We also hypothesized that, similar to previous work on parents' responses, there would be a difference in entourage responses based on mode of access.

## Results

### All Respondents

Over the 2-year study period, 69,260 Information Assessment Method questionnaires were completed. Questionnaires completed by participants outside the countries of interest in this study and by participants who did not identify as parents or entourage members were excluded (Figure 3). In total, 51,325

completed Information Assessment Method questionnaires were included in the analysis, pertaining to 1079 *Naître et Grandir* webpages (mean 48; range 1-637). Most respondents were in Canada (29,972/51,325, 58.4%) and France (18,461/51,325, 36%) (Figure 4). Parents comprised 79.2% (40,628/51,325) of

participants, and grandparents were the most common entourage members (6309/51,325, 12.3%), followed by professionals, family, and friends (4388/51,325, 8.5%). The response rates of parents and entourage exhibited similar patterns (Figure 5).

Figure 3. Information Assessment Method (IAM) questionnaires included in the analysis.

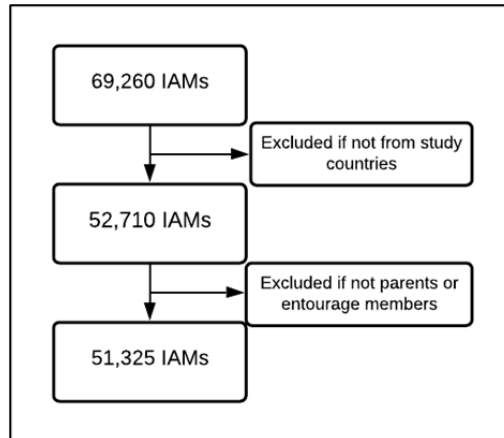


Figure 4. Respondent distribution by country.

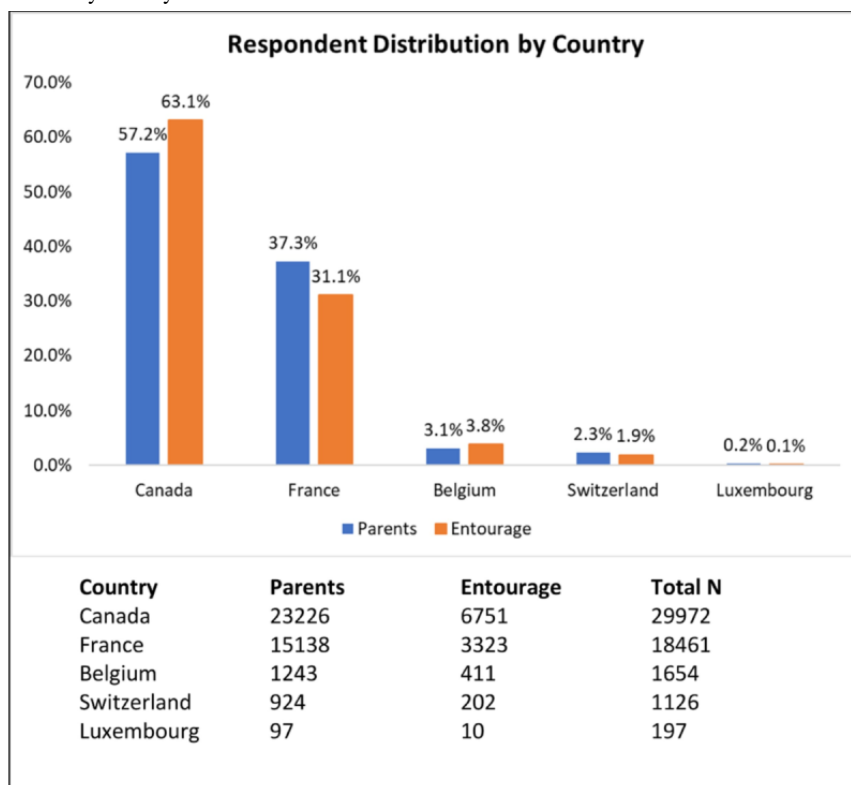
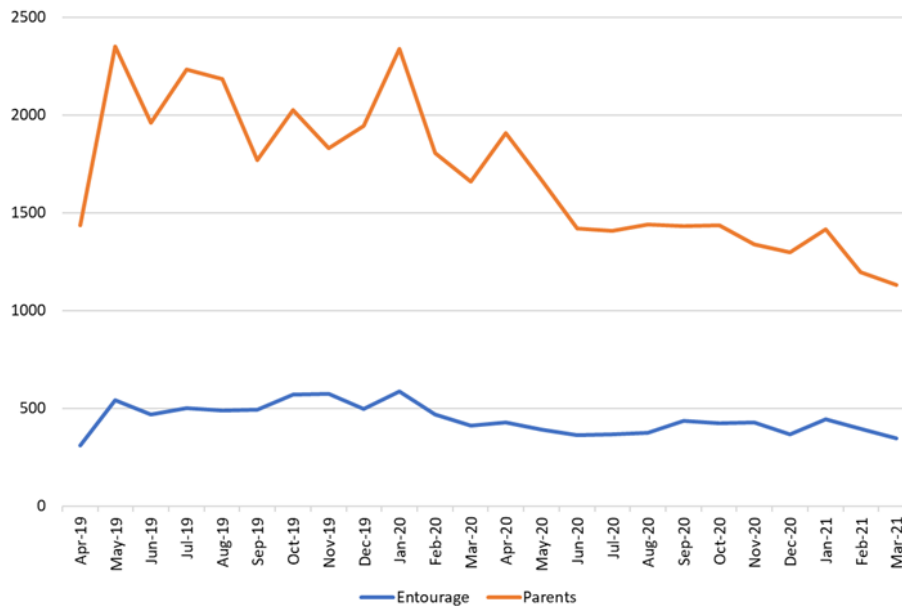


Figure 5. Response rate by month.



### Comparing Parents and Entourage

Of the 51,325 Information Assessment Method questionnaires, 40,628 (79.2%) were completed by parents and 10,697 (20.8%) were completed by entourage members.

Parents were more likely to report using parenting information to better understand (mean difference 0.084, 95% CI 0.073-0.094), to decide to do something (mean difference 0.156, 95% CI 0.146-0.166), or to do something in a different manner

(mean difference 0.052, 95% CI 0.042-0.061). They were also more likely to report that it helped them improve the health or well-being of a child (mean difference 0.039, 95% CI 0.028-0.049) and to be less worried (mean difference 0.104, 95% CI 0.093-0.114). The entourage members were more likely to use the information in discussion with someone else (mean difference 0.166, 95% CI 0.155-0.176) and report that the information helped them decide what to do with someone else (Table 1).

**Table 1.** Perceived information outcomes: Information Assessment Method responses of entourage members and parents.

Questions and response options	Entourage members (n=10,697), n (%)	Parents (n=40,628), n (%)	All participants (n=51,325), n (%)
<b>Q1. Is this information relevant?</b>			
Very relevant (this is the information I expected)	7444 (69.6)	27,817 (68.5)	35,261 (68.7)
Relevant	2993 (27.9)	11,707 (28.8)	14,700 (28.6)
Somewhat relevant	123 (1.1)	654 (1.6)	777 (1.5)
Very little relevant (this is not the information I expected)	137 (1.3)	450 (1.1)	587 (1.1)
<b>Q2. Did you understand this information?</b>			
Very well (I understood everything)	9870 (92.3)	37,834 (93.1)	47,704 (92.9)
Well	777 (7.3)	2698 (6.6)	3475 (6.8)
Poorly	26 (0.2)	51 (0.1)	77 (0.2)
Very poorly (I did not understand much)	24 (0.2)	45 (0.1)	69 (0.1)
<b>Q3. What do you think about this information?<sup>a</sup></b>			
This information allowed me to validate what I do or did	5611 (52.5)*	25,922 (63.8)	31,533 (61.4)
This information taught me something new	4753 (44.4)*	22,869 (56.3)	27,622 (53.8)
This information reassured me	2966 (27.7)*	17,037 (41.9)	20,003 (39.0)
This information refreshed my memory	3811 (35.6)*	9348 (23.0)	13,159 (25.6)
This information motivated me to learn more	2550 (23.8)*	8846 (21.8)	11,396 (22.2)
I do not like with this information	204 (1.9)	900 (2.2)	1104 (2.2)
<b>Q4. Will you use this information?</b>			
Yes	10,082 (94.3)	38,970 (95.9)	49,052 (95.6)
No	615 (5.8)	1658 (4.1)	2273 (4.4)
<b>Q4a. How will you use this information for you or for a child in your care?<sup>a</sup></b>			
This information will help me to better understand.	4691 (46.5)	21,208 (54.4)	25,899 (52.8)
I will use this information to do something.	3637 (36.1)	20,143 (51.7)	23,780 (48.5)
I will use this information to do something in a different manner.	3026 (30.0)	13,585 (34.9)	16,611 (33.9)
I will use this information in a discussion with someone else.	4264 (42.3)	9473 (24.3)	13,737 (28.0)
I will use this information in another way.	356 (3.5)	760 (1.9)	1116 (2.3)
<b>Q5. Using this information, do you expect any benefits for you and at least one child (0-8 years)?</b>			
Yes	10,044 (93.9)	38,477 (94.7)	48,521 (94.5)
No	653 (6.1)	2151 (5.3)	2804 (5.5)
<b>Q5a. Which benefits do you expect for you and at least one child (0-8 years)?<sup>a</sup></b>			
This information will help me to improve the health or well-being of my child.	6690 (62.5)	26,976 (66.4)	33,666 (65.6)
This information will help me to be less worried.	3480 (32.5)	17,424 (42.9)	20,904 (40.7)
This information will help me to prevent a problem or the worsening of a problem.	3184 (29.8)	12,406 (30.5)	15,590 (30.4)
This information will help me to handle a problem.	3226 (30.2)	12,966 (31.9)	16,192 (31.6)
This information will help me decide what to do with someone else.	2137 (20.0)	5597 (13.8)	7734 (15.1)
Another benefit.	408 (3.8)	871 (2.1)	1279 (2.5)

<sup>a</sup>More than 1 option could be selected.



### Comparing Website and Newsletter Respondents

Of 10,697 Information Assessment Method questionnaires completed by the entourage, 1953 (18.3%) accessed the webpage through the newsletter and 8744 (81.7%) directly through the website. Respondents through the newsletter were more likely to report using the information to do something (mean difference 0.117, 95% CI 0.092-0.141) or do something differently (mean difference 0.067, 95% CI 0.044-0.090) and expected that the information would help to improve the health or well-being of

a child (mean difference 0.090; 95% CI 0.067-0.112). Respondents who accessed *Naitre et Grandir* directly through the website were more likely to report that using the information would help them be less worried (mean difference 0.047; 95% CI 0.024-0.069), handle a problem (mean difference 0.083; 95% CI 0.062-0.104), and decide what to do with someone else (mean difference 0.040, 95% CI 0.020-0.058). Both groups were equally likely to report using the information in discussion with someone else (mean difference 0.015; 95% CI -0.009-0.040) (Table 2).

**Table 2.** Perceived information outcomes: Information Assessment Method responses of entourage newsletter and website respondents.

Questions and response options	Entourage newsletter (n=1953), n (%)	Entourage website (n=8744), n (%)	All entourage (n=10,697), n (%)
<b>Q1. Is this information relevant?</b>			
Very relevant (this is the information I expected)	1547 (79.2)	5897 (67.4)	7444 (69.6)
Relevant	390 (20.0)	2603 (29.8)	2993 (28.0)
Somewhat relevant	7 (0.4)	116 (1.3)	123 (1.2)
Very little relevant (this is not the information I expected)	9 (0.5)	128 (1.5)	137 (1.3)
<b>Q2. Did you understand this information?</b>			
Very well (I understood everything)	1891 (96.8)	7979 (91.3)	9870 (92.3)
Well	59 (3.0)	718 (8.2)	777 (7.3)
Poorly	1 (0.1)	25 (0.3)	26 (0.2)
Very poorly (I did not understand much)	2 (0.1)	22 (0.3)	23 (0.2)
<b>Q3. What do you think about this information?<sup>a</sup></b>			
This information allowed me to validate what I do or did	1118 (57.3)	4493 (51.4)	5611 (52.5)
This information taught me something new	898 (46.0)	3855 (44.1)	4753 (44.4)
This information reassured me	519 (26.6)	2447 (28.0)	2966 (27.7)
This information refreshed my memory	839 (43.0)	2972 (34)	3811 (35.6)
This information motivated me to learn more	427 (21.9)	2123 (24.3)	2550 (23.8)
I do not like with this information	29 (1.5)	175 (2.0)	204 (1.9)
<b>Q4. Will you use this information?</b>			
Yes	1902 (97.4)	8180 (93.6)	10,082 (94.3)
No	51 (2.6)	564 (6.5)	615 (5.8)
<b>Q4a. How will you use this information for you or for a child in your care?<sup>a</sup></b>			
This information will help me to better understand.	865 (45.5)	3826 (46.8)	4691 (46.5)
I will use this information to do something.	850 (44.7)	2787 (34.1)	3637 (36.1)
I will use this information to do something in a different manner.	659 (34.7)	2367 (28.9)	3026 (30.0)
I will use this information in a discussion with someone else.	754 (39.6)	3510 (42.9)	4264 (42.3)
I will use this information in another way.	53 (2.8)	303 (3.7)	356 (3.5)
<b>Q5. Using this information, do you expect any benefits for you and at least one child (0-8 years)?</b>			
Yes	1891 (96.8)	8153 (93.2)	10,044 (93.9)
No	62 (3.2)	591 (6.8)	653 (6.1)
<b>Q5a. Which benefits do you expect for you and at least one child (0-8 years)?<sup>a</sup></b>			
This information will help me to improve the health or well-being of my child.	1365 (69.9)	5325 (60.9)	6690 (62.5)
This information will help me to be less worried.	561 (28.7)	2919 (33.4)	3480 (32.5)
This information will help me to prevent a problem or the worsening of a problem.	605 (31.0)	2579 (29.5)	3184 (29.8)
This information will help me to handle a problem.	456 (23.4)	2770 (31.7)	3226 (30.2)
This information will help me decide what to do with someone else.	327 (16.7)	1810 (20.7)	2137 (20.0)
Another benefit.	77 (3.9)	331 (3.8)	408 (3.8)

<sup>a</sup>More than 1 option could be selected.



## Discussion

### Principal Findings

Results support our first hypothesis that individuals in the entourage were more likely to report using the information in discussion with others. Parents, on the other hand, were more likely to report using the information to do something. This may reflect the trustworthiness of the information on *Naître et Grandir*—the entourage felt comfortable sharing it and parents feel comfortable applying it.

Our second hypothesis was also supported. Results suggest that the differences in perceived outcomes reported by the entourage depend on how they access the information. When the information is acquired through active seeking by the respondents through the *Naître et Grandir* website, there were differences in the reported use and benefits. These findings can be explained by the literature on information seeking behavior (Table 3), specifically Bates's integrated model of information seeking [40], in which, there are 2 forms of information seeking: directed, through searching and monitoring when there is a known information need, and undirected, through browsing and being unaware when the information need is unknown.

**Table 3.** Applying of the integrated model of information seeking [40] to this study's context.

Form	<i>Naître et Grandir</i> website	<i>Naître et Grandir</i> newsletter
Information need	Known	Unknown
Information seeking mode	Directed and active	Undirected and passive

In our study, respondents arrived on the website through directed and active searching that was likely triggered by a known information need such as an existing health problem. The entourage members responding through the website were also aware of the information need by the parents, either because it was stated explicitly by the parents or understood implicitly through social interactions. The entourage members in this context may have closer social ties and may be involved in the decision making, either directly or indirectly, by providing social support. The entourage in this group were thus more likely to report that the information they found would help them to be less worried, help them handle a problem, and help them decide what to do with someone else. On the other hand, entourage respondents through the newsletter were less likely to have a known information need and would have clicked on one of the relevant articles out of interest or curiosity (undirected and passive information seeking). This group was more likely to report that the information would help them improve the health or well-being of a child.

### Comparison With Prior Work

We identified the role of known and unknown information needs on the outcomes of proxy information seeking by entourage members, by comparing entourage website and newsletter users. This is the first unique contribution of our study, as most similar studies [14-16,19] have focus on directed consumer health information seeking on the internet triggered by a known information need. Our study also describes these outcomes from the entourage or proxy seeker's perspective. Another study [11], which explored negative outcomes of seeking consumer health information on the internet from the individual's perspective, reported that in situations wherein informational support from the entourage is unsolicited and the individual does not feel that the information is relevant to their situation, interpersonal tensions between both parties may develop.

We explored the phenomenon of proxy consumer health information seeking using an evidence-based web-based consumer health information source that caters to lower health literacy. Thus, common barriers to positive outcomes such as health literacy and misinformation were somewhat removed,

and we could describe the outcomes experienced by parents and their entourage in this context. A recent scoping review [41], which explored parents' web-based health information-seeking behaviors to inform vaccination choices for their children, reported significant misinformation on the topic on the internet and suggested parents' digital health literacy may influence their decisions.

Our results are transferable to other contexts. While we do not claim statistical generalizability as the study sample was self-selected, respondents were not limited by demographic criteria and thus represent a diverse sample of parents and their entourage. Moreover, our respondents rated webpages presenting a wide number of health and well-being topics (ie, not focused on any specific illness or condition). A recent systematic review [22], which explored health information seeking on the internet by parents for their children, identified lack of generalizability as the most frequently mentioned limitation of the studies included in the review. In fact, an agenda item for future research studies was the need for studies with generalizable samples outside clinical environments with specific populations of children who are ill [22]. While the review [22] explored parent health information seeking on the internet as a form of proxy seeking, their findings do not apply to other types of proxy seeking [22]. In this study, we provided insight into another type of proxy seeking and the reported outcomes.

### Limitations

Our study has 3 main limitations. First, participants were self-selected volunteers who completed one questionnaire at one point of time (a source of selection bias). This likely led to an overestimation of positive outcomes due to social desirability bias [42]. However, this bias will have influenced both parents and the entourage in the same manner and thus did not affect the comparative analysis. Moreover, we cannot assume website users and newsletter users were mutually exclusive. Second, we did not explore variables such as the strength of the social ties between the entourage and the parents and child for whom they were using *Naître et Grandir*. Other studies [16,43,44] have reported that proxy information seekers are likely to have strong ties with the people they are helping and tend to provide

other forms of social support such as emotional support. This limitation will be addressed in a future study with entourage members.

### Conclusions

The results will be used to refine and improve the existing conceptual framework on consumer health information outcomes on the internet by filling in the gap on the role of the information need. When information is acquired through active directed seeking by the respondents from the *Naître et Grandir* website, they were likely to use it and report positive outcomes related

to an existing problem. When information is acquired from the weekly newsletter, respondents were more likely to report more general positive outcomes. Regardless of how they accessed information, members of the entourage were likely to discuss it with others. Practical intervention strategies can focus on improving proxy health information seeking on the internet and extend social support networks for people without an effective entourage. Future studies can explore how members of the entourage use the information from *Naître et Grandir* with others in their social circle.

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### Authors' Contributions

PP, TS, and RG provided supervision. All authors contributed to the study design and review of this manuscript. RES performed the statistical analysis.

### Conflicts of Interest

RG and PP are consultants for *Naître et Grandir*.

### Multimedia Appendix 1

Information Assessment Method questionnaire.

[[DOCX File, 16 KB - pediatrics\\_v5i1e32406\\_app1.docx](#)]

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## Abbreviations

**OECD:** Organization for Economic Cooperation and Development

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Original Paper

# Online-Delivered Over Staff-Delivered Parenting Intervention for Young Children With Disruptive Behavior Problems: Cost-Minimization Analysis

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## Abstract

**Background:** High-prevalence childhood mental health problems like early-onset disruptive behavior problems (DBPs) pose a significant public health challenge and necessitate interventions with adequate population reach. The treatment approach of choice for childhood DBPs, namely evidence-based parenting intervention, has not been sufficiently disseminated when relying solely on staff-delivered services. Online-delivered parenting intervention is a promising strategy, but the cost minimization of this delivery model for reducing child DBPs is unknown compared with the more traditional staff-delivered modality.

**Objective:** This study aimed to examine the cost-minimization of an online parenting intervention for childhood disruptive behavior problems compared with the staff-delivered version of the same content. This objective, pursued in the context of a randomized trial, made use of cost data collected from parents and service providers.

**Methods:** A cost-minimization analysis (CMA) was conducted comparing the online and staff-delivered parenting interventions. Families (N=334) with children 3-7 years old, who exhibited clinically elevated disruptive behavior problems, were randomly assigned to the two parenting interventions. Participants, delivery staff, and administrators provided data for the CMA concerning family participation time and expenses, program delivery time (direct and nondirect), and nonpersonnel resources (eg, space, materials, and access fee). The CMA was conducted using both intent-to-treat and per-protocol analytic approaches.

**Results:** For the intent-to-treat analyses, the online parenting intervention reflected significantly lower program costs ( $t_{168}=23.2$ ;  $P<.001$ ), family costs ( $t_{185}=9.2$ ;  $P<.001$ ), and total costs ( $t_{171}=19.1$ ;  $P<.001$ ) compared to the staff-delivered intervention. The mean incremental cost difference between the interventions was \$1164 total costs per case. The same pattern of significant differences was confirmed in the per-protocol analysis based on the families who completed their respective intervention, with a mean incremental cost difference of \$1483 per case. All costs were valued or adjusted in 2017 US dollars.

**Conclusions:** The online-delivered parenting intervention in this randomized study produced substantial cost minimization compared with the staff-delivered intervention providing the same content. Cost minimization was driven primarily by personnel time and, to a lesser extent, by facilities costs and family travel time. The CMA was accomplished with three critical conditions in place: (1) the two intervention delivery modalities (ie, online and staff) held intervention content constant; (2) families were randomized to the two parenting interventions; and (3) the online-delivered intervention was previously confirmed to be non-inferior

to the staff-delivered intervention in significantly reducing the primary outcome, child disruptive behavior problems. Given those conditions, cost minimization for the online parenting intervention was unequivocal.

**Trial Registration:** ClinicalTrials.gov NCT02121431; <https://clinicaltrials.gov/ct2/show/NCT02121431>

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## KEYWORDS

online parenting intervention; child disruptive behavior problems; cost-minimization analysis; online versus staff delivery; evidence-based parenting support; population reach

## Introduction

The most prevalent mental health problems in childhood require effective interventions that are deliverable with sufficient population reach in a cost-efficient manner. This need is especially true of early-onset disruptive behavior problems (DBPs), which pose a significant public health challenge. Approximately 10-15% of preschoolers and children at school entry exhibit at least mild to moderately severe DBPs [1]. Early-onset DBPs elevate the risk of a range of adverse outcomes such as subsequent mental health problems, academic failure, substance misuse, delinquency, risky sexual behavior in adolescence, and chronic mental health problems and life consequences in adulthood [2-5]. Parenting and family-focused interventions provide the most robust evidence-based prevention and treatment for DBPs across several contexts and child/family populations [6-9]. Due to the high prevalence of DBPs, there is a substantial need for services; however, too few children with DBPs receive such interventions despite intervention efficacy. Contributing factors include strained resources, understaffing, and low program availability on the programmatic side, while parents encounter barriers to participation, including transportation, childcare, work schedules, and perceived stigma [10,11]. Therefore, the expansion of intervention strategies beyond traditional delivery methods is essential to meet these needs.

Internet delivery of evidence-based parenting interventions for child DBPs could potentially improve the reach of these interventions [12,13]. Therefore, a noninferiority trial was conducted to test whether an online-delivered parenting intervention, derived from the evidence-based Triple P-Positive Parenting Program, performed as well as a staff-delivered version of the same program in addressing child DBPs. The trial involved randomization of 334 children (aged 3-7 years) with clinical levels of DBPs, and their families, to the two intervention arms. DBPs assessed by both independent observation and parental reports defined the primary outcome. Details and results of the trial are reported elsewhere [14]. The main finding was that the online intervention substantially reduced child DBPs to a comparable extent as the staff-delivered intervention. During the trial, pertinent cost data were collected on both interventions and provided the basis for this study.

A cost-minimization analysis (CMA) was determined to be the most appropriate form of economic evaluation for assessing an intervention option that is noninferior in its primary outcome [15]. From this perspective, if two interventions produce similar effects, the less costly option is favorable. This method is standard in pharmaco-economics when comparing two clinically

effective and equivalent therapies. While CMA is less common in other disciplines, it has been recognized as an appropriate method for comparing interventions delivered through technology-based methods against in-person delivery formats [16]. Previous work has identified the importance of evaluating internet-based interventions' costs, not just to the provider but also to those costs that fall on the user [17,18].

## Methods

This study's objective is to examine the costs of an online parenting intervention for childhood DBPs compared with a staff-delivered version of the same intervention. A CMA was completed in both intent-to-treat (ITT) and per-protocol (PP) contexts to achieve this objective.

### Description of the Online and Comparison Interventions

The online-delivered intervention (ODI) was Triple P Online, derived from the Triple P-Positive Parenting Program system of parenting interventions [19,20]. The ODI content draws on 17 core Triple P positive parenting skills and seeks to promote parental self-regulation. Examples of covered topics include understanding the causes of children's behaviors, strategies for fostering child development and skill acquisition, managing misbehavior effectively, planning to prevent problems, preparing for potential relapses of problematic behavior, and maintaining changes over time. The ODI incorporates video modeling of principles and specific parenting strategies, concrete tasks for parents to undertake with their children, and opportunities to engage in goal setting, constructive self-evaluation, and improvement. Structurally, the ODI consists of 8 modules, which are sequenced and take approximately 45-60 minutes each. The program includes easy navigation, video excerpts, personalized elements (eg, goal setting, content review, feedback, and a customizable workbook), interactive exercises, and downloadable worksheets. Following baseline assessment and randomization, the parent was shown how to access the online program and received a succinct orientation. During ODI implementation, a staff member made brief contact with the parent by phone, email, or text at 2, 4, 8, and 13 weeks to check on technical problems and prompt utilization of the program but did not provide any content coaching or clinical assistance.

The comparison was the staff-delivered intervention (SDI), Level 4 Standard Triple P-Positive Parenting Program, which involves 10 in-person 60-75-minute sessions delivered by a trained and accredited practitioner. The SDI parallels the ODI in terms of parenting principles and strategies imparted,

promotion of parental self-regulation, video modeling within a session, and between-session practice activities for parents.

### Study Sample and Clinical Trial Design

The sample consisted of 334 families of children ages 3-7 years who exhibited pronounced levels of oppositional and disruptive behaviors: 63% (212/334) boys and 37% (122/334) girls. The racial distribution for the parents was: 63% (210/334) non-Hispanic White, 21% (69/334) African American, 8% (27/334) Hispanic White, and 8% (27/334) other races. The families included 69% two-parent (230/334) and 31% (104/334) one-parent households. For educational attainment of the participating parents, 14% (47/334) had high-school graduation or less, 28% (92/334) some college, and 57% (192/334) college graduation.

The families were enrolled in a clinical trial in which they were randomly assigned to either the ODI or the SDI for the goal of acquiring positive parenting strategies to reduce child DBPs and improve child and family functioning. Characteristics of the trial included demographic and baseline equivalence across conditions, multi-source outcome measures (ie, observers, parents, and teachers), post-intervention and follow-up (12 months after baseline) outcome assessments, independent assessment of intervention fidelity, and analyses using both ITT and PP methods. A full description of the trial and outcomes is reported elsewhere [14]. The study design for the costing analysis was built on this randomized clinical trial.

The full sample consisted of 168 (50%) and 166 (50%) families for the ODI and SDI groups, respectively; all included in the ITT analysis. The PP-based costing analysis included the 54 (34%) ODI and 106 (66%) SDI families. They had completed their assigned program in its entirety, which met a conservative completion threshold even though other families excluded from the PP sample had completed most but not all of the programs. The critical consideration for this cutoff is to ensure that the PP analysis captures the costs of each intervention when taken to completion.

### Study Design for the Costing Analysis

The costing analysis goal was to determine if there was a significant difference in the resources required to administer and deliver the ODI compared with the SDI. The study team designed the collection and analysis of resource utilization data to estimate the incremental differences between the online and staff-delivered versions of the intervention. The identification and measurement of resource utilization were guided by program and participant perspectives.

As is typically the case for parenting interventions with children and families, the bulk of resource utilization was personnel-related, especially for the SDI condition. As a result, the burden of data collection fell on intervention staff who regularly completed written logs to document all time spent on intervention delivery and administration, including clinical supervision. Personnel recorded their time on these logs in 15-minute increments and placed each time segment into one of several activity categories provided on each time log. For family-specific time, staff indicated time for a specific family/case. Intervention staff recorded administrative and supervisory time without reference to any particular family/case. Additionally, each SDI parent completed a brief form to document resource utilization related to their family's participation. These forms were either mailed directly or scanned and emailed to the cost team, where graduate assistants coded the logs into Excel spreadsheets.

Table 1 delineates the activity categories included in each log for each intervention. The direct resource category comprises intervention delivery and communication with each family, including activities before, during, and after intervention sessions. The administrative resource category refers to activities attributable to the intervention (eg, professional supervision) but not to any specific family. The nondirect resource category consists of personnel time spent on behalf of families outside of intervention-session delivery, including travel, waiting on families, and communication about families.

**Table 1.** Staff activities and resource categories captured on family-specific and administrative log forms in the implementation of the online-delivered (ODI) and staff-delivered (SDI) interventions.

Activity category	Resource category	Family-specific log		Administrative log	
		SDI	ODI	SDI	ODI
Preparation for session	Direct	√			
In-person session	Direct	√			
Orientation session	Direct		√		
Documentation task	Direct	√	√		
Other contact	Direct	√	√		
Peer supervision	Administrative			√	
Individual supervision	Administrative			√	
Staff meeting	Administrative				√
Other meeting	Administrative			√	√
Consultation with techs	Administrative				√

Parents receiving the SDI completed a brief meeting form for every session. Parents documented the mode of transportation to and from the session, miles traveled in a personal vehicle, work hours lost to participate, and any other expenses incurred by the family to participate (eg, childcare for other children in the family).

Nonpersonnel resource consumption for the cost analysis included personnel travel costs, meeting space, and office space. Space used for session delivery and other related intervention tasks was also used for purposes other than the ODI and SDI. Therefore, information was collected about the space, and personnel time was used as the driver for the value of space. Finally, two other nonpersonnel costs were added, including \$15 per SDI family for a workbook (Materials category) and \$50 per ODI family for a fee paid to use the online system (Fees category).

The following procedures were followed to estimate total costs from personnel and nonpersonnel resources. All SDI personnel time was valued at \$44 per hour, while ODI direct and nondirect time was valued at \$44 and administrative time at \$32 per hour. All adult family time from intervention participation was valued at \$20 per hour. Participant travel was valued at \$0.55 per mile. Space utilized for SDI delivery, SDI and ODI program introduction (orientation), and support of delivery and administrative personnel was valued at \$0.096 per square foot hour of personnel time based on typical local rates for office space rental. The space used for the SDI sessions and SDI/ODI orientation was 102 square feet, for other SDI personnel was 126 square feet, and for other ODI personnel, time was 112 square feet. Resource consumption data were collected from 2014 to 2017, and salaries reflect an average of how personnel were compensated during this period. All costs were valued or

adjusted in 2017 US dollars. Families were in the program for less than one year; therefore, no discounting of costs is included in these estimates. For the primary cost analyses, all families were included regardless of whether a family completed the intervention, which preserved the ITT design. The second set of cost analyses was conducted to gauge the PP costs of the two interventions, including only the families who completed their assigned intervention.

### Ethics Approval

Ethical approval for this study was obtained from the University of South Carolina Institutional Review Board on April 11, 2013 (reference Pro00024933).

## Results

### Personnel Time

To summarize direct, nondirect, and administrative personnel time spent on the intervention, the time reported on all logs was summed by intervention and divided by the number of families participating in each intervention. Table 2 provides a breakdown of the personnel time per family, as reported by intervention staff. On average, personnel spent 17 hours more delivering and administering the SDI than the ODI, most of the difference occurring in the direct personnel time resource category (13.5 more hours). This additional time occurred not just from session delivery (8.2 more hours) but also from other direct times, including preparation, communication with families, and documentation (5.3 more hours). Most of the remaining difference in total personnel time was from 2.6 additional hours per SDI family spent on administrative tasks with less than an hour spent on nondirect tasks.

**Table 2.** Personnel time per family case (in hours) for online-delivered (ODI) and staff-delivered (SDI) interventions.

Resource category	Intervention Format		Incremental difference (SDI-ODI)
	SDI (n=166)	ODI (n=168)	
<b>Direct personnel time</b>	15.9	2.5	13.4
Session delivery time	8.3	0.0	8.3
Other direct time	7.6	2.5	5.1
Nondirect personnel time	0.6	<0.1	0.6
Administrative personnel time	3.0	0.6	2.4
Total personnel time	19.5	3.1	16.4

### Family Time

Total SDI family time spent engaging in the intervention was estimated from personnel-reported logs for sessions. For the ODI, family time spent engaging in the intervention was based on a backend database linked to the delivery platform, which tracked the parent's time logged into the Triple P Online program. On average, SDI families spent 10.5 hours of their own time receiving intervention sessions in-person, while ODI families spent 7.7 hours of their own time receiving the intervention online. Participation in SDI also required participants to travel to the session location. On average, SDI

families reported 104 total miles of travel to and from intervention sessions using personal vehicles. Families did not report travel by taxi or bus. Few SDI families (4%) indicated the need to miss work to attend intervention sessions for an average of 10 hours lost per family that reported any time missed and 0.4 hours per family overall. SDI families did not indicate a need to pay any other expenses not included in travel.

### Total Costs

The total costs per family for SDI and ODI, including personnel and nonpersonnel resources and participant resources, are delineated in Table 3 for the full sample preserving the ITT



design. In general, the SDI had significantly higher costs per family when compared with the ODI. Incremental cost differences per family for the SDI over the ODI were \$903 for program costs ( $t_{168}=23.2$ ;  $P<.001$ ); \$262 for family costs

( $t_{185}=9.2$ ;  $P<.001$ ); and \$1164 for total costs ( $t_{171}=19.1$ ;  $P<.001$ ). Incremental program costs, found at the bottom of [Table 3](#), include program costs (personnel and nonpersonnel resources), family costs, and total costs combining both. All costs were valued or adjusted in 2017 US dollars.

**Table 3.** Comparison of staff-delivered (SDI) and online-delivered (ODI) interventions for program, family, and total costs per case on an intent-to-treat basis.<sup>a</sup>

Resource category (costs per family case)	Intervention format		<i>t</i> test (df)	<i>P</i> value
	SDI (n=166)	ODI (n=168)		
<b>Per-family program costs</b>				
<b>Personnel</b>				
Direct	\$699	\$107		
Nondirect	\$26	\$0		
Administrative	\$131	\$19		
Total personnel costs	\$856	\$127		
<b>Nonpersonnel</b>				
Space	\$215	\$12		
Fees	\$0	\$50		
Materials	\$15	\$0		
Travel	\$10	\$0		
Total nonpersonnel costs	\$240	\$62		
Total program costs	\$1091 (SD \$499)	\$188 (SD \$51)	23.2 (168)	<.001
<b>Family costs</b>				
Time	\$297	\$144		
Other: travel	\$104	\$0		
Other: lost work	\$8	\$0		
Total family costs	\$405 (SD 357)	\$144 (SD 89)	9.2 (185)	<.001
Total costs per family (program + family costs)	\$1496 (SD 778)	\$332 (SD 108)	19.1 (171)	<.001

<sup>a</sup>All costs were valued or adjusted in 2017 US dollars.

The same cost analysis was repeated focusing exclusively on completer cases in a PP basis and is delineated in [Table 4](#). Incremental cost differences for the SDI over the ODI were

\$1171 for program costs ( $t_{114}=34.0$ ;  $P<.001$ ); \$312 for family costs ( $t_{116}=9.2$ ;  $P<.001$ ); and \$1483 for total costs ( $t_{115}=26.4$ ;  $P<.001$ ).

**Table 4.** Comparison of staff-delivered (SDI) and online-delivered (ODI) interventions for program, family, and total costs per case on a per-protocol basis (completer cases only).<sup>a</sup>

Resource category (costs per family case)	Intervention format		<i>t</i> test (df)	<i>P</i> value
	SDI (n=106)	ODI (n=54)		
<b>Per-family program costs</b>				
<b>Personnel</b>				
Direct	\$903	\$102		
Nondirect	\$31	\$0		
Administrative	\$131	\$19		
Total personnel costs	\$1062	120		
<b>Nonpersonnel</b>				
Space	\$266	\$12		
Fees	\$0	\$50		
Materials	\$15	\$0		
Travel	\$10	\$0		
Total nonpersonnel costs	\$291	\$62		
Total program costs	\$1353 (SD 347)	\$183 (SD 52)	34.0 (114)	<.001
<b>Family costs</b>				
Time	\$412	\$247		
Other: travel	\$142	\$0		
Other: lost work	\$8	\$0		
Total family costs	\$559 (SD 340)	\$247 (SD 55)	9.2 (116)	<.001
Total costs per family (program + family costs)	\$1912 (SD 564)	\$430 (SD 91)	26.4 (115)	<.001

<sup>a</sup>All costs were valued or adjusted in 2017 US dollars.

## Discussion

### Principal Results

This study provides some of the first data directly comparing resource investments for internet-delivered versus standard staff-delivered behavioral interventions in which programmatic content is held constant. This comparison is important considering the previously reported confirmation that the internet-delivered intervention (Triple P Online) is as efficacious as the well-established, evidence-based standard intervention (Level 4 Standard Triple P) in achieving significant reductions in child behavior problems. The main economic finding is that the internet-delivered program costs were significantly less than the standard staff-delivered program. This cost differential stems from a much smaller investment required for the internet-program provision and a lower burden on internet-program participants. Personnel costs were the most significant drivers of the difference between the delivery modalities. The personnel activities related to direct personnel time, including session delivery and delivery-support tasks such as preparation and documentation, were the most significant drivers of the difference. Internet-program participants reflected a lower burden because of less programming time and travel-related costs.

When comparing interventions from an economic perspective, cost-effectiveness is much more common than CMA because incremental effectiveness and costs are taken into account. In this study, however, CMA is more suitable because the two interventions were comparably efficacious [14], which obviates the need for cost-effectiveness analysis. The apparent simplicity of CMA should not detract from the fact that it rests on the same theoretical underpinnings as more complex economic evaluation methods such as cost-effectiveness analysis [21].

Internet-delivered interventions undoubtedly have the potential to reach a large number of persons in the population, conceivably leading to large-scale positive changes in preventing and reducing childhood problems for a relatively small investment [22] through the provision of evidence-based parenting support [23-25].

Internet-delivered interventions provide an alternative method for families to receive needed evidence-based services with the potential to overcome obstacles to in-person delivery. The flexibility of access promotes a learner-centered approach, enabling participation at a time that suits the parent. Although there is still a cost for online delivery associated with participant time, it is possible that given the flexibility of when this time is expended, that time comes at a lower cost to the participant than the more constrained scheduling of time in staff delivery. Internet-delivered interventions take on even greater importance

when in-person delivery is too difficult or even unsafe such as during a pandemic or adverse weather events that might preclude safe travel to clinical services but do not disrupt internet access.

### Comparison With Prior Work

Two problems sometimes encountered with internet-based interventions are low participation rates and high dropout [26-28]. These problems could bias the costs of an internet-based intervention toward being less costly. However, this issue did not bear out with this study, in which cost minimization was greater for PP over ITT analysis. Had high dropout from the ODI biased the results, cost minimization would have been greater for ITT, which retained dropouts in the analysis.

### Strengths and Limitations

In a CMA, the most careful consideration of costs is typically confined to categories expected to differ between modalities rather than a complete accounting of all implementation costs. In this study's CMA, all the main program costs for both delivery modalities were likely captured in the analysis. The data describe not only cost minimization but also an accurate estimate of each program's cost. This study was limited to just over 150 participants in each modality. If the program were scaled to include a larger number of participants and implemented similarly as in this study, the cost per family in the ODI would likely stay roughly the same without escalation of administrative costs from scaling up. It is less clear how costs for the SDI might escalate when scaling up.

It is often contended that while the costs of implementing an internet-delivered program are expected to be lower than the staff-delivered counterpart, the development or upfront costs are often higher for such a program. For example, the internet-delivered program in this study required only a modest access fee for implementation. However, program delivery utilized an already developed platform, which did not enter the cost analysis. Development costs were not included in the CMA. However, it is not necessarily the case that the internet program's development costs exceeded those for the staff-delivered program. This study's standard staff-delivered program (Level 4 Standard Triple P) went through more than two decades of content, materials, and component development and validation studies, which undoubtedly contributed substantial costs to program development. The initial training of program personnel similarly contributed to upfront costs that did not enter the CMA.

In some contexts, the inclusion of the development costs might initially suggest that an online-delivered intervention is more costly until a large enough number of individuals receive the intervention to make up for those higher upfront costs. This should not be considered a limitation for this study as the cost of accessing the online program was included in the CMA. A related issue pertains to ongoing developmental costs. Costs can be incurred to update or modify online programs to refresh video content, accommodate platform changes, and keep up with technological advances such as artificial intelligence. Although perhaps not as obvious, in-person programs can also incur costs to remain contemporary and evidence-based.

Two additional limitations relate to potentially peripheral or optional costs. The first involved the availability of onsite

childcare during SDI sessions. It is debatable whether this childcare cost during intervention delivery should be attributed to the program costs since the protocol does not specifically reference childcare, and many families did not use it. Given that onsite childcare costs were neither tracked nor included in the CMA, the reported cost differential is likely a conservative estimate that would have been larger if those costs had been included. The second optional cost pertains to the brief telephone contacts by staff to check on technical problems and prompt utilization for the ODI, which were not prescribed in the online program but were included in the present cost evaluation. Had this cost been left out, the ODI direct personnel costs (mean of \$107/family) would have been lower, further increasing the SDI-ODI cost differential.

The proportion of completers in ODI was about half of that in SDI. Several factors might have contributed to this lower completion rate. These include the possibility that parents who have achieved their intended goals, in the absence of a practitioner setting appointment times and creating an expectation that session attendance is necessary, might find it easier to discontinue. There are no sanctions for an early exit from the online-delivered program. Session completion could potentially be improved by providing at least some professional phone support during the intervention [29]. However, the provision of professional support increases delivery costs without necessarily improving child outcomes. However, professional support can potentially improve session completion and child outcomes when a parent enters the program with mental health concerns and low self-efficacy (eg, depression) [27]. Some parents prefer to do the online program independently and are not seeking additional professional support, nor do they accept it when offered.

Within the Triple P system, although Level 4 Standard Triple P is the individual program recommended for children with significant conduct problems, it is possible that briefer lower-intensity versions might also benefit some children. These lighter-touch, low-intensity programs such as Level 2 Positive Parenting Seminars, Level 3 Primary Care Triple P, and Level 3 Brief Discussion Groups have been shown to work primarily as preventive interventions rather than as interventions for children with more severe conduct problems. These briefer variants with fewer sessions are disadvantaged by reduced opportunities for parent coaching and at-home practice.

### Conclusions

The online-delivered parenting intervention in this randomized controlled trial produced substantial cost minimization compared with the staff-delivered intervention that provided the same content. The mean differential for total costs was \$1164 per case for the intent-to-treat analysis containing all cases and \$1483 per case for the per-protocol analysis containing only cases where the family completed its assigned intervention. Cost minimization was driven primarily by personnel time and, to a lesser extent, by facilities costs and family travel time. The CMA was accomplished with three critical conditions in place: (1) the two intervention delivery modalities (ie, online and staff) held parenting intervention content constant; (2) families were randomized to the two parenting interventions; and (3) the

online-delivered intervention was confirmed to be non-inferior to the well-established evidence-based staff-delivered intervention in significantly reducing the primary outcome, child disruptive behavior problems. Given those conditions, cost minimization for the online parenting intervention was unequivocal.

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### Authors' Contributions

RJP, CWM, MRS, and PSC significantly contributed to the conception and design of this study. JBI, RJP, and CWM acquired the data. JBI and PSC analyzed and interpreted the economic data. JBI and RJP drafted the initial manuscript. All authors were involved with the editing of the manuscript and approved the final version submitted for publication. JBI, RJP, and CWM had access to the data in this study and take responsibility for data integrity and accuracy. As principal investigator, RJP takes responsibility for all aspects of the work.

### Conflicts of Interest

JBI, PSC, RJP, and CWM have no conflicts of interest to declare. MRS disclosed that the Parenting and Family Support Centre is partly funded by royalties stemming from published resources of the Triple P-Positive Parenting Program, which was developed and is owned by the University of Queensland (UQ). Royalties are also distributed to the Faculty of Health and Behavioral Sciences at UQ and contributory authors of published Triple P resources. Triple P International (TPI) Pty Ltd is a private company licensed by Uniquet Pty Ltd on behalf of UQ, to publish and disseminate Triple P worldwide. MRS receives royalties and consultancy fees from TPI. TPI had no involvement in the study's design, the collection, analysis, or interpretation of its data, nor in the writing of this article.

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## Abbreviations

- CMA:** cost-minimization analysis
- DBP:** disruptive behavior problem
- ITT:** intent-to-treat
- NIH:** National Institute of Health
- NIMH:** National Institute of Mental Health
- ODI:** online-delivered intervention
- PP:** per-protocol
- SDI:** staff-delivered intervention
- TPI:** Triple P International



UQ: University of Queensland

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Original Paper

# Assessment of the Readability of Web-Based Patient Education Material From Major Canadian Pediatric Associations: Cross-sectional Study

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## Abstract

**Background:** Web-based patient education materials (PEMs) are frequently written above the recommended reading level in North America. Poor PEM readability limits the accessibility of medical information for individuals with average literacy levels or lower. Pediatric hospital and association websites have not only been shown to be a preferred source of information among caregivers but have also become a necessity during the COVID-19 pandemic. The readability of Canadian pediatric association websites has not yet been assessed.

**Objective:** The aim of this study is to determine if the content of PEMs from Canadian pediatric associations is written at a reading level that the majority of Canadians can understand.

**Methods:** A total of 258 PEMs were extracted from 10 Canadian pediatric associations and evaluated for their reading level using 10 validated readability scales. The PEMs underwent a difficult word analysis and comparisons between PEMs from different associations were conducted.

**Results:** Web-based PEMs were identified from 3 pediatric association websites, where the reading level (calculated as a grade level) was found to be an average of 8.8 (SD 1.8) for the Caring for Kids website, 9.5 (SD 2.2) for the Pediatric Endocrine Group website, and 13.1 (SD 2.1) for the Atlantic Pediatric Society website. The difficult word analysis identified that 19.9% (SD 6.6%) of words were unfamiliar, with 13.3% (SD 5.3%) and 31.9% (SD 6.1%) of words being considered complex ( $\geq 3$  syllables) and long ( $\geq 6$  letters), respectively.

**Conclusions:** The web-based PEMs were found to be written above the recommended seventh-grade reading level for Canadians. Consideration should be made to create PEMs at an appropriate reading level for both patients and their caregivers to encourage health literacy and ultimately promote preventative health behaviors and improve child health outcomes.

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**KEYWORDS**

health literacy; accessibility; online health information; pediatrics; patient education

## Introduction

The internet is a valued source of health care information for patients and caregivers worldwide [1,2]. Patients have been

shown to rate web-based health information as one of the most useful health care resources, second only to direct communication from a physician or nurse [3]. The internet not only serves as a source of supplemental reading following a doctor's visit but can also inform patients on best health

practices and encourage them to seek medical treatment for symptoms. This is particularly relevant during the COVID-19 pandemic as patients are seeking information about unprecedented medical concerns with limited access to health care [4,5].

Pediatric hospital and association websites are preferred sources of health information by caregivers among internet resources [6]. It is especially important that these websites are accurate and accessible to prevent misinformation. If the content is too difficult to understand, caregivers and patients may resort to using less accurate internet sources. This may exacerbate disparities in health outcomes since individuals with higher health literacy will have greater functional access to health-related content than those with literary barriers. These disparities have been highlighted through multiple studies, where low caregiver health literacy was shown to be associated with poor preventative health behaviors, increased pediatric emergency department use, nonurgent visits, and poorer child health outcomes [7-9].

In Canada, the average proficiency in literacy corresponds approximately to an eighth- to ninth-grade reading level, where over 45% of Canadian adults have been shown to have low literacy skills [10,11]. The readability of educational material is recommended to be at least 2 or more grade levels below the average Canadian reading level to ensure comprehension [12]. Therefore, all patient-related material should be written at a maximum of a seventh-grade reading level. As health literacy commonly requires the use of a combination of prose literacy, document literacy, and/or numeracy skills, adults may have a harder time understanding health-related content than typical prose [13]. Even with adequate literacy skills, many caregivers still have difficulty understanding well-established health-related information in order to care for their infant [14]. Health-related reading materials should be further simplified to account for these additional challenges.

Pediatric health literacy has been explored globally, focusing on a variety of topics and subspecialties within pediatrics. Overall, studies in North America, France, Australia, the United Arab Emirates, Turkey, and Brazil have found that pediatric health information has been written above an acceptable reading level [15-20]. Topics have ranged from mental health, otolaryngology, orthopedics, oral health, oncology, and consent and discharge forms [21-27]. In Canada, although a variety of topics and subspecialties have been studied as they relate to health literacy, such as oncology, microtia and aural atresia, and emergency medicine [28-30], no study has evaluated the pediatric information developed by major pediatric associations and societies from multiple disciplines. This study aims to evaluate the reading level of the web-based Canadian pediatric patient education material (PEM) from pediatric associations and societies and to provide specific recommendations to improve readability.

## Methods

### Sample Collection

During May and June 2020, all internet-based PEMs were downloaded from the pediatric associations' websites. A total of 10 national associations were identified and are listed in Table 1 along with the number of unique PEMs obtained from each association. The downloaded PEMs included materials describing any topic with intended use by parents, guardians, or children on the pediatric websites. Therefore, this excluded any material intended for health care providers. PDF files were manually converted to plain text for further analysis. Text sections containing nonmedical information such as page numbers, disclaimers, tables, diagrams, phone numbers, emails, and webpage navigation were removed from each of the PEMs before analysis.

**Table 1.** A list of the pediatric associations that provide patient education material and the number of documents obtained from each.

Canadian pediatric association	Documents obtained, n
Canadian Pediatric Society	205
Canadian Pediatric Endocrine Group	46
Atlantic Pediatric Society	7
Canadian Association of Pediatric Surgeons	0
Canadian Association of Child Neurology	0
Canadian Pediatric Cardiology Association	0
Canadian Pediatric Anesthesia Society	0
Canadian Association of Pediatric Nephrologists	0
Canadian Academy of Child and Adolescent Psychiatry	0
Canadian Association of Pediatric Ophthalmology	0

### Document Readability Analysis

A readability assessment was performed on the PEMs using the software package Readability Studio Professional Edition (version 2019.3; Oleander Software Ltd). The readability scales

used to determine the reading level, which was reported as a grade level, of the PEMs included 8 numerical scales and 2 graphical scales. The 8 readability scales included the Degrees of Reading Power-grade equivalent test (DRP-GE); Flesch-Kincaid Grade Level (FK); Simple Measure of

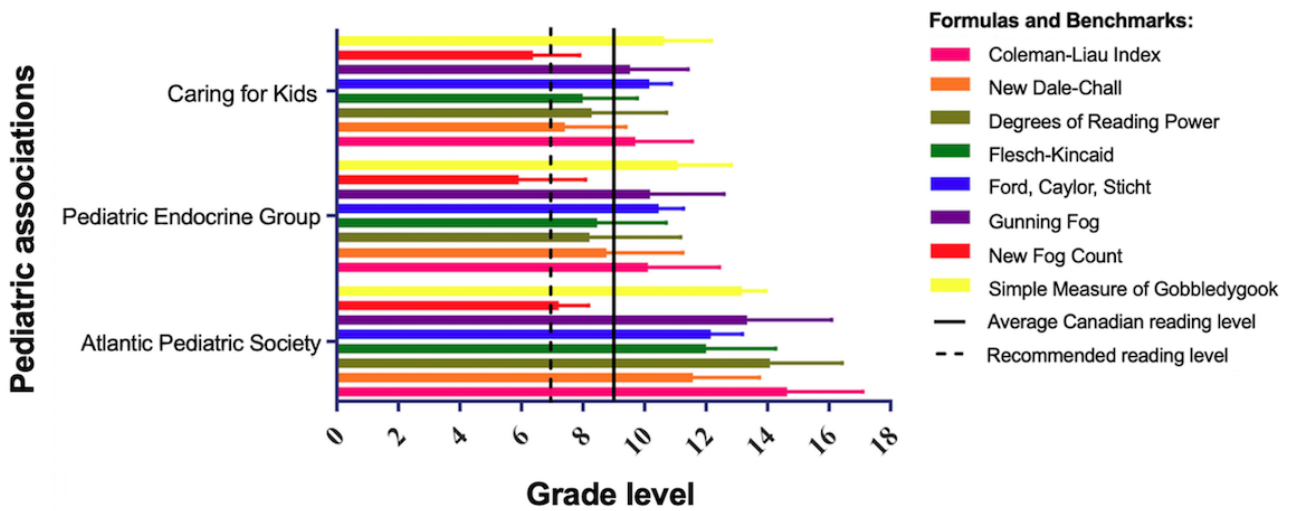


Gobbledygook index (SMOG); Coleman-Liau index (CLI); Gunning Fog index (GF); New Fog Count (NFC); New Dale-Chall readability formula (NDC); and Ford, Caylor, Sticht scale (FORCAST). The 2 graphical scales included the Raygor Readability Estimate Graph (RREG) and the Fry Readability Graph (FRG). These 10 scales are often used when assessing medical text and offer externally validated measures of readability [31-33].

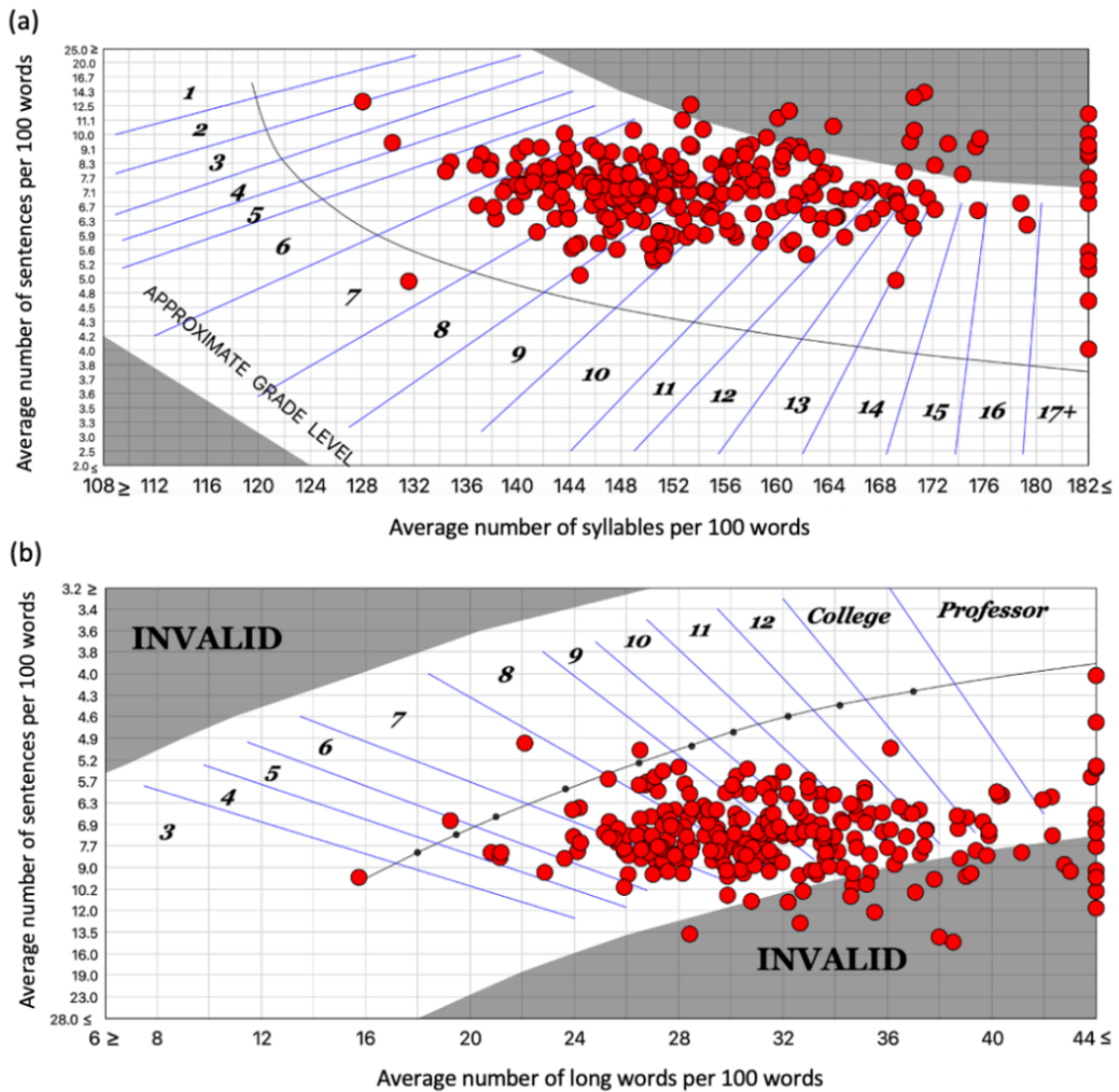
PEMs often contain text that must be modified before the analysis to appropriately apply the readability scales. This includes the removal of charts as well as the modification of bullet points to form complete sentences for analysis. To address

the limitation of narrative-based readability scales, PEMs were individually edited to create high- and low-sentence documents, as performed by Perni et al [32]. For example, in high-sentence documents, each individual bullet point was treated as an independent sentence and resulted in a lower grade level estimate. On the other hand, low-sentence documents had each bullet point separated with a comma, with the final bullet point ending the sentence; this resulted in a higher grade level estimate [31,32]. The high- and low-level estimates were then averaged for further analysis. The associations' readability level using the 8 numerical scales can be seen in Figure 1, and the 2 graphical scales can be seen in Figure 2.

**Figure 1.** The reading level of patient education materials (PEMs) developed by the Atlantic Pediatric Society, Pediatric Endocrine Group, and Canadian Pediatric Society (Caring for Kids) as calculated by various numerical readability scales, compared to the average Canadian reading level and the recommended reading level for PEMs.



**Figure 2.** (A) The Fry Readability Graph of all high-sentence estimate web-based patient education materials (PEMs) collected from Canadian pediatric associations. The Fry Readability Graph visually demonstrates the readability of PEMs by the intersection of the number of syllables per 100 words and the number of sentences per 100 words. (B) The Raygor Readability Estimate Graph of all high-sentence estimate web-based PEMs collected from Canadian pediatric associations. The Raygor Readability Estimate Graph visually demonstrates the readability of the PEMs by the intersection of the number of long words per 100 words and sentences per 100 words. Within both graphs, the numbers within the graph indicate the approximate reading level (reported as a grade level) and the circles indicate reading levels of individual PEMs.



**Difficult Word Analysis**

A difficult word analysis was performed to identify the number and percentage of complex words (composed of 3 or more syllables), long words (composed of 6 or more letters), and unfamiliar words in each PEM according to the NDC criteria [34,35]. Once all the words were extracted from the PEMs, they were compared to the NDC word list as well as the New General Service List (NGSL). Words that appeared in either of the lists were removed and considered to be nonjargon words. All words that appeared in less than 3 PEMs were excluded from the analysis. Words with 3 or more syllables were then extracted, and the various tenses of the 10 most frequently identified words, where applicable, were combined. Alternative words were then proposed for any 3-syllable word that appeared in 3 or more PEMs, either using the Readability Studio Software,

the Merriam-Webster thesaurus, or in consultation with a physician, to identify synonyms that can decrease the difficulty of the word.

**Statistical Methods**

Graphical data in Figure 1 were reported as the arithmetic means with the error bars representing the standard deviations. Data sets had their normality tested using a Shapiro-Wilk test when central limit theorem conditions were not met. Equal variance was tested using a Brown-Forsythe test to determine if the data would need to be transformed before analysis. Normally distributed data with equal variance then underwent a one-way analysis of variance (ANOVA). If the data were not normally distributed, then a nonparametric Kruskal-Wallis test was employed. Multiple comparisons tests, such as Tukey tests, were used to identify differences between sample means in the

ANOVA analysis [36]. The data were analyzed using Graph Pad Prism (version 9; GraphPad Software Inc).

## Results

### Document Readability Analysis

Following conversion to plain text, high- and low-sentence PEMs were subjected to 8 readability tests, including the DRP-GE, FK, SMOG, CLI, GF, NFC, NDC, and FORCAST. Figure 1 illustrates a summary of the results for the pediatric associations. The reading levels (reported as grade levels) measured by the 8 readability scales were averaged for each pediatric association, where the mean and standard deviations are reported as follows: Caring for Kids (8.8, SD 1.8), Pediatric Endocrine Group (9.5, SD 2.2), and the Atlantic Pediatric Society (13.1, SD 2.1). The overall mean was 9.1 (SD 2.4), with a grade-level range of 5 to 17. Note that Caring for Kids is a website developed by the Canadian Pediatric Society.

When the 8 readability scores of the individual PEMs were averaged, only 18 (7%) and 144 (55.8%) of the 258 PEMs, were below a seventh-grade and ninth-grade level, respectively. The RREG score of the high-sentence PEMs (Figure 2) ranges from a third-grade reading level to a grade level equivalent to that in university, with 26 (10.1%) and 127 (49.2%) of the 258 PEMs written at a grade level below 7 and 9, respectively. The FRG score of the high-sentence estimate, as seen in Figure 2, ranges from a third-grade to a 17th-grade (university-educated) reading level, with 14 (5.4%) and 118 (45.7%) of the 258 PEMs written at a grade level below 7 and 9, respectively.

The grade levels calculated by all 8 scales from the Atlantic Pediatric Society's PEMs were also compared to those from Caring for Kids and the Pediatric Endocrine Group. Comparisons with 7 out of 8 reading tests were found to be statistically significant for both pediatric associations, where the NFC test was the only test to show no statistical significance (Table 2).

**Table 2.** Comparison of the reading level scores calculated by 8 readability scales of patient education materials (PEMs) from the Atlantic Pediatric Society (APS) with 2 other pediatric associations' PEMs.

Readability test	P value across all PEMs	P value for the pairwise comparison of the APS <sup>a</sup> PEMs <sup>b</sup> to other pediatric associations' PEMs <sup>c</sup>	
		Caring for Kids	Pediatric Endocrine Group
CLI <sup>d</sup>	<.001	<.001	<.001
NDC <sup>e</sup>	<.001	<.001	.02
DRP-GE <sup>f</sup>	<.001	<.001	<.001
FK <sup>g</sup>	<.001	<.001	.001
FORCAST <sup>h</sup>	<.001	<.001	<.001
GF <sup>i</sup>	<.001	<.001	<.001
NFC <sup>j</sup>	.08	.38	.13
SMOG <sup>k</sup>	<.001	.003	<.001

<sup>a</sup>APS: Atlantic Pediatric Society.

<sup>b</sup>PEM: patient education material.

<sup>c</sup>P values for comparisons across the different pediatric associations' PEMs were calculated using analysis of variance (ANOVA) with a Welch correction nonparametric equivalent when applicable. P values for pairwise comparisons between PEMs were calculated using the Tukey, Tamhane, and Dunnett test.

<sup>d</sup>CLI: Coleman-Liau index.

<sup>e</sup>NDC: New Dale-Chall readability formula.

<sup>f</sup>DRP-GE: Degrees of Reading Power–grade equivalent test.

<sup>g</sup>FK: Flesch-Kincaid Grade Level.

<sup>h</sup>FORCAST: Ford, Caylor, Sticht scale.

<sup>i</sup>GF: Gunning Fog index.

<sup>j</sup>NFC: New Fog Count.

<sup>k</sup>SMOG: Simple Measure of Gobbledygook index.

### Difficult Word Analysis

From the difficult word analysis, it was determined that of all the words found in the PEMs, on average, 13.3% (SD 5.3%) were complex words which contained 3 or more syllables, 31.9% (SD 6.1%) contained 6 or more letters, and 19.9% (SD 6.6%)

were unfamiliar words. All PEMs collected had a target audience of caregivers or pediatric patients (described as patients between the ages of 0 and 19). The most frequent terms included cannabis, marijuana, medication(-s), calcium, cortisol, and hepatitis. Table 3 describes the most frequent difficult words in compliance with the criteria described in the methods section.

**Table 3.** Difficult words found in the patient education materials analyzed, with alternative word recommendations.

Organization	Difficult word <sup>a</sup>	Frequency	Alternatives <sup>b</sup>
Atlantic Pediatric Society	Pediatric(-s), Pediatrician(-s)	41	Doctor for kids, doctor
	Adolescent(-s), Adolescence	7	Kids, children, teenage
	Developmental	4	Growth, stage, other abled
Pediatric Endocrine Group	Calcium	226	N/A
	Cortisol	180	Stress hormone
	Puberty, Pubertal, Puberties	161	N/A
	Genital(-s, -ia)	148	Private parts
	Injection(-s), Injectable	148	Shot
	Activate, Activated, Activating	125	Turn on, start, trigger
	Adrenal(-s)	102	N/A
	Vitamin	90	N/A
	Medication(-s)	90	Treatment, drug
	Pituitary	85	Brain gland
Caring for Kids	Cannabis, Marijuana	362	CBD <sup>c</sup> , THC <sup>d</sup>
	Medication(-s)	151	Treatment, drug
	Hepatitis	143	N/A
	Media	137	Online, T.V. <sup>e</sup> , print
	Diabetes	126	High sugars
	Vaccination(-s), Vaccinated	119	Shot
	Influenza	103	Flu
	Vitamin(-s)	101	N/A
	Breastfeeding	99	Nursing, feeding
	Pediatric, Pediatrician(-s)	97	Doctor for kids, doctor

<sup>a</sup>The following inclusion criteria were used for identifying a difficult word: (1) any word with  $\geq 3$  syllables that was used at least once in  $\geq 3$  patient education materials and (2) was unlisted on either the New Dale-Chall list of familiar words or the New General Service List.

<sup>b</sup>Alternatives selected are those that are considered synonymous and that decrease the individual word's syllables and/or letter count.

<sup>c</sup>CBD: cannabidiol.

<sup>d</sup>THC: tetrahydrocannabinol.

<sup>e</sup>T.V.: television.

## Discussion

### Principal Findings

PEMs found on pediatric associations' websites serve as an important link between health care professionals and caregivers. Through these web-based resources, parents can access reputable information endorsed by health care professionals to inform childcare practices on a day-to-day basis [1-3]. Although these resources are readily available with internet access, they are not always functionally accessible to all caregivers and patients. Pediatric PEMs have consistently been shown globally to be written at higher reading levels than recommended for a public audience, which is consistent with this study's findings [9,15-20].

Based on the analyses using the DRP-GE, FK, SMOG, CLI, GF, NFC, NDC, and FORCAST scales, PEMs available on

Canadian pediatric association websites were found to be written at a ninth-grade reading level (mean 9.1, SD 2.4) on average, wherein only 7% (18/258) of PEMs were written below the recommended seventh-grade reading level. Similar results were shown by the RREG and FRG (Figure 2), wherein only 5.4% (14/258) to 10.1% (26/258) of PEMs were found to be written below a seventh-grade reading level. This suggests that the PEMs cannot be easily understood by most Canadians, and even less so by pediatric patients. This is particularly true for the Atlantic Pediatric Society's PEMs, which are written at a university reading level (mean 13.1, SD 2.1). In Table 2, it can be seen that the Atlantic Pediatric Society's PEMs were statistically significantly different from other pediatric associations' PEMs in a majority of the readability tests employed. This suggests that the Atlantic Pediatric Society should consider all parameters used in each readability test, such as word and sentence length, the number of syllables in each word, and the familiarity of the words used, to improve

readability. In addition to reducing the reading level of the text directed to caregivers, pediatric associations should consider stratifying their websites to include simpler educational materials directed to children.

Although the study itself uses 8 numerical and 2 graphical readability indices to better represent the many parameters that are factored into readability, special emphasis should be given toward readability formulas designed for health care materials. This includes the SMOG and FRG, with the SMOG considered as the gold standard by many large institutes such as the National Cancer Institute [37]. When factoring this into account, the average reading level of the PEMs would be closer to an 11th-grade rather than a ninth-grade reading level. Although this study focused on PEMs derived from only Canadian pediatric hospitals and associations, patients retrieve information from a variety of other sources. Health content obtained from common sources, such as Wikipedia and other popular websites containing health information, has also been shown to be written at a reading level far above the seventh grade [38-40]. These findings suggest that even if pediatric patients use education materials outside of those analyzed in this study, they may still face challenges in identifying information that is at an appropriate reading level.

The difficult word analysis revealed long words were the most common type of difficult word in the PEMs. This is in line with another recent Canadian publication on cancer-related PEMs [34]. Difficult terminology should be replaced with more familiar alternatives whenever possible to improve the ease of understanding. For example, “beneficial” could be replaced with “helpful,” and “clinician” could be replaced with “doctor” for simplicity. Although the substitution of terminology is ideal, it may not be applicable to cases in which information must be fully and accurately communicated. In these situations, a clear definition should be included when the word is introduced. Although the content of the PEMs was analyzed for reading level and word difficulty in this study, additional factors such as organization, layout, and design can impact PEMs’ readability. Therefore, further studies should be undertaken once additional instruments, such as the Suitability Assessment of Materials and PMOSE/IKIRSCH document readability formula, are validated for medical literature [41,42].

### Limitations

The readability tests used in this study consider parameters such as word and sentence length, number of syllables per word,

words per sentence, and the difficulty level of words [31-33]. Although the use of multiple tests allows for more dimensions of readability to be considered, there are still limitations to using readability tests overall. Tests that assess syllable count may overestimate the readability of the text. Monosyllabic medical terminology, such as the word “stent,” contributes to a lower readability score, but that may not necessarily reflect a person’s ability to understand the terminology [15,31]. Conversely, tests that assess word familiarity may underestimate the readability of the text. Well-known medical terminology, such as the word “pediatrician,” acts to increase readability scores but may not contribute to increased difficulty in understanding the text. Furthermore, the act of defining difficult words within the text, which would greatly improve comprehension, is also not considered to impact readability. Additionally, the readability tests in this study do not account for the formatting of the text or the inclusion of diagrams. Although bullet points were analyzed as both sentences and comma-separated phrases, this does not fully capture the improvement to readability that lists provide. The evaluation of communication tools such as tables and images should be considered for future studies, as they can also serve to improve the ease of understanding [12]. Lastly, interpretations of the results must be taken into context as only Canadian pediatric associations were assessed, with just 3 of the 10 associations having PEMs on their websites. The results are therefore not representative of the totality of the information that caregivers and pediatric patients would be exposed to.

### Conclusions

Overall, web-based PEMs developed by Canadian pediatric associations exceed the recommended seventh-grade reading level. Difficult words should be replaced when possible or defined, and educational content directed specifically toward pediatric patients should be included. Additional consideration should be placed on the incorporation of multimedia PEMs [43]. Qualitative studies should be conducted in the future to better understand caregiver and provider information needs, as well as the barriers toward implementing more functionally accessible PEMs on pediatric association websites [44-46]. Additionally, the quality of the PEMs should be evaluated to determine if the information provided is accurate [47-49]. Once collected, this data can be used to inform changes that improve the usefulness, quality, and accessibility of pediatric PEMs. As the role of technology in health care increases, it is important that all individuals are able to understand and use reputable resources on the internet.

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### Conflicts of Interest

None declared.

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## Abbreviations

**ANOVA:** analysis of variance  
**CLI:** Coleman-Liau index  
**DRP-GE:** Degrees of Reading Power–grade equivalent  
**FK:** Flesch-Kincaid Grade Level  
**FORCAST:** Ford, Caylor, Sticht scale  
**FRG:** Fry Readability Graph  
**GF:** Gunning Fog index  
**NDC:** New Dale-Chall readability formula  
**NFC:** New Fog Count  
**NGSL:** New general service list  
**PEM:** Patient education material  
**RREG:** Raygor Readability Estimate Graph  
**SMOG:** Simple Measure of Gobbledygook index

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Original Paper

# Locating Youth Exposed to Parental Justice Involvement in the Electronic Health Record: Development of a Natural Language Processing Model

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## Abstract

**Background:** Parental justice involvement (eg, prison, jail, parole, or probation) is an unfortunately common and disruptive household adversity for many US youths, disproportionately affecting families of color and rural families. Data on this adversity has not been captured routinely in pediatric health care settings, and if it is, it is not discrete nor able to be readily analyzed for purposes of research.

**Objective:** In this study, we outline our process training a state-of-the-art natural language processing model using unstructured clinician notes of one large pediatric health system to identify patients who have experienced a justice-involved parent.

**Methods:** Using the electronic health record database of a large Midwestern pediatric hospital-based institution from 2011-2019, we located clinician notes (of any type and written by any type of provider) that were likely to contain such evidence of family justice involvement via a justice-keyword search (eg, prison and jail). To train and validate the model, we used a labeled data set of 7500 clinician notes identifying whether the patient was ever exposed to parental justice involvement. We calculated the precision and recall of the model and compared those rates to the keyword search.

**Results:** The development of the machine learning model increased the precision (positive predictive value) of locating children affected by parental justice involvement in the electronic health record from 61% (a simple keyword search) to 92%.

**Conclusions:** The use of machine learning may be a feasible approach to addressing the gaps in our understanding of the health and health services of underrepresented youth who encounter childhood adversities not routinely captured—particularly for children of justice-involved parents.

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**KEYWORDS**

parental incarceration; machine learning; natural language processing; parental justice involvement; adverse childhood experiences; pediatrics; pediatric health; parenting; digital health; electronic health record; eHealth

## Introduction

Parental justice involvement (eg, prison, jail, parole, or probation) is an unfortunately common and disruptive household adversity for many youths in the United States. Over 5.7 million US children, or nearly 1 in every 14 youth, have experienced a parent's incarceration in jail or prison, and these are disproportionately youth of color, youth in poverty, and youth in rural areas [1]. Even worse, nearly half of all US children have at least one parent with a record of crime which can affect where a family lives, works, and their eligibility for governmental economic assistance [2]. Children of incarcerated parents are at risk for out-of-home placement [3,4], delinquency [5], poor behavioral health symptoms, [5-7], and school problems [8] with challenges lasting through adulthood [9,10]. The National Academies of Sciences, Engineering, and Medicine (NASEM) [11,12] and the US Department of Health and Human Services [13] have recently advocated for greater information on these youths to inform when, how, and where to best support their health and well-being [11,13]. However, data on this adversity is not routinely collected in pediatric health care settings (and if it is, it is not discrete and unable to be readily analyzed), so we know very little about these youths using reliable measures of health. Because of these gaps [7], few efforts exist to track or facilitate timely follow-up with the remaining children when a parent is arrested (or incarcerated) in order to link comprehensive family support services that could likely mitigate these poor outcomes. Until routine screening on this adversity or novel, cross-sectorial data linkages with justice/court systems become commonplace, leveraging data science tools are feasible, timely, and cost-effective.

Due to advances in artificial intelligence, researchers are learning to leverage clinician notes and other text in the electronic health record to assist in identifying families affected by the social determinants of health. Prior work using natural language processing and machine learning to extract social risk information from clinical notes of adult patients in the United States has been effective [14-17]; however, there is limited use of this work within pediatric settings. The use of machine learning-based algorithms in pediatric medicine has been explored to optimize detection/diagnosis, treatment, and outcome/risk predictions in children who suffer from specific conditions such as severe sepsis [18], autism spectrum disorder [19-22], traumatic brain injuries [23], substance use disorder [24], and asthma [25]. The benefits and drawbacks of their usage in pediatric clinical care have been described by others [26,27]. The application of these techniques to advance our understanding of the health and clinical care of youth who suffer from various adversities holds great promise, yet, few have leveraged such approaches in pediatric research.

To our knowledge, only one study explored the use of natural language processing to locate adults with a history of personal incarceration using the Veterans Administration health record [28]. No study, to date, has examined the use of natural language processing to locate children of justice-involved parents, absent self-report screening tools, nor has research leveraged advanced machine learning models to enhance model accuracy. A recently published study (led by the first author) appears to be the first

to leverage natural language processing tools to identify children with any type of contact with the justice system (personal or family) in one large pediatric system [29]. Despite these youths making up only 2% of the pediatric population, they accounted for more than half of substance use and trauma-related diagnoses, nearly half of all stress-related diagnoses, and a third of all psychiatric disorders and suicide-related diagnoses within this institution spanning a 14 year time period [29]. A closer review of 1000 random clinician notes pulled from the search revealed that the exposure to parental incarceration was the most frequent type of justice involvement [29]. These findings, in combination with the identified gaps in the sciences on children of justice-involved parents [7], provide a great rationale for the development of machine learning to specifically locate children with a history of parental incarceration.

The first step to validating a machine learning model for exposure to parental justice involvement is understanding whether it can accurately identify the exposure. The development of such a validated model could address research gaps and provide a foundation for exploring how data science can be leveraged to locate other at-risk groups in the pediatric electronic health record. This manuscript describes such a process and validation in hopes to inspire others to think creatively about how to address gaps in our understanding of various types of childhood adversities, specifically on the health of children of justice-involved parents and other at-risk pediatric groups. Doing so creates a novel way to apply these tools to promote child health equity.

## Methods

### Overview

In this work, we trained a state-of-the-art natural language processing model to automatically retrieve patient notes that contain evidence of parental incarceration. First, we located patient notes that are likely to contain such evidence via a keyword search. Then, we manually reviewed and labeled a large sample of those notes with respect to whether they actually identify the patient as being exposed to justice-involved parents. Finally, we used this labeled data set of notes to train and validate a model that classifies notes as true exposure to a history of parental justice involvement versus no exposure. All study procedures were reviewed and approved by Nationwide Children's Hospital Institutional Review Board.

### Setting

We queried EPIC medical records on 1.2 million youth under 18 years of age in the electronic health record database of a large, urban, Midwestern, pediatric hospital-based institution from 2011-2019. The hospital-based system is one of the largest institutions in the United States and includes a network of 13 primary care centers, behavioral health clinics, 7 urgent care clinics, two emergency departments and 527 inpatient beds on the main campus, plus 146 offsite inpatient beds as part of its neonatal network. The institution provides care for about 1.3-1.5 million patient visits annually, including roughly 89,000 annual primary care visits. Medicaid is the primary insurer for half of all patients seen, and nearly 80% of the patients are seen within primary care. Approximately 56% of the current total pediatric

population self-identified or family-identified as White, 22% identified as Black or African American, 7% identified as Latino, 3% identified as African, 4% identified as Asian, and 6% identified as Biracial/multi-racial. In addition, English-speaking patients comprised 86% of the total pediatric population, followed by Spanish (5%), Somali (3%), Nepali (1%), and “all other” languages (4%). These racial and ethnic demographic characteristics are in line with the total population characteristics of the city in which this health institution is located.

### Selection of Bidirectional Encoder Representations from Transformers

BERT (Bidirectional Encoder Representations from Transformers) is a state-of-the-art natural language processing model based on a neural network (deep learning). It is unique in its ability to pick up contextual information within and across sentences [30]. The BERT model expands on the idea of context-free word embeddings (such as word2vec) by quantifying each word within its textual context using a transformer network with attention mechanism. The BERT model also utilizes self-attention to weight its input features (represented as contextualized word tokens). In practice, BERT uses a neural network to create a numerical representation of a chunk of text up to approximately 500 words long, which can then be used for classification.

### Query Details and Data Preparation

We conducted an automated search over the free-text clinical notes available within EPIC [31]. Any type of clinician note from any type of medical provider was eligible. Information about personal or familial incarceration is not routinely asked about, and providers were not mandated to document such information. We chose terms to capture the four primary types of justice involvement following arrest in the United States (eg, jail, prison, parole, and probation). Therefore, our text search first identified any note that contained at least one of the following familial terms (“mother” or “mom” or “father” or “dad” or “parent” or “grandpa” or “grandma” or “grandparent”), and at least one of the following justice terms (“prison” or “sentenced” or “incarcerated” or “probation” or “parole” or “jail”). We included grandparent familial terms as previous research via the Bureau of Justice Statistics found that nearly 45% of incarcerated mothers in state prisons and 12% of incarcerated fathers had their children cared for by grandparents during their incarceration [32]. We subsequently filtered out duplicate notes, notes that used justice terms only as part of a default screening sentence (eg, a tuberculosis risk assessment screening that clued providers about how “incarcerated adolescents” is a high-risk group), and notes in which familial terms and justice terms were more than 500 words apart (to comply within the computational requirements in order to apply BERT).

To prepare the notes for training and processing, we broke down each note into individual words (tokenization). The note was then reduced to the 500 tokens (words) window containing the maximal amount of justice keyword terms. The resulting note snippets were then used to train and evaluate the BERT model. To begin our training process, we randomly sampled 7500 notes

for manual annotation. Previous work has shown the BERT model can perform well on similar tasks when fine-tuned with as few as 5600 examples [30]. We used a sample size of 7500 to allow for a similar fine-tuning sample size alongside a larger testing and validation sample size for a more robust evaluation. We compiled the notes into a secure database (REDCap Survey) and highlighted the associated familial/justice keywords. A trained undergraduate student manually reviewed and annotated each note as a true or false case of parental justice involvement. To decrease error in inaccurate annotation, the student was able to flag a note to prompt the first author (a previous prison nurse familiar with justice-based language) to review if assistance was needed in deciphering whether a note contained a true case of parental justice involvement. In addition, the first author randomly selected 500 notes (using a random number generator via Python) to verify appropriate annotation for parental justice involvement. Along with parental justice involvement, we also recorded other types of familial or personal justice-system involvement (eg, by a different family member), if applicable.

### Model Development and Training Plan

We used a publicly available BERT implementation [30] that was pretrained with a large corpus of clinical notes [33]. We adjusted the neural network output to perform a binary classification and then fine-tuned the whole network with our data set of notes that contained documented exposure to parental justice involvement. To avoid overfitting, we used 80% of the data for training, 10% for internal validation (ie, determining the number of training epochs), and 10% to test model performance. To increase robustness against the inherent randomness of neural network optimization, we repeated this process in a 10-rep, 10-fold cross-validation scheme (a common split for model training) [34] and reported average results across all folds and repetitions.

### Statistical Analysis for Algorithm Performance

We begin by reporting descriptive statistics of the manual review of the 7500 notes. In addition, we also report the average number of total words per clinician note and the percentage of notes containing each of the keywords of interest stratified by evidence of justice involvement (all notes, clinician notes with evidence of justice involvement, and clinician notes with no evidence of justice involvement). Then, we evaluate the BERT model in terms of its precision (or positive predictive value) and recall (or sensitivity). Precision is measured as the fraction of notes retrieved by the algorithm (true positives and false positives) that actually contain evidence of parental justice involvement according to our chart review (true positives). Recall is measured as the fraction of all notes with evidence of parental incarceration (true positives and false negatives) that is retrieved by the algorithm (true positives). We report the precision-recall curve (averaged across 10 training repetitions), as well as the ideal F1 score (a balanced measure of recall and precision). Finally, we use our additional manual chart review to report descriptive statistics of the false positive notes retrieved by our model.

## Results

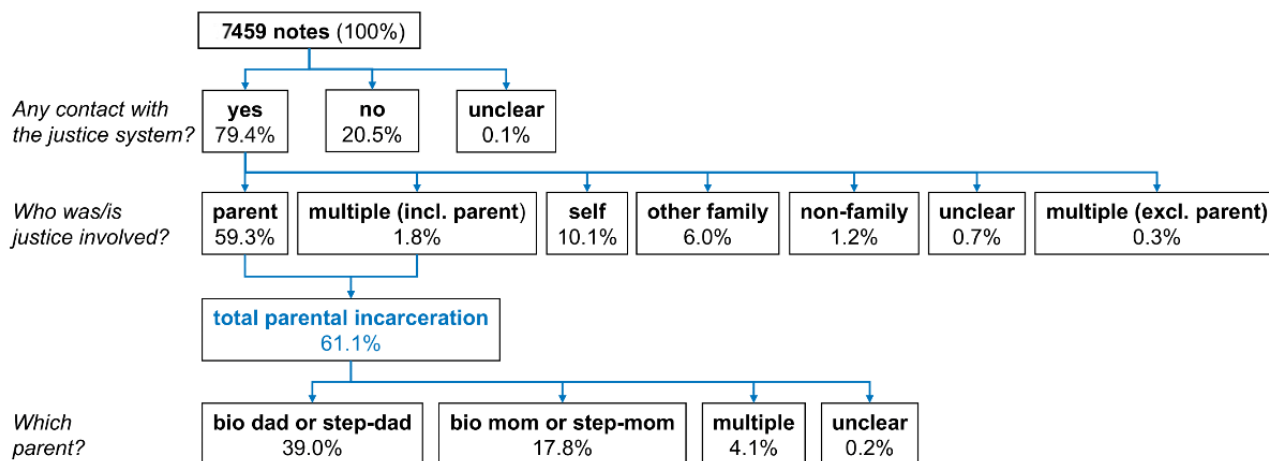
### Keyword Search and Manual Chart Review Annotation Results

Approximately 0.2% of the total clinician notes (N=133,211) contained the justice and family keywords and resulted in about 38,614 unique patients (or 3.30% of the total patient population during 2011-2019). **Figure 1** summarizes the results of our manual review of 7459 randomly selected clinician notes (after 41 duplicate notes were excluded). Of these 7459 notes, 5926 (79.4%) notes contained evidence that the patient had exposure to some type of contact with the justice system (personal, familial, and nonfamilial). The majority (4554/7459, 61.1%) of the notes indicated exposure to a parental justice involvement (biological or step), followed by self or personal justice involvement (57/7459, 10.1%) and other family member justice involvement (451/7459, 6.0%). Paternal (biological or step) involvement with the justice system was found in approximately 2909 (39.0%) notes, while maternal (biological or step) involvement was found in 1328 (17.8%) notes, and 306 (4.1%) notes indicated more than one parent. In addition, less than 4 (0.1%) of the notes were flagged by the annotator as “unclear” and verified as “unclear” by the first author. Of the 500 notes that were randomly selected to be reviewed by the first author to assess the accuracy of notation, none were annotated incorrectly for parental justice involvement exposure. These results suggest that our initial keyword search was effective at

retrieving notes of interest but also retrieved a large proportion of “false positives,” which we aimed to further filter out by training a natural language processing model.

**Figure 1**) Manual chart review results from a sample of notes that matched our keyword search (any clinician note that contained at least one familial term (“mother” or “mom” or “father” or “dad” or “parent” or “grandpa” or “grandma” or “grandparent”), and at least one justice term (“prison” or “sentenced” or “incarcerated” or “probation” or “parole” or “jail”). All percentages are relative to 7,459 notes. **Table 1** outlines the clinician note characteristics such as the average number of total words per note and the percentage of notes containing each of the keywords of interest stratified by evidence of any type of justice involvement. The average number of total words per clinician note that contained evidence of justice involvement was higher than the average word count per note of those that did not contain evidence of justice involvement (1121.9 words per note compared to 977.6 words per note, respectively). In addition, notes with evidence contained a higher percentage of all of the family-related keywords, with “mother” being the most frequent family term. The family terms “grandpa,” “grandma,” and “grandparent” were twice as frequent in the notes that contained evidence of justice involvement. In addition, the most frequent justice-related keyword was “incarcerated.” The justice-related keywords “jail” and “sentenced” appeared more frequently in notes that contained no evidence.

**Figure 1.** Manual chart review results from a sample of notes that matched our keyword search (any clinician note that contained at least one familial term (“mother” or “mom” or “father” or “dad” or “parent” or “grandpa” or “grandma” or “grandparent”), and at least one justice term (“prison” or “sentenced” or “incarcerated” or “probation” or “parole” or “jail”). All percentages are relative to 7459 notes.





**Table 1.** Clinician note characteristics, including the average number of words and percentage of keywords in each clinician note.

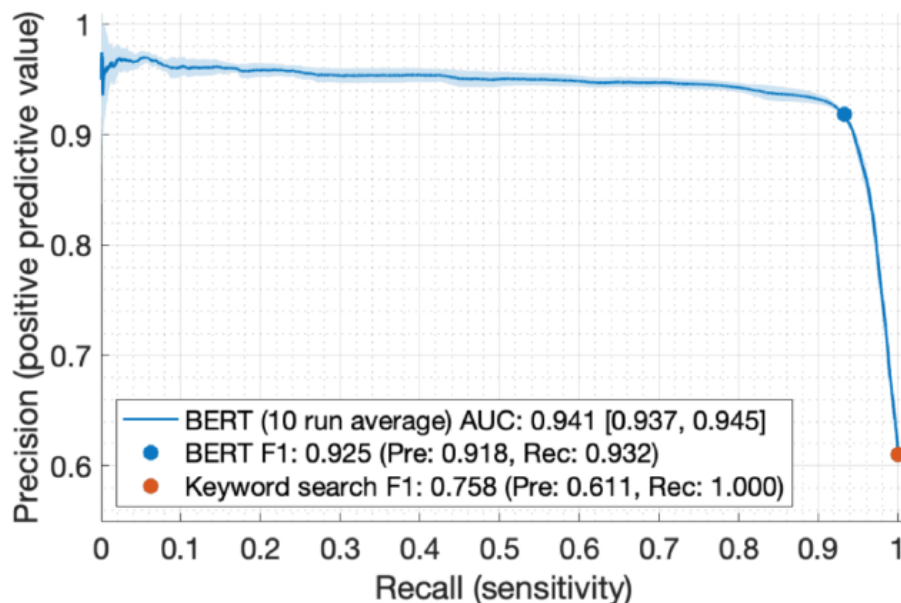
Clinician note characteristics	Total clinician notes (N=7459)	Clinician notes with evidence of any type of justice involvement (n=5926)	Clinician notes with no evidence of justice involvement (n=1529)
Number of words per note, mean (SD)	1084.3 (776.5)	1121.9 (781.3)	977.6 (752.5)
<b>Notes containing family keywords (%)</b>			
Mother	86.3	88.4	78.0
Father	67.3	71.9	49.6
Parent	62.6	63.7	58.1
Mom	56.3	57.2	53.0
Dad	36.6	38.5	29.2
Grandpa	9.1	10.3	4.7
Grandma	7.6	8.4	4.6
Grandparent	7.2	8.1	3.7
<b>Notes containing justice keywords (%)</b>			
Incarcerated	41.0	43.3	32.2
Jail	37.1	34.6	46.8
Prison	20.7	22.4	14.2
Probation	15.9	18.2	7.0
Parole	2.2	2.5	1.0
Sentenced	1.6	1.4	2.5

**Model Performance**

Figure 2 summarizes the note retrieval performance of our keyword search and subsequent BERT model. Under the assumption that the keyword search is perfectly sensitive (ie, it is unlikely that a note contains clear evidence of parental justice involvement but at the same time does not contain any of our

keywords), the keyword search alone can be considered as having a recall of 1, precision of 0.611, and a resulting F1 score of 0.758. Application of the BERT model on all retrieved notes increased overall precision while only sacrificing a small amount of recall. For example, a decision threshold that optimizes BERT's F1 score to 0.925 results in a precision of 0.918 (50.2% increase) and a recall of 0.932 (6.8% decrease).

**Figure 2.** Cross-validated precision-recall curve for identifying notes with evidence of parental justice involvement for the BERT model, compared to keyword search. The curve depicts average performance of 10 independent training runs, with shaded areas indicating a 95% CI. AUC: area under the curve; BERT: Bidirectional Encoder Representations from Transformers; Pre: precision; Rec: recall.





## False Positive Analysis

Utilizing the note annotations summarized in [Figure 1](#), we found that 53.8% (208/387) of all notes that our BERT model falsely flagged for exposure to parental justice involvement still contained evidence of other types of contact with the justice system (eg, sibling, self, etc). This percentage was higher than the baseline proportion of such notes that were retrieved by the keyword search (1324/7459, 17.6%).

## Discussion

### Principal Findings

In this paper, we applied the use of natural language processing (NLP) and machine learning to locate children ever exposed to parental justice involvement in the electronic health record of a large Midwestern pediatric health system—an innovative approach to aggregating health data on an understudied and stigmatizing childhood adversity. The use of machine learning greatly improved the precision of locating children who have justice-involved parents from 61% (using a keyword search) to 92%. To our knowledge, only one study has validated the use of NLP to locate adults with a history of personal incarceration using the Veterans Administration health record.[\[28\]](#) In their study, the NLP keyword search resulted in an F1-score (a balanced measure of recall and precision) of 0.58; and after integrating NLP and a simplistic machine learning approach, the F-1 score improved to 0.75 [\[28\]](#). Our study achieved a similar increase, but our keyword search resulted in an F-1 score of 0.76, and after integrating BERT, the F-1 score improved to 0.93.

Our findings also revealed that when notes were falsely flagged by the model for exposure to parental justice involvement, a much higher percentage of notes flagged still contained evidence of another type of contact with the justice system compared to such notes located by the basic keyword search. In addition, compared to notes with no evidence, clinician notes with evidence of justice involvement were slightly longer and had a higher frequency of all family- and justice-related keywords except for the justice keywords “jail” and “sentenced.” This may relate to the number of notes that contained evidence of personal youth involvement with the justice system, rather than parental (as youth typically have shorter sentences that align with “jail”). Importantly, the grandparent-related terms were nearly double in frequency and are in line with research noting that nearly half of all youth with incarcerated mothers are cared for by grandparents [\[32\]](#). Other keywords such as “caregiver” and “legal guardian,” “justice,” “legal,” and “crime/criminal” may also be important to include in future research.

We are among the first to leverage data science approaches to address gaps in the pediatric health sciences related to underrepresented groups of youth. The total time for the development of our machine learning model included several weeks to annotate clinician notes, 2 months of data scientist work, and cost about \$12,000 at this particular institution. The computer code associated with this model will remain publicly available at no cost to those who are interested in testing its application in other pediatric electronic health record systems [\[35\]](#) (please email if the web address embedded in the citation

becomes faulty). Cost-effective, less-invasive, and time-saving approaches to cohort identification could surely advance our understanding and advocacy of historically marginalized and underrepresented groups of youth and families. The child health consequences of complex social phenomena such as mass incarceration must be explored, and efficient approaches to recognition in the clinical setting can aid in that process as we await wide-scale screening of childhood adversities within health care systems and settings.

Further validation with multiple data sources is needed (eg, comparison of findings to those youth identified with exposure to parental justice involvement using adverse childhood experiences screening tool checklists, or other cross-sector administration data to verify parental contact with the system) to strengthen its future use and will be an important next step. Eventual integration of these models in larger pediatric learning health systems such as PEDSnet (a multi-specialty network that conducts observational research and clinical trials across multiple children's hospital health systems) [\[36\]](#) could also be explored to understand whether differences in care and health care use exist for youth who have a justice-involved parent across systems. Once these models are extensively researched and validated, the use of these techniques could extend beyond cohort identification and eventually be used to link families to supportive behavioral health treatment, case management social services, and other positive prosocial or community resources to mitigate child stress and adversity.

The underlying approach has the potential to be extended to the identification of other types of childhood adversity (eg, sex trafficking). Until routine screening for adverse childhood experiences becomes commonplace, artificial intelligence could be an important tool to accelerate efforts for greater understanding of at-risk populations. Implications for doing so are great, as better science and greater understanding of children of justice-involved parents could spur greater investment and intervention development designed to improve their health and well-being and decrease their risk for future justice system involvement. As NASEM recommends in their latest report on increasing opportunity for all youth, we need “greater collaboration among our health, justice, and child welfare systems to transform child health”[\[11\]](#). We feel strongly that the use of artificial intelligence within pediatric health settings could accelerate these collaborative cross-sector efforts.

It is important to note that the use and application of artificial intelligence and algorithms to address the needs of our justice system (eg, risk prediction and prediction of public threats to safety) are widely investigated and contested [\[37\]](#). The use of such algorithms in pediatric health care settings to identify and locate patients with varying exposures to the justice system is novel and certainly warrants similar investigation and ethical scrutiny. It would be important to consider when, why, and who should be able to access and use data on health-related social risk factors such as familial justice involvement [\[38\]](#). While all personal arrests and incarcerations are public knowledge, the use of this information in pediatric research is novel. Most institutional review boards have additional regulatory procedures or special review processes to ensure protections of justice-involved youth and adults in research, but youth who

have family members who are justice-involved are not typically considered. Addressing the ethical challenges related to the development and implementation of machine learning to identify children of justice-involved parents is imperative and necessitates the engagement and involvement of these youth and their caregivers. Future research in this area could benefit from comparative investigations of other types of machine learning models and the integration of emerging frameworks designed to facilitate responsible and ethical digital technology for research purposes [39,40]. More research is also needed (and underway) to better understand family perceptions and attitudes surrounding the use of artificial intelligence to mine sensitive and stigmatizing information even amid the best intentions of bettering care and assisting these youths.

### Limitations

Our study is not without limitations. It is important to note that all estimates of youth exposed to parental justice involvement are unverified and only captured (1) families that disclosed and (2) a provider who was willing to document the exposure. Potential selection biases in our model may exist as there may be differences in providers who ask about justice involvement compared to those who do not, providers who choose to record the information received compared to those who do not, and families who feel comfortable or safe providing such information compared to those who feel discriminated,

ostracized, ashamed, or stigmatized in systems not designed to support or assist families affected by justice involvement. Our results likely underestimate the total number of children who have experienced justice-involved parents seen in our system and may represent a subset for which clinicians have a higher index of suspicion. Even given the potential biases in the identified population, our model improves the accuracy of locating patients who are apt to disclose parental justice involvement (with or without direct questioning of a provider) and allows identification of a high-risk cohort for research. Last, we were unable to verify our machine learning algorithm with the “ground truth” because screening for adverse childhood experiences such as parental incarceration is not routinely conducted in any setting of care within this institution. Apart from these important limitations, we feel our study has provided an important innovation to pediatric research.

### Conclusions

Machine learning is a novel cohort identification method that may be able to fulfill the gaps in the sciences related to our understanding of the health of children of justice-involved parents. Doing so could inform intervention development and effective policy creation to improve the cross-sector care and health of children of justice-involved parents—and other youth with various types of justice system involvement.

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### Conflicts of Interest

None declared.

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## Abbreviations

**BERT:** Bidirectional Encoder Representations from Transformers

**NASEM:** National Academies of Sciences, Engineering, and Medicine

**NLP:** natural language processing

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Review

# Effectiveness of Mobile Apps in Promoting Healthy Behavior Changes and Preventing Obesity in Children: Systematic Review

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## Abstract

**Background:** Mobile apps have been increasingly incorporated into healthy behavior promotion interventions targeting childhood obesity. However, their effectiveness remains unclear.

**Objective:** This paper aims to conduct a systematic review examining the effectiveness of mobile apps aimed at preventing childhood obesity by promoting health behavior changes in diet, physical activity, or sedentary behavior in children aged 8 to 12 years.

**Methods:** MEDLINE, Embase, PsycINFO, CINAHL, and ERIC were systematically searched for peer-reviewed primary studies from January 2008 to July 2021, which included children aged 8 to 12 years; involved mobile app use; and targeted at least one obesity-related factor, including diet, physical activity, or sedentary behavior. Data extraction and risk of bias assessments were conducted by 2 authors.

**Results:** Of the 13 studies identified, most used a quasi-experimental design (n=8, 62%). Significant improvements in physical activity (4/8, 50% studies), dietary outcomes (5/6, 83% studies), and BMI (2/6, 33% studies) were reported. All 6 multicomponent interventions and 57% (4/7) of standalone interventions reported significant outcomes in ≥1 behavioral change outcome measured (anthropometric, physical activity, dietary, and screen time outcomes). Gamification, behavioral monitoring, and goal setting were common features of the mobile apps used in these studies.

**Conclusions:** Apps for health behavior promotion interventions have the potential to increase the adoption of healthy behaviors among children; however, their effectiveness in improving anthropometric measures remains unclear. Further investigation of studies that use more rigorous study designs, as well as mobile apps as a standalone intervention, is needed.

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**KEYWORDS**

childhood obesity; mobile health; health behaviors; prevention; study design; systematic review; mobile phone

## Introduction

An estimated 150 million children worldwide currently live with obesity, and this number is projected to increase to 254 million by 2030 [1]. Childhood obesity, which tends to persist

into adulthood [2], is one of the most pressing public health challenges of the 21st century. It is associated with an increased risk of developing lifelong chronic conditions such as type 2 diabetes, hypertension, and cardiovascular disease [3], as well

as psychosocial consequences such as depression and anxiety [4].

Concurrent with the rising rates of childhood obesity, the adoption of mobile devices, such as smartphones and tablets, and the use of mobile apps on these devices, have also increased among children of all ages [5]. For example, in the United States, rates of smartphone ownership among children aged 8 to 12 years and 13 to 18 years have grown substantially from 25% to 41% and from 67% to 84%, respectively, from 2015 to 2019 [5]. Furthermore, 41% and 52% of Canadian children, aged 9 to 11 years and 12 to 14 years, respectively, reported playing games or using apps on electronic devices at least 5 days a week [6]. Owing to the increasing popularity of mobile devices and apps, many health and fitness apps targeting key modifiable risk factors such as diet, physical activity, and reduction of sedentary behavior have been developed and used in health promotion interventions for children [7]. These interventions tend to be (1) based on at least one behavioral change theory; (2) targeted at  $\geq 1$  behavioral, anthropometric, psychological, or process outcomes; and (3) multicomponent, where mobile apps are used in addition to other intervention components such as physical games, food or physical activity diaries, wearable technology, and SMS text messaging [8].

To date, studies have shown mobile apps have a promising role in increasing motivation and promoting goal-setting behavior to address childhood obesity [9]. Multicomponent intervention bundles involving mobile apps appear to be more effective than standalone mobile app interventions in addressing behavioral outcomes such as diet, physical activity, and sedentary behavior [10]. However, the results from these studies have generally been inconsistent, and the efficacy (performance of an intervention under ideal circumstances) and effectiveness (performance of an intervention in real-life conditions) of mobile apps in delivering interventions to address childhood obesity remain unclear [11]. Most studies have focused on investigating the feasibility, usability, and acceptability of mobile health interventions rather than assessing efficacy and effectiveness via controlled trials [8].

Systematic reviews have focused on mobile health interventions that target diet, physical activity, and sedentary behavior, which are factors associated with childhood obesity; however, most examined mobile apps in combination with other interventions such as exergames (digital games that involve physical movements for active gameplay), video games, websites, and SMS text messaging [12-15]. Of the few reviews that focused solely on mobile apps, most involved adolescents [9,15] or a mix of pediatric and adult populations [10]. Therefore, there is a knowledge gap in the literature on the effectiveness of mobile health technologies that promote healthy behavior change to prevent childhood obesity in school-aged children (8 to 12 years), which is a critical period for children to develop positive habits and behaviors as they form their own identities. The objective of this study is to conduct a systematic review to examine the effectiveness of mobile apps that promote healthy behavior changes in diet, physical activity, or sedentary behavior in children aged 8 to 12 years.

## Methods

### Literature Search

This systematic literature review was conducted and is reported according to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement [16]; the protocol was not preregistered in any database. Medical Subject Heading terms and keywords related to (1) mobile app development, (2) obesity prevention and healthy behaviors, and (2) mixed methods research interventions were identified with guidance from a research librarian (CP). The search strategy was designed such that the results contained at least one search term from each of these 3 categories. Using this strategy, the electronic databases MEDLINE, Embase, PsycINFO, CINAHL, and ERIC were searched in July 2021 to identify records published between January 2008 and June 2021. The year 2008 was selected as the lower limit of publication years as it coincides with the launch of both the Android market [17] and Apple App Store [18], which are platforms for users to download apps on their digital devices. To retrieve pediatric articles, search filters were used for MEDLINE [19], Embase [20], and CINAHL [21], whereas age groups and education level limiters were used for PsycINFO and ERIC, respectively. The complete search strategy is presented in [Multimedia Appendix 1](#). Gray literature was searched by screening the reference lists of the included articles, research studies listed in the US National Library of Medicine clinical trials database (using search terms *Obesity*, *Childhood*, and *Mobilehealth*), the first 100 results from a search of keywords *childhood obesity* and *mobilehealth* on Google Scholar, and results from the title and abstract search of ProQuest Dissertations and Theses Global with search terms *childhood obesity* and *mobile*. Only peer-reviewed studies resulting from the gray literature search were considered.

### Eligibility Criteria

The eligibility criteria for articles included (1) peer-reviewed primary studies written in English; (2) published between January 2008 and the end of June 2021; (3) children aged 8 to 12 years as participants (studies with children participants outside the age range but with some within the target age range were deemed eligible); (4) the use of a mobile app by children and their immediate caregivers; and (5) targeting behavior change in at least one obesity-related factor, including diet, physical activity, or sedentary behavior. Participants of all health statuses—healthy weight, at risk, or with obesity or overweight—were considered. To provide a broad overview of the current published literature, experimental (eg, randomized controlled trial [RCT]), quasi-experimental, observational, and mixed methods studies were included. Articles that described only the use of websites, email, or SMS text message-based interventions were excluded.

### Study Selection

After removing duplicates, a single author (KWY) performed an initial screening based on the title and abstract to identify full-text articles for assessment of eligibility. Any uncertainty that arose from this process was discussed with SA, and decisions were made by consensus. Articles that could not be excluded based on the information provided in the title and

abstract were included in the full-text review. KWY and AK then reviewed the full-text articles independently, after which they compared their decisions on eligibility, discussed and resolved any discrepancies by consensus, and finalized the list of articles to be included in this review.

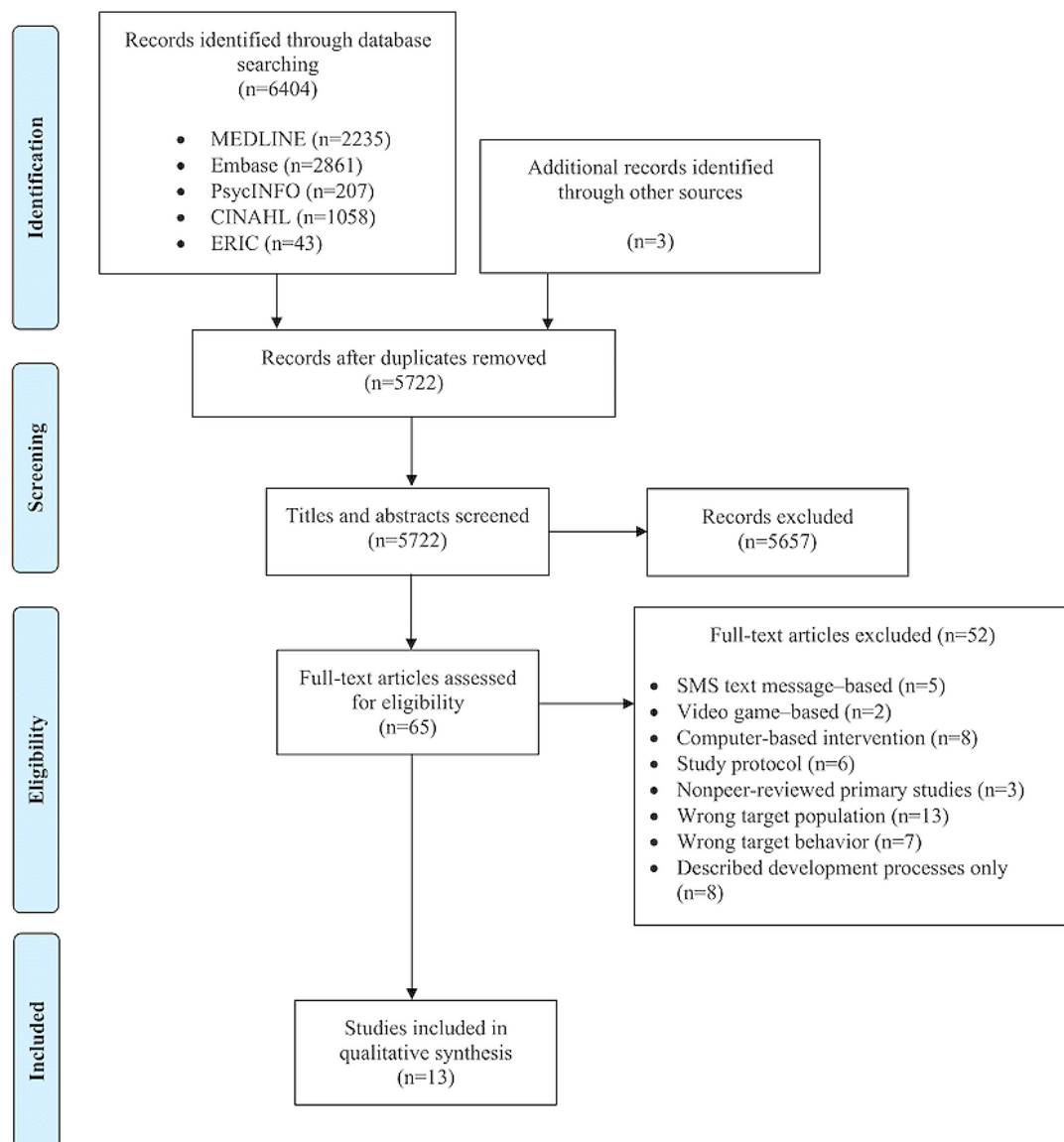
### Data Extraction and Quality Assessment

Information on study design, inclusion criteria, sample size, sociodemographic characteristics of participants, study details (eg, behavior change theory and study length), description of the mobile app, and outcome measures (eg, anthropometry, physical activity, diet, screen time, sedentary behavior, and process evaluation) were independently extracted by KWY, AK, and ADK, following a predetermined data extraction template developed by KWY based on interventions and outcomes identified during the development of the research aim, eligibility criteria, and search strategy ([Multimedia Appendix 2](#)). Discussions between KWY, AK, ADK, and SA (as needed) occurred regularly to reach a consensus in cases of disagreement. KWY and ADK independently assessed the risk of bias of the included studies using the Cochrane Risk of Bias 2 tool for randomized trials [22] and the Risk of Bias in Nonrandomized Studies of Interventions tool for observational and quasi-experimental studies [23]. Any discrepancies in the ratings were resolved via discussion between the authors until a consensus was reached.

## Results

### Study Characteristics

A total of 13 studies met the eligibility criteria ([Figure 1](#)), of which 8 (62%) were from the United States [24-31], and the remaining 5 (38%) studies were from Australia [32], Canada [33], the Netherlands [34], New Caledonia (Overseas France) [35], and Portugal [36]. The number of participants per study ranged from 18 to 2477, with 15% (2/13) of studies including only male [32] or only female [27] participants. The age of the participants ranged from 4 to 21 years, with 46% (6/13) of studies involving only adolescents (aged >10 years) [25,28,32,34-36]. Across the studies, there were diverse representations from various racial or ethnic minority groups, including African [31,32], African American [25-27,30], American Indian or Alaska native [27,31], Asian [26,32], Hispanic [25,26,31,32], Pacific Islander [27,35], and Middle Eastern [32]. In 38% (5/13) of studies, more than half of the study participants were from racial or ethnic minority populations [25-27,29,31]. Targeted recruitment of participants from low socioeconomic backgrounds was conducted in 38% (5/13) of studies [27,29-32]. Approximately 15% (2/13) of studies included only participants who were at risk for developing obesity, as determined by their failure to meet international physical activity or screen time guidelines [32] and positive results on a food addiction scale [25]. Of the 13 studies, 4 (31%) were randomized intervention studies [27,28,32,34].

**Figure 1.** PRISMA (Preferred Reporting Item for Systematic Reviews and Meta-Analyses) flow diagram summarizing the study selection process.

### Risk of Bias Assessment

Of the 4 randomized intervention studies included, 3 (75%) were rated as having some concerns regarding their overall bias [27,28,34], whereas 1 (25%) study had a low risk of bias [32] (Table 1). A potential major source of bias in the 31% (4/13) of studies that used an RCT design [27,28,32,34] was from the randomization process itself; 75% (3/4) of studies [23,24,28] did not elaborate on the randomization methods other than providing a statement that the study was randomized. Owing to the nature of the interventions, blinding of participants and those delivering the intervention from group allocation were impossible for all studies. Of the 4 RCT studies, 1 (25%) attempted to blind assessors from treatment allocations but were only successful at baseline and not at follow-up [32]. Only 75% (3/4) of RCT studies reported incomplete outcome data because of participant absence on the day of data collection [32,34], loss to follow-up [27,32], withdrawal from the study [32], and malfunctioning of the measuring devices [34]. 50% (2/4) of

RCT studies reported objective measures, such as BMI and step count, as primary outcomes [32,34]. The prespecified intentions for data analysis were only available for 50% (2/4) of the RCT studies in the form of a clinical trial register [37] and a published protocol [38].

Of the 9 nonrandomized intervention studies, 5 (56%) were assessed as having a moderate risk of bias [24,30,31,33,35] and 4 (44%) as having a serious risk of bias [25,26,29,36] (Table 2). Baseline confounding was found to be a serious risk of bias in 33% (3/9) of studies, with 67% (2/3) of studies measuring but not controlling for potential confounding factors [25,29] and 33% (1/3) of studies neglecting to consider previous exposure to interventions as a potential confounder for a small subset of participants in a retreat [26]. Of the 9 studies, all but 1 (11%) study [36] scored a low or moderate risk for missing data. A prespecified analysis plan was available for 22% (2/9) of studies in the form of a trial register [39] and study protocol [40].

**Table 1.** Risk of bias assessment scores for randomized trials.

Study	Randomization process	Deviations from intended interventions	Missing outcome data	Measurement of the outcome	Selection of the reported result	Overall bias
Byrne et al [28]	Some concerns	Low	Low	Low	Some concerns	Some concerns
Nollen et al [27]	Some concerns	Low	Some concerns	Low	Some concerns	Some concerns
Smith et al [32]	Low	Low	Low	Low	Low	Low
van Woudenberg et al [34]	Some concerns	Low	Low	Low	Low	Some concerns

**Table 2.** Risk of bias assessment scores for nonrandomized trials.

Study	Confounding	Selection of participants	Intervention classification	Deviations from intended intervention	Missing data	Measurement of outcomes	Selection of reported result	Overall bias
Bell et al [31]	Moderate	Low	Low	Low	Low	Moderate	Moderate	Moderate
Blackman et al [29]	Serious	Low	Low	Low	Moderate	Low	Moderate	Serious
Dunton et al [26]	Serious	Low	Low	Low	Low	Low	Moderate	Serious
Galy et al [35]	Moderate	Moderate	Low	Low	Moderate	Low	Moderate	Moderate
Patten et al [33]	Moderate	Low	Low	Low	Low	Low	Low	Moderate
Pretlow et al [24]	Moderate	Low	Low	Low	Low	Moderate	Moderate	Moderate
Sousa et al [36]	Moderate	Low	Low	Low	Serious	Moderate	Low	Serious
Struempfer et al [30]	Moderate	Low	Low	Low	Moderate	Moderate	Moderate	Moderate
Vidmar et al [25]	Serious	Low	Moderate	Low	Low	Low	Low	Serious

## Study and Intervention Design

Table 3 outlines the study and the intervention design features. Quasi-experimental study designs were the most prevalent (8/13, 62%) and included within-subject design (1/8, 13%) [33], one-group posttest-only design (1/8, 13%) [26], and pretest–posttest designs (6/8, 75%) [24,25,29–31,36]. The remaining 38% (5/13) of studies were cluster RCTs [32,34], RCTs [27,28], and an exploratory study [35] (which was used during a preliminary investigation of a research question with minimal available published evidence). The intervention duration ranged from <1 month (5/13, 38%) [26,28,31,33,34], with one of the studies testing a suite of imagination-based mobile games lasting 1 hour [33]; between 1 month and 3 months (3/13, 23%) [27,29,35]; and between 3 and 6 months (5/13, 38%) [24,25,30,32,36]. Only one of the studies included

a follow-up assessment to determine the sustainability of changes 8 months after the end of a 20-week intervention [32]. Of the 13 studies, 2 (15%) were treatment interventions for overweightness or obesity [24,25], 3 (23%) were obesity prevention interventions [27,30,32], and 8 (62%) were healthy behavior promotion interventions [26,28,29,31,33–36]. The targeted healthy behaviors included physical activity [26,29,31–35], screen time or sedentary behavior [26,29,32], and nutritional intake [24,25,27,28,30–32]. Most studies targeted only a single healthy behavior. All studies included apps developed solely for the purpose of their intervention. Of the 13 studies, 11 (85%) included the use of only a single app, whereas 1 (8%) study used a collection of 4 apps [29], and another used a collection of 7 apps [30] as part of the intervention.



**Table 3.** Study design and intervention type of studies included.

Study	Study design			Intervention type			Multicomponent	Duration	Behavior change theory	
	Quasi-experimental		RCT <sup>a</sup>	Exploratory	Healthy behavior promotion	Obesity prevention				Obesity treatment
	Within-subject	One-group posttest-only	Pretest-posttest							
Bell et al [31]			✓ (control)		✓		✓	3 weeks	Self-determination theory; social cognitive theory	
Blackman et al [29]			✓		✓			6 weeks	Fogg Behavior Model	
Byrne et al [28]			✓		✓			9 days	Social cognitive theory	
Dunton et al [26]	✓				✓			1 day	N/A <sup>b</sup>	
Galy et al [35]				✓	✓			4 weeks	N/A	
Nollen et al [27]			✓			✓		12 weeks	Behavioral weight control principles	
Patten et al [33]	✓				✓			1 hour	N/A	
Pretlow et al [24]			✓				✓	20 weeks	Addiction treatment model	
Sousa et al [36]			✓ (control)		✓		✓	6 months	N/A	
Smith et al [32]			✓ (cluster)			✓	✓	20 weeks	Social cognitive theory; self-determination theory	
Struempfer et al [30]			✓			✓	✓	17 weeks	Experiential learning theory	
Vidmar et al [25]			✓				✓	26.1 weeks	Addiction treatment model	
van Woudenberg et al [34]			✓ (cluster)		✓			1 week	Self-determination theory	

<sup>a</sup>RCT: randomized controlled trial.

<sup>b</sup>N/A: not applicable.

### Behavior Change Theory

Of the 13 studies, all but 4 (31%) studies [26,33,35,36] used a behavior change theory as the foundation for app and intervention design to promote healthy behavior change among participants (Table 3); 8 different behavior change theories were reported, with 7 (54%) studies using 1 behavior change theory [24,25,27-30,34], and 2 (15%) studies combining 2 behavior

change theories [31,32]. Approximately 23% (3/13) of interventions [28,31,32] used social cognitive theory [41], which suggests that learning and acquiring certain behaviors occur through reciprocal interactions between individuals and their environment. Another 15% (2/13) of studies [24,25] used the same app and adopted an addiction treatment model [42]. Other behavior change theories included the self-determination theory

[31,32,34], behavioral weight control principles [27], the Fogg Behavior Model [29], and the experiential learning theory [30].

### App Design Features

The most common app design feature was gamification (7/13, 54%), whereby healthy behavior promotion was integrated into the app via digital pets [28], simulated gardening [31], on-screen instructions for individual and small-group play [29,33], and team challenges [35]. User progress was rewarded through song-based rewards [27], a wall of fame [36], and augmented reality trophies [31]. Another common design feature was behavioral monitoring (6/13, 46%), which included self-reporting via questionnaire administration [24-26,34]; self-monitoring of healthy behaviors and anthropometric measures [36]; and collection of information from accelerometers [32,34], food scales [24,25], and body weight scales [24,25]. Another common feature was goal setting (5/13, 38%) for physical activity [32,35]; screen time [27,32]; fruits and vegetables [27]; sugar-sweetened beverages [27]; and the reduction in food amounts, food problems, and snacking [24,25]. Push notifications [32,34], SMS text messages [24,25], and emails [28] were used to deliver tailored motivational messages. When a participant experienced excessive weight loss, one of the apps automatically alerted the research team [24,25]. Approximately 38% (5/13) of studies representing 4 apps incorporated social support features, including peer assessments [32], peer nominations for influence agents [34], app bulletin boards [24,25], discussion forums [36], and in-app chat groups [24,25,36]. A total of 2 apps from 23% (3/13) of studies [24,25,28] allowed users to take photographs of their meals in the app and submit them to a research server for review and scoring.

### Outcome Measures

A summary of the reported outcome measures is presented in Table 4 and Table 5. Approximately 62% (8/13) of studies reported significant improvements in at least one of the measured healthy behaviors. Measures of physical activity were the most commonly reported outcomes in the intervention studies [26,29,32-36]. Of the 7 studies that included physical activity as an outcome, 4 (57%) reported statistically significant increases in physical activity levels following app use, as measured by moderate to vigorous physical activity (MVPA) via estimation from heart rate [33] and accelerometry [26,32], number of steps [26,32], and metabolic equivalents as determined by accelerometry [29]. Participants who used Biba Games, a suite of mobile apps aimed at encouraging imagination-based outdoor play via playful directives, displayed greater amounts of MVPA than regular playground gameplay, as demonstrated by a significant increase in heart rate measured in beats per minute (mean change 17.8, SD 28.3%;  $P<.05$ ) [33]. In a 6-week smartphone game-based app program aimed at promoting physical activity in an afterschool program, participants achieved greater metabolic equivalents during gameplay with mobile app games than with nonguided free play

( $P=.02$ ) [29]. The investigation of the acceptability and validity of a 4-day ecological momentary assessment protocol using mobile surveys to measure physical activity and sedentary behavior in children revealed significantly higher step counts ( $P<.001$ ) and the likelihood of  $\geq 5$  minutes of MVPA ( $P<.001$ ) during ecological momentary assessment-reported physical activity [26]. Finally, in Active Teen Leaders Avoiding Screen-time (ATLAS), which was a 20-week multicomponent obesity prevention intervention using smartphone technology, significant intervention effects were found for muscular fitness (mean 0.90, SE 0.49 repetitions;  $P=.04$ ) and resistance training skills (mean 5.70, SE 0.67 units;  $P=.001$ ) [32].

Dietary outcomes were reported in 46% (6/13) of intervention studies and included fruit and vegetable intake [27,30,31], sugar-sweetened beverage intake [27,31,32], the likelihood of eating breakfast [28], self-efficacy toward fruit and vegetable consumption [31], and attitude toward healthy eating [36]. Of the 4 studies that measured at least one dietary intake outcome, 2 (50%) reported significant improvements in fruit and vegetable intake [30] and sugar-sweetened beverage consumption [32], both of which were measured using self-reported questionnaires. Body Quest: Food of the Warrior [30] is a multicomponent elementary school-based childhood obesity prevention program aimed at increasing fruit and vegetable consumption, increasing physical activity, and promoting family involvement via a mix of traditional curriculum teaching, iPad app-based education, weekly fruit and vegetable tastings, and weekly take-home activities. Intervention participants demonstrated significant increases in fruit ( $P<.01$ ) and vegetable ( $P<.001$ ) consumption over the course of the program, increasing from 7 to 8 weekly fruit and vegetable servings in total. At the end of the program, participants consumed significantly more weekly servings of fruits ( $P<.001$ ) and vegetables ( $P<.001$ ) than the control group. In ATLAS [32], participants demonstrated a significant reduction in sugar-sweetened beverage consumption, as measured by the number of glasses per day (mean 0.60, SE 0.26 glasses per day;  $P=.01$ ), after the 20-week intervention. The use of a mobile app as a standalone childhood obesity prevention tool resulted in a mix of nonsignificant and significant intervention effects. In a 12-week mobile technology intervention for obesity prevention among girls of diverse racial and ethnic backgrounds [27], participants tested a mobile app that facilitated goal setting, self-monitoring, and positive reinforcement to promote healthy behaviors. A 24-hour dietary recall failed to detect any significant improvements in fruit and vegetable consumption and sugar-sweetened beverage consumption. However, participants who tested a digital pet mobile game app aimed at improving eating behaviors demonstrated a significant increase in their likelihood of consuming breakfast ( $P<.05$ ) [28]. All 23% (3/13) of studies that measured changes in the perception of healthy diet practices reported significant improvements, including adopting a more positive perception toward healthy dietary changes [28,31,36] and an increased likelihood of consuming breakfast [28].

**Table 4.** Measured anthropometry and physical activity outcomes and effect size of included studies.

Study	Anthropometry				Physical activity					
	BMI	BMI z score	BMI percentile	Waist circumference	Body fat percentage	MVPA <sup>a</sup>	Step count	MET <sup>b</sup>	Physical strength or fitness	Attitude or perception
<b>Bell et al [31]</b>										
Significance		NS <sup>c</sup>	NS							
Statistics		<i>P</i> =.30	<i>P</i> =.32							
<b>Blackman et al [29]</b>										
Significance								✓		
Statistics								<i>P</i> =.02		
<b>Byrne et al [28]</b>										
Significance										
Statistics										
<b>Dunton et al [26]</b>										
Significance						✓	✓			
Statistics						<i>P</i> <.001	<i>P</i> <.001			
<b>Galy et al [35]</b>										
Significance						NS	NS		NS	NS
Statistics										
<b>Nollen et al [27]</b>										
Significance	NS									
Statistics	<i>d</i> =0.03; <i>P</i> =.91									
<b>Patten et al [33]</b>										
Significance						✓				
Statistics						<i>d</i> =0.53; <i>P</i> <.05				
<b>Pretlow et al [24]</b>										
Significance			✓							
Statistics			<i>P</i> <.01							
<b>Sousa et al [36]</b>										
Significance										NS
Statistics										$\eta_p^2$ =0.01; <i>P</i> =.19
<b>Smith et al [32]</b>										
Significance	NS			NS	NS	NS	NS		✓	
Statistics	<i>P</i> =.84			<i>P</i> =.16	<i>P</i> =.99	<i>P</i> =.14 (weekday); <i>P</i> =.80 (weekend)	<i>P</i> =.41 (week- day); <i>P</i> =.57 (week- end)		<i>P</i> =.04 (muscular fit); <i>P</i> <.001 (RT <sup>d</sup> )	
<b>Struempfer et al [30]</b>										
Significance										
Statistics										
<b>Vidmar et al [25]</b>										

Study	Anthropometry					Physical activity				
	BMI	BMI z score	BMI percentile	Waist circumference	Body fat percentage	MVPA <sup>a</sup>	Step count	MET <sup>b</sup>	Physical strength or fitness	Attitude or perception
Significance		✓	✓							
Statistics		<i>P</i> <.001	<i>P</i> <.001							
<b>van Woudenberg et al [34]</b>										
Significance										NS
Statistics										<i>P</i> =.66

<sup>a</sup>MVPA: moderate to vigorous physical activity.

<sup>b</sup>MET: metabolic equivalent.

<sup>c</sup>NS: nonsignificance.

<sup>d</sup>RT: resistance training.

**Table 5.** Measured dietary, screen time, feasibility and process evaluation outcomes and effect size of included studies.

Study	Dietary			Screen time	Feasibility or process evaluation
	Fruits and vegetables	Sugar-sweetened beverages	Breakfast likelihood		
<b>Bell et al [31]</b>					
Significance	NS <sup>a</sup>	NS		✓	
Statistics	$P=.41$ (fruit); $P=.38$ (vegetable)	$P=.75$		$P=.01$	
<b>Blackman et al [29]</b>					
Significance					✓
Statistics					
<b>Byrne et al [28]</b>					
Significance			✓	✓	✓
Statistics			$\eta_p^2=0.20$ ; $P<.05$	$\eta_p^2=0.23$ ; $P<.05$	
<b>Dunton et al [26]</b>					
Significance					
Statistics					
<b>Galy et al [35]</b>					
Significance					✓
Statistics					
<b>Nollen et al [27]</b>					
Significance	NS	NS		NS	
Statistics	$d=0.44$ ; $P=.13$	$d=-0.34$ ; $P=.09$		$d=0.09$ ; $P=.76$	
<b>Patten et al [33]</b>					
Significance					
Statistics					
<b>Pretlow et al [24]</b>					
Significance					✓
Statistics					
<b>Sousa et al [36]</b>					
Significance				✓	
Statistics				$\eta_p^2=0.03$ ; $P=.03$	
<b>Smith et al [32]</b>					
Significance		✓		✓	✓
Statistics		$P=.01$		$P=.03$	
<b>Struempfer et al [30]</b>					
Significance	✓				
Statistics	$P<.001$ (fruit); $P<.001$ (vegetable)				
<b>Vidmar et al [25]</b>					
Significance					✓
Statistics					



Study	Dietary		Screen time		Feasibility or process evaluation
	Fruits and vegetables	Sugar-sweetened beverages	Breakfast likelihood	Attitude or perception	
<b>van Woudenberg et al [34]</b>					
Significance					
Statistics					

<sup>a</sup>NS: nonsignificance.

BMI or BMI-derived measures were reported in 38% (5/13) of studies and included BMI [27,32], BMI *z* score (zBMI) [25,31], BMI percentile [31], and percentage over BMI relative to the 95th percentile (%BMI<sub>p95</sub>) [25] and 50th percentile (%BMI<sub>p50</sub>) [24], all of which were derived from height and weight data measured by trained research personnel. Of the 5 studies, 2 (40%) reported significant improvements [24,25]; both reported on the same weight loss intervention but in different settings—clinical [25] and community [24]—and measured various BMI-derived measures from baseline to program completion. The intervention was a multicomponent program based on an addiction treatment model that involved app use, as well as weekly phone meetings and group meetings to guide participants into staged, incremental food withdrawal to address problem foods, snacking, and meal size reduction. In the community setting, participants demonstrated a significant decrease in %BMI<sub>p50</sub> from baseline to the end of the intervention (baseline: mean  $-0.051$ , SD  $0.013$  %BMI<sub>p50</sub> per day;  $P < .01$ ). In addition, participants in the health care setting [25] also experienced a significant decrease in %BMI<sub>p95</sub> (coefficient  $= -0.02$ ; 95% CI  $-0.03$  to  $-0.01$ ;  $P < .001$ ), which is a more stringent measure, upon program completion compared with age-matched controls, with a significant decrease noted at 1, 3, and 6 months. Approximately 15% (2/13) of other studies that reported BMI only [27,32] found no significant differences in intervention completion despite comparable intervention durations (between 12 and 20 weeks).

Other reported measures included waist circumference [32], body fat percentage [32], strength and fitness measurements [32,35], recreational screen time [27,32], importance of eating healthy [28], attitudes and perceptions toward physical activity [35,36], and nutrition [31,36]. In an app-based digital pet intervention, when asked about the importance of healthy eating, participants who received only positive feedback from their digital pets (ie, happy pet avatar) reported viewing healthy eating as less important than those who received both positive and negative feedback (ie, sad pet avatar;  $P < .01$ ), illustrating the motivational value of negative feedback [28]. Significant intervention effects were found for screen time (mean  $-30.00$ , SE  $10.08$  minutes per day;  $P = .03$ ) in ATLAS [32]. Intervention participants of Virtual Sprouts, a 3-week intervention that involved a mobile gardening game and a classroom component, compared with the control group, achieved significant improvements in self-efficacy to eat ( $+1.6\%$  vs  $-10.3\%$ ;  $P = .01$ ) and cooking ( $+2.9\%$  vs  $-5.0\%$ ;  $P = .05$ ) fruits and vegetables [31]. A significant effect on the self-reported perception of nutrition (mean change  $0.02$ , SD  $0.48$ ;  $P = .03$ ) was reported

among participants of TeenPower, a mobile health intervention aimed at promoting healthy behaviors in adolescence [36], compared with the control group (mean change  $-0.07$ , SD  $0.42$ ). No relationship was found between intervention effectiveness, as indicated by significant changes in reported outcome measures, and study quality, as assessed by the risk of bias assessment (Table 1 and Table 2).

### Feasibility and Process Evaluation

Feasibility and process evaluation data were reported in 46% (6/13) of studies. Of the 3 studies that examined program satisfaction via surveys [32] and semistructured focus groups [29], 3 (67%) reported high levels of satisfaction. Approximately 31% (4/13) of studies measured user enjoyment, of which 75% (3/4) reported high levels of participant enjoyment [28,29,35], and 25% (1/4) reported that only 44% of participants agreed that the intervention was enjoyable [32]. Other feasibility measures included ease of use, perspectives on app features [29], and sustained interest in the intervention [28,35]. Approximately 23% (3/13) of studies reported on process indicators, including compliance measured via attendance tracking [32], recruitment and retention rates [25], and facilitator rating of participant compliance [24,25].

## Discussion

### Principal Findings

Interventions that used mobile health apps and included children aged 8 to 12 years were effective in improving healthy behaviors associated with childhood obesity, such as diet, physical activity, and sedentary behavior, with 62% (8/13) of studies reporting significant positive changes in at least one healthy behavior outcome. However, there was a lack of strong evidence to suggest the effectiveness of these interventions in improving anthropometric measures, with only 40% (2/5) of studies, both describing the same intervention but performed in different settings (clinical and community), reporting at least one significant change in BMI *z* score [25] and BMI percentile [24,25]. This discrepancy between healthy behavior improvements and insignificant improvements in anthropometric measures may be accounted for by the use of different assessment methods. Except for physical activity, measures of healthy behaviors tended to be assessed by self-report questionnaires, which may be more prone to bias and inaccuracy than anthropometric outcomes, which are typically measured by trained research personnel.

Of the 13 studies included in this review, 8 (62%) described healthy behavior promotion interventions [26,28,29,31,33-36],

which is indicative of the gradual shift in focus from treatment to preventive health. Although mobile apps have the potential to improve healthy behaviors, our review indicates that not all apps are equal in their effectiveness. Of the 12 apps included in this review, 9 (75%) apps (of the 13 studies, 10 (77%) studies represented these apps) reported significant results in  $\geq 1$  outcome measure [24-26,28-33,36]. Approximately 46% (6/13) of studies [24-26,28,29,33] found significant results in all outcome measures assessed and targeted no more than 2 outcomes, suggesting the increased effectiveness of apps with a narrow behavior change target. Automatic data collection [24,25,32] and gamification [27-29,31,33,35,36] were the key features of apps that resulted in effective interventions. Multicomponent interventions appear to be superior compared with standalone app interventions.

### Quasi-Experimental Designs Provide Flexibility for Proof-of-Concept Studies

Quasi-experimental study designs were the most common among the interventions described, with the one-group pre–posttest design being the most popular [24,25,29,30]. With a multitude of possible study designs (eg, interrupted time series and designs with or without control groups), quasi-experimental designs provide versatility, particularly in the context of limited resources. RCTs may require a large sample size and, as a result, greater amounts of resources such as funds and research personnel [43]. Researchers may have considered the unethical nature of performing randomization in at-risk populations, which could have been addressed by a stepped-wedge or waitlist study design but at the cost of a delay in treatment in the waitlist control group [44]. Quasi-experimental experiments can provide insight into correlation because of their design flexibility in the inclusion of retrospective control groups and multiple measures over time and can inform researchers whether it is worthwhile to conduct an RCT afterward to confirm causation [45].

### Behavioral Versus Adiposity Measures for Evaluation of Childhood Obesity Interventions

Although only 33% (2/6) of studies reported significant improvements in adiposity measures [24,25], 73% (8/11) of studies reported significant improvements in at least one healthy behavior outcome, such as physical activity and fruit and vegetable intake. This absence of significant improvements in adiposity measures in the presence of improvements in behavioral measures has been previously reported [12] and may be explained by the limited duration of the reported interventions, as many were considered proof-of-concept studies with limited resources. For instance, participants in the pilot study by Patten et al [33] engaged in only 2 separate 20-minute play sessions (with and without the use of the mobile app) separated by 10- to 15-minute breaks. Given the pilot nature of the study, the authors discussed the limited budget as a potential challenge and further acknowledged that the results may be insufficient to support the presence of meaningful interactions and generalizability to the population of interest. Using solely adiposity measures, such as BMI and other BMI-derived measures (eg, zBMI, %BMI<sub>p95</sub>, and %BMI<sub>p50</sub>), has been found to be insufficient for evaluating the effects of interventions for childhood obesity [46]. For example, results from a 9-week

multicomponent, community-based childhood obesity intervention indicated that changes in zBMI were independent of changes in important health outcomes, such as cardiovascular fitness and physical activity, upon intervention completion [46].

### Effectiveness of Multicomponent Versus Standalone App Interventions

Although the aim of this review was to determine the effectiveness of mobile apps in promoting healthy behaviors, with 46% (6/13) of studies being multicomponent interventions, it is difficult to identify the unique contribution to behavior change associated with the app versus other intervention components. All 6 multicomponent intervention studies reported at least one significant outcome, whereas only 57% (4/7) of standalone intervention studies reported significant outcomes. This observation is consistent with the results of other systematic reviews of healthy behavior change interventions [10,47] and suggests that the inclusion of an app in a multicomponent intervention may result in greater effectiveness in achieving healthy behavior changes. In our review, multicomponent interventions tended to be longer (17 weeks to 6 months) than standalone interventions (1 hour to 12 weeks). Previous literature has noted the correlation between a longer follow-up period for multicomponent interventions and their efficacy [47]. Furthermore, given the difficulty in conducting intensive interventions (eg, on a daily basis) because of resource and time constraints, the inclusion of a mobile app in a multicomponent intervention may potentially serve as a tool that consistently motivates healthy behavior changes between intervention activities and study visits. However, results from multicomponent intervention studies should be interpreted with caution as they may be biased or underpowered [48].

The tendency for multicomponent interventions to be more efficient has been described previously [49]; however, few studies have directly investigated the effect of the individual components of a multicomponent intervention. Therefore, the effects of the multicomponent interventions reported in this review cannot be attributed solely to the inclusion of the apps. Other intervention components or combinations of components, such as intervention length, irrespective of app use, may have contributed to the reported intervention effects [50].

### App Features of Effective Interventions

The inclusion of certain features in an app may increase the effectiveness of the interventions [51]. The ability of an app to automatically collect and record health data using wirelessly connected devices such as accelerometers and scales may make it more convenient for users to keep track of their progress and receive continuous feedback and, thus, serve as an enabling factor for healthy behavior changes, as they facilitate personalized experiences based on users' preferences and needs [52]. Furthermore, 30% (3/10) [24,25,32] of studies reporting at least one significant outcome incorporated the use of wireless technology to gather data from an external device directly to a mobile device. In accordance with the Fogg Behavior Model [53], decreasing barriers to use (via automatic data collection and data integration) may decrease the level of effort required by users and, in turn, increase the likelihood that users will engage in healthy behavior changes.

The incorporation of gamification in apps has previously been found to be associated with increased motivation and the establishment of long-lasting habits [54]. Approximately 71% (5/7) of studies that incorporated elements of gamification reported at least one significant healthy behavior outcome [28,29,31,33,36]. The analysis of health and fitness apps related to diet and physical activity by Lister et al [55] suggests that the use of gamification to increase motivation may only lead to temporary healthy behavior changes, as gamification often fails to address the individual's *ability* and the *presence of triggers* (cues to prompt target behavior), which when combined with *motivation*, form the 3 elements of the Fogg Behavior Model [53]. Mobile app developers are encouraged to integrate key aspects of behavior change theories to promote healthy behavior changes; 75% (3/4) [28,29,31] of studies included in this review that incorporated gamification and at least one behavior change theory in its app design reported at least one significant healthy behavior outcome.

### Strengths and Limitations

This review was conducted under the guidance of a research librarian to ensure thoroughness of the search following PRISMA guidelines [16]. Study screening, data extraction, and risk of bias assessments were performed by at least two independent reviewers and discussed until consensus was reached. The narrow scope of this review provides a thorough overview of the literature to those interested in healthy behavior promotion studies targeting children that focused on mobile apps rather than other eHealth technologies such as SMS text messages and web-based technologies. Limitations are that because of the limited evidence base that is currently available, most studies included were quasi-experimental, and as evident from the risk of bias assessment, approximately half of the studies were rated as having a serious risk of bias. Even among the 4 RCTs, 3 (75%) were rated as having concerns regarding

their risk of bias. Given that all but one of the studies included in this review were conducted in Western countries, this review may not be generalizable to the larger global community. It should also be noted that a meta-analysis was not completed because of the diverse nature of the outcomes and the reporting of the studies included in this review. Our results may be limited by our choice, the number of databases searched, and publication bias. Finally, we were unable to retrieve the relevant data specifically for the subgroups of children aged 8 to 12 years, as not all included studies reported the breakdown of participants' ages, and thus, our assessment may be more generalizable to children outside this age group. Future studies should include a formal evaluation of behavior change theory application to measure the extent of theory application in mobile apps and intervention designs.

### Conclusions

The results of this systematic review suggest the potential of apps as components of healthy behavior promotion interventions to increase the adoption of healthy behaviors among children. However, the effectiveness of these mobile health interventions in improving anthropometric measures remains unclear. Dietary factors and physical activity measures emerged as the most common significant outcomes reported; gamification, wireless connection to external sensors, goal setting, and social support were common app features of interventions that reported significant outcomes. Further investigation is needed to determine the effectiveness of mobile apps as standalone interventions. With most of the literature comprising quasi-experimental studies that were relatively short in duration, future research in this area should use more rigorous study designs and be longer in duration (ie, >1 year) to truly generate a comprehensive understanding of the efficacy of mobile apps in healthy behavior promotion interventions for children.

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### Conflicts of Interest

None declared.

Multimedia Appendix 1

Literature search strategy.

[[DOCX File, 23 KB - pediatrics\\_v5i1e34967\\_app1.docx](#)]

Multimedia Appendix 2

Data extraction template.

[[DOCX File, 18 KB - pediatrics\\_v5i1e34967\\_app2.docx](#)]

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## Abbreviations

**%BMI<sub>p50</sub>**: percentage over BMI relative to the 50th percentile

**%BMI<sub>p95</sub>**: percentage over BMI relative to the 95th percentile

**ATLAS**: Active Teen Leaders Avoiding Screen-time

**MVPA**: moderate to vigorous physical activity

**PRISMA**: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

**RCT**: randomized controlled trial

**zBMI**: BMI z score

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Original Paper

# Effectiveness of Pediatric Teleconsultation to Prevent Skin Conditions in Infants and Reduce Parenting Stress in Mothers: Randomized Controlled Trial

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## Abstract

**Background:** In Japan, eHealth for infants and mothers is currently an important aspect, but its effectiveness has rarely been examined. For infants, skin problems, including atopic dermatitis (AD), which is known to lead to other allergic diseases, are one of the most common conditions. Mothers of infants are prone to experiencing parenting stress, which adversely affects mothers' and children's well-being. Additionally, studies have reported that AD among offspring enhances parenting stress, and postnatal maternal psychological problems can increase the risk of AD in children.

**Objective:** This study evaluated the effectiveness of pediatric teleconsultation for preventing AD in infants and reducing parenting stress in mothers in Japan.

**Methods:** The study was an open-label, randomized, parallel-armed controlled trial. In total, 318 pairs of infants and mothers in the Yokohama City Sakae Ward were recruited when they submitted birth cards to the ward, received the explanation about the trial, and provided informed consent on the website for this trial. Eligible pairs of infants and mothers were randomly assigned to the intervention group (n=140) or the control group (n=138). Participants in the intervention and control groups received routine postnatal care from local government services. In addition, participants in the intervention group had the option to combine routine pediatric services with teleconsultation and email newsletters without charge from the date of registration until the infant turned 4 months. Primary outcomes were (1) the prevalence of AD in infants diagnosed based on the United Kingdom Working Party criteria and (2) parenting stress and mental status of mothers assessed using the Parenting Stress Index-Short Form (PSI-SF) and General Health Questionnaire-12 (GHQ-12). Data were collected by the ward office staff and researcher during the 4-month checkup.

**Results:** The prevalence of AD in infants was significantly lower in the intervention group than in the control group during the 4-month checkup (20% vs 33%,  $P=.02$ ; relative risk ratio, 0.709 [95% CI 0.519-0.969]). No significant differences were observed

in the PSI-SF and GHQ-12 scores between the 2 groups. There was a significant difference in the prevalence of AD between participants who used teleconsultation services and email newsletters, participants who did not use teleconsultation services but received email newsletters, and participants who neither received nor used either service (18% vs 22% vs 33%,  $P=.048$ ).

**Conclusions:** This is the first randomized controlled trial demonstrating that routine pediatric care combined with teleconsultation and email newsletters was effective in reducing the prevalence of AD in infants. The findings highlight the potential of pediatric eHealth to become a useful new strategy for preventing AD.

**Trial Registration:** University Hospital Medical Information Network Clinical Trials Registry UMIN000029774; [https://upload.umin.ac.jp/cgi-open-bin/ctr\\_e/ctr\\_view.cgi?recptno=R000034022](https://upload.umin.ac.jp/cgi-open-bin/ctr_e/ctr_view.cgi?recptno=R000034022)

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## KEYWORDS

teleconsultation; email newsletters; eHealth; pediatrician; infant; mother; atopic dermatitis; parenting stress; randomized controlled trial; stress; dermatitis; parenting; pediatrics; email; children; Japan

## Introduction

The exchange of valid health-related information between health care professionals and their patients can facilitate successful diagnosis, treatment, and prevention as well as research and evaluation, thereby advancing the health of individuals and communities. In this context, telemedicine and eHealth refer to the location-independent delivery of health care services through information and communication technologies. Telemedicine and eHealth are widely used services due to their functionality, ease of use, cost-effectiveness, time-saving features, and accessibility for patients who live far from health care facilities [1-3]. eHealth for expectant or nursing mothers has attracted particular attention because women of reproductive age are particularly frequent users of the internet, social media, and smartphone apps and thus appear to be prime candidates for this form of health care delivery [4].

Telemedicine and eHealth intervention services provided to pediatric patients with conditions such as autism, attention deficit hyperactivity disorder, and chronic diseases have been demonstrated to positively influence pediatric patients as well as families and health care providers [5-8]. Systematic reviews have indicated that telemedicine services for pediatric care result in comparable or improved outcomes relative to in-person services [7,8]. Moreover, parents have reported experiencing actual and perceived benefits of eHealth services, including ease of use, higher confidence in and satisfaction with infant care, and efficient knowledge transmission [9].

In Japan, a few reports have described the use of perinatal eHealth services provided by health care providers, such as teliagnosis for fetal cardiac diseases [10-12], construction of electronic medical records for perinatal care [13], and digitalization of a maternal and child health handbook [14]. Moreover, no randomized controlled trial (RCT) has examined the effectiveness of eHealth for infants and mothers.

As one of the most common conditions afflicting newborns and young infants, skin disorders appear to be prime candidates for telemedicine services. More than 50% of newborns and young infants have skin conditions such as infantile eczema, diaper dermatitis, intertrigo, and seborrheic dermatitis [15]. In particular, atopic dermatitis (AD) or skin inflammation should be prevented because it may increase the risk of other allergic

diseases [16]. Previous RCTs on eHealth for AD have focused on patients [17,18], the feasibility of web-based consultations [19], or equivalence to ordinary in-person care [20]. However, to date, no study has examined whether eHealth can prevent infants from developing AD.

Parents of children with AD encounter significant and persistent challenges to successfully manage the condition [21]. Mothers, who are often the primary caregivers, experience a higher degree of psychological stress while raising offspring with serious illnesses, with corresponding negative impacts on parents' and children's well-being [22]. A mother's mental state—manifested in low maternal sensitivity, perinatal anxiety, or postpartum depression—is a modifiable risk factor for the development of childhood AD [23-25]. Recent studies have emphasized the need for and usefulness of parenting training programs as easily accessible interventions to help reduce parental stress [26,27]. Thus, adequate psychological support and training would help in reducing parental stress and in better management of the condition of atopic children.

In Japan, reports from the Sukoyaka (meaning “healthy and happy” in Japanese) Family 21, a national campaign for maternal and child health, have highlighted the ineffectiveness of current measures to improve women's mental health, the insufficiency of childcare and development consultation services, and the necessity of support from pediatricians as well as obstetricians, midwives, and public nurses [28,29]. Studies conducted in other countries indicate that the use of eHealth-based services in such scenarios can effectively and feasibly address problems among parents of children with AD [30-33]. Accordingly, we propose that telemedicine services could reduce parental vulnerability by addressing knowledge deficits regarding disease management and parenting methods while also alleviating stress-inducing logistical barriers such as travel, time, and cost.

In this study, we implemented pediatric teleconsultation and evaluated its effectiveness for improving skin conditions in infants, especially in terms of preventing AD and reducing parenting stress in mothers in Japan. Compared with the control group receiving routine postnatal care via local government services, we hypothesized that the additional service comprising teleconsultation and email newsletters provided by pediatricians would be an effective strategy for preventing AD in infants and reducing parenting stress in mothers at 4 months postpartum.

## Methods

### Study Design

This study was an open-label, randomized, parallel-armed, controlled trial. Data collection was blinded to the intervention assignment of the participants. We registered this trial design, including the hypotheses and outcome measures, at the University Hospital Medical Information Network Clinical Trials Registry (trial registration number: UMIN000029774), although we did not publish the protocol paper of this study.

### Participants, Recruitment, and Randomization

The study participants were infant and mother dyads in the Yokohama City Sakae Ward. The pairs were recruited when mothers submitted their infants' birth cards (a document submitted to the local government upon an infant's birth) at the Yokohama City Sakae Ward Office, received an explanation about the study, and provided informed consent on the Sakae Infants and Mothers with the Pediatric Teleconsultation (SIMPLE) Study website that was exclusively set up for this study. Recruitment took place from November 1, 2017, to May 31, 2018. There were no other specific inclusion criteria for the trial.

Exclusion criteria included the unwillingness or inability to comply with the study requirements and procedures; a discretionary decision by study staff that either the mother or the infant might not be suitable for participating in this trial; a mother's inability to understand Japanese (although communication through a Japanese interpreter could be performed in exceptional circumstances); infants born before 37 weeks of gestation; infants born after 42 weeks of gestation; twins or multiple births; and infants needing neonatal intensive care. These criteria were available for review on the SIMPLE

Study website. We did not exclude any infant-mother pairs following the development of maternal mental health problems or infant skin problems.

Shortly after enrollment, a simple randomization method was used to assign participants to the intervention or control group with a ratio of 1:1 in the order of registration on the SIMPLE Study website.

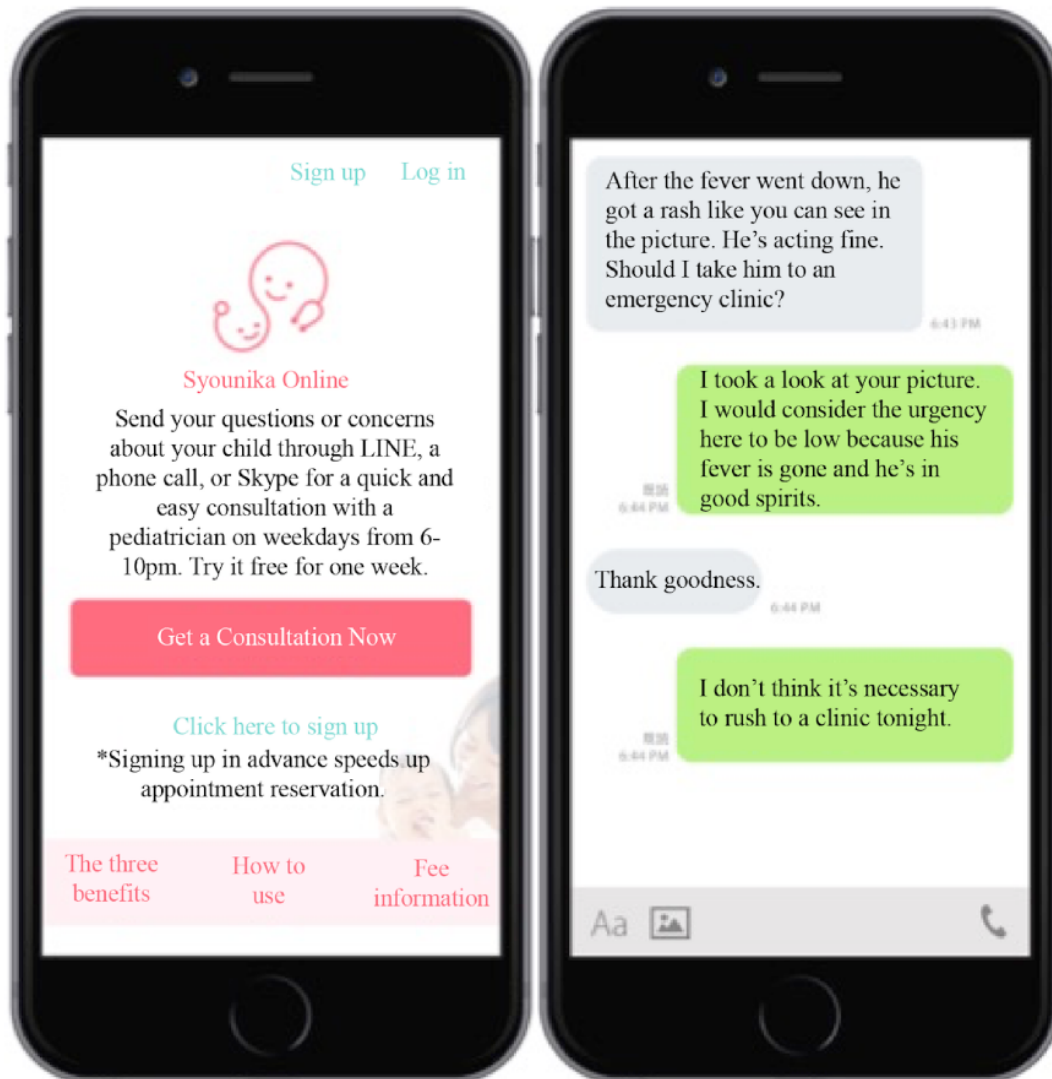
### Intervention

In addition to routine postnatal care through local government services such as home visits by public nurses and breastfeeding consultation services by midwives, participants in the intervention group had the option to use a pediatric teleconsultation service named "Syounika (meaning "pediatric" in Japanese) Online" and receive email newsletters without any charge from the time of registration to 4 months of age. The email newsletters were delivered once every 3 days (30 times in total) during the intervention period.

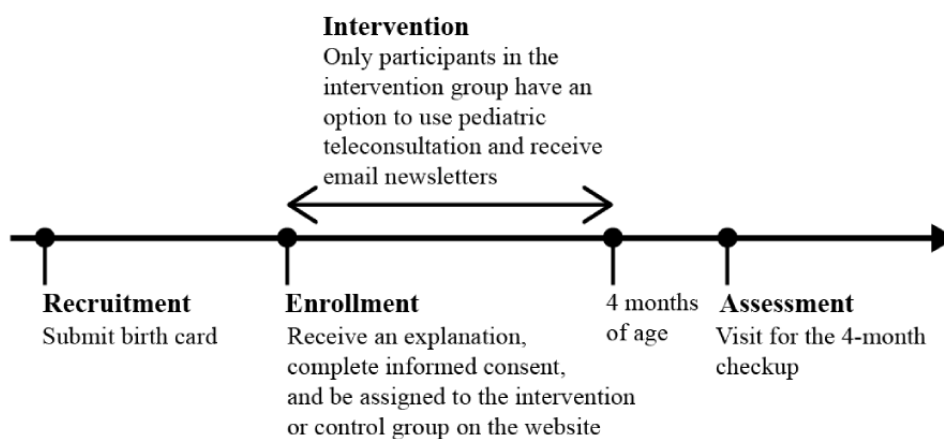
The Syounika Online Service was launched by Kids Public Inc in 2016. The core service is teleconsultation through video calls, voice calls, or text messages via smartphones. Users can consult with pediatricians about any matters regarding their children's health and parenting for 10 minutes from 6 PM to 10 PM on weekdays (Figure 1). Syounika Online also delivers email newsletters containing useful information about children's health and parenting, such as infant skin care, breastfeeding, and maternal self-care. Syounika Online collaborated with local governments, companies, health insurance providers, and paid subscribers to recruit users across the country.

All data were collected by the ward office staff and the researcher at the community health center in the Yokohama City Sakae Ward when participants visited there for the 4-month checkup. Figure 2 describes the flow of the study.

**Figure 1.** Syounika Online Service (translated from Japanese to English). Skype was no longer available during the trial.



**Figure 2.** Outline of the study flow.



**Primary Outcomes**

The primary outcomes were the prevalence of AD in infants, parenting stress, and mothers’ mental health status at the 4-month checkup.

**Prevalence of AD in Infants**

The diagnosis of AD was based on the United Kingdom Working Party (UKWP) criteria [34]. In addition to itchy skin in the last 12 months, the infant should meet at least three of the following criteria: (1) history of skin creases, such as in the folds of the elbows, behind the knees, fronts of the ankles, or around the neck (including the cheeks in children under 10



years); (2) a personal history of asthma or hay fever (or history of atopic disease in a first-degree relative for children under 4 years); (3) a history of generally dry skin in the last year; (4) visible flexural eczema (or eczema involving the cheeks or forehead and the outer limbs in children under 4 years); (5) onset under the age of 2 years (not applicable if child is currently under 4 years). All the infants were assessed by 1 pediatrician who was blinded to the intervention assignment of participants to ascertain whether there was visible flexural eczema.

### **Parenting Stress and Mental Status of Mothers**

Parenting stress was measured using the original Japanese version of the Parenting Stress Index-Short Form (PSI-SF; 19 items)—an abridged version of the full-length PSI [35]—which was developed in 1983 for screening and triage purposes to evaluate the parenting system and identify issues that may cause problems in the child's or parent's behavior. The Japanese version of the PSI-SF has been demonstrated as a valid and reliable tool, and it consists of 19 items and 2 subscales, namely parental stress and child-related stress [36,37]. Higher PSI-SF scores indicated higher levels of parental stress. Araki et al reported a Cronbach alpha coefficient of .82 for the total PSI-SF score [36]. The Cronbach alpha coefficient in this study was .873.

Current mental health was measured using the General Health Questionnaire-12 (GHQ-12; 12 items) [38]. GHQ-12 is a valid, internationally used measure of mental status in a population and has been used in several studies to assess the medium- and long-term postpartum mental health status of mothers [39]. Participants with GHQ-12 scores  $\geq 4$  were classified as the high GHQ score group [40]. Higher GHQ-12 scores indicated higher severity of a mental health problem. The Cronbach alpha coefficient in this study was .774.

### **Secondary Outcomes**

Secondary outcomes were breastfeeding rates and the developmental quotient (DQ) of infants, which were examined by a pediatrician through questionnaires at the 4-month checkup. Breastfeeding rates were determined by asking mothers through a questionnaire about the proportion of time spent on breastfeeding the infants (100%, 80%-99%, 20%-79%, 1%-19%, or 0%). The DQ was assessed using the Enjoji Scales of Infant Analytical Development, which has been universally used in Japan [41]. This test can be administered to infants and children ranging from newborns to 4 years and 7 months, and it assesses 6 categories (locomotor, manual activity, language, emotional status, intelligence, and social behavior). The DQ was calculated using the following formula:  $DQ = (\text{assessed age} / \text{real age}) \times 100$ .

### **Sample Size**

Because no previous studies have examined the effectiveness of eHealth in this setting, we estimated the required sample size from the limited data on the prevalence of AD and the PSI-SF total scores presented in previous studies [37,42].

Based on the prevalence of AD at the 4-month checkup, we estimated a sample size of 132 infants per group, with an AD prevalence of 18% in the intervention group and 33% in the

control group,  $\alpha=.05$ , and a power of 80% ( $[1-\beta] \times 100$ , where  $\beta=.2$ ).

Based on the PSI-SF total scores at the 4-month checkup, we estimated a sample size of 86 mothers per group with the mean and SD of the PSI-SF total scores being 37 and 7, respectively, in the intervention group and 40 and 7, respectively, in the control group, along with  $\alpha=.05$  and  $\beta=.2$ . These values were approximated by referring to the PSI parenting stress index handbook [37].

Overall, we expected a dropout rate of approximately 10% and set the target number of participants to 300, which was estimated as follows: There were an estimated 132 infants per group, thus making 264 dyads. Assuming a 10% nonresponse rate, 264 would correspond to 90% of the study participants. To factor in nonresponses, the sample size was inflated by a factor of 0.9, that is 293 ( $264/0.9$ ), which was rounded up to 300. This sample size was insufficient for detailed analysis of GHQ-12 score groups, but we expect our data to contribute to future meta-analyses on this topic.

### **Statistical Analysis**

Data were analyzed by intention-to-treat using SPSS version 25.0 (IBM Corporation). For categorical and count characteristic variables (AD,  $\text{GHQ-12} \geq 4$ , and breastfeeding rate), we used the Pearson chi-square or Fisher exact test to detect statistical differences in the distributions between the intervention and control groups. For continuous characteristic variables (PSI-SF total stress, child domain, parent domain, locomotion, hand exercise, common practice, human interaction, speech, language comprehension, and average of DQ), we tested for differences between the 2 groups using the *t* test for normally distributed variables and the Mann-Whitney *U* test for non-normally distributed variables. The results of the outcomes assessed at the 4-month checkups were analyzed using a per-protocol analysis to examine the individual effectiveness of the teleconsultation and email newsletters by comparing three groups: participants who received and used teleconsultation services and email newsletters; participants who did not use teleconsultation services but received email newsletters; and participants who neither received nor used either service.

In presenting the differences between the groups, we calculated the differences as follows: For categorical variables, we calculated differences in percentages; for continuous variables, we calculated differences between means. We set the level of statistical significance at 0.05.

### **Ethical Considerations**

This study received ethical approval from the institutional review board of the National Center for Child Health and Development before participant recruitment commenced (approval number: 1570). We obtained informed consent on the internet from the adult participants at the time of enrollment. The protocol for this study is available on the SIMPLE Study website. We arranged for participants in the control group to have access to Syounika Online without charge from 5 to 8 months of age. We did not prohibit any participants from using Syounika Online at their own expense.

## Results

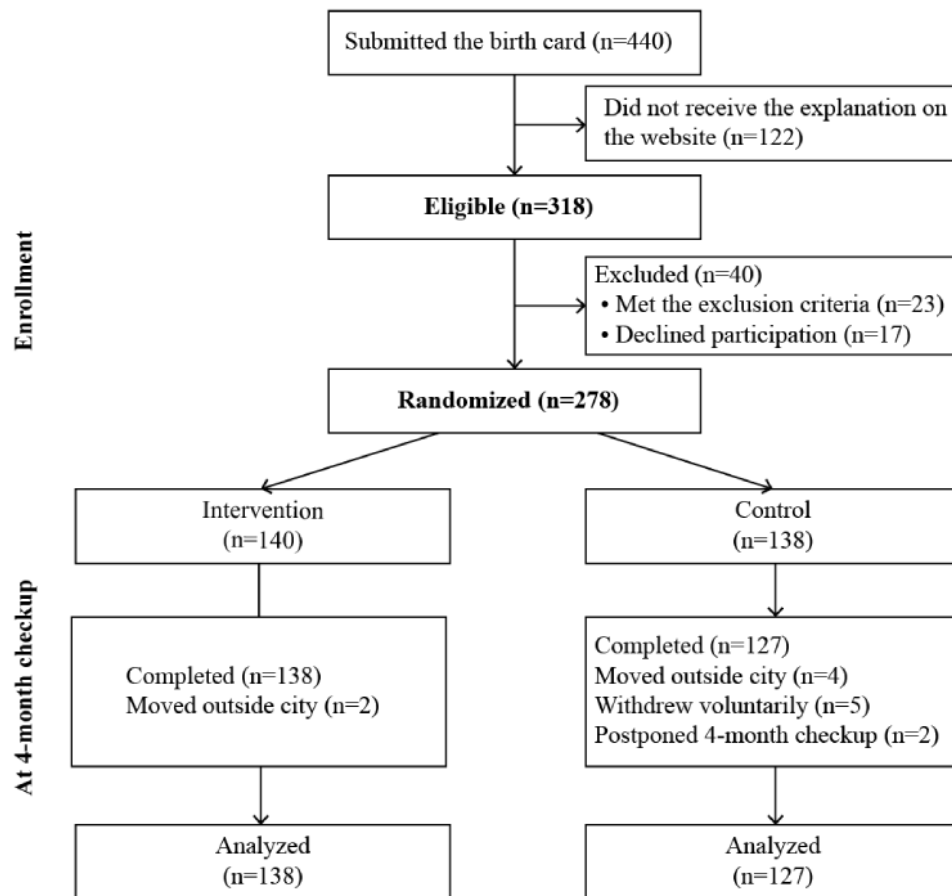
### Participant Details

Among the 440 pairs of infants and mothers who submitted their birth cards to the Yokohama City Sakae Ward Office during the recruitment period, we assessed the eligibility of the 318 pairs who accessed the SIMPLE Study website to receive an explanation of this study (Figure 3). In total, 23 pairs were excluded because infants were born before 37 weeks or after 42 weeks of gestation, and there were twins or multiple births, or infants requiring neonatal intensive care. Further, 17 pairs

declined participation. Finally, 278 infant-mother pairs were enrolled. We allocated 140 pairs to the intervention group and 138 pairs to the control group. Furthermore, 13 pairs were excluded from the analysis because 6 moved out of the city, 5 withdrew participation voluntarily, and 2 postponed their 4-month checkups. No pairs crossed over between trial arms. Finally, we analyzed the data of 265 infant-mother dyads among the 278 pairs (95.3%).

Table 1 summarizes the characteristics of the participants and their families. We detected no significant differences in their characteristics.

Figure 3. Participant flowchart.



**Table 1.** Characteristics of infants and mothers in intervention and control groups (N=265).

Characteristics	Intervention		Control		P value <sup>a</sup>
	Values	n <sup>b</sup>	Values	n	
<b>Infants</b>					
Female, n (%)	67 (48.6)	138	52 (40.9)	127	.22
Birth weight (g), mean (SD)	3102 (359.8)	138	3060 (391.8)	127	.45
Birth height (cm), mean (SD)	49.4 (1.8)	138	49.3 (1.9)	127	.75
Neonatal problem, n (%)	18 (13.1)	137	21 (16.5)	127	.49
<b>Mothers</b>					
Age (years), mean (SD)	33.0 (4.8)	138	33.0 (5.0)	127	.90
Employment, n (%)	68 (50.4)	135	61 (49.2)	124	.90
History of hospitalization or long-term treatment, n (%)	30 (21.7)	138	28 (22.1)	127	.99
Current illness, n (%)	13 (9.5)	137	15 (11.8)	127	.56
Parity: primiparous, n (%)	67 (48.6)	138	63 (49.6)	127	.90
Gravidity, mean (SD)	1.9 (1.0)	137	2.1 (1.5)	127	.62
Threatened abortion or premature delivery, n (%)	19 (14.0)	136	11 (8.7)	127	.24
Gestational age (weeks) , mean (SD)	39.0 (1.1)	138	39.0 (1.1)	127	.88
<b>Method of birth, n (%)</b>					.99
Spontaneous vaginal birth	102 (73.9)	138	94 (74.0)	127	
Instrumental vaginal birth	14 (10.1)	138	13 (10.2)	127	
Cesarean section	22 (15.9)	138	20 (15.8)	127	
<b>Delivery location, n (%)</b>					.85
Hospital	70 (50.7)	138	64 (50.8)	126	
Clinic	68 (49.3)	138	61 (48.4)	126	
Maternity home	0 (0.0)	138	1 (0.8)	126	
<b>Families</b>					
Father's age (years), mean (SD)	34.6 (6.2)	138	34.6 (5.8)	127	.98
Father's employment, n (%)	132 (97.8)	135	126 (99.2)	127	.62
Family members who smoke, n (%)	39 (28.3)	138	36 (28.4)	127	.99
Family history of atopic dermatitis, n (%)	32 (23.2)	138	40 (31.5)	127	.17
Family history of bronchial asthma, n (%)	38 (27.7)	137	30 (23.6)	127	.48

<sup>a</sup>P values for categorical variables were calculated using either the Pearson chi-square or Fisher exact test; P values for continuous variables were calculated using *t* tests.

<sup>b</sup>Some n values are lower than others due to missing data.

### Usage Status of Syounika Online

Among the 138 intervention group participants, 59 (42.4%) used the teleconsultation service 116 times. Skin problems in infants (n=32, 28%) were the most common reasons for consultations, followed by gastrointestinal problems (n=26, 22%) and breastfeeding problems (n=15, 13%). In the control group, 1 participant used the teleconsultation service 17 times at her own expense.

The email newsletters from Syounika Online were delivered 30 times and contained 28 pieces of advice on skin care in infants and 25 pieces of advice on breastfeeding. Overall, the 138

participants in the intervention group and 1 participant in the control group received the newsletters, and their opening rates were 30% to 58%.

### Main Analysis

The results of the primary and secondary outcomes are summarized in [Table 2](#).

Analysis of the primary outcomes revealed that the prevalence of AD was significantly lower in the intervention group than in the control group (20% vs 33%,  $P=.02$ ; relative risk ratio, 0.709 [95% CI 0.519-0.969]).

**Table 2.** Primary and secondary outcomes assessed at the 4-month checkups (N=265).

Outcomes	Intervention (n=138)	Control (n=127)	Difference (95% CI)	P value
Atopic dermatitis, n (%)	28 (20)	42 (33)	-0.13 (-0.23 to -0.02)	.02
<b>Parenting stress and mental status of mothers</b>				
PSI-SF <sup>a</sup> (total stress), mean (SD)	39.1 (9.8)	37.1 (9.1)	1.95 (-0.34 to 4.25)	.10
PSI-SF (child domain), mean (SD)	18.2 (5.4)	17.3 (5.0)	0.89 (-0.36 to 2.14)	.20
PSI-SF (parent domain), mean (SD)	20.9 (5.7)	19.8 (5.3)	1.07 (-0.27 to 2.41)	.18
GHQ-12 <sup>b</sup> $\geq 4$ , n (%)	45 (33)	44 (35)	0.02 (-0.09 to 0.13)	.79
<b>Developmental quotient</b>				
Locomotion, mean (SD)	100 (28)	102 (28)	-1.97 (-8.79 to 4.84)	.37
Hand exercise, mean (SD)	112 (24)	105 (28)	6.92 (0.52 to 13.33)	.08
Common practice, mean (SD)	65 (21)	65 (21)	0.43 (-4.57 to 5.43)	.87
Human interaction, mean (SD)	118 (21)	116 (23)	2.22 (-3.05 to 7.48)	.61
Speech, mean (SD)	110 (26)	105 (25)	5.10 (-1.16 to 11.36)	.11
Language comprehension, mean (SD)	55 (41)	54 (39)	1.18 (-8.53 to 10.88)	.99
Average <sup>c</sup>	93 (16)	91 (18)	2.31 (-1.87 to 6.49)	.28
<b>Breastfeeding rate</b>				
100%, n (%)	79 (57)	59 (46)	0.11 (-0.01 to 0.23)	.09
$\geq 80%$ , n (%)	104 (75)	95 (75)	0.01 (-0.10 to 0.11)	.99
0%, n (%)	8 (6)	9 (7)	-0.01 (-0.07 to 0.05)	.80

<sup>a</sup>PSI-SF: Parenting Stress Index-Short Form.

<sup>b</sup>GHQ: General Health Questionnaire.

<sup>c</sup>This value represents the average of the 6 subscores of the developmental quotient.

## Discussion

### Prevalence of AD in Infants

This study found that the teleconsultation service targeting mothers significantly reduced the prevalence of AD among infants in the intervention group relative to those in the control group. The findings highlight the significance of eHealth and teleconsultation service as an effective management strategy for pediatric AD. Preventing skin problems among infants enhances their quality of life and mitigates against the future development of other allergic diseases [43,44]. Infants with an early eczema onset, especially within 4 months after birth, are at an increased risk of developing food allergies at 3 years of age [45]. Moreover, AD is also known to decrease quality of life among family members and caregivers, deteriorating personal relationships, psychosocial functioning, sleep, and finances [46-48]; the parents' ability to manage their children's behavior and illness is influenced by the severity of AD [49]. Our findings show that interventions that facilitate parents' active engagement can improve treatment outcomes and the holistic well-being of the family.

The intention-to-treat analysis showed that the prevalence of AD based on the United Kingdom Working Party criteria was significantly lower in the intervention group than in the control group at the 4-month checkup. This result suggests that

combining typical pediatric services with teleconsultation and email newsletters is effective in preventing AD in infants. We attribute the reduced prevalence of AD in the intervention group to several possible reasons. One reason may be that Syounika Online recommends daily moisturizing skin care based on the reports that this can reduce the risk of AD or eczema and improve skin barrier function [42,50]. Participants who adhered to the service's advice may have prevented the onset of AD. Another reason may be that frequent email newsletters with advice on skin care for infants might increase parents' awareness about the importance of infant skin problems or trigger them to visit the hospital earlier than when they otherwise might.

The per-protocol analysis comparing the 3 groups showed a significant difference in the prevalence of AD among them, which suggests that the combined service with teleconsultation and email newsletters and the service with email newsletters alone could be effective in reducing the prevalence of AD. This finding is supported by Santer et al, who reported that a web-based intervention to support families of children with AD had the potential to improve Patient-Oriented Eczema Measure scores [18].

If we consider that fewer participants in the intervention group dropped out than in the control group, then assuming that the 2 dropouts in the former developed AD and the 11 dropouts in the latter did not, the prevalence of AD would be 21% in the

intervention group and 30% in the control group. This does not seem inconsistent with the original result, although the difference in the dropout rates is a limitation of this study.

### Parenting Stress and Mental Status of Mothers

The PSI-SF scores observed in the groups of our study were similar to those in a normal population, as indicated by a previous study that reported mean PSI-SF scores of 17.0 in the child domain and 19.4 in the parent domain [51] at 4 months. In contrast, the prevalence of high GHQ-12 scores was over 30% in the intervention and control groups, which is substantially higher than the 7.7% that Yamamoto et al found among postpartum Japanese women at 4 months after delivery [40]. The higher level of parental or psychological stress observed in the mothers in our study indicates the need for further interventions to reduce the stress level among this population.

The lack of difference in maternal scores related to parenting stress and mental health status across the intervention and control groups suggests that although the combination of typical pediatric services with teleconsultation and email newsletters may be ineffective for reducing parenting stress, it does not burden mothers with the information delivered via the service. In addition, we could not assess the impact of the telehealth interventions because logistical difficulties prevented us from being able to collect baseline data on maternal mental health. The intervention group may have contained a higher proportion of stressed mothers than the control group despite the randomization procedure.

Second, PSI-SF and GHQ-12 scores might be inappropriate outcome measures for this study. Ngai et al reported that telephone-based cognitive behavioral therapy was associated with significantly lower levels of parenting stress using the Chinese version of the PSI-SF [30]; however, we used the Japanese version of PSI-SF, which consists of a different number of items. Notably, our teleconsultation service did not specifically target maternal mental health, but it rather focused more broadly on pediatric health and parenting. Sawyer et al reported that an app-based nurse-moderated program was not effective in reducing depressive symptoms measured using the Parenting Sense of Competence Scale and did not improve maternal caregiving measured using the PSI [31]. In contrast, Shorey et al reported that a technology-based supportive educational parenting program was effective in enhancing parenting self-efficacy measured using the Parenting Efficacy Scale, parental bonding measured using the Parent-to-Infant Bonding Questionnaire, perceived social support measured using the Perceived Social Support for Parenting, and parenting satisfaction measured using an evaluation subscale of the What Being a Parent of a Baby Is Like in reducing postnatal depression measured using the Edinburgh Postnatal Depression Scale and postnatal anxiety measured using the State-Trait Anxiety Inventory [32]. Future research should have a different perspective on the parenting stress observed in this study and use appropriate measurements such as the Parenting Efficacy Scale, Parent-to-Infant Bonding Questionnaire, Perceived Social Support for Parenting, What Being a Parent of a Baby Is Like,

Edinburgh Postnatal Depression Scale, or State-Trait Anxiety Inventory to assess the postpartum mental status of mothers.

### Limitations

There were several limitations in this study. First, more participants in the intervention group than in the control group dropped out, although this may not have had a profound impact on the results according to the imputation. Second, the participants with a family history of AD were less common in the intervention group; however, the subgroup analysis showed that there was no significant difference in the prevalence of AD. Third, because we adopted a combined service with teleconsultation and email newsletters as the intervention, it was not possible to deduce the individual effectiveness of the interventions. Fourth, due to the limited duration of this study, we collected the outcome data only once and could not follow up on the participants for a longer period. Fifth, we could not collect the skin treatment history of the infants and baseline data on maternal mental health. Future studies are required spanning a longer duration at multiple sites to provide evidence for long-term effectiveness and more detailed information.

### Overview

This study examined the effectiveness of a combined pediatric service with teleconsultation and email newsletters among infants and mothers in Japan. As we recruited pairs of infants and mothers from a whole ward and 60% of these recruited pairs were analyzed, our findings should be generalizable to many other areas in Japan whose surroundings are similar. The intervention to support infants and mothers by pediatricians via smartphone-based internet services was novel in Japan. To the best of our knowledge, this is the first RCT to show an association between eHealth and a reduced prevalence of AD in infants.

### Others: DQ of Infants and Breastfeeding Rates

There was no difference in the DQ between the intervention and control groups. The DQ of hand exercise in the intervention group tended to be higher; however, the difference has little clinical relevance. As the DQ is based on developmental and chronological ages, a longitudinal study might provide more accurate information about the long-term effects of interventions on the DQ. Future studies should investigate long-term effectiveness because we assessed infants' development only at 4 months of age.

Although there was also no difference in breastfeeding rates between the intervention and the control groups, more infants in the intervention group tended to receive exclusive breastfeeding and fewer tended to receive exclusive formula feeding. This distinction may indicate that a combined pediatric service with teleconsultation and email newsletters could encourage mothers to breastfeed. Future research should incorporate larger studies to address this topic.

### Adverse Events

There were no adverse events in this trial.



## Conclusions

Although a combined pediatric service with teleconsultation and email newsletters was not effective in reducing parenting stress in mothers, this is the first RCT to demonstrate that telehealth was effective in reducing the prevalence of AD in

infants. Such educational programs are a necessary complement to clinical and public services attempting to improve skin conditions in infants. We hope that pediatric eHealth will become a new, widely used strategy for preventing AD, which may also lead to a reduction in other allergic diseases.

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## Conflicts of Interest

TA received payment for writing from Kids Public Inc. The other authors report no conflicts of interest.

## Multimedia Appendix 1

CONSORT-eHEALTH checklist (V 1.6.1).

[[PDF File \(Adobe PDF File\), 1144 KB - pediatrics\\_v5i1e27615\\_app1.pdf](#)]

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## Abbreviations

**AD:** atopic dermatitis

**DQ:** developmental quotient

**GHQ-12:** General Health Questionnaire-12

**PSI-SF:** Parenting Stress Index-Short Form

**RCT:** randomized controlled trial

**SIMPLE:** Sakae Infants and Mothers with the Pediatric Teleconsultation

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Original Paper

# Facebook Support Groups for Pediatric Rare Diseases: Cross-Sectional Study to Investigate Opportunities, Limitations, and Privacy Concerns

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## Abstract

**Background:** Because of the nature of rare diseases with affected individuals being widely geographically dispersed, finding an in-person/offline support group itself can be a challenge. Affected individuals therefore turn to social networking platforms such as Facebook for online support groups.

**Objective:** We aim to put into perspective the opportunities Facebook offers as a tool for pediatric rare disease support groups by investigating its use, advantages, and limitations including privacy concerns. We analyze group accessibility and usage, advantages specific to rare diseases, perceived privacy, and views on using Facebook for communication between health professionals and parents, pharmaceutical companies, and study recruitment.

**Methods:** We contacted 12 Facebook support groups for 12 respective rare diseases with pediatric onset and invited group members to participate in a cross-sectional online survey.

**Results:** Of 231 respondents, 87.0% (n=201) of respondents were female, 12.6% (n=29) were male, and 0.4% reported another sex (n=1). Respondents' mean age was 41.56 years (SD 9.375); 91.3% (n=211) of respondents were parents (183 mothers, 27 fathers, 1 other sex); 59.7% (n=138) reported a self-initiated search for the Facebook group, 24.2% (n=56) received recommendations from their health professionals, and 12.6% (n=29) recommendations from someone else affected by the disease. On average, support group members visited Facebook at least once a day, visited and passively participated (read/liked posts) several times a week, and participated actively (commented/posted) once a month. As much as 79.2% (183/231) agreed that they would like to have health professionals as members of the respective Facebook group. Group members expressed more concern about privacy issues on Facebook in general than in their respective Facebook support groups, with concerns mostly related to Facebook itself and nongroup members.

**Conclusions:** Our study confirmed that Facebook enhances support group accessibility for parents of children with rare diseases. Group participants perceive a reduction and elimination of distance, a common challenge in rare disease, and Facebook support groups create an environment of perceived privacy. The group's privacy setting can be a critical factor for active support group participation. Sharing personal information and pictures on Facebook is very common among group participants, which shows the importance of discussing and protecting children's privacy rights in this context.

**Trial Registration:** German Clinical Trials Register DRKS00016067; [https://www.drks.de/drks\\_web/navigate.do?navigationId=trial.HTML&TRIAL\\_ID=DRKS00016067](https://www.drks.de/drks_web/navigate.do?navigationId=trial.HTML&TRIAL_ID=DRKS00016067)

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**KEYWORDS**

Facebook; support group; parental support; pediatric rare diseases; privacy paradox; children's privacy



## Introduction

The types of emotions most frequently expressed by parents of children with a rare disease include fear, worry, frustration, uncertainty, helplessness, and vulnerability [1]. Parents often feel dissatisfied with the overall level of support for their child with a rare disease [1]. Affected individuals are often geographically dispersed, because rare diseases by definition have a very low prevalence. According to the European definition, a disease is considered rare when its prevalence is below 1 in 2000 [2]. Therefore, many parents have never come into contact with another parent taking care of a child with a similar condition [1]. Social isolation and the feeling of being disconnected from society are common experiences [3]. For many rare diseases, medical and scientific knowledge remains scarce [2]. At the same time, these diseases are often serious and chronic, thereby increasing psychological, social, economic, and cultural vulnerability [2]. Consequently, parents of children with rare diseases encounter substantial challenges and have special supportive care needs [1,3].

Support groups offer improved social support [1,4,5] through befriending other people with similar experiences; learning about the disease, treatments, and coping skills; emotional support; and feeling empowered [4]. However, due to the nature of rare diseases with affected individuals being widely geographically dispersed, finding an in-person/offline support group itself can be a challenge. Affected individuals therefore turn to social networking platforms such as Facebook for online support groups. The use of social media for health communication offers increased interactions; more available, shared, and tailored information; and peer, emotional, and social support [6].

Facebook is one of the longest existing social networking platforms [7], and with more than 2.4 billion monthly active users also one of the largest [8]. In March 2019, Facebook support groups were available for more than 4000 pediatric rare diseases with approximately 1.8 million group members in more than 6000 groups [9]. Facebook has an international scope, provides options for individual and group communication [7], offers an unlimited number of participants, and is very cost-effective [10]. Nevertheless, Facebook support group accessibility is limited by access to a computer and the internet [10], related handling skills, and age restrictions. Concerning informational exchanges on social media, the reliability [6], accuracy [10], quality [11], application to personal situations [6], and the possible misinterpretation [10] of information found online and on social media have been questioned. Especially considering how frequently Facebook is being used for support groups, an investigation into whether Facebook represents a suitable tool for pediatric rare disease support groups is needed to improve the much needed support for parents of children with rare diseases.

The usage of Facebook for parent support groups can involve sharing a child's personal health information online. Sharing information online can be potentially harmful due to the ability to identify individuals and the potential misuse of this information by organizations and individuals [12]. Known

negative consequences of sharing information about a child on social media include embarrassment, humiliation, and bullying [13]. The involvement of sharing private information about children online thus encloses a controversial discussion on a child's digital identity and protecting children's rights online [13].

Integrative privacy theories define privacy as a right that should be protected and as individual control of personal information in the form of restricted access [14,15]. Information and communication have been identified as the most relevant dimension of privacy when discussing internet privacy [16]. While the United Nations' Convention on the Rights of the Child protects children's privacy, honor, and reputation [17], only little guidance is provided by specific privacy laws regarding children's need for protection from their parents' online disclosure [13]. When considering how to protect a child's privacy online, different approaches to decision making on online information disclosure can play a role, such as decision making based on risk-benefit calculations or decision making based on benefits with little to no risk assessment [18]. A discrepancy between expressed privacy concerns and actual information disclosure, which often becomes evident in online communication, is described as the privacy paradox [18].

It is important to analyze how privacy dimensions, approaches to decision making on online information disclosure, and the privacy paradox play a role in the use of Facebook as a tool for pediatric rare disease support groups to improve the protection of children's privacy rights and awareness of the risks related to sharing information online.

The role of health professionals in Facebook support groups has not yet been defined. To date, only few studies have examined the opportunities Facebook offers for a communication between parents and health professionals, pharmaceutical companies, and study recruitment [19-24]. Social media can improve patient-to-patient and patient-to-health professional dialogue and can be used for data collection, intervention, promotion, and education [6]. A study on support groups for autism spectrum disorder showed that parents whose diagnosing clinician had referred them to a support group were more likely support group participants [25]. Furthermore, Facebook has been successfully used for study recruitment in rare diseases, resulting in high numbers of study participants with low associated costs, thus improving recruitment for rare disease research [21]. Social media can be used for recruitment of geographically dispersed [20] and socially and culturally diverse [19] individuals. Given all these opportunities, it is of interest to gain insights into group participants' perspective toward involvement of health professionals and the instrumentalization of Facebook for study recruitment and by pharmaceutical companies.

Only little research exploring the topic of online support groups for pediatric rare diseases has been conducted so far. A few analyses of specific online and Facebook support groups have been performed, for example, on groups for cleft lip and palate [22], clubfoot [5], Hirschsprung disease [23], and autism spectrum disorders [24,25]. These analyses have shown support group benefits which can be classified into the following 3 main

categories: informational support, emotional support, and connecting with others. Our prior large quantitative analysis regarding the extent of Facebook support groups for pediatric rare diseases has shown that both the total number of support groups and the number of diseases for which a support group can be found have increased [9]. With two-thirds of these groups being private Facebook groups, we found that the need for privacy should be further explored [9]. Also, given the already widespread use of Facebook as a tool for support groups for pediatric rare diseases, an analysis of its strengths and limitations could allow health professionals to improve their understanding of this tool and, consequently, use Facebook more meaningfully in their counseling and guidance of affected individuals and their family members [9].

With this study, we therefore aim to put into perspective the opportunities Facebook offers as a tool for pediatric rare disease support groups by investigating its use, advantages, and limitations including privacy concerns. We analyze group accessibility and usage, advantages specific to rare diseases, perceived privacy, and views on using Facebook for communication between health professionals and parents, pharmaceutical companies, and study recruitment.

Our results can offer improved knowledge about the opportunities of Facebook support groups as well as their disadvantages. These findings may allow Facebook and similar

social media platforms to discover starting points for improving their toolkits and offerings. Parents and caretakers of children with rare diseases can directly or indirectly benefit from this increase in information directly or indirectly through receiving guidance on important points to be considered prior to joining a group from their treating physicians when searching for ways to receive much-needed social support. By informing medical professionals and, subsequently, parents about potential privacy concerns, active decision making on online information disclosure considering children's privacy rights can be initiated.

## Methods

We contacted 12 Facebook support groups for 12 respective rare diseases with pediatric onset and invited group members to participate in a cross-sectional online survey. For each of these diseases a Facebook group was contacted (Table 1). Group administrators were contacted by either email or Facebook messenger. The members of the respective groups were subsequently invited through a wall post within the actual closed Facebook groups.

The date of first enrolment was July 19, 2019, while the survey was closed on October 10, 2019. Respondents had to be group members of Facebook support groups for rare diseases with childhood onset; this inclusion criterion had to be confirmed in the questionnaire.

**Table 1.** List of each disease for which a Facebook group was contacted.

Orphanet disease description	Orphanet disease synonym	ORPHAcode	OMIM <sup>a</sup> number
15q13.3 Microdeletion syndrome	Del(15)(q13.3)	199318	612001
Lamb–Shaffer syndrome	SOX5 haploinsufficiency syndrome	530983	616803
Alacrimia–choreoathetosis–liver dysfunction syndrome	NGLY1 deficiency	404454	615273
Optic atrophy–intellectual disability syndrome	BBSOAS	401777	615722
17p11.2 microduplication syndrome	Potocki–Lupski syndrome	1713	610883
Prader–Willi syndrome	Prader–Labhart–Willi syndrome	739	610883
Rare nonsyndromic intellectual disability	CHAMP1 variant	101685	616579
Rett syndrome	—	778	312750
MAGEL2-related Prader–Willi-like syndrome	Schaaf–Yang syndrome	398069	615547
Smith–Magenis syndrome	17p11.2 microdeletion syndrome	819	182290
16p13.2 Microdeletion syndrome	Del(16)(p13.2)	500055	602519
White–Sutton syndrome	Intellectual disability-microcephaly-strabismus-behavioral abnormalities syndrome	468678	616364

<sup>a</sup>OMIM: Online Mendelian Inheritance in Man.

We developed the survey according to the information needed from participants to evaluate usage, advantages, and limitations with a focus on privacy concerns. It included 3 demographic questions, 11 questions about frequency and details of group usage, 9 statements on positive/negative aspects and privacy concerns, and 3 statements on involvement of medical professionals. Opinions on attitudinal/opinion-based questions were elicited using a 5-point Likert scale or binary (yes/no) scale (Multimedia Appendix 1). The online survey was provided using SurveyMonkey [26]. Prior to participation, respondents

were informed about the research project's purpose and the voluntary and anonymous nature of their participation. Respondents were informed that withdrawal was possible at any given time and without consequences. No further incentive or reimbursement was given. Starting the questionnaire constituted informed consent to study participation.

By contacting 12 groups we expected to reach the target sample size of 100 respondents. This sample size was thought to provide a sufficient overview of usage data trends and the range of opinions about positive and negative aspects of Facebook usage

for childhood rare disease support groups. Being a purely descriptive study, power calculations were not needed. Effectively, exceeding these expectations, a sample size of 238 respondents was reached, of whom 7 were excluded as the inclusion criterion question had not been answered.

The study and recruitment method have been reviewed by the Ethics Commission of Cologne University's Faculty of Medicine (19-1027) and all research had been carried out within the scope of the approved study.

Survey answers were statistically analyzed by standard descriptive statistical methods using IBM SPSS statistics version 26. Metric data (age) were presented using mean and SD, ordinal data by the median and IQR, and binary and categorical variables using counts and percentages. Kendall  $\tau$  was used to calculate rank correlations.

## Results

### Overview

In total, 231 respondents affirmed participation in a Facebook support group for a rare disorder; 7 did not respond to this question and were thus removed from the sample. Of the total respondents, 87.0% (n=201) were female, 12.6% (n=29) were male, and 0.4% reported another sex (n=1). Respondents' mean age was 41.56 years (SD 9.375), with a median of 39 years (range 21-80 years) and an IQR of 10 years (Q1=35, median=39, Q3=45).

Of the 231 study respondents, 91.3% (n=211) were parents (183 mothers, 27 fathers, and 1 other sex), 5.6% (n=13) other relatives (eg, grandmothers, child), 1.7% (n=4) patients, 1 friend, 1 health professional, and 1 with no specified connection (0.4% each).

As much as 59.7% (138/231) reported a self-initiated search for the Facebook group, 24.2% (56/231) received recommendations from their health professionals, and 12.6% (29/231) recommendations from someone else affected by the disease. A total of 5/231 respondents created the group (2.2%), 1/231 respondent found the group via disease-related website (0.4%), and 1/231 via Facebook post (0.4%).

### Accessibility and Group Usage

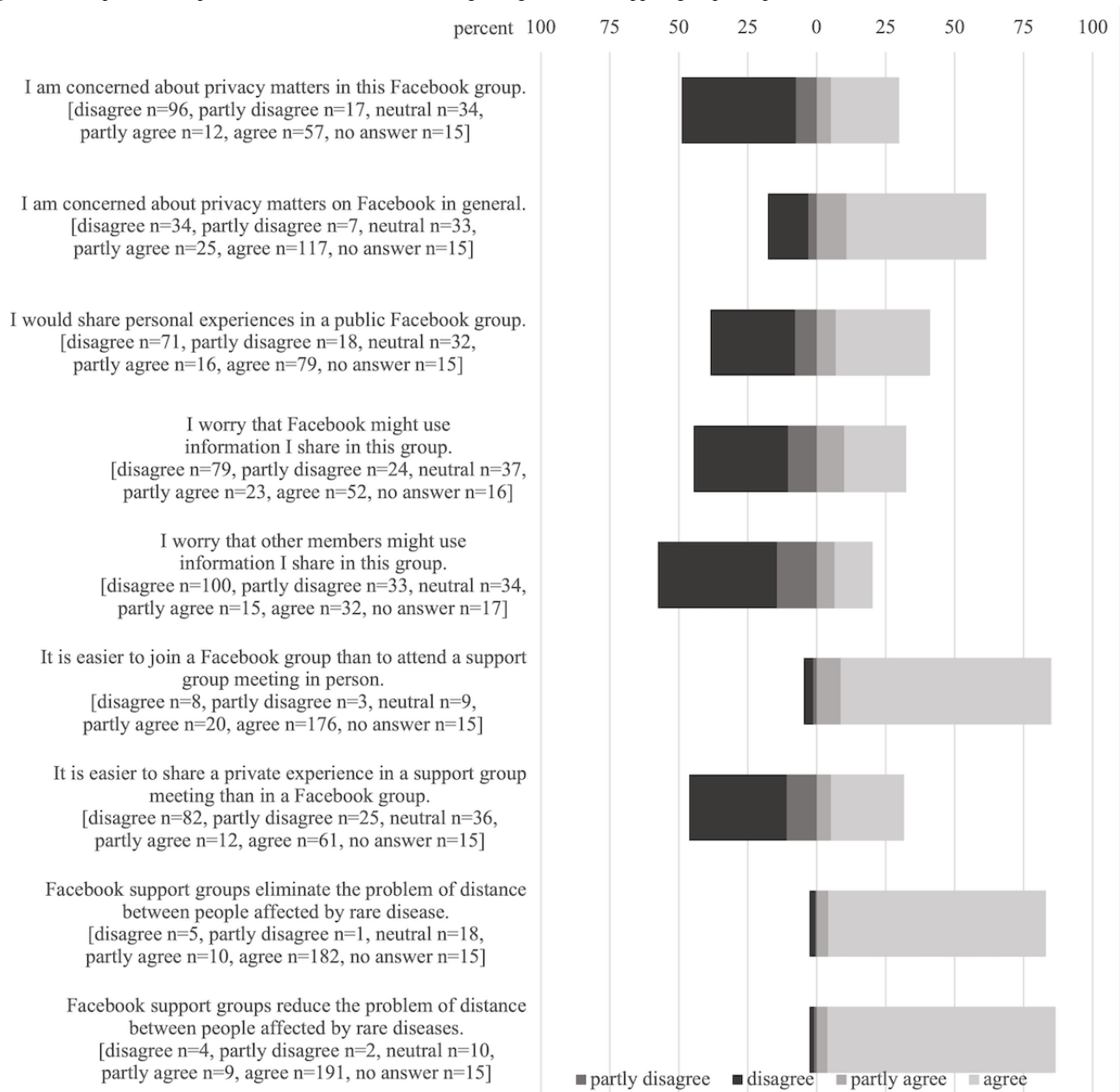
On average, support group members visited Facebook at least once a day, visited and passively participated (read/liked posts) several times a week, and participated actively (commented/posted) once a month. Answers ranged from less than every 3 months to at least once a day for all questions (Table 2). Kendall  $\tau$  showed a weak positive correlation between overall Facebook usage and support group usage ( $r=0.334$ ,  $P<.0001$ ).

Most members used the Facebook group to find medical information about the disease, to read about personal experiences concerning the disease, to get advice on caring for someone with this disease, and to share their personal experiences concerning the disease. They agreed that Facebook reduces and eliminates the problem of distance between people affected by rare diseases (Figure 1).

**Table 2.** Facebook overall and Facebook support group usage frequencies (N=231).

Frequency	Overall Facebook usage, n (%)	Facebook support group usage, n (%)	Passive participation, n (%)	Active participation, n (%)
At least once a day	175 (75.8)	89 (38.5)	71 (30.7)	20 (8.7)
Several times per week	38 (16.5)	88 (38.1)	100 (43.3)	38 (16.5)
Once a week	7 (3.0)	31 (13.4)	34 (14.7)	41 (17.7)
Once a month	2 (0.9)	9 (3.9)	9 (3.9)	62 (26.8)
Once every 3 months	0 (0.0)	3 (1.3)	3 (1.3)	27 (11.7)
Less than once every 3 months	2 (0.9)	5 (2.2)	5 (2.2)	34 (14.7)
No answer	7 (3.0)	6 (2.6)	9 (3.9)	9 (3.9)
Total	231 (100.0)	231 (100.0)	231 (100.0)	231 (100.0)
Median	At least once a day	Several times per week	Several times per week	Once a month
IQR	0	Several times per week to at least once a day	Several times per week to at least once a day	Once every 3 months to several times per week

**Figure 1.** Group member's perceived benefits and concerns regarding Facebook support groups for pediatric rare diseases.

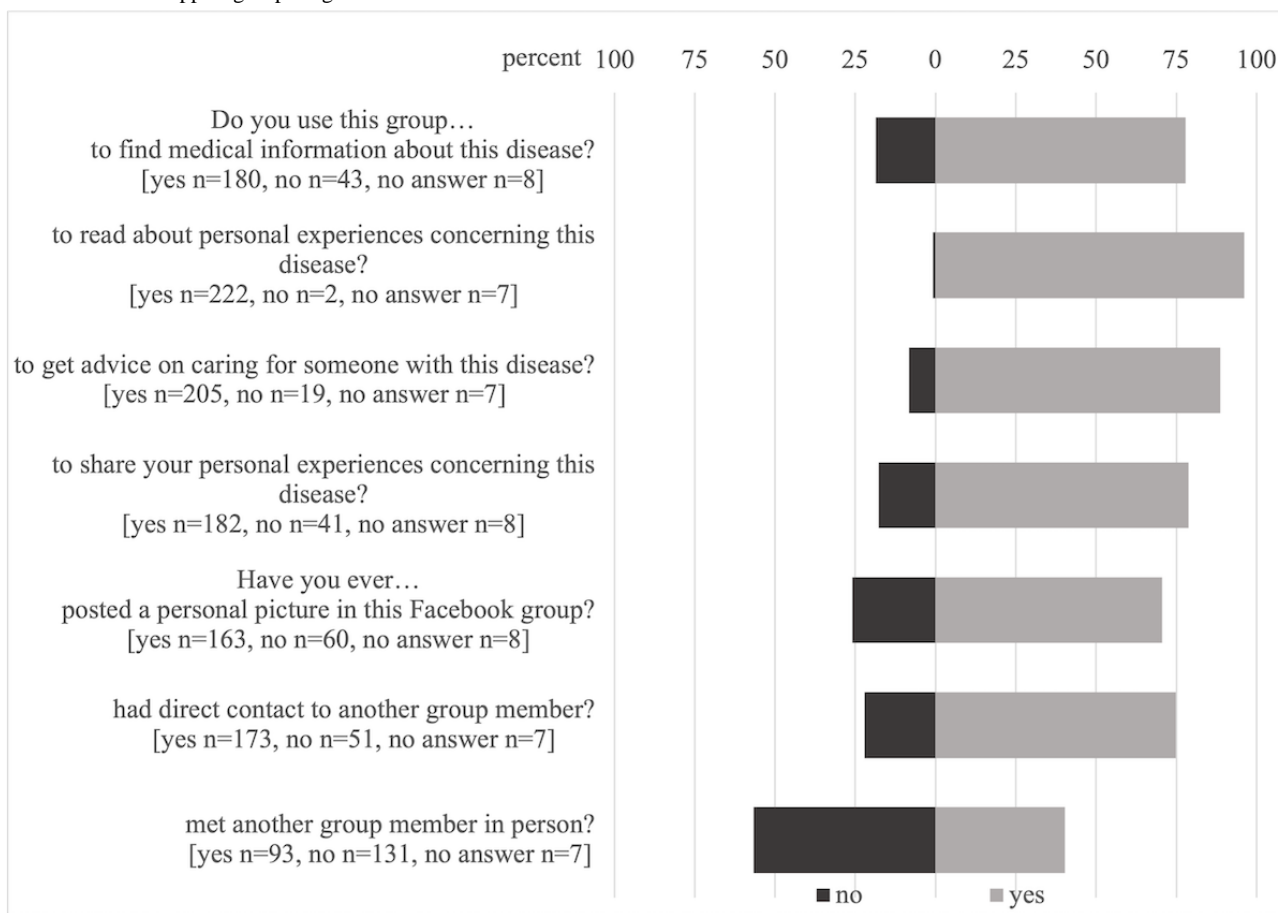


### Support Group Benefits

In our survey, we investigated 3 main categories of perceived benefits: informational support (finding medical information,

getting advice on caring for someone with this disease), emotional support (reading or sharing personal experiences), and connecting with others (Figure 2).

**Figure 2.** Facebook support group usage.



**Privacy Perception and Concerns**

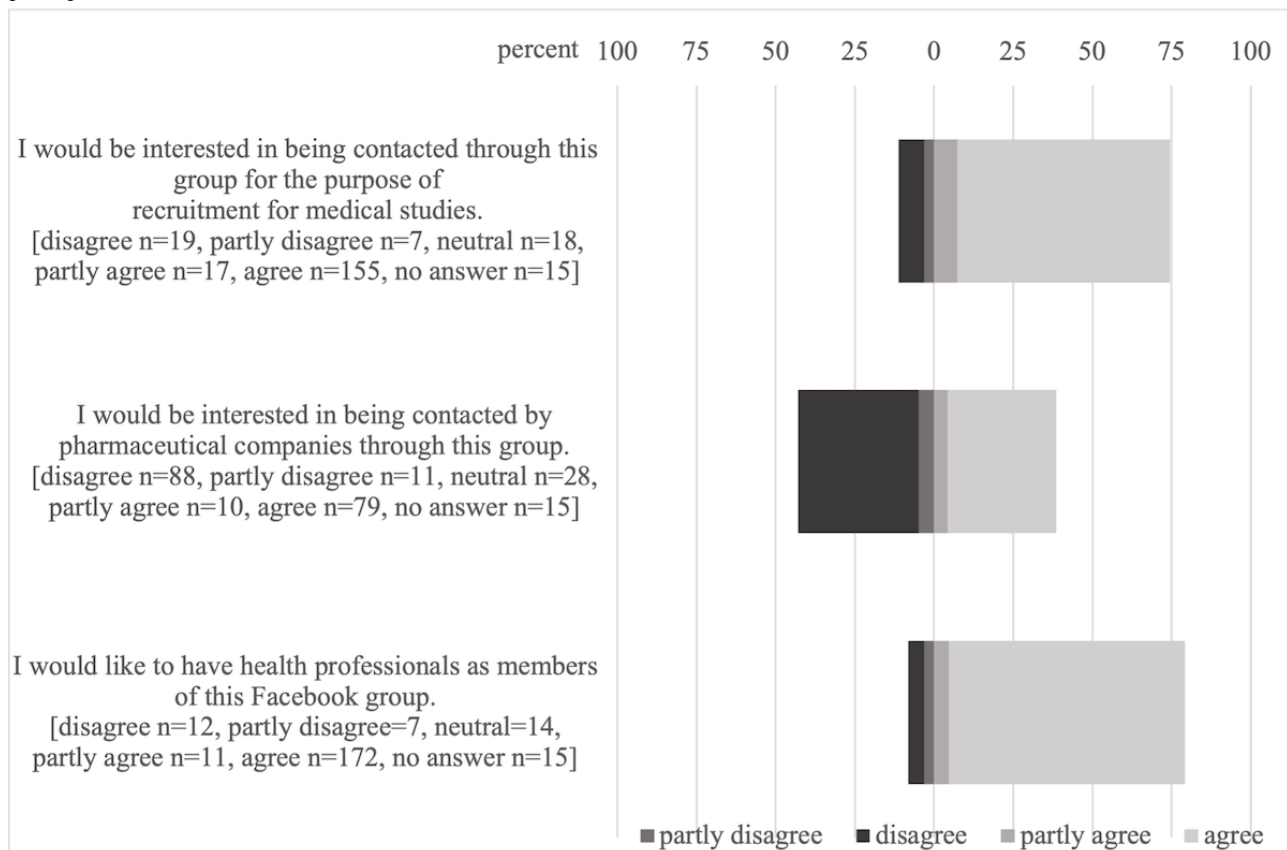
Information shared in a public Facebook group is accessible to every Facebook user worldwide; however, a private group offers a more selected audience. Group members expressed more concern about privacy issues on Facebook in general than in their respective Facebook support groups, with concerns mostly related to Facebook itself and nongroup members. Twice as many respondents agreed to being concerned about privacy matters on Facebook in general than to being concerned about privacy matters in their Facebook group (Figure 1).

**Using Facebook for Communication With Health Professionals, Pharmaceutical Companies, and Study Recruitment**

Concerning group member’s perspectives on being contacted through their respective group, 67.1% (155/231) and 7.4% (17/231) fully and partly agreed, respectively, that they would be interested in being contacted through this group for the purpose of recruitment for medical studies and 34.2% (79/231) and 4.8% (11/231) fully and partly agreed, respectively, that they would be interested in being contacted by pharmaceutical companies. As much as 74.5% (172/231) and 4.8% (11/231) fully and partly agreed, respectively, that they would like to have health professionals as members of the respective Facebook group (Figure 3).



**Figure 3.** Group member's perspective on involvement of health professionals, pharmaceutical companies and study recruitment in Facebook support groups for pediatric rare diseases.



## Discussion

### Accessibility and Group Usage

Our study confirmed that Facebook enhances support group accessibility for parents of children with rare diseases. For most participants (196/231, 84.8%) it was easier to join a Facebook group than to attend a support group meeting in person. Reasons may include lack of in-person support group due to large geographic distances, limited time, and means of transportation. This increased accessibility is an important advantage specifically for the field of rare diseases with often large geographic distances between affected individuals.

Group members' regular participation rates (Table 2) likely indicate high accessibility and practicality. Only 31.6% (73/231) of respondents agreed to finding it easier to share a private experience in a support group meeting than in a Facebook group, suggesting that Facebook support groups could possibly be considered an equally adequate setting for support groups. By providing options for both passive (read/like) and active (comment/post) participation, Facebook allows different degrees of involvement, which can facilitate group participation.

### Support Group Benefits

These 3 main categories of perceived benefit (informational support, emotional support, and connecting with others) are common benefit categories previously investigated in studies on pediatric rare diseases or online support [1,4-6,11,22-24].

### Informational Support

As 77.9% (180/231) of respondents used their Facebook group to find medical information about the respective disease, our study strengthens previous studies' findings that social media, including Facebook, is being used to search for medical information [5,6,11,22,23]. Increased knowledge can reduce stress related to parental incompetence and may result in better use of resources in the family [27]. Disease-specific Facebook support groups also facilitate the exchange of personal experiences in caring for someone affected; 88.7% (205/231) of respondents to our survey used their Facebook group to obtain advice on caretaking. This can ultimately improve parental management and care of rare conditions and have an empowering effect on parents who can become experts in their child's care [11].

### Emotional Support

Reading and sharing personal experiences is a starting point for emotional support in patient-to-patient communication. Seeing others' similar experiences can install a sense of belonging [25], seeing same struggles can make one feel less alone, and seeing others' positive developments can give hope. Almost all group members (222/231, 96.1%) used the Facebook group to read personal experiences and 78.8% (182/231) also shared personal experiences. About 70.6% (163/231) had already posted a personal picture in their group (Figures 1 and 2). Group participants' frequent reading and sharing of personal experiences confirm that emotional support is a fundamental element of support groups, including support groups for rare diseases [4,6,22,24].

### **Connecting With Others**

Facebook support groups and social media in general enable parents to connect with others [1,4,6,11,22,28]. This is especially important for those affected by rare diseases, because distance between affected individuals is a challenge in rare diseases which highly contributes to social isolation. Most respondents to our study agreed that Facebook reduces (200/231, 86.6%) and even eliminates (192/231, 83.1%) the problem of distance between people affected by rare diseases (Figure 2).

Facebook provides multiple communication functions including group and individual communication [7]. Usage of these functions is evident in our study: all respondents participated in group communication and 74.9% (173/231) reported direct contact to another group member via personal messaging services. Connections are also reported outside the virtual world: about 40.3% (9/231) had already met another group member in person (Figure 2). A study on online support groups for autism spectrum disorders indicated that a connection via Facebook could also be the starting point of organizing meetings for particular events [24].

These findings underline that parents and caregivers of children with rare diseases use Facebook support groups to connect and build relationships, and that Facebook is particularly useful for connecting with others affected by rare diseases by addressing the problem of distance between affected individuals.

### **Privacy**

Two-thirds of support groups for pediatric rare diseases on Facebook are private groups [9], reflecting on members' need for privacy when sharing personal information and experiences online. In our survey, participants were divided about whether or not they would share personal experiences in a public group. About 41.1% (95/231) would share personal experiences in a public Facebook group, whereas 38.5% (89/231) would not, while 13.9% (32/231) remained neutral (Figure 1). These negative answers showed that privacy setting can be decisive for active support group participation. Privacy concerns generally appear to be mostly directed at Facebook itself and users who are not involved in the group: while only 29.9% (69/231) were concerned about privacy matters in their Facebook group, 61.5% (142/231) were concerned about privacy matters on Facebook in general and 32.5% (75/231) worried that Facebook might use information they shared in their group compared with 20.3% (47/231) who worried that other members might use this information (Figure 1). This suggests that their Facebook groups achieve a certain environment of perceived privacy.

As we have shown, most respondents of this study shared private information on Facebook, even though they had privacy concerns. This shows that the privacy paradox, which describes the discrepancy between expressed privacy concerns and actual information disclosure [18], is also applicable to pediatric rare disease support group members. More discussions on actual privacy, perceived privacy, and responsible decision making on online information disclosure with regard to protecting children's privacy rights are needed. With an increasing number of Facebook support groups and increasing relevance for

affected families, ultimately, guidelines on sharing children's personal information online will be needed.

### **Using Facebook for Communication With Health Professionals, Pharmaceutical Companies, and Study Recruitment**

Giving recommendations to look for a Facebook group appears to be common practice, with 24.2% (56/231) of the participants having been referred to the Facebook group by a health professional (Figure 3). Having investigated the opportunities and limitations of Facebook support groups, our study can improve health professional's knowledge on this type of support groups. When giving the recommendation to look for a support group on Facebook, health professionals can use this knowledge to inform individuals about the points that should be considered prior to joining a group, which include benefits that are to be expected, which prerequisites and limitations could possibly be encountered, and that sharing personal (health) information online requires careful consideration.

### **Study Strengths and Limitations**

Our study had a larger than expected sample size, with various diseases and support groups being represented. There were only few ethical implications because data were collected anonymously and respondents were given the option to omit questions if they did not feel comfortable answering. This may result in a low social desirability bias and central coherence bias. Nevertheless, representability and external validity can be questioned. Only groups addressing 12 pediatric rare diseases were invited, and our demographic analysis shows that males were under-represented. The study results might be influenced by a response/selection bias, because anyone completing the survey self-selected to do so, especially regarding the question on study recruitment. Future research should involve a more in-depth analysis of participant's privacy concerns and behavior, including participant's decision-making process on online information disclosure with regard to children's privacy rights.

### **Conclusion**

We have shown that Facebook is a suitable tool for pediatric rare disease support groups, offering the distinct advantages of high accessibility and practicality. Group participants perceive a reduction and elimination of distance between affected individuals, a common challenge in rare disease, and Facebook support groups create an environment of perceived privacy allowing participants to share personal experiences and pictures.

We confirmed that participants of Facebook support groups for pediatric rare diseases benefit from informative support, emotional support, and the opportunity to connect with others. Our study has confirmed that most support group members use their Facebook group to find medical information, and further research is needed regarding how parents process and apply information found in online support groups to evaluate the risk of information inaccuracy and misinterpretation. Through our recruitment methods we provide an example of how Facebook support groups can be used for study recruitment and our survey showed that many group participants are in favor of study recruitment through their Facebook support groups.

We found that a group's privacy setting can be a critical factor for active support group participation. Furthermore, we have shown the importance of discussing children's privacy rights: sharing personal information and pictures on Facebook is very common among group participants. Group member's privacy concerns appear to be mostly directed at Facebook itself and to users not involved in the group, which offers potential starting points for improving privacy in Facebook support groups. Our study showed that the privacy paradox is applicable to group

members' online information disclosure habits: parents share private information even though they are concerned about privacy matters on Facebook. Parents could benefit from guidance on responsible decision making about online information disclosure with regard to protecting children's privacy rights. Ultimately, guidelines on sharing children's personal information online could be a useful tool for finding the right balance between the risks of information disclosure and the benefits of participating in a support group on Facebook.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Questionnaire: Pediatric rare disease support groups on Facebook.

[[DOCX File , 19 KB - pediatrics\\_v5i1e31411\\_app1.docx](#) ]

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Original Paper

# Refinement of a Parent–Child Shared Asthma Management Mobile Health App: Human-Centered Design Study

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## Abstract

**Background:** The school-age years, approximately ages 7 through 11, represent a natural transition when children begin assuming some responsibility for their asthma management. Previously, we designed a theoretically derived, tailored parent–child shared asthma management mobile health app prototype, Improving Asthma Care Together (IMPACT).

**Objective:** The purpose of this study was to use human-centered design (HCD) to iteratively refine IMPACT to optimize user experience and incorporate evidence-based longitudinal engagement strategies.

**Methods:** This study used a mixed methods design from December 2019 to April 2021. Our app refinement used the HCD process of research, ideation, design, evaluation, and implementation, including 6 cycles of design and evaluation. The design and evaluation cycles focused on core app functionality, child engagement, and overall refinement. Evaluation with parent–child dyads entailed in-person and remote concept testing and usability testing sessions, after which rapid cycle thematic analyses identified key insights that informed future design refinement.

**Results:** Twelve parent–child dyads enrolled in at least one round of this study. Eight of the 12 child participants were male with a mean age of 9.9 (SD 1.6) years and all parent participants were female. Throughout evaluation cycles, dyads selected preferred app layouts, gamification concepts, and overall features with a final design prototype emerging for full-scale development and implementation.

**Conclusions:** A theoretically derived, evidence-based shared asthma management app was co-designed with end users to address real-world pain points and priorities. An 8-week pilot study testing app feasibility, acceptability, and preliminary efficacy is forthcoming.

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## KEYWORDS

parent–child shared management; school-age children; asthma; participatory design; mHealth; prototype; usability; family health informatics

## Introduction

Over 5 million children in the United States have asthma, making it the most common chronic condition of childhood [1]. Asthma management is largely dependent upon symptom recognition, monitoring, and response as well as timely and

appropriate medication use [2,3]. Despite national asthma management guidelines, it is estimated that over 50% of US children with asthma are uncontrolled, placing them at higher risk of exacerbation and poorer outcomes [4]. Childhood asthma exacerbations account for 767,000 emergency department visits, 74,000 hospitalizations, and 13.8 million missed school days



annually [1]. As a consequence, children with poor asthma control and their parents experience lower quality of life and negative academic and work performance [5-7].

The school-age years, approximately ages 7 through 11, represent a natural transition in asthma management responsibility. School-age children must start assuming some responsibility for asthma-related care as they spend increasing time away from parents at school and other extracurricular activities [8]. Unfortunately, there is frequent disagreement between parents and children with respect to asthma symptom frequency and severity, asthma management practices, and overall level of control, with parents often reporting fewer symptoms, higher medication adherence, and better control than their children [9-12]. This disagreement may be contributing to an overestimation of childhood asthma control and subsequent undertreatment. Careful and deliberate parent-child shared asthma responsibility improves asthma symptom assessment, medication adherence, and overall asthma control [13-15]. A critical gap among existing asthma management interventions is the failure to account for and facilitate shared management responsibility. A parent-child shared asthma management solution is needed to facilitate optimal comanagement of asthma and to prepare the child to assume increasing asthma management responsibility.

With an estimated 85% of US adults owning a smartphone [16] and 69% tracking their health online [17], the ubiquity of smartphones has led to an explosion of mobile health (mHealth) self-management apps. Among adults with asthma, effective mHealth interventions combine medical guidelines, personalized self-monitoring, and behavior change techniques [18-20]. Presently, there are far fewer mHealth asthma apps for youth, with the majority specifically designed for adolescents [21-23]. While many of these apps have demonstrated preliminary efficacy [23], they are designed to support self-management versus parent-child shared asthma management, which limits their utility in school-age children. Among the apps specifically developed for children, they are almost entirely focused on education rather than engaging the child in assuming some responsibility for monitoring their own health [21]. While school-age children are often familiar with using a smartphone, only an estimated 17% of US children have their own smartphone [24], therefore an app designed for a parent and child to use together to support asthma management represents an important area of opportunity. To that end, there is now a need for mHealth interventions that leverage lessons learned from the adult literature and are specifically designed to facilitate parent-child shared management of asthma.

Human-centered design (HCD) is an approach to participatory design wherein end users are engaged throughout the iterative design process [25,26]. Previously, we reported on our use of HCD to develop a preliminary prototype of a parent-child shared asthma management mHealth intervention and companion wearable device [27]. The prototype features and functions were developed to address asthma management needs and priorities identified by parent-child dyads. These app features and functions were also evaluated and approved by an asthma clinician to ensure they aligned with the national asthma management guidelines [2,3]. Likewise, the prototype was

theoretically derived from Social Cognitive Theory and the Common Sense Model of Parent-Child Shared Regulation [28,29]. Social Cognitive Theory stresses that goal setting, action planning, and self-monitoring are important behavior change processes. The Common Sense Model of Parent-Child Shared Regulation emphasizes the contributions that both parent and child make toward shared management of health. Therefore, the app was specifically designed for parent-child dyads to use together to facilitate shared management; each week, parents and children select a small, achievable shared management goal, review goal-specific guidance, anticipate barriers, and monitor their goal progress on the subsequent week. Notably, this original prototype prioritized the integration of behavior change, personalized self-monitoring, and medical guidelines [27,30].

The true viability of any mHealth behavior change intervention app is dependent upon ongoing use. While our study team iteratively developed the features and functions of the original app prototype, in-depth usability testing of user experience (UX) and subsequent design iteration were beyond the scope of the original project. Refinement was necessary to ensure that the UX was optimized. Similarly, the literature has clearly shown that overall mHealth app engagement wanes over time, thus limiting the potential efficacy of any app [31]. Given that this mHealth app was designed to function as a behavioral health intervention, integration of engagement strategies was also necessary to promote longitudinal engagement with app. Therefore, before proceeding to full-scale app development and pilot testing, the purpose of this study was to use HCD to refine the original parent-child shared asthma management mHealth prototype, Improving Asthma Care Together (IMPACT), to optimize UX and engagement. The specific aims were to (1) assess and iteratively refine the mHealth app based upon usability findings, (2) incorporate longitudinal engagement strategies within the app, and (3) innovate a home-based multimodal solution to overcome barriers imposed by the COVID-19 pandemic.

## Methods

### Design and Sample

This study used a mixed methods design and included a series of design-evaluation cycles from December 2019 to April 2021. Study recruitment occurred from December 2019 to December 2020. A convenience sample of fourteen 7- to 11-year-old children with asthma and one of their parents was recruited from the principal investigator's (JS) research database, which includes parent-child dyads who have participated in previous studies for school-age children with asthma. Recruitment for these prior studies included flyer distribution by school nurses as well as study flyer posting in pediatric provider offices, community locations (eg, libraries, Boys and Girls clubs), and social media. Child eligibility included (1) age 7-11 years, (2) parent-reported asthma diagnosis, (3) parent-reported prescription for daily asthma medication, and (4) able to speak and understand English. The prescription for daily asthma medication was used as a proxy to indicate persistent asthma, considered more severe than intermittent or exercise-induced asthma [3]. Parent/caregiver inclusion criteria included (1) 18

years or older, (2) child’s primary caregiver, (3) able to understand and read English, (4) reside with the child for at least 50% of the time, and (5) a legal guardian who may consent for the child to participate. Exclusion criteria included prior participation in the original prototype development as well as current asthma exacerbation, such as wheezing or respiratory distress, as this is a serious health event that requires careful monitoring and would distract dyads from participation. However, dyads were eligible to participate once the exacerbation resolved.

**Ethics**

The University of Washington Human Subjects Division reviewed this study and deemed it as exempt (#00003144). Written informed consent was obtained from all parent participants, on behalf of themselves and their child, and assent from all child participants.

**Original IMPACT Prototype**

IMPACT was designed to serve as an asthma monitoring system as well as behavioral intervention to promote parent–child shared asthma management. The original IMPACT prototype comprised 3 key features: asthma symptom tracking, asthma control (measured by the Childhood Asthma Control Test or C-ACT [32]), and asthma shared management goal setting and progress reporting. Child-reported asthma symptom events are tracked with the app dashboard in graphical format. Likewise, the app was designed to prompt parent–child dyads to complete

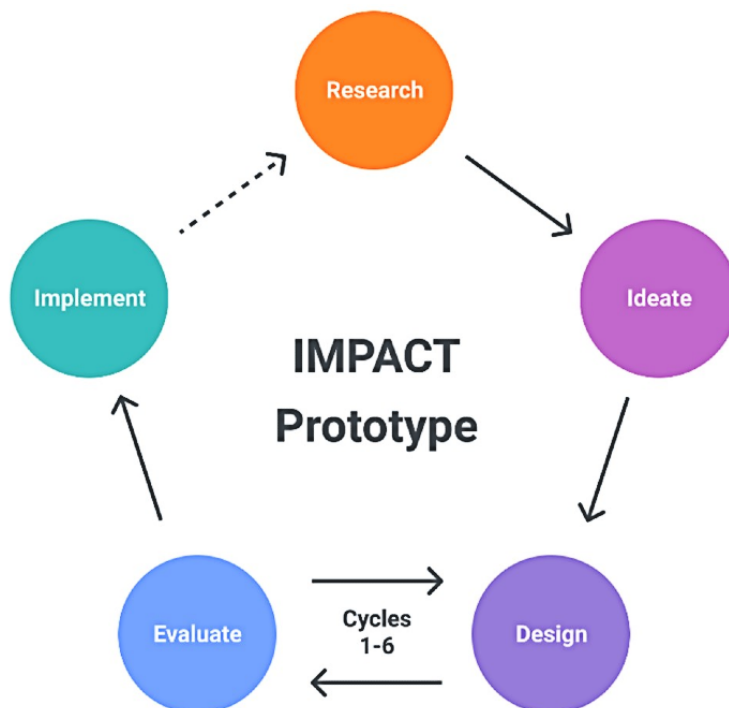
the C-ACT weekly, with scores visualized over time in the app dashboard. Finally, each week, parent–child dyads would select 1 or 2 asthma shared management goals that were provided by the app. The following week, dyads would report on their goal progress. Overall, shared management was supported by gradually transferring asthma management responsibility to the child while supported and supervised by the parent. Within the app, the parent–child dyad selects a weekly asthma management task or activity for which the child will begin assuming responsibility. Goal-specific guidance and support (when available) are provided, such as scheduling medication reminders, to assist the dyad with achieving the goal. Such intentional shifting of asthma management responsibility through mutual goal setting ensures the child learns critical management tasks and skills while supported by the parent [9,10,29].

**App Refinement Process**

**Overview**

A hallmark of HCD is design iteration that follows a cyclic as opposed to linear process (Figure 1). The core study team included a designer (QZ), a pediatric asthma clinician-scientist (JS), a UX researcher (EEC), and a senior HCD expert (JAK). This study followed the HCD process steps: research, ideate, design, evaluate, and implement to refine the IMPACT prototype and incorporate longitudinal engagement strategies [25,33]. The app refinement process required numerous cycles of design and evaluation, which is expected in HCD.

Figure 1. Human Centered Design Process.



**Research**

During this phase, our team conducted a scoping literature review of mHealth app engagement strategies. Next, our team conducted a market research review to understand existing apps designed for use by school-age children, including health- and

non-health-related apps. We then assessed the extent to which existing asthma apps facilitated parent–child shared management.

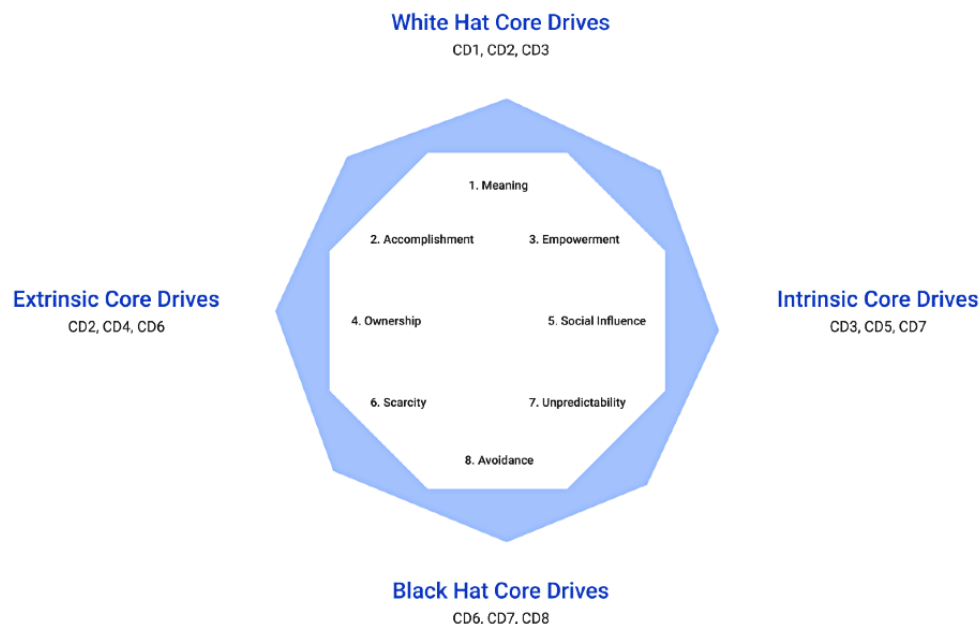
## Ideation

The ideation phase of HCD entails generating ideas and solutions to address user needs and priorities [33]. To guide our work in designing for engagement, our team conducted a literature review of common approaches to promoting app engagement [18,24,30,34,35]. Based upon this review, our team decided to incorporate gamification to promote app engagement and subsequently adopted the Octalysis Framework for Gamification and Behavioral Design [36]. Guided by the concept of motivation from social psychology, the Octalysis Framework intentionally accounts for intrinsic, extrinsic, positive, and negative motivations. Intrinsic motivation refers to activities performed out of pure enjoyment with no tangible rewards, whereas extrinsic motivation refers to behaviors performed in pursuit of tangible external rewards [37,38]. Positive motivators stimulate positive emotions such as joy, satisfaction, and a sense of meaning, whereas negative motivators may elicit feelings such as surprise, fear, or concern for a loss of progress or reward. The Octalysis Framework is depicted as an octagon with each

side representing 1 of 8 core drives (CDs) of motivation (Figure 2) [36]. CDs associated with extrinsic motivation (CD 2, 4, 6) are located to the left of the model, whereas those associated with intrinsic motivation are represented on the right (CD 3, 5, 7). Positive motivators are located at the top of the model (CD 1, 2, 3), whereas the bottom portion of the model represents negative motivators (CD 6, 7, 8; Figure 2).

Guided by the Octalysis Framework, the study team conducted brainstorming sessions for new features and enhancements of the IMPACT app, using rough sketches and short descriptions to communicate and align ideas across the team. Next, we employed affinity mapping, where ideas were grouped into themes, and team members ultimately voted on their top engagement ideas. Finally, we used effort versus impact matrices to prioritize design ideas and refinements. Although parent–child dyads were not engaged in the initial ideation phase, their feedback from subsequent stages, including new app features or concepts, were prioritized in future design iterations (see the “Results” section for details).

**Figure 2.** Octalysis framework and core drive motivations. Adapted, with permission, from [38].



## Design

The original mHealth IMPACT app prototype was developed using Figma, a digital design and prototyping platform that supports the prototyping spectrum from wireframes through high-fidelity interactive prototypes (Figma, Inc). Given that the original prototype was housed within Figma, the designer (QZ) continued to use Figma for subsequent design ideas to facilitate a cohesive UX. During the design phase, the designer digitally drafted the prioritized design ideas, usually providing 2 or 3 variations. The study team reviewed the designs together and typically selected 2 versions to move forward to user testing in the evaluation phase. The inclusion of the asthma clinician-scientist study team member during such early design stages ensured that prospective designs represented asthma management best practices. As is depicted in Figure 1, numerous rounds of design and evaluation occurred as the app was progressively refined. Initial design rounds used low-fidelity

wireframes to depict the basic app structure (information architecture) and functionality (eg, screens showing paths users take, or “user flows”). Later design rounds focused on visual design and microinteractions of the app features, which necessitated high-fidelity prototyping within Figma.

## Evaluate

The study team used numerous techniques within the evaluation stage, including concept testing, usability testing, and semistructured interviews [33,39,40]. Concept testing entails seeking feedback and preferences from users about specific concepts and designs. For example, presenting different layouts of a dashboard to determine which was more effective for users, a technique known as parallel prototyping [41]. We also used card sorting, which entailed presenting numerous feature options generated from the ideation phase to users and asking them to categorize their preferences in order of importance.

Usability testing, by contrast, was used to test specific tasks within the app to determine whether users were able to use the app as intended [33,39,40]. These tasks are referred to as “flows,” representing the series of screens users encounter as they perform a task. Usability sessions were moderated by the UX researcher (EC) and observed by the designer, which facilitated understanding user feedback. Through the use of the “think-aloud” technique, a cognitive interviewing method, participants were asked to perform a task within the app while the researcher observed [42]. Users were asked to describe their use of the app as they performed the tasks, including what they liked or disliked, what was confusing, and whether they would change anything. All evaluation sessions also incorporated semistructured interviews to elicit any user feedback, suggestions, or other comments.

Following each evaluation session, the UX researcher and designer debriefed the session and discussed their takeaways from the session (eg, user preferences for specific designs, or challenges using a specific flow). As is typical in HCD, each usability testing cycle was followed by rapid thematic analyses to identify key insights [25]. Key insights were then translated into recommended refinements by the UX researcher. These refinements were prioritized using a common usability scoring system (1=highest priority, 4=lowest priority) [43]. Level 1 (high priority) items prevent users from completing a task, Level 2 items create a significant delay in task completion, Level 3 have minor effects on usability, and Level 4 (lowest priority) are subtle with minimal effects. For this project, high-priority items reflected essential functions, new features, or other substantive app changes. Substantive design changes always were tested in a future evaluation cycle. Conversely, lower-priority items—often minor functionality issues such as type of clock face or button—were revised without further testing. Depending on the evaluation findings, the study team decided to either iterate the design further (re-enter the design phase) or move the prototype to implementation. We originally planned 3 cycles of design and evaluation, but as a result of delayed study timelines due to the COVID-19 pandemic, we extended our threshold for concluding iterations to Spring 2021.

### Implement

Implementation entails handoff of the final designs to the developer team for full-scale development of the app. Implementation usually follows numerous rounds of design and evaluations until a final design emerges.

### Procedures for Evaluation and Refinement

As depicted in [Figure 1](#), this study consisted of research, ideation, numerous design, and evaluation cycles, followed by implementation. Study participants were directly involved in evaluation sessions. Procedures for engagement with study participants during evaluation sessions are herein described. For each session, the UX researcher generated an evaluation session plan including introductory script, task planning (concept testing or usability testing), and open-ended questions for the semistructured interview. Sessions were planned such that child activities were prioritized first to retain their attention.

Once the session plan was complete, the UX researcher contacted the parent of prospective parent–child study participants in the principal investigator’s research database via email. Those who were interested scheduled a study session with the UX researcher. Prior to the COVID-19 pandemic, study sessions were conducted at participant homes or a community library. Participant use of the Figma prototype app was recorded using Mr. Tappy (Mr. Tappy), a kit comprising a magnetic base that attaches to a mobile device with a digital camera on an adjustable metal arm. The UX researcher was able to view the user’s actions via the Mr. Tappy browser-based viewer.

During the COVID-19 pandemic, the stay-at-home orders necessitated to transition to a remote study protocol. All remote study sessions were conducted via Zoom videoconference (Zoom Video Communications, Inc.). As an alternative to Mr. Tappy, which would require mailing to and from participant homes, the UX researcher would access the Figma app prototype, share their screen, and enable “remote control” of their mouse and keyboard. These settings allowed users to freely control their engagement with the app while Zoom recorded the session.

Following informed consent and child assent (electronic consent and assent for remote sessions), the UX researcher moderated the study session following the session plan while the designer observed and took notes. Sessions were approximately 60 minutes in duration. Rapid cycle thematic analyses were completed after each session, as discussed earlier, which informed the subsequent design refinements. Parent–child dyads received US \$50 digital gift card following each evaluation session.

## Results

### Participants

Twelve parent–child dyads enrolled in at least one round of this study. Eight of the 12 child participants were male with a mean age of 9.9 (SD 1.6) years. Nine of the child participants identified as White, 2 as Black, and 1 as mixed race. All of the parent participants identified as female, which is consistent with our prior study samples. Nine parent participants identified as White, 2 as Black, and 1 as mixed race. None of the study participants identified as Hispanic or Latinx.

Sample sizes for the 6 evaluation cycles ranged from 3 to 6 dyads. Usability best practices call for 4 or 5 participants per session, which typically will identify 80% of usability problems [44,45]. Larger samples are generally considered overly burdensome, redundant, and time-consuming. Parent–child dyads participated in at least one evaluation session, with 1 dyad participating in 5 sessions ([Table 1](#)). The inclusion of some dyads in multiple cycles was beneficial as it ensured they were familiar with the app objectives and core functionality, allowing them to swiftly focus on new design enhancements and changes. By contrast, inclusion of novel dyad users within study cycles, particularly later cycles, ensured we had diverse perspectives and feedback.



**Table 1.** Dyad participation by evaluation cycle (N=12 parent–child dyads).

Dyad number	Evaluation cycle
1	1, 3, 4, 5, 6
2	1, 2, 4, 6
3	1, 3, 4, 5, 6
4	4, 5, 6
5	1
6	4
7	5, 6
8	5
9	2
10	1
11	1, 3
12	2, 4

**Research**

**Engagement Strategies**

We found that gamification, or the incorporation of gaming elements in nongaming uses, is increasingly employed in the mHealth market [35,46]. Originating from the videogaming industry, gamification integrates fun elements and human motivation to maintain user engagement. Gamification strategies appear highly variable and dependent upon the user, context, and activity or goal. Some examples include badges, leader boards, social engagement, and challenges or quests [35]. Despite this variability, gamification shares the ultimate goal of motivating users to continue using the app [47].

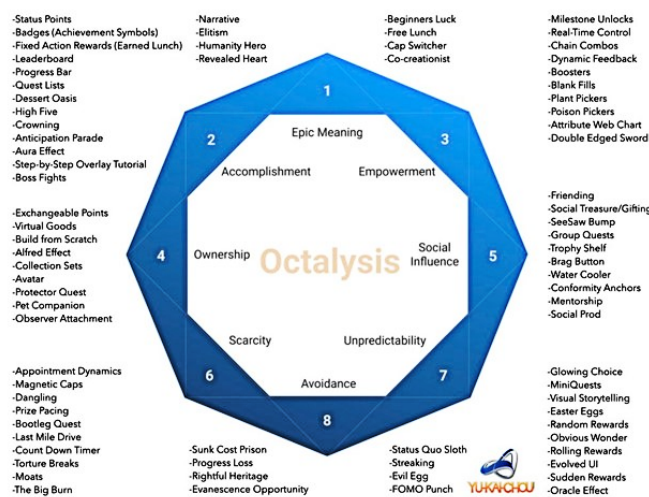
**Existing Apps for Children**

Among existing apps for children, we found several common strategies, including the use of avatars, badges, and streaks. Similarly, child-facing app designs were streamlined, colorful, and intuitive with emphasis on visuals. Notably, mHealth apps designed for childhood asthma were predominantly educational, affirming our unique perspective targeting parent–child shared management responsibility.

**Ideation**

Using the detailed Octalysis Framework (Figure 3), which provides feature examples mapped to each CD, the study team brainstormed and then prioritized various concepts that could be incorporated into our app (Table 2).

**Figure 3.** Octalysis Framework for gamification and behavioral design. Reproduced, with permission, from [38]. UI: user interface.





**Table 2.** Ideation phase: gamification brainstorming results.

Core drive and concept brainstorm	Priority <sup>a</sup>
<b>CD 1<sup>b</sup>: Epic meaning (positive motivation)</b>	
N/A <sup>c</sup>	N/A
<b>CD 2: Development (extrinsic, positive motivation)</b>	
Setting and achieving measurable goals (promotes accomplishment) <sup>d</sup>	1
Positive reinforcement (congratulations when goal met) <sup>d</sup>	1
Leveling up or other reward system <sup>d</sup>	2
Progress bar for rewards <sup>d</sup>	2
Badges for achievements	2
To-do list for app activities <sup>d</sup>	3
Step-by-step onboarding <sup>d</sup>	4
Hotspots during onboarding <sup>d</sup>	4
<b>CD 3: Empowerment (intrinsic, positive motivation)</b>	
Choice of a list of recommended goals and option to write own goals (blank fill) <sup>d</sup>	1
Real-time feedback during goal progress reports <sup>d</sup>	1
Customize app backgrounds or decor with accumulated rewards	4
<b>CD 4: Ownership (extrinsic)</b>	
Customize profile with avatar <sup>d</sup>	1
Virtual pet or mascot <sup>d</sup>	2
Accumulated rewards as currency for a virtual “good”	2
<b>CD 5: Social influence (intrinsic)</b>	
Shared app engagement with parent and child <sup>d</sup>	1
Option to share results with health care provider <sup>d</sup>	3
Asthma tips from health care professionals (mentorship)	4
Chat forum (collaboration)	4
Leaderboard to inspire competition	4
<b>CD 6: Scarcity (extrinsic, negative motivation)</b>	
Progressively more difficult to earn rewards <sup>d</sup>	2
Reward options progressively expand with ongoing use <sup>d</sup>	2
<b>CD 7: Unpredictability (intrinsic, negative motivation)</b>	
Unlocking new rewards <sup>d</sup>	2
Streaks	3
<b>CD 8: Avoidance (negative motivation)</b>	
Surprise rewards	3

<sup>a</sup>1=highest priority and 4=lowest priority.

<sup>b</sup>CD: core drive.

<sup>c</sup>N/A: not applicable.

<sup>d</sup>Depicts concepts that emerged in the final prototype.

## Design

### Overview

As depicted in [Figure 1](#), this project entailed 6 cycles of design and evaluation such that insights from evaluation informed future design refinements. The design foci, evaluation methods, and key insights of each cycle are discussed below and in [Table 3](#). Several concepts were never prototyped, including chat forums and leaderboards, due to patient privacy concerns. Expert

asthma tips were not prototyped as these are redundant with existing asthma apps. We primarily used medium-fidelity Figma prototyping during design (and evaluation), which entails certain clickable elements within the design. For the last design and evaluation cycle, a high-fidelity Figma prototype was used, which had fully integrated clickable elements such that users could simulate real-world use and navigate as if it were a real app.

**Table 3.** Design foci, evaluation, and key insights by cycle (N=12 dyads).

Cycle	Participants and visit type	Design foci	Evaluation	Key insights
1	n=6 dyads In-person	<i>Baseline mid-fidelity prototype functionality and layout:</i> <ul style="list-style-type: none"> <li>• Dashboard: Asthma Symptoms and C-ACT<sup>a</sup></li> <li>• Goal-setting flow</li> <li>• Progress reporting flow</li> </ul>	<i>Concept test:</i> <ul style="list-style-type: none"> <li>• Dashboard display for asthma symptoms and C-ACT (PP<sup>b</sup>)</li> </ul> <i>Usability test:</i> <ul style="list-style-type: none"> <li>• Goal-setting flow (TA<sup>c</sup>, SS<sup>d</sup>)</li> <li>• Progress report flow (TA, SS)</li> </ul>	<i>Concept test:</i> <ul style="list-style-type: none"> <li>• Separate symptom and C-ACT graphical displays.</li> <li>• Simplify layout.</li> <li>• Modify color scheme.</li> </ul> <i>Usability test:</i> <ul style="list-style-type: none"> <li>• Retain goal choices, improve flow.</li> <li>• Response or celebration for achieved goal.</li> <li>• Need more child engagement.</li> <li>• Good parent–child interaction during use.</li> </ul>
2	n=3 dyads In-person	<i>Mid-fidelity prototype functionality and layout:</i> <ul style="list-style-type: none"> <li>• Add avatar for user profiles</li> <li>• Simplified dashboard</li> <li>• Revised goal-setting flow</li> <li>• Enhanced progress reporting flow</li> <li>• C-ACT flow</li> </ul>	<i>Concept test:</i> <ul style="list-style-type: none"> <li>• Various avatar options (PP)</li> </ul> <i>Usability test:</i> <ul style="list-style-type: none"> <li>• Goal-setting flow (TA, SS)</li> <li>• Progress report flow (TA, SS)</li> <li>• ACT completion and interpretation (TA, SS)</li> </ul>	<i>Concept test:</i> <ul style="list-style-type: none"> <li>• Preferred animal avatars.</li> <li>• Liked ability to customize.</li> </ul> <i>Usability test:</i> <ul style="list-style-type: none"> <li>• Flows improved and clear.</li> <li>• Love celebration response when goal achieved.</li> <li>• Color schemes much improved.</li> <li>• Add legend for C-ACT interpretation.</li> </ul>
3	n=3 dyads Remote	<i>Mid-fidelity prototype and child engagement strategies:</i> <ul style="list-style-type: none"> <li>• Introduce animal mascot and reward system concepts</li> <li>• Revise C-ACT flow with legend</li> </ul>	<i>Concept test:</i> <ul style="list-style-type: none"> <li>• Animal mascots (PP)</li> <li>• Color themes (PP)</li> <li>• Reward systems (TA)</li> </ul> <i>Usability test:</i> <ul style="list-style-type: none"> <li>• Legend for C-ACT (TA, SS)</li> </ul>	<i>Concept test:</i> <ul style="list-style-type: none"> <li>• Love the animal mascot and rewards, preferred dog theme.</li> <li>• Integrate animal mascot with reward system.</li> </ul> <i>Usability test:</i> <ul style="list-style-type: none"> <li>• C-ACT legend is clear.</li> <li>• Show symptoms first on dashboard.</li> <li>• New feature suggestions—medication tracking, data export.</li> </ul>
4	n=6 dyads Remote	<i>Mid-fidelity prototype and animal mascot:</i> <ul style="list-style-type: none"> <li>• Introduce home spirometer concept</li> <li>• Refined dog mascot and reward theme</li> </ul>	<i>Concept test:</i> <ul style="list-style-type: none"> <li>• Spirometer integration with app (SS)</li> </ul> <i>Usability test:</i> <ul style="list-style-type: none"> <li>• Dog mascot with bone reward system (TA, SS)</li> </ul>	<i>Concept test:</i> <ul style="list-style-type: none"> <li>• All participants desire home spirometer integration.</li> </ul> <i>Usability test:</i> <ul style="list-style-type: none"> <li>• Children love dog mascot that grows with rewards.</li> <li>• Easily understood reward system, progress bars.</li> </ul>
5	n=5 dyads Remote	<i>Mid-fidelity prototype and introduce concepts:</i> <ul style="list-style-type: none"> <li>• Onboarding</li> <li>• To-do list</li> <li>• New background or accessories</li> <li>• Streak</li> <li>• Medication tracking</li> <li>• Spirometer in dashboard and performance incentive</li> </ul>	<i>Concept test:</i> <ul style="list-style-type: none"> <li>• Onboarding (PP)</li> <li>• To-do list (PP)</li> <li>• Background and accessories (TA, SS)</li> <li>• Streak (PP, SS)</li> <li>• Medication tracking (PP, SS)</li> <li>• Spirometer in dashboard (TA, SS)</li> </ul>	<ul style="list-style-type: none"> <li>• Dyads preferred sequential onboarding flow with prompts.</li> <li>• Scrollable to-do list with “done” checkmarks. Add prompt on dashboard if there are items to do.</li> <li>• Children did not care for new backgrounds or accessories. Prefer additional pets/mascots.</li> <li>• Children did care for streaks.</li> <li>• Dyads prefer calendar plus reminders for medication tracking.</li> <li>• Spirometer tracking needs to be simplified with export function.</li> <li>• Different spirometer performance incentive (windmill) ok, but could be improved.</li> </ul>

Cycle	Participants and visit type	Design foci	Evaluation	Key insights
6	n=5 dyads Remote	<i>High-fidelity prototype:</i> <i>Introduce:</i> <ul style="list-style-type: none"> <li>Animal mascot unlocks</li> <li>“Maintenance phase”</li> </ul> <i>Refine:</i> <ul style="list-style-type: none"> <li>Onboarding</li> <li>To-do list</li> <li>Medication tracking</li> <li>Spirometer incentive and tracking</li> </ul>	<i>Concept test (TA, SS):</i> <ul style="list-style-type: none"> <li>New animal mascot unlocks (TA, SS)</li> <li>Maintenance phase concept (TA, SS)</li> </ul> <i>Usability test:</i> <ul style="list-style-type: none"> <li>Onboarding (TA, SS)</li> <li>To-do list (TA, SS)</li> <li>Medication tracking (TA, SS)</li> <li>Spirometer incentive and tracking (TA, SS)</li> </ul>	<i>Concept test:</i> <ul style="list-style-type: none"> <li>Love animal mascot unlocks.</li> <li>Love maintenance phase concept, suggest “mute” for goals, retain everything else.</li> </ul> <i>Usability test:</i> <ul style="list-style-type: none"> <li>Refinements were all clear.</li> <li>Keep calendar for medication use and add option for medication reminders.</li> <li>Consider minor edits for consistent language, color scheme.</li> </ul>

<sup>a</sup>C-ACT: Childhood Asthma Control Test.

<sup>b</sup>PP: parallel prototyping.

<sup>c</sup>TA: think aloud.

<sup>d</sup>SS: semistructured interview.

### Cycles 1 and 2

The highest priority items from the ideation phase related to core functions within the app, specifically evaluating goal setting, the interaction between parent and child, and a new priority, an avatar for child users to excite them about ongoing use of the app. These items cross numerous CDs. Based upon these priorities, the designer expanded the original prototype to include positive reinforcement when a dyad reported successful achievement of a goal. An avatar concept was also prototyped to customize user profiles, with various options including animals, robots, dinosaurs, and monsters. These priority items were tested with users in cycles 1 and 2, with

refinements made after each cycle based upon user feedback (described in the “Evaluation” section).

### Cycles 3 and 4

The next batch of priority concepts related to developing a virtual pet or mascot and reward system for app usage, with the intent to promote and maintain child user engagement. Numerous prototypes were developed with animal or creature mascots, including a monkey, underwater theme, animated lungs, monster, and a dog (Figure 4). Several rewards systems were similarly developed such that users earned rewards for various goal achievements. A variety of progress bars, displays options, and rewards were prototyped around the mascot concept.

Figure 4. App mascot prototypes.



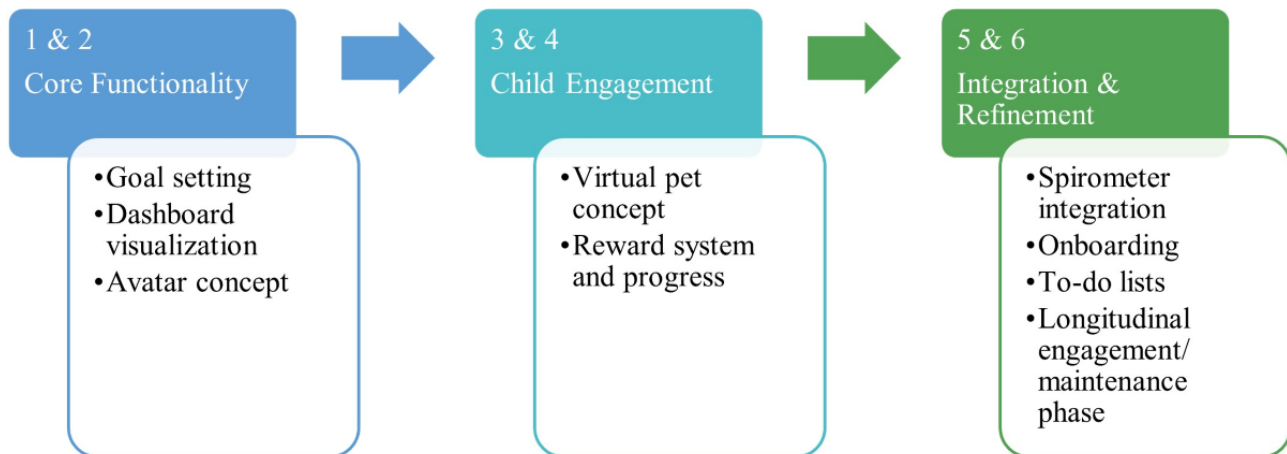
### Cycles 5 and 6

The final design cycles focused on several of the items from Table 2, including 2 versions of a to-do list, onboarding

guidance, and several longitudinal app engagement concepts. Onboarding guidance prototypes included carousels of app features, spotlights on app functionality, and options for video tutorials. Longitudinal engagement strategies included

expanding the animal mascot concept to provide options for unlocking additional mascots, using accumulated rewards to purchase new app backgrounds or accessories for the animal, and the concept of streaks. We also designed for integration of a home-based spirometer within the app, which emerged from parent participant feedback during prior remote evaluation sessions amidst the COVID-19 pandemic. The study team developed a spirometry tracking graph within the IMPACT app dashboard as well as visual incentives for optimal spirometry performance. Finally, we designed an export feature, which would provide users the option to export app data (C-ACT, spirometry results, etc.) to their health care provider.

**Figure 5.** Design and evaluation foci by cycle.



### Cycles 1 and 2

To test the core app functionality, cycles 1 and 2 prioritized evaluating the original prototype dashboard and goal-setting flows. The dashboard, or home screen, depicts graphical representations of the child's asthma symptoms and a weekly C-ACT. Concept testing was used to determine parent and child preferences for dashboard layout and color schemes.

*I would totally have nothing on here except the symptom box and move everything down to the navigation bar...so you are only focusing on which is important, which is symptoms. [P3]*

We also concept tested avatar options with child participants, with animal avatars emerging as preferred.

Usability testing was used to test the goal setting, progress report, and ACT flows. The goal-setting flow was very clear, with one parent commenting,

*Oh boy, I love these goals! [P2]*

During the semistructured interview, another parent asked what would happen after dyads completed the intervention. This parent suggested that the team consider an additional app phase that did not focus on changing shared management behaviors, but rather on maintaining them along with ongoing asthma symptom and control tracking (later addressed in design cycle 6). The remaining flows tested well with minor refinements recommended.

## Evaluation

### Overview

Most evaluation cycles used concept testing, to determine specific concepts to integrate within the app, as well as usability testing, to determine whether users were able to use the implemented concepts as intended. Overall, evaluation cycles initially prioritized core app functionality, then child engagement, and finally integration of all concepts and refinement (Figure 5). Key insights by cycle are presented in Table 3.

### Cycles 3 and 4

Cycles 3 and 4 focused on evaluating the animal mascot and reward system child engagement strategies. A series of parallel prototyping concept tests revealed that dyads strongly preferred a dog mascot and that the reward system be cohesive with the mascot. Ultimately, a dog bone reward scheme was selected. During the interview, one child suggested we build on the dog mascot concept:

*You can feed the animals to make them bigger and better...and they can get different colors. [C3, 11 years, during cycle 3]*

This suggestion was integrated into cycle 4, with the dog mascot initially displayed as a puppy that progressively grows through reward achievements. Usability testing revealed the growing puppy mascot was unanimously favored.

Amidst the COVID-19 pandemic, many parents with children with asthma expressed concern about decreased access to their health care provider. A specific concern was restrictions placed on spirometry, which is an aerosolizing procedure. In light of these parent-identified concerns, we introduced an additional concept for testing, home spirometry. One parent commented,

*Yes, that would be extremely useful. That would give us the information to decide whether to go to the doctors or emergency. [P1]*

Another shared,

*I think this would be great! It also generates more data to give to the doctor...He [the child] might be*



*fine when he goes to see the doctor once a year, but the rest of the year he wheezes, and I worry.* [P2]

Finally, interviews revealed that dyads would also like to see the app incorporate medication tracking and reminders.

*Medication reminders. We need a reminder...that's what we need more than anything.* [P1]

### Cycles 5 and 6

Cycle 5 was entirely focused on concept testing various options for onboarding, app tasks, streaks, medication tracking, and spirometry integration. Dyads were very decisive on preferred formats. Child participants clearly did not care for the streak concept,

*Streaks just feel more like work.* [C4, 10 years]

Children also preferred that we expand the mascots to allow for additional dog “unlocks” within the reward system as opposed to earning accessories or app background changes. The introduction of medication reminders and tracking as well as spirometry were both unanimously favored.

Cycle 6 concept testing evaluated the maintenance phase concept to follow intervention completion, which originated from a parent participant, whereby the goal setting was muted, and dyads may continue to use the other app features long term. Dyads loved this addition as it would enable ongoing app use even after the intervention was complete. High-fidelity usability testing revealed only minor refinements, indicating readiness to move to implementation.

### Implementation

Once the high-fidelity prototype was finalized, the study team worked alongside the engineering team to construct user stories that specify feature requirements within the app. User stories are written from the perspective of the user, such as “as a user, I want to be able to track my asthma control within the app” [48]. Screenshots, Figma prototype links, and descriptions of the related prototype features often accompanied the user stories. Globally, user stories help provide the “why” for software developers alongside the prototype [49]. Practically, they constitute a step-by-step guide for development of a product and subsequent internal testing to ensure the developed app functions as intended [48-50]. Developer effort and timelines are also estimated based upon user stories. Given that the development and study teams co-constructed the user stories, any questions or clarifications related to the proposed design were addressed collaboratively. In total, these user stories constitute the design specifications for the engineering team.

## Discussion

### Principal Findings

The purpose of this study was to use HCD to refine the original parent-child shared asthma management IMPACT app and to incorporate longitudinal app engagement strategies. The study team successfully refined the app, incorporated longitudinal engagement strategies, and added dyad-prioritized new features. Final testing indicated that parent-child dyads found the refined

IMPACT prototype addressed their prevailing asthma needs and priorities in an engaging, easy-to-use app.

Partnering with our end users ensured that our final design met the needs and priorities of children with asthma and their parents. Evidence has shown that such participatory design practices increase the likelihood of intervention uptake and efficacy [51,52]. Our participants were very clear that they did not desire another educational intervention, but rather a system to address challenges in monitoring symptoms and transitioning asthma responsibility to the child in a safe manner. Parent participants were especially enthusiastic about the shared management goals, which break down key asthma management tasks while facilitating parent-child shared monitoring and management. The incorporation of spirometry was also in direct response to a serious parental concern about barriers to health care access amidst the COVID-19 pandemic. Our study also serves as an example for integrating other mHealth best practices, including theoretically informed intervention techniques, clinical guidelines, and validated assessment tools [53-55].

Drawing upon the Octalysis Framework, our final design successfully integrated concepts from 6 of the 8 gamification CDs, excluding CD 1 (epic meaning) and CD 8 (loss and avoidance). Epic meaning, or being part of something bigger than oneself, does not align well with an mHealth app, which is specifically designed to support an individual's health. We concept tested a CD 8 concept, streaks, though none of our participants recommended retaining the concept. The final IMPACT design included more extrinsic than intrinsic motivations, though both are accounted for in the design. This is not unexpected as extrinsic motivations, such as tangible rewards, are more straightforward for children and frequently used in child-facing gamified systems [34,56-58]. Similarly, some intrinsic motivations, such as social sharing, are inappropriate for mHealth apps due to patient confidentiality concerns. However, an ideal gamified system does not need to integrate all CDs, but rather ensure each of the 4 motivation dimensions are accounted for in the design [36].

Despite the surge in mHealth interventions, to our knowledge, none have been designed to promote parent-child shared asthma management. Just as children need to learn self-care practices in a stepwise fashion (ie, feeding, dressing), so too do they need to learn self-management in a similar progression. Unfortunately, evidence shows that youth often abruptly assume complete management of their asthma during adolescence, often resulting in worsened health status and poor health outcomes [11]. Despite this evidence, guidance facilitating parent-child shared asthma management is lacking in the literature and existing mHealth apps [11]. Interventions specifically designed to facilitate safe and intentional parent-child shared management through concrete, task-based goal setting represent a novel approach to teaching children essential asthma management skills while still under the supervision of their parent. Such innovations hold the promise of improving a child's health in the present as well as building lifelong self-management skills.

To our knowledge, there are few, if any, studies describing the iterative design of a dyadic health management app [59]. Our

study represents an exemplar for integrating mHealth best practices, particularly behavior change, personalized self-monitoring, and medical guidelines [27,30], while concurrently accounting for a dyad's unique circumstances, family needs and priorities, and social environment [45,59]. As equal participants, parent and child feedback was carefully considered and incorporated into the app to ensure that the needs of both types of users are accounted for. While we anticipated parental hesitation to allow their child to assume asthma responsibility, we actually found that most were relieved and excited to be developing an app that would meet their needs. Multiple rounds of design and evaluation were necessary to successfully incorporate these preferences within the app; dyads often would resolve disagreements about app designs without study team facilitation. The result was an mHealth solution that represents not only a solution to dyad-identified needs and priorities, but also one that models a paradigm shift from personal to family informatics [59]. Such solutions hold tremendous promise in supporting families in navigating parent-child shared management of health.

## Limitations

While this study has many strengths, there are important limitations that warrant consideration. The convenience sample of parent-child dyads was small and somewhat homogenous (primarily male children and female parents), which limits generalizability of study findings. The sample was recruited from the principal investigator's research database, which is not representative of all school-age children and their parents and did not screen for other comorbidities. It is also possible that study dyads experienced social desirability bias. Finally, our recruitment was confined to one geographic area, again limiting potential generalizability of our findings.

## Conclusions

The final IMPACT app is a theoretically derived, tailored parent-child shared asthma management intervention and monitoring system. IMPACT was iteratively co-designed by our interdisciplinary study team as well as end users to ensure that the app meets the needs and priorities of children with asthma and their parents. The final IMPACT prototype is presently being fully developed for an anticipated 8-week pilot RCT in which we will test the feasibility, acceptability, and preliminary efficacy of the app.

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## Conflicts of Interest

None declared.

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## Abbreviations

**AM:** affinity mapping  
**C-ACT:** Childhood Asthma Control Test  
**CD:** core drive  
**HCD:** human-centered design  
**IMPACT:** Improving Asthma Care Together  
**mHealth:** mobile health  
**PP:** parallel prototyping  
**SS:** semistructured interview  
**TA:** think aloud  
**UX:** user experience

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Original Paper

# Multimedia Knowledge Translation Tools for Parents About Childhood Heart Failure: Environmental Scan

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## Abstract

**Background:** Childhood heart failure is a factor in many hospital admissions each year. It can impose a steep learning curve for parents who need to learn the key information to care for their child at home. In this study, we conducted an environmental scan to identify and assess web-based knowledge translation tools about childhood heart failure for parent audiences developed within North America.

**Objective:** The aim of this study is to inventory tools publicly available to parents about childhood heart failure from popular web-based venues, assess how each tool communicates health information, and explore how they were developed.

**Methods:** Our search strategy included two commonly used multimedia-based platforms: two app stores (Google Play and Apple App Store) and one search engine (Advanced Google Search). Common search terms were used, and results were uploaded to Microsoft Excel for screening between 2 reviewers. The inclusion criteria for the tools were as follows: content focused on educating parents about their child's heart failure, developed in the English language, and originating within Canada and the United States. A total of 2 reviewers screened the app store and internet search results for relevant tools. Each tool was assessed using the Suitability Assessment of Materials (SAM), a validated tool that objectively assesses the suitability of how health information is communicated to a particular audience. Key informants who were involved in tool development were identified and invited for a qualitative interview using a semistructured format to provide data about the development process. Key themes were identified in the semistructured interview process.

**Results:** Frequencies and SAM percent ratings of eligible tools were reported. No apps exist for parents relating to pediatric heart failure. Overall, 17 relevant internet tools were identified, and their suitability was assessed for the parent audience. Most tools scored well in layout and type, but they scored lower in readability and graphics. Qualitative interviews with key informants revealed three key themes: timely and introductory knowledge, credible and trustworthy knowledge, and challenges and evolution in knowledge.

**Conclusions:** This is the first environmental scan looking for parent tools relating to childhood heart failure in Canada and the United States. Findings from this study reveal that there are no apps on this topic and there is a small number of tools for parents on the internet (n=17). Using the SAM, no tools scored in the superior range, and further work in knowledge translation strategies

needs to be done in this area to improve more effective education to parents and caregivers who have a child with heart failure. These findings will inform the development of a new resource on children's heart failure that targets parents and caregiver audiences.

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## KEYWORDS

environmental scan; pediatrics heart failure; parent audience; knowledge translation; web-based educational tools

## Introduction

### Background

Parents who have a child with heart failure need understandable and reliable knowledge. Approximately 11,000 to 14,000 annual pediatric hospitalizations in the United States are due to children's heart failure, with 87% of all initial cases diagnosed after an exacerbation in heart failure symptoms requiring invasive, life-saving medical intervention [1]. Heart failure in children can invoke uncertainty, heighten stress levels, and impose a steep learning curve on parents.

Since the release of North American evidence-based guidelines [2,3], more children with heart failure have been surviving, and parents have been caring for them in the outpatient setting. Parents are in the unique position of being termed *proxy health information seekers*, as they require advanced and ongoing information to provide day-to-day management for their ill child [4,5]. Aside from their health care team, a source where parents rely heavily upon for health information to make daily decisions about their child's care is the internet [5]. Parents who have children with chronic health conditions have identified they require adequate and appropriate information to care for their child [6]. However, despite the call for this necessary information among parents, the literature still suggests that they feel generally unsupported in their quest for health information [7]. Undoubtedly, this need exists for parents of children with heart failure given the scarce amount of literature on this topic.

Multimedia-based educational tools (eg, e-books, apps, videos, and whiteboard animations) posted on the internet are novel strategies that can fill this knowledge gap by providing easy to access educational content to parents and caregivers who need it [8]. These tools have the ability to creatively accentuate evidence-based health information, resulting in better uptake by parent audiences [9]. They positively influence learning styles by providing complex information that is palatable, relevant, and understandable [10]. Knowledge translation tools have been created for parent audiences in other contexts and have been shown to provide understandable, accessible, and evidence-based knowledge that helps improve care [11]. Multimedia-based knowledge translation tools have not been widely explored in the context of childhood heart failure. To date, there is currently no understanding of what web-based knowledge translation tools exist for parent audiences about pediatric heart failure and how they are rated in terms of how they communicate medical information to parent audiences.

### Objectives

Our research seeks to better understand what tools are currently available for parents who have a child with heart failure and to

assess each tool's ability to enhance their knowledge. Therefore, the aim of our study is to understand what publicly available educational tools are available to parents of children with heart failure on the web and app stores.

## Methods

### Overview

The environmental scan (ES) methodology is used to scan the *scan the environment* in an organized manner for gray information pertaining to a specific topic or context [12]. Our ES was conducted in 4 stages searching Canadian and US-based educational tools for children's heart failure that targeted parental audiences in June 2020.

A multimedia tool was included if it (1) was developed in either Canada or the United States, (2) focused solely on children's heart failure content, (3) was developed in English language, and (4) targeted a parent or caregiver audience. Tools were only included if they were from Canada and the United States to preserve the feasibility of the study. Duplicate tools were excluded. Given the anticipated limitation in tools, a date range was not applied to the internet search to maximize our findings.

Data collection occurred in four separate phases: (1) app search, (2) internet search, (3) Suitability Assessment of Materials (SAM) evaluation, and (4) key informant interviews. Key informant interviewers serve to augment the findings of the search as they will provide richer detail about each resource's development process. [Multimedia Appendix 1](#) outlines the screening process of the app and internet search.

### Ethics Approval

As our study included a qualitative interview component with key informants, ethical approval was obtained from the University of Alberta Research Ethics Office (Pro00106559).

### Phase 1: App Search

Two app stores (Apple App Store and Google Play) were searched using the broad layman search term *heart failure* by the primary researcher (CC). Using the same term, a second researcher (JB) used a web scraping search strategy to ensure comprehensiveness. Web scraping is the systematic process of using a web *bot* (or software agent) to produce more comprehensive search results [13]. Searches were limited in the advanced search function to either Canada or the United States, totaling 2 searches. Modeled after previous ES methods [14], only the first 50 apps from the Canadian and US search in each app store were archived for review. The primary reviewer (CC) compiled all the internet and app results into Microsoft Excel spreadsheets for screening. Screening for eligibility was

completed by the primary reviewer, and all data were verified independently by a second reviewer (HS) to ensure accuracy.

### Phase 2: Internet Search

The primary reviewer (CC) performed the search using three broad laymen's search terms in the *all these words* function of Google Advanced Search: (1) *child heart failure*, (2) *pediatric heart failure*, and (3) *child heart failure guidelines*. The primary reviewer ran each term separately for each country (eg, Canada or the United States), resulting in 6 separate searches. Other strategies to increase search results included disabling cookies and turning off personalization to help reduce search bias. Again, no date restriction was placed to maximize our search results. To keep the search feasible, the search was limited to English language tools and within Canada and the United States. Another reason to limit the search to any North American tools was to tailor our findings to apply to an educational tool we are developing about children's heart failure that will be used in this area.

Similar to other ES methods [12], the first 100 webpage results from each search string were archived using screenshots and uploaded into a Microsoft Excel spreadsheet for screening by two reviewers (CC and HS). Adapted from methods used for data extraction and screening in systematic review processes to avoid data extraction errors [15], CC completed the initial screen and data extraction, and HS verified all data line by line. All discrepancies in data extraction and relevancy were flagged and discussed between the 2 reviewers, with no disagreements needing to be brought forth to the senior author (SDS). To increase the quality and accuracy in data collection, CC (an experienced pediatric heart failure clinician) educated the second reviewer about children's heart failure [15]. All included internet educational tools were downloaded and examined in detail.

To prevent missing any relevant educational tools in the search process, the primary reviewer also consulted with a subject expert (JC) in the field of pediatric heart failure (eg, pediatric cardiologist) to review the list of screened websites, identifying any further relevant tools that may exist but were missed. An additional tool was identified by our subject expert (April 2020). This tool was posted to the web after the date of our initial search, and it was added to our relevant list of tools for health literacy appraisal.

Descriptive statistics and frequencies in Microsoft Excel were used to analyze the characteristics of both app and internet resources. A list of any relevant web-based tools in either the app or internet search was reported for the apps and web-based tools.

### Phase 3: SAM

All relevant internet and app resources that met the inclusion criteria were downloaded in full and scored independently by two reviewers (CC and HS) using the SAM scoresheet. The SAM assessment is a validated tool, developed by experts in health education for adults, that assesses the readability, usability, and suitability of health information [16]. SAM evaluation can pinpoint specific strengths or deficiencies in educational materials or compare different education materials for specific patient populations and suggest areas of

improvement or refinement [16]. This method of scoring has not been applied in the pediatric heart failure context but in other pediatric contexts [17,18]. The original SAM scoring tool was developed by Doak et al [16] and was subsequently adapted with permission by Smith [19]. The version developed by Doak et al [16] includes 6 domains with 22 subfactors. The updated version by Smith [19] includes the 6 domains but with only 21 subfactors, omitting the scope evaluation within the content section. The modified version by Smith [19] was used, as the scope of this assessment was already tailored to include only tools about children's heart failure that specifically educated the parental audience.

A rating score was obtained from each assessment (not suitable=0, adequate=1, and superior=2). Scores were then transformed into percentages (percent ratings; eg, 0%-39%=not suitable material, 40%-69%=adequate material, and 70%-100%=superior material). A rating of not suitable would indicate that a web-based resource requires some refinement to make it more suitable for the intended audience, whereas a superior rating would indicate that no further refinements are needed and a high level of health literacy [16]. Resources were not excluded from inclusion based on their SAM score, but rather the assessment was completed to provide a sense of the overall scope and quality of educational content that is available to parents who care for a child with heart failure. To ensure minimal bias in the review process [20], CC and HS both independently SAM rated each relevant educational tool, and then scores were disclosed and discussed. Any highly discrepant scores (>10 points difference) were discussed in detail among reviewers to understand the large variability in scores (eg, errors in scoring). Given the subjective nature of this scoring tool, an average overall rating between both reviewers for each domain was generated, giving an average SAM score for each resource.

### Phase 4: Key Informant Qualitative Interviews

Key informant interviews were conducted to complement the SAM ratings and add depth about the characteristics, distribution, and development process of each tool. Interviews with key interviewees were conducted by CC who contacted organizations from the information provided on the webpage. To maximize the number of informant responses, 3 attempts were made to contact each key informant (n=17) either by phone or by the email provided on the tool's webpage. This approach was modeled after the method developed by Dillman [21] for achieving responsiveness in the context of surveys. All interviews were conducted and recorded using the Zoom video conference platform [22]. All interviews were live coded to allow for context and meaning to be present in the results [23]. All participants provided written consent before the interview.

Data collection and analysis occurred iteratively, allowing for a more precise and purposeful process. The number of interviews achieved was not decided based on data saturation but on the positive responses accepting the invitation to participate in a qualitative interview by key informants who played an integral role in tool development.

Thematic analysis was used to synthesize and identify common themes among key informants described in the semistructured interviews. Thematic analysis was modeled after the study by

Braun and Clarke [24]. Outlined in their approach are four key stages: familiarization with the data, initial coding, searching for categories among the initial open codes, and constructing final major themes that best represented the data. A data-driven inductive approach was used to link the developed codes and themes to the data themselves [25]. The interviewer became immersed in the data through repeated listening of the recorded video interviews with live coding into summary tables. Codes remained genuine as they stayed as close to the participants' own words. Codes started more general and became more focused as they were grouped into categories and then major themes. All codes and videos were then re-examined to ensure consistency and accuracy of the interpretation.

## Results

### Overview

A detailed flowchart outlining the screening process is presented in [Multimedia Appendix 1](#). The screening and SAM ratings occurred over a 9-month period (July 2020 to March 2021).

### Phase 1: App Search

The app search was conducted in July 2020. In total, 112 apps were retrieved, 89 from the layman search strategy, and 24 additional from the scraper method. Unfortunately, no apps met the inclusion criteria, highlighting a knowledge gap in this platform for parents and caregivers about children's heart failure.

### Phase 2: Internet Search

The internet search was completed in August 2020. A combined total of 575 websites were retrieved across 6 search terms. Screening of the 455 websites occurred between two screeners (CC and HS). Details of the included web-based pediatric heart failure tools are shown in [Multimedia Appendix 2](#). A total of 16 relevant tools met the inclusion criteria, 13 from the United States and 3 from Canada. An additional relevant tool from the United States was identified following consultation with a subject expert (JC) in the field of children's heart failure. This tool was not missed in the original search; it was developed and posted on the internet after August 2020. The most relevant internet tools were in the form of webpages (n=13) and handouts (n=3). The content for the relevant tools focused on a varying range of information (eg, general information, symptoms, treatment strategies, and testing).

### Phase 3: SAM Evaluation Rating Scores

The average overall SAM factor rating between the 2 reviewers ranged from a low suitability score of 38% (16/42) to a high score of 62% (26/42; [Multimedia Appendix 3](#)). The total possible SAM suitability scores were out of 42 (100%). No tool scored 100% (26/26). Overall, 15 tools' ratings were in the adequate range (40%-69%), and 2 tools' ratings were in the not suitable range (0%-39%). No tools scored within the superior range (70%-100%).

Each tool was scored individually according to each of the 6 SAM factors in each domain (eg, content, literacy demand, graphics, layout and typography, learning stimulation and motivation, and cultural appropriateness). Raw scores for each factor of the 17 tools were combined on each SAM factor, and

a percentage score was calculated, demonstrating the overall current state of web-based tools included in this ES ([Multimedia Appendix 4](#)). Overall, most of the tools had a higher reading level than recommended, averaging over a ninth-grade reading level (13/17, 76%). Layout and type scores were all within the superior range—typography (17/17, 100%), layout (10.5/17, 62%), and subheadings (7/17, 41%). In contrast, all graphic scores were in the not suitable range—cover graphics (12.5/17, 74%), type of illustrations (10.5/17, 62%), relevance of graphics (10.5/17, 62%), graphic explanation (17/17, 100%), and graphic caption (16/17, 94%).

### Phase 4: Key Informant Interviews

#### Overview

Key informant interviews were conducted between April and June 2021. Of the 17 relevant webpage educational tools, only 16 (94%) had contact information available. In addition, 1 tool only included a *customer support* tab as opposed to a contact tab (eg, Contact Us or phone number). When the customer support tab was clicked on, the researcher was directed to a generic table of contents related to the website with no further contact information provided. After 3 attempts, 41% (7/17) of the organizations did not respond. In addition, 29% (5/17) of the organizations declined an interview with the rationale that their tool was developed by an outside vendor (n=4) or that the individual who made the tool was no longer employed at the organizations (n=1). Of the key informants who agreed to an interview, an average of 2 attempts were made before a response was received. Of the 17 key organizations, 4 (24%) agreed to participate in a qualitative interview. Moreover, 3 interviews had 1 participant, and the fourth interview had 3 participants. From all 4 interviews, interviewees were either medical professionals (n=4) or employed in leadership roles within the organization (n=2; eg, manager or director).

In total, 3 major themes arose from the semistructured qualitative interviews, which focused on the content, knowledge distribution and development process, and perceived impact. These three major themes are as follows: timely and introductory knowledge, credible and trustworthy knowledge, and challenges or evolution. Interviews were assigned a reference marker (eg, I2) for quotes present in support of the themes identified in our results.

#### Timely Introductory Knowledge

Participants in this study agreed that the knowledge included in their tools was very timely and focused more on the introductory phase, meaning that this tool was typically used shortly after the child was diagnosed with heart failure. However, participants did express that this tool could be provided to parents at times when they needed a review of the information. A participant explicitly stated, "the tool is mostly intended to be given at diagnosis but can be distributed for a refresher if needed" [I4].

Another participant highlighted that they also revise or add content to their tool based on trends from social media posts or parent inquiries to their foundation, highlighting that their tool was timely by addressing current parent questions, "Content in the tool is based on social media posts" [I1].



To also ensure that parents were not overloaded with too much information at the time of diagnosis, other key informants strategically placed knowledge in small chunks to avoid overwhelming parents. This was highlighted with the quote: “From our parent meetings, parents prefer knowledge in bite-size pieces” [I4]. This was a strategy that allowed parents to build on their knowledge rather than try to learn it all at once, demonstrating that key informants were aware of the huge learning curve that happens with parents who are in this situation.

### ***Credible and Trustworthy Knowledge***

All the participants in the interviews described the information presented in their tools as evidence-based. A participant shared that “guidelines are biggest go-to for information” [I2], meaning that they drew most of their information from published peer-reviewed material, along with some anecdotal knowledge from years of clinical experience. A second participant also confirmed that their tool was also “most based off medical guidelines” [I2 and I4].

Participants indicated that their information was mostly distributed in the hospital setting despite being posted on the web. They indicated that their information could be handed out in the form of printouts or families can be shown how to access digital or multimedia tools that were posted on their hospital webpage or reputable organization by hospital staff on the parent’s mobile device. A participant stated:

*I share the website with the parent using their phone. They search on their phone, and I confirm it is the correct website. This is so they can find the information in the future.* [I4]

### ***Challenges and Evolution in Knowledge***

Despite the good intentions of health care professionals to share complex knowledge with parents in easier-to-understand formats, this piece is complex and presents challenges. Some of the challenges were issues related to the web-based sharing of information. A challenge that inherently comes with web-based knowledge sharing is optimizing search engines. A participant shared that their organization is working with the Google search engine as they acknowledged that their tool is not easily found on the first few pages of results, affecting the reach to their intended parent audience. They highlighted that they are “working with Google to improve their search optimization so parents can find their tools” [I4].

Another challenge faced by developers of the tools in our interviews is that the tools often do not include credible references, making it difficult for parents to discern whether the information is evidence-based. A participant acknowledged this, saying that “we do not include the references in our tools we distribute to families” [I3].

An additional challenge outlined in the interviews was related to having the tools available in only the English language when there are families where English is not their first language. This posed a challenge to the health care providers in the interviews because they felt that perhaps their tool was not as effective at translating that critical knowledge. At times, a participant stated

that they would have to spend more time with the parents to ensure they understood the material because they could not read or write in the English language. A participant expressed, “Our Center has a large population of individuals fluent in Spanish. There are times we have read the pamphlets to families because they could not read English themselves” [I4].

The last challenge that participants outlined was making the time for refinements or updates to their tools. A participant described, “Heart failure is a complex disease so we are always looking to refine our tools.” [I2]. All participants acknowledged that they do not have regular set time intervals for editing and updating their tools. They all typically completed this task when they “thought about it” or when clinical practice changes occurred (I1, I2, I3, and I4). Some of the participants work with others who could alert them when updates were needed (eg, nursing staff or family comments) or simply relied on memory to update the documents.

## ***Discussion***

### ***Principal Findings***

This is the first ES to conduct a search for internet sources for parent audiences relating to children’s heart failure within North America. First, our ES identified that no apps exist on this topic, highlighting a significant knowledge gap for parents who are trying to seek information from this digital platform. Furthermore, our research highlighted that 17 web-based tools about children’s heart failure exist tools and were assessed to be adequate using SAM percent ratings.

We have highlighted that a modest number of relevant educational tools exist from our internet search (n=17), with varying degrees of content and health literacy for parent audiences. Notably, 88% (15/17) of the tools found appeared to be developed by clinicians for parents, instead of having parents actively involved in the development process. There were 2 tools that involved parent recommendations and feedback from a parent advisory group but were not created using parent experience evidence. Given the complexity of health journeys for families who have a child with heart failure, there is a critical need and gap to develop a tool based on parents’ lived experience to help deliver tools that are relevant and applicable to parent needs.

Of the relevant internet-based parent tools, no tool scored in the superior range, highlighting that work in the area of health communication and literacy could be improved upon. Most tools scored lower in the summary and review subsection, literacy subsection, and overall graphics section. Improving on these key aspects will provide parents, especially parents with lower literacy skills, information that is easier to understand with improved repetition of key information. However, the field of pediatric cardiology poses its own unique challenge in that this field contains many words with >2 to 3 syllables (eg, echocardiogram or cardiomyopathy). This aspect undoubtedly played a factor that increased the reading level and reduced the score in many of the tools. One of the key informants in the qualitative interviews highlighted their process for dealing with complex medical language to ensure that language was



consistent, well defined in simpler terms, and providing information in *bite-size pieces* for parents and caregivers to enhance their uptake.

In the category of graphics, SAM scores identified that major refinements are needed in this area. An explanation for this lower score was that all relevant tools were website based and it was difficult to score these tools in relation to a *graphic cover* as suggested in the tools' instructions. The recommended illustrations that Doak et al [16] outlined in their tool stated that simple line drawings can promote *realism* without distracting the details. As noted, this tool was developed in 1996 and intended mostly for print materials, so reviewers acknowledge that technology has advanced to include more digitalized, web-based infographics that can be just as impactful as line drawings. Infographics in today's educational materials involve simpler computer infographics with more vivid, crisp colors that attracts the reader's attention. Perhaps, updating of the assessment tool to include those aspects would have scored a few of the tools in the superior range, as reviewers found some of the graphics to be well done.

It is imperative that we improve knowledge translation strategies to improve the health literacy of parents and caregivers who care for children with heart failure in the home environment. Knowledge translation strategies that include parents as cocreators bring their unique perspective or lived experience that will improve uptake and understanding, as families in similar contexts will likely share similar knowledge needs [26]. When parents have a lack of understanding toward treatments or health conditions, worse outcomes occur in children's health [27]. One way to mitigate these poor outcomes is to have robust health information available on the internet, and in alternative formats, that is based on research knowledge and parental lived experience. This is done through the avenues of improving parental and caregiver knowledge bases to make better decisions, reducing parental stress levels and invoking improved conversations with their child's health provider through questions [28,29]. In addition, when clinicians are armed with credible and effective sources of information that can be easily shared with their parent audience, better relationships will result as parents will have more confidence in their health care provider.

As all tools did not include evidence-based references to indicate that they were developed from peer-reviewed research, the average parent would have difficulty discerning if the material from any of the tools were credible or even evidence-based. Recent published literature has demonstrated that a large portion of parents who searched the internet had difficulty discerning if the literature they found was from a credible source; furthermore, they were not confident in bringing it to a trusted health care professional [29]. Even more troubling is the fact that parents will make health decisions based on the information they find on the internet [28], which may or may not be based on the most credible sources. Despite clinicians' good intentions of simplifying information to parents by not citing the source of their information, diligently citing evidence where they derived the material may relieve the stress of parents trying to discern whether the tool is evidence-based material.

## Limitations

As this search was conducted in July 2020, it is possible that more tools are now available to parents and caregivers or that the current tools scored in our search have now been updated to reflect different or enhanced content. As we know, the internet and app stores are rapidly adding more content or updating existing materials daily. Our search was only a snapshot in time and would be difficult to replicate the same results.

A limitation of our search was the use of only a single search engine (Google) to provide results, which may have exposed our results to an element of search bias. Published literature on search engines, such as Google, has suggested that theories relating to filter bubbles or personalized algorithms can change results based on who searches for health information [30-32]. Although we took steps to reduce this bias, by deleting cookies and turning off personalization, this is not a perfect process. Another solution would be to use engines, in addition to Google, in the web-based search process to provide more robust results.

Although the scoring of health information was performed using a validated SAM instrument, limitations still remain. We noticed that updates to the tool may be required in some sections that scored lower (eg, type of illustration) as the tool gave a higher score for simple adult-appropriate line drawings that are not congruent with today's color infographics that can be generated from graphic artists. Current graphics are now designed as colorful infographics and characters, rather than simple line drawings or sketches, which the authors thought to be distracting. Scoring methods indicate that line drawings provide the least amount of distraction [16]. There would have been an improvement in scores if the tool had been updated to include simple computer infographics that are now commonly designed in current educational materials.

In addition, the 2 reviewers found the culture section in the instrument very difficult to score. This was evidenced by the similarity and lack of variability of scores. Culture within the context of children's heart failure was very difficult to define within the context of pediatric heart failure solely based on a web-based tool or handout. Perhaps more detailed instructions and a definition for culture could be provided, making it more user-friendly. We did find that most graphics included varying types of races and genders among the photos of parents and children. Perhaps if there were tools included in video format, culture scores would vary more as there would be an increased presence of tone and gender role presentations.

## Conclusions

This ES sought to explore what multimedia educational information or tools existed on the internet and within app stores for parent audiences about children's heart failure. From our search, we found 17 parent tools and no apps relating to children's heart failure that were developed in Canada and the United States. This highlights a gap in knowledge for parents who prefer this type of web-based content for learning about this important topic. Using SAM scoring, most web-based tools scored overall in the adequate range, meaning that they were adequate to teach parents, but there are some key improvements, especially in reading level and graphics, that can be made to

maximize their educational effectiveness. The qualitative interviews with key informants who developed the tools highlight three key themes: timely introductory knowledge, credible and trustworthy knowledge, and challenges and points

in how organizations plan to evolve this knowledge in the future. Further research is required to evaluate the effectiveness of such parent-targeted tools and their impact on parents' ability to learn and care for these children more confidently in the home setting.

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## Authors' Contributions

CC and SDS led the design of the study, and CC was the primary reviewer and drafted the manuscript. SDS contributed to the design of the study with her vast experience in this area and provided revisions on the draft manuscript. HS was the secondary reviewer and evaluator of the relevant app and internet resources. JB, who has expertise in internet searches, completed the web scraper app search. JC was the substantive expert who reviewed the search results, made suggestions for an additional resource, and provided feedback for the manuscript.

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## Conflicts of Interest

None declared.

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### Multimedia Appendix 1

Screening of apps and web-based tools.

[\[DOCX File , 40 KB - \*pediatrics\\_v5i1e34166\\_app1.docx\* \]](#)

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### Multimedia Appendix 2

List of included web-based pediatric heart failure tools (n=17).

[\[DOCX File , 16 KB - \*pediatrics\\_v5i1e34166\\_app2.docx\* \]](#)

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### Multimedia Appendix 3

Average overall Suitability Assessment of Materials percent rating for individual web-based tools.

[\[DOCX File , 14 KB - \*pediatrics\\_v5i1e34166\\_app3.docx\* \]](#)

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### Multimedia Appendix 4

Combined average Suitability Assessment of Materials percent rating score for all web-based tools (n=17) categorized by domain.

[\[DOCX File , 15 KB - \*pediatrics\\_v5i1e34166\\_app4.docx\* \]](#)

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## Abbreviations

**ES:** environmental scan

**SAM:** Suitability Assessment of Materials

**WCHRI:** Women's and Children's Health Research Institute

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Original Paper

# Considerations for a Social Media Physical Activity Program: Exploratory Study

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## Abstract

**Background:** Social media may be a powerful platform to combat parents' and children's low physical activity levels.

**Objective:** This study surveyed parents' beliefs about physical activity in order to expand the extant literature concerning the interest in and the design of an effective and feasible social media physical activity (SMPA) program.

**Methods:** Primary caregivers (n=250; 215 [86%] mothers, 164 [65.6%] White) of children aged 6-12 years completed an online questionnaire. Interest was examined through responses on the questionnaire; beliefs (ie, perceptions, knowledge, and support) about physical activity were examined using Spearman correlations; and to support the SMPA program design, researchers examined a combination of multiple-choice and free-response questions. For the free-response questions, the researchers performed open coding related to perceived benefits, barriers, and motivators.

**Results:** Parent respondents (n=215, 86%) were interested in a SMPA program tailored for families. Regarding beliefs, parents exhibited a monotonic relationship between 2 questions related to perceptions of physical activity levels in their children ( $r_{s(250)}=.310, P<.001$ ), knowledge about physical activity and motor skills ( $r_{s(250)}=.328, P<.001$ ), and support of physical activity and motor skills ( $r_{s(250)}=.385, P<.001$ ). Parents perceived benefits of a SMPA program, highlighting family time and health. Barriers included time constraints, a lack of motivation, and environmental factors.

**Conclusions:** Parents are interested in supporting healthy family behaviors using a SMPA program. An effective program should emphasize motor skill activities, be fun and family oriented, and incorporate incentives, goal setting, and advice and tips. SMPA also needs to address identified barriers, such as those regarding time and environment.

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**KEYWORDS**

physical activity; motor skills; programs and interventions; social media

## Introduction

Physical activity is defined as any bodily movement produced by skeletal muscles that results in energy expenditure above the resting metabolic rate [1], often categorized into light (minimal energy expenditure), moderate (requires some effort), and vigorous (activities that lead to harder breathing, puffing, and panting). Currently, physical activity levels are extremely low for children [2] and adults [3] in the United States. Only 42% of children aged 6-11 years achieve the recommended goal of

60 minutes per day of moderate-to-vigorous physical activity (MVPA) each day [2]. In comparison, merely 11% of adults achieve the recommended goal of 150 minutes of MVPA or 75 minutes of vigorous physical activity (VPA) per week [3]. Even further reductions in physical activity levels have been observed in both adults [4] and children [5] during the COVID-19 pandemic, which has limited physical activity opportunities (eg, sports and physical education). Such data are concerning in the light of evidence supporting that low physical activity levels adversely affect physical and mental health [6]. Thus, increasing



the avenues for physical activity is a pertinent concern in our evolving society. This need is also supported by Chen et al [7], who highlighted the need for physical activity during the COVID-19 pandemic, with access to programming that is simple and can be completed in the home.

It is imperative to incorporate families in the design and implementation of health programs. Most aspects of health (eg, health socialization, disease prevention, and recuperative care) are centered and accomplished within families [8]. Additionally, children's lives are generally structured within a family, and children tend to emulate their parents' (or caregivers') habits, including physical activity behaviors [9]. Research indicates that physical activity programs that incorporate families, especially those tailored to the participating children, effectively increase physical activity in children [10,11] and adults [12]. Although families are an ideal setting for understanding and intervening on child physical activity, they are complex and multidimensional social groups in terms of their composition, structure, and functions. Defining "family" is challenging because families are diverse, and the term "family" holds different meanings and functions for every individual. In research that focuses on family-based interventions, family is often defined differently but incorporates at least 1 parent and 1 child [12]. It is important to note that as children transition into adulthood, the influence of parents on children's physical activity decreases [13]. Therefore, family physical activity interventions are generally conducted in children versus adolescents [9,10]. Moreover, family involvement in children's physical activity programs is a critical determinant and best practice [14,15]. However, despite positive findings, the components of an effective physical activity program for families are not yet agreed upon due to heterogeneity among studies, such as the length of intervention and methodological quality [12].

The use of technology to promote physical activity has become increasingly popular. For example, virtual reality applications, such as Pokémon Go, have been shown to increase physical activity levels of its users by an average of nearly 1500 steps per day in 30 days [16]. More specifically, social media has grown as a flexible, popular platform consisting of social networks, supports, connections, or social interactions [17] among people [18]. The idea that social media is characterized by "user generated" content [17], a term that has existed for at least a decade [17], remains well accepted today [18]. Through social media, users can share information with others, provide social support, and access programs [19]. Although an increasing variety of applications can be considered social media, or used to access social media, only applications and platforms with the qualities mentioned earlier are considered social media for this paper's purposes. It should be noted that this excludes virtual reality and exergaming applications [20]. Under this definition, some of the most popular platforms are Facebook, YouTube, and Instagram [21]. In the past 15 years, adult Americans' social media usage increased from 5% usage in 2005 to approximately 72% in February 2019 [21]. Researchers have begun leveraging these cost-effective cyber environments to promote health behaviors and aid in behavior change [19]. However, social media has not been highly utilized to target low levels of

physical activity [19,22,23]. More insight related to social media usage and perceptions of target audiences is needed to inform the development of a program delivered to families via social media platforms that are designed to increase physical activity in both parents and their children (ie, a social media physical activity [SMPA] program for families).

From a feasibility standpoint, it is also critical to measure parental interest in a SMPA program, understand what families believe will support their engagement in such a program, and incorporate these factors into program design. However, little research has used and assessed SMPA programs [22,23], with most queries focused on internet- and technology-based programs [12,24]. Robbins et al [22] evaluated the feasibility, acceptability, and preliminary efficacy of a 12-week social media intervention on adolescents' (aged 10-13 years) BMI, physical activity, and diet quality [22]. The intervention included an after-school club for adolescents, parent-adolescent meetings, and a parent Facebook group. This study found that adolescents had significantly greater autonomous motivation for physical activity after completing the intervention. Additionally, Wojcicki et al [23] investigated the feasibility of an 8-week Facebook physical activity intervention for teenagers (aged 13-15 years) exhibiting low levels of physical activity. The intervention consisted of access to a private Facebook group with 2 daily wall posts containing youth-based physical activity information and resources [23]. There were no changes in objective physical activity (ie, measured by an accelerometer); however, adolescents reported increases in subjective physical activity (ie, self-reported) [23]. In both these studies, Facebook was a feasible delivery mode and was supported by both parents and children.

Physical activity programs for families have been delivered online or through eHealth applications. However, it is essential to note that these programs do not incorporate social media elements, such as user-generated information, social support, or participant interaction [12,24]. In a systematic review of physical activity programs for families, 6 (13%) of the 47 studies were delivered online and 1 (2%) communicated with participants through email [12]. Notably, 4 (67%) of the 6 studies cited positive effects and 5 (83%) of the 6 studies were favored by participants [12]. Another systematic review specifically examined eHealth programs for families, and 6 (86%) of the 7 studies included had additional components besides online delivery (eg, face-to-face and telephonic components) [24]. Interestingly, the 1 (14%) study that was conducted entirely online was the only one that found significant BMI changes [24]. Even though only 1 (14%) study found significant effects, overall study participants favored the internet as a medium for health programs [24]. These findings demonstrate that online programs tailored for families are feasible and highly favored, but social media has not been a widely utilized platform.

Given that SMPA programs have not been broadly implemented for families, it is vital to understand parental interest and program design considerations to support buy-in for a SMPA program. In addition to understanding parents' interest in a SMPA program, it is also critical to understand their viewpoints on such programs' targeted behaviors that are critical to

children's healthy growth and development, specifically physical activity and secondarily gross motor skills. Motor skills are defined as the "building blocks" of more advanced, complex movements required to participate in sports, games, or other physical activities [25]. Motor skills are included as a secondary targeted behavior of a physical activity program because of their essential role in supporting movement and their associations with positive trajectories of health [26]. Motor skills are defined as movement behaviors required to participate in sports, games, and other context-specific physical activities [26]. The literature supports that proficiency in a wide range of motor skills, often called motor competence, is needed to support lifelong movement and physical activity [26]. Motor skills are positively associated with physical activity, health-related fitness, perceived motor competence, weight status, and academic performance in children [26].

The research on parents' beliefs of their children's physical activity and motor skills is sparse [27], and the limited findings in this area are mixed [28-35]. Evidence supports that those parents who are knowledgeable about physical activity and motor skills are more likely to support these behaviors in their children [28,29] and that their children are more likely to have greater motor abilities [30]. However, research has found that parents hold inaccurate perceptions about physical activity and motor skills, as they tend to overestimate their children's physical activity [31-33] and motor abilities [34,35]. More research is needed to measure parents' beliefs of their child's engagement in motor skills and physical activity in order to determine the extent to which families believe that participating in a physical activity program is essential and would be beneficial.

This study aims to (1) gauge interest in a SMPA program delivered to families, (2) examine parental beliefs about physical activity (as a proxy measure for buy-in to a SMPA program), and (3) gather information to inform the design of SMPA programs to best suit the needs of their participants, thereby maximizing efficacy and feasibility. These aims were addressed by a questionnaire designed to elucidate the relationship between parental beliefs about physical activity and motor skills in their children and gain insight into the benefits parents perceived could be gleaned from program participation and the motivators/barriers parents perceived to program engagement.

## Methods

### Study Approval

The institutional review board (health sciences and behavioral sciences) at the University of Michigan reviewed this study and approved it with exemption (HUM00161089). The study was conducted entirely online, and no identifying data were collected.

### Measures

Experts in the fields of kinesiology and public health developed an online questionnaire to assess parent beliefs. The group of 3 experts included a professor of kinesiology with over 15 years of experience working in the field of motor development who conducts motor skill interventions in children, a professor of

health behavior research who has more than 10 years of experience in scientific and clinical aspects of behavioral medicine and public health, and a PhD candidate who holds a Certified Health Education Specialist (CHES) certification and a master's degree in health behavior and health education with over 6 years of experience working with children. The questionnaire was developed through extensive literature review and screening, piloting to families, and reworking. The questionnaire consisted of 42 questions (ie, 39 multiple-choice and 3 free-response questions) divided into 3 sections: demographics, beliefs about physical activity and motor skills, and social media use and interest in a SMPA program. The questionnaire was distributed through an online platform Qualtrics (Provo, UT, USA) and took approximately 23 minutes to complete. It should be noted that the survey inquired about parents' interest in a SMPA program for families, but there was no clear definition for what this social media program would look like nor was a definition of "family" provided. We sought to receive input about program design from their perspective and allow parents to offer opinions and ideas unrestrictedly.

### Participants

Participants were a convenience sample who self-selected to participate in this study. Participants were recruited in the summer of 2019 through flyers placed around the community, a posting on the university research registry, and emails sent to a listserv for a local summer camp program. The questionnaire was available from June to August 2019. Inclusion criteria were being the parent or primary guardian of a child aged 6-12 years and residing in Michigan.

### Data Analyses

Quantitative data were analyzed using IBM SPSS Statistics (version 26), with  $\alpha$  levels set to .05 a priori. Qualitative data were analyzed using qualitative analysis software NVivo 12 (QSR International, Doncaster, Australia). Data analysis was conducted using the grounded theory methodology outlined by Charmaz [36], utilizing line-by-line coding and constant comparative methods. This process involves taking an inductive approach to understanding and learning from the data. Coding was conducted by the first and third authors (KS and SR). The authors first engaged in line-by-line coding of all the responses, developed focused codes, and then derived themes about each of the 3 questions' responses, comparing across all responses. The 2 authors had 91% agreement in coding across the 3 qualitative questions analyzed (ie, question about benefits, 92%; question about barriers, 91%; and question about motivation, 90%). Discrepancies were discussed and resolved among the 2 authors.

### Interest

Interest was examined using percentages of responses to the 2 multiple-choice questions, *Are you interested in participating in a family-based physical activity program through social media?*, with the choices being *not interested*, *somewhat interested*, and *very interested*, and *What do you usually do on the internet? Check all that apply. (Email, browse on the web, social media, text messaging, other).*

### **Beliefs About Physical Activity and Motor Skills**

Spearman correlations were used to examine beliefs about physical activity and motor skills or specifically the associations between multiple-choice questions asking about parents' perceptions, knowledge, and support of physical activity and motor skills: values of  $\geq .80$  were considered very strong; .60-.79, strong; .40-.59, moderate; .20-.39, weak; and 0-.19, very weak [37]. For parental perceptions, the association between the 2 questions *How physically active would you say your child is?*, measured on a 5-point Likert scale (eg, very inactive to very active), and *Do you think your child needs to be more physically active?*, measured with a dichotomous response (ie, yes or no), was examined. To compare these questions, responses to the former question was dichotomized into 2 variables (ie, active and inactive), with the neutral statement being categorized as inactive. Follow-up sensitivity analyses were conducted to examine the effect on Spearman correlation results if neutral answers were categorized as active instead of inactive. For parental knowledge, the association between the 2 questions *Do you think your child needs to be more physically active?* and *Do you think your child needs improvements in their motor skills?*, both measured dichotomously, was examined. Parental support of physical activity and motor skills was analyzed via the association between the 2 questions *How often do you give your child opportunities to engage in physical activity?* and *How often do you encourage your child to develop motor skills?* Possible answer choices to both questions were *every day, 2-3 times per week, once a week, a few times a month, once a month, and never*.

### **Program Design**

Program design was examined through 3 multiple-choice questions and coding of 3 free-response questions to help inform the program design for SMPA programs. The 3 multiple-choice

questions were *How often did you use social media platforms (Facebook, Twitter, Instagram, texting apps, and fitness apps) in the past month?*, with choices being *never, rarely, sometimes, very often, and always*; *What information or content would be most helpful for your family?*, with choices being *goal setting, family activities, advice and tips, educational videos, social support, and other*; and *How would you like to receive this information?*, with choices being *email, text messages, social media messaging, social media group, and other*. Participants were permitted to select multiple choices for the latter 2 questions. The 3 coded free-response questions were *What are some of the benefits you foresee for your family to be part of a social media-based physical activity and fundamental motor skill program?*, *What are some of the barriers you foresee for your family to be part of a social media-based physical activity and fundamental motor skill program?*, and *What would motivate you and your family to be involved in a social media-based physical activity and fundamental motor skill program?*.

## **Results**

### **Participant Details**

A total of 335 participants started the questionnaire. Of these, 65 (19.4%) were removed because they completed less than 34% of the questionnaire (ie, completed only the demographic section or less), 9 (2.7%) whose child was not within the age range were removed, and 11 (3.3%) who did not reside in Michigan were removed. There were a total of 250 primary caregivers (215 [86%] mothers, 105 [42%] aged 30-39 years; see Table 1) included in the data analyses. Children of parent respondents had a mean age of 8.7 years, and 139 (55%) were girls.

**Table 1.** Sociodemographic characteristics of participants (N=250).

Characteristics	n (%)
<b>Relationship to the child</b>	
Mother	215 (86.0)
Father	18 (7.2)
Grandparent	3 (1.2)
Legal guardian	6 (2.4)
Other	8 (3.3)
<b>Parents' age (years)</b>	
20-29	30 (12.0)
30-39	105 (42.0)
40-49	90 (36.0)
50-59	21 (8.4)
60-69	3 (1.2)
≥70	1 (0.4)
<b>Child's race/ethnicity</b>	
White	164 (65.6)
Hispanic or Latinx	13 (5.2)
Black or African American	26 (10.4)
Native American Indian	1 (0.4)
Asian	5 (2.4)
Other/biracial	40 (16)
<b>Parents' highest level of education</b>	
Less than high school degree	5 (2.0)
High school degree or equivalent	14 (5.6)
Some college but no degree	46 (18.4)
Associate degree	25 (10.0)
Bachelor's degree	69 (27.6)
Graduate degree	87 (34.8)
Other	4 (1.6)
<b>Total number of adults in the household</b>	
1	30 (12.1)
2	190 (76.3)
3	24 (9.6)
4	4 (1.6)
≥5	1 (0.4)
<b>Total household income (US \$)</b>	
≤24,999	34 (13.6)
25,000-49,999	42 (16.8)
50,000-99,999	74 (29.6)
100,000-149,999	49 (19.6)
≥150,000	50 (20.0)
<b>Total number of children in the household</b>	
1	48 (19.2)



Characteristics	n (%)
2	104 (41.6)
3	51 (20.4)
4	26 (10.4)
≥5	21 (8.4)

### Interest

Of the 250 parents who completed the survey, 214 (85.6%) were interested in a family-based SMPA program. Of these, 97 (45.2%) were somewhat interested and 86 (40.4%) were very interested, while 178 (83.2%) of parents reported that they usually engage in social media use.

### Beliefs About Physical Activity and Motor Skills

There was a weak but significant positive association between the 2 questions on parents' perceptions of their child's physical activity ( $r_{s(250)}=.310$ ,  $P<.001$ ). We found that 204 (81.6%) of the 250 parents responded that their child was active and 125 (50%) responded that their child needs to improve their physical activity levels. When neutral answers were categorized as active instead of inactive for the sensitivity analysis, there was a slight change in the Spearman correlation ( $r_{s(250)}=.136$ ,  $P<.03$ ). Although dichotomizing the neutral answers in the opposite direction did produce slightly different statistics, the primary findings remained the same. There was a weak but significant positive association between the questions regarding parents' knowledge of their child's physical activity and motor skills ( $r_{s(250)}=.328$ ,  $P<.001$ ). We found that 125 (50%) of the parents responded that their child does not need to be more physically active, and 131 (52.4%) of the parents responded that their child does not need to improve motor skills. Additionally, 220 (88%) of the parents acknowledged a difference between physical activity and motor competence, and 249 (99.6%) responded that motor competence supports healthy development. There was also a weak but significant positive association between the questions about parents' support of their child's physical activity and motor skill behaviors ( $r_{s(250)}=.385$ ,  $P<.001$ ). We found that 207 (82.8%) of the parents reported providing their child with physical activity opportunities every day, while only 136 (54.5%) of the parents reported providing their children with motor skill opportunities every day. In addition, 21 (8.4%) of the parents responded that they encourage motor skills a few times a month to never, while only 2 (0.8%) of the parents responded that they promote physical activity a few times a month to never.

### Program Design

#### Quantitative Feedback

In response to the questions about social media use, 212 (84.8%) of the 250 parents responded that within the past month, they use Facebook *sometimes*, *very often*, or *always*. Within the past month, 209 (83.6%) of the parents responded that they used

texting apps (eg, text messaging, iMessage, WeChat, and WhatsApp) *sometimes*, *very often*, or *always*. Parents also indicated that they used fitness apps, such as MyFitnessPal, Strava, RunKeeper, and Nike Training Club ( $n=112$ , 44.8%); Instagram ( $n=96$ , 38.4%); and Twitter ( $n=41$ , 16.4%) *sometimes*, *very often*, or *always*. In response to the questions regarding SMPA program content, parents responded that it would be helpful to provide materials and information regarding *goal setting* ( $n=154$ , 61.6%), *family activities* ( $n=191$ , 76.4%), *advice and tips* ( $n=133$ , 53.2%), *social support* ( $n=90$ , 36%), and *educational videos* ( $n=86$ , 34.4%). Regarding how often parents would like to receive physical activity and motor skills content, 137 (54.9%) of the parents preferred *email*, 85 (34%) preferred *social media groups*, 82 (32.8%) preferred *text messages*, and 45 (18%) preferred *social media messaging*.

#### Qualitative Feedback

Qualitative analysis of the 3 free-response questions yielded predominant themes about program design, including benefits, barriers, and motivators (see Table 2). Parents who responded to the question *Do you think your child needs to be more physically active?* with yes or no both contributed equally ( $n=123$  [49%] said yes) to the qualitative responses. For question 9, regarding benefits, 7 themes were derived from 212 responses: *family time*, *health improvement*, *accountability and motivation*, *fun and enjoyment*, *community relationships*, *modeling*, and *no benefit*. Within these responses, 128 (60.4%) were related to the theme of *family time*, 112 (52.8%) to *health improvement*, 37 (17.5%) to *accountability*, 28 (13.2%) to *fun and enjoyment*, 18 (8.5%) to *community relationships*, 17 (8%) to *modeling*, and 7 (3.3%) to *no benefit*. Question 10, concerning barriers, revealed 7 main themes from a total of 207 responses: *time*, *environment*, *motivation and interest*, *technology*, *health concern*, *money issues*, and *no barrier*. Within these responses, 137 (66.2%) encompassed the theme of *time*, 60 (28.9%) encompassed *motivation and interest*, 56 (27.1%) encompassed *environment*, 19 (9.2%) encompassed *technology*, 8 (3.9%) encompassed *health concern*, 7 (3.4%) encompassed *money issues*, and 12 (5.8%) encompassed *no barrier*. From Question 11, about motivators, 8 prominent themes arose from 195 total responses: *social support*, *health benefits*, *incentive*, *tracking and goal setting*, *cost*, *ease of use and access*, *fun and competition*, and *does not know*. Among these responses, 70 (35.9%) were related to *incentives*, 52 (26.7%) to *fun and competition*, 39 (20%) to *social support*, 26 (13.3%) to *ease of use and access*, 24 (12.3%) to *health benefits*, 20 (10.3%) to *tracking and goal setting*, 18 (9.2%) to *does not know*, and 7 (3.6%) to *cost*.



**Table 2.** Interest in a social media program.

Theme	Definition	Examples	Responses, n (%)
<b>Question 9. What are some of the benefits you foresee for your family to be part of a social media–based physical activity and fundamental motor skill program? (N=212)</b>			
Family time	Building better family relationships and spending more quality time together	<ul style="list-style-type: none"> <li>• <i>Spending time together would be number one. We love to connect as a family.</i></li> </ul>	128 (60.4)
Health improvement	An array of health benefits, such as increasing physical activity, overall health, endurance, and strength	<ul style="list-style-type: none"> <li>• <i>Getting healthy together.</i></li> <li>• <i>Better mental and physical health.</i></li> </ul>	112 (52.8)
Accountability and motivation	A way to be held to a certain standard or be motivated to participate in certain tasks	<ul style="list-style-type: none"> <li>• <i>Having something for the whole family keeps everyone accountable.</i></li> </ul>	37 (17.5)
Fun and enjoyment	A fun way to spend time with family members and bring happiness to those involved	<ul style="list-style-type: none"> <li>• <i>It seems like it would be more fun to do it together. We could motivate and encourage each other.</i></li> </ul>	28 (13.2)
Community relationships	Creating new relationships and friends with community members	<ul style="list-style-type: none"> <li>• <i>Connecting with other families, a sense of community.</i></li> <li>• <i>Creating new friendships.</i></li> </ul>	18 (8.5)
Modeling	Demonstrating the importance of physical activity	<ul style="list-style-type: none"> <li>• <i>Showing that being active is important for adults and kids.</i></li> <li>• <i>Being a role model.</i></li> </ul>	17 (8.0)
No benefit	Not foreseeing any benefit to the program	<ul style="list-style-type: none"> <li>• <i>I don't think we could benefit from social media activities.</i></li> </ul>	7 (3.3)
<b>Question 10. What are some of the barriers you foresee for your family to be part of a social media–based physical activity and fundamental motor skill program? (N=207)</b>			
Time	An inability to find time to participate in the program due to school/work schedules	<ul style="list-style-type: none"> <li>• <i>Finding the time and weather are our biggest barriers.</i></li> </ul>	137 (66.2)
Motivation and interest	A lack of motivation, interest, or energy due to busy lives	<ul style="list-style-type: none"> <li>• <i>My child not being interested, me losing motivation.</i></li> </ul>	60 (28.9)
Environment	Environmental factors that are a concern, such as location, weather, and access to safe areas	<ul style="list-style-type: none"> <li>• <i>We do not have sidewalks where we live.</i></li> </ul>	56 (27.1)
Technology	Issues with technology, privacy, or social media	<ul style="list-style-type: none"> <li>• <i>Invasion of privacy.</i></li> <li>• <i>Our kids are not on social media yet, due to age.</i></li> </ul>	19 (9.2)
Health concern	Underlying health conditions that could be a problem when participating	<ul style="list-style-type: none"> <li>• <i>My current fitness/health level not being optimal.</i></li> </ul>	8 (3.9)
Money issues	The price of the program as a financial barrier	<ul style="list-style-type: none"> <li>• <i>Extra costs will affect our ability to participate.</i></li> </ul>	7 (3.4)
No barrier	No barriers foreseen	<ul style="list-style-type: none"> <li>• <i>We are active already.</i></li> </ul>	12 (5.8)
<b>Question 11. What would motivate you and your family to be involved in a social media based–physical activity and fundamental motor skill program? (N=195)</b>			
Incentive	A tangible object/monetary reward as compensation for completing portions of the program	<ul style="list-style-type: none"> <li>• <i>Some sort of reward would be the highest motivator.</i></li> <li>• <i>Maybe earning rewards or “badges.”</i></li> </ul>	70 (35.9)
Fun and engaging	Incorporating aspects of fun and competition into the program to make it more enticing to participants	<ul style="list-style-type: none"> <li>• <i>If my child sees it as fun.</i></li> <li>• <i>It has to be engaging.</i></li> </ul>	52 (26.7)

Theme	Definition	Examples	Responses, n (%)
Social support	Increased support from a social circle that allows participants to connect in new ways	<ul style="list-style-type: none"> <li><i>I think if there were accountability partners, I would be motivated to participate. Friends have a way of keeping you honest.</i></li> </ul>	39 (20.0)
Ease of use and access	Allowing the program to be easy to use, accessible to all, and carefully planned out	<ul style="list-style-type: none"> <li><i>Knowing more about the program and being aware of what was going to be posted ahead of time.</i></li> </ul>	26 (13.3)
Health benefits	Health improvements from participation	<ul style="list-style-type: none"> <li><i>Seeing how it could keep my child healthy.</i></li> <li><i>Improving our health.</i></li> </ul>	24 (12.3)
Tracking and goal setting	Using various tracking and goal-setting mechanisms to actively see progress over time	<ul style="list-style-type: none"> <li><i>Goal setting with daily/weekly check ins.</i></li> <li><i>Keeping track of progress.</i></li> </ul>	20 (10.3)
Does not know	Uncertain or unsure of what would motivate the participants	<ul style="list-style-type: none"> <li><i>Not sure.</i></li> </ul>	18 (9.2)
Cost	Making the price of the program fair and flexible for participants	<ul style="list-style-type: none"> <li><i>The program is free and interesting to kids and adults.</i></li> </ul>	7 (3.6)

## Discussion

### Principal Findings

The purpose of this study was to gauge interest in a SMPA program for families, examine parental beliefs about physical activity and motor skills, and gather information to inform the design of a SMPA program. Through the use of an online questionnaire, it was found that a large majority of parents (214/250, 85.6%) are interested in a family-based SMPA program. Previous research supports our findings—that parents and children favor online physical activity programs, including SMPA programs for families [12,22-24].

This study found that parents hold accurate beliefs based on their perceptions, knowledge, and support of physical activity and motor skills. Parents had accurate perceptions that their child's physical activity and motor skills are associated, demonstrated knowledge that there is a difference between motor skills and physical activity, and supported physical activity and motor skills. Despite a large number of responses indicating that parents thought their child achieves the daily amount of physical activity recommended, it is important to note that approximately 125 (50%) of the parents believed that their child needed to increase their physical activity levels or motor skills. Responses indicated that at least half (n=125, 50%) of the parents had the motive to buy-in to a SMPA program. Based on research illustrating low levels of physical activity [2] and motor skills [38] in children, and that parents overestimate their children's physical activity levels [31-33] and motor skills [34,35], it is likely that some parents perceive their children as more active than they actually are or to have more advanced motor skills than they actually do. Thus, it can be reasonably assumed that the percentage of parents whose children need to increase their physical activity levels or motor skills to meet national recommendations [2] is more significant than this study found.

Based on the findings that more parents provide their children with daily physical activity opportunities compared to motor skill opportunities (n=207 [82.8%] vs n=136 [54.5%]), and that a larger percentage of parents indicated that their child needed to be more physically active relative to the percentage of parents who indicated that their child needed to improve their motor skills (n=125 [50%] vs n=119 [47.6%]), it appears that parents may regard physical activity as more important than motor skills. Interestingly, 220 (88%) of the 250 parents acknowledged a difference between physical activity and motor competence, and 249 (99.6%) correctly responded that motor skills support healthy development. These findings are supported by a recent study that examined the relationship between motor skills and the home environment, which found that parents recognize motor skills as critical underlying factors regarding physical activity [30]. These findings suggest that parents may intend to provide their children with the same quantity of motor skill development opportunities as physical activity opportunities. Still, they lack the knowledge regarding how to do so. Although research is limited on parents' knowledge of physical activity and motor skills [27], we know that knowledgeable parents are more likely to support physical activity and motor skills in their children [28,29] and parents of children who value motor skills have higher motor skill proficiency [30]. Such research emphasizes the importance of educating parents about motor skills and providing motor skill opportunities for their children.

Parents' responses to the various closed and open-ended questions provide key elements that should be incorporated into the program design of a SMPA program. First, given the importance of motor skills [26] and the finding that physical activity opportunities are more commonly provided than motor skill opportunities, a SMPA program must include components that will educate parents about motor skills and incorporate motor skill opportunities. Next, most parents responded that content focusing on family activities would be helpful and that family time would benefit from a SMPA program. About half

of the parents (133/250, 53%) responded that they are interested in *health* components as well. However, previous research supports that physical activity programs may be efficacious to emphasize components and content unrelated to weight loss or health improvement [12]. Thus, SMPA should predominately feature fun and family-oriented content. Lastly, parents indicated that they would like the content of a SMPA program to focus on goal setting and program advice and tips. Incorporating goal setting and program advice and recommendations has been shown to be successful in previous online interventions for children [24]. Thus, we recommend that a SMPA program include fun activities that promote the use of motor skills, involve multiple or all family members to encourage together-time, and deliver goal-setting prompts and tips to help families maximize participation in and benefit from the program.

Parents also highlighted barriers and motivators that should be incorporated into program design. The most prevalent barriers to program participation that parents identified were time, motivation and interest, and environmental factors. Parents noted being unable to find the time to complete the program, having a lack of motivation, and limitations due to environmental factors, such as cold winter weather and a lack of safe outdoor space. Thus, a SMPA program should feature physical activity and motor skill activities of various durations and include workouts that can be done both indoors and in a variety of outdoor environments, especially given that access to exercise facilities/opportunities has been shown to dictate the use of these environments for exercise and physical activity [39]. Environmental factors impacting Michiganders' participation in a SMPA program may differ from families in other regions. A program that is fun and engaging and promotes together-time, as suggested earlier, as well as one that considers various environmental and time constraints, is likely to consequently minimize the barrier of motivation and interest. With regard to motivators to program participation, incentives, fun and engaging, and social support were among the top 3 themes of free-response answers. Incorporating rewards into physical activity interventions for families has previously been found to significantly increase the pedometer step count in children compared to the control group [40]. It has been suggested as a means of augmenting motivation elsewhere [12].

Further, our study found that parents participating in the questionnaire were already active on varying social media platforms, with Facebook being the most often utilized. Our results align with Pew Research that social media is popular among adults and that Facebook is the most utilized platform [21]. However, Pew Research cited that Instagram and YouTube were the subsequent 2 most utilized platforms [21]. In this study, only 96 (38.5%) of the 250 parents reported using Instagram *sometimes*, *often*, and *always*. Although a specific option to choose YouTube was not included, participants were provided an opportunity to name any social media platform for the question *How would you like to receive this information?* [21]. However, no participants wrote YouTube. The finding that parents were highly active on social media supports the idea that Facebook is a promising and favorable mechanism to deliver a SMPA program, which has been previously established [19,22,23]. However, participants of this study demonstrated a

preference for email delivery of physical activity and motor skill programs when asked directly. This platform is easily accessible for parents, and children do not necessarily have to be on social media to participate in the program, as the mode of delivery would be via parents. Given that a wide variety of social media platforms have been found to be effective in eHealth interventions, such as text messaging, web-based chat groups, and mobile phone applications [24], any form of social media used in a SMPA program would likely be both accessible and successful in the dissemination of physical activity and motor skill program content. Finding the best social media platform for such a program should involve both parents and children, as they are the stakeholders [41].

Importantly, this study shows that there is both widespread interest in and potential program buy-in for the largely unstudied concept of a SMPA program for families, particularly among a Michigan sample of parents. We also interpreted various novel feedback and insight about a SMPA program specifically tailored to families into meaningful advice for researchers seeking to design such a program. In particular, we found that a SMPA program should include motor skill-focused educational content, activities that promote together-time, advice and tips, and prompts for regular goal setting, environmentally and time conscious workouts, and incentives. Ideal mediums for content delivery were found to be Facebook and email.

### Strengths

The strengths of this study include a large, diverse sample of 250 participants whose characteristics of ethnicity and income brackets aligned with US Census data [42] for Michigan. It is important to note that our sample does not align as well with national US Census data and the National Health and Nutrition and Examination Survey, as we had overrepresentation of Whites and a lower representation of Hispanic or Latinx and Asians [43,44]. Another strength is that independent coders were used to examine the free-response questions. This study aimed to understand the feasibility of a SMPA program designed based on families' needs.

### Limitations

This study was conducted using an online questionnaire through Qualtrics. There are advantages and disadvantages to using an online platform for data collection. A large, diverse sample of participants from across Michigan was able to be obtained. Since the data were collected via a convenience sample, it is important to acknowledge that it is possible that the questionnaire was completed by parents who have a high level of knowledge about and support of motor skills and physical activity regarding healthy development or whose children engage in above-average levels of physical activity or motor skills. We understand that the recruiting methods may have biased the type of parents who responded [39]. It is commonly known that participants of higher socioeconomic status and higher education levels may have more knowledge and opportunities.

Further, we acknowledge that gauging interest in a program that offers appealing health and activity benefits is likely to yield high interest rates, as seen in this study. However, given

that interest rates are also likely influenced by perceptions of exercise, which can often be negative [45], the authors feel the interest rates presented are not biased. Additionally, since all data were collected via a questionnaire, no comparisons to actual physical activity levels and motor skill abilities could be made. Caution must be taken in generalizing the results of this study, given that the sample was limited to Michigan residents and not fully representative of national demographics of parents of children aged 6-12 years. It is recommended that future research be conducted on a broader scale to expand the understanding of feasibility and interest in SMPA programs for families in populations this study did not adequately represent. A larger-scale study is critical important, given that the perceptions of and the ability to participate in physical activity can vary depending upon social determinants of health, as well as race and ethnicity [46,47]. Nevertheless, these findings will meaningfully assist in the development of a SMPA program.

## Conclusion

Social media has become a popular medium for communication and information dissemination over the past 15 years [21]. The current COVID-19 pandemic has particularly emphasized the importance of technology, including social media, to facilitate social connections and engagement in different health behaviors. The benefits of social media may be a powerful tool to support a physical activity program for families [19]. This study found a need for the development of a social media program to support families' physical activity. This study also found that an effective SMPA program should emphasize motor skill activities, be family oriented, and incorporate incentives, goal setting, and advice and tips. A SMPA program must be developed with identified barriers, such as the environment (eg, weather, space, and accessibility), time (eg, duration and ease of use), and type of program (eg, fun and engaging), in mind. Future research and program development should continue to centralize best practices and rigor while tailoring programs to the needs of those receiving them [9].

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## Conflicts of Interest

None declared.

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## Abbreviations

**MVPA:** moderate-to-vigorous physical activity

**SMPA:** social media physical activity

**VPA:** vigorous physical activity

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Original Paper

# Community Mental Health Clinicians' Perspectives on Telehealth During the COVID-19 Pandemic: Mixed Methods Study

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## Abstract

**Background:** In March 2020, a rapid shift to telehealth occurred in community mental health settings in response to the need for physical distancing to decrease transmission of the virus causing COVID-19. Whereas treatment delivered over telehealth was previously utilized sparingly in community settings, it quickly became the primary mode of treatment delivery for the vast majority of clinicians, many of whom had little time to prepare for this shift and limited to no experience using telehealth. Little is known about community mental health clinicians' experiences using telehealth. Although telehealth may make mental health treatment more accessible for some clients, it may create additional barriers for others given the high rates of poverty among individuals seeking treatment from community mental health centers.

**Objective:** We examined community mental health clinicians' perspectives on using telehealth to deliver trauma-focused cognitive behavioral therapy to youth. We sought to better understand the acceptability of using telehealth, as well as barriers and facilitators to usage.

**Methods:** We surveyed 45 clinicians across 15 community clinics in Philadelphia. Clinicians rated their satisfaction with telehealth using a quantitative scale and shared their perspectives on telehealth in response to open-ended questions. Therapists' responses were coded using an open-coding approach wherein coders generated domains, themes, and subthemes.

**Results:** Clinicians rated telehealth relatively positively on the quantitative survey, expressing overall satisfaction with their current use of telehealth during the pandemic, and endorsing telehealth as a helpful mode of connecting with clients. Responses to open-ended questions fell into five domains. Clinicians noted that (1) telehealth affects the content (ie, what is discussed) and process (ie, how it is discussed) of therapy; (2) telehealth alters engagement, retention, and attendance; (3) technology is a crucial component of utilizing telehealth; (4) training, resources, and support are needed to facilitate telehealth usage; and (5) the barriers, facilitators, and level of acceptability of telehealth differ across individual clinicians and clients.

**Conclusions:** First, telehealth is likely a better fit for some clients and clinicians than others, and attention should be given to better understanding who is most likely to succeed using this modality. Second, although telehealth increased convenience and accessibility of treatment, clinicians noted that across the board, it was difficult to engage clients (eg, young clients were easily distracted), and further work is needed to identify better telehealth engagement strategies. Third, for many clients, the telehealth

modality may actually create an additional barrier to care, as children from families living in poverty may not have the requisite devices or quality broadband connection to make telehealth workable. Better strategies to address disparities in access to and quality of digital technologies are needed to render telehealth an equitable option for all youth seeking mental health services.

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## KEYWORDS

telehealth; COVID-19; evidence-based practice; community mental health; trauma-focused cognitive behavioral therapy; implementation science; youth mental health

## Introduction

The public health response to the COVID-19 pandemic has resulted in a rapid transformation in mental health care delivery of psychosocial treatments. Within a matter of days in the spring of 2020, clinicians went from primarily treating clients in their offices to almost exclusively treating clients via telehealth (ie, telecommunications platforms through which mental health treatments can be delivered; also referred to as telemental therapy, virtual therapy, and teletherapy). Although real-time (ie, not prerecorded) clinician delivery of evidence-based practices (EBPs) using telehealth are effective for several mental health conditions for adults (eg, anxiety disorders, depression, obsessive-compulsive disorder [OCD], panic disorder, posttraumatic stress disorder [PTSD], psychotic disorders) and children (eg, depression, OCD, PTSD, tic disorders), this treatment modality was not widely adopted by US health systems prior to the pandemic [1-15].

In light of this rapid transformation, the American Psychological Association (APA) conducted surveys of its members to understand telehealth use prior to and after the pandemic, which captured this surge in use. Prior to 2020, only 1% of clinicians saw clients exclusively over telehealth and only 20% used telehealth with any of their clients [16,17]. Within 3 months of the start of the pandemic, 92% of clinicians were seeing clients over telehealth, and within 6 months, this proportion had risen to 96%. Even the Veteran's Health Administration system, which had a robust telehealth system prior to the pandemic, increased their telemedicine use by 12-fold [18], with over 1 million mental health telephone and video encounters with veterans occurring in a single month of the pandemic [19]. The unprecedented shift toward telehealth has been made possible in large part due to the temporary lifting of regulatory barriers such as billing, insurance coverage, insurance reimbursement, and licensure regulations that limit treatment of clients across state lines [20]. For example, in the United States, emergency mandates and policies allow for temporary reimbursement of remote mental health services and for practice across state lines (eg, a clinician licensed in Pennsylvania can see a client located in New Jersey). The uptake in the use of telehealth has been accompanied by expansions in telehealth infrastructure and advances in telehealth technology, which are ongoing [21]. Some have suggested that even when the pandemic is over and the state of emergency has passed, a full return to in-person services is unlikely [22].

Telehealth is often described as a tool to reduce barriers to care for clients who may otherwise have difficulty attending appointments. For some clients, however, telehealth and

technology-based services may actually exacerbate existing socioeconomic disparities, particularly within low-income populations such as those seeking treatment in community mental health (CMH) settings [23]. Digital disparities, including differential access to technological devices and quality internet, and disparities in technological literacy, may exacerbate inequities in access to mental health treatment. Although 75% of US adults have access to broadband internet in their homes, the 25% who lack access have disproportionately lower income and education, and are more likely to be racial minorities, older, rural residents, widowed, and living with disabilities [24]. Given the sociodemographic characteristics of clients who seek care in CMH settings, inequitable care is an urgent concern, particularly because reliable access to the internet has been characterized as a "super-determinant" of health [25]. A recent study found that within a sample of Medicare beneficiaries, around 40% lacked access to either a computer with high-speed internet or a smartphone with a data plan and 26% lacked access to both, and these patterns of inequity exist for children as well [26,27]. This level of access may be even lower among Medicaid beneficiaries.

These access issues are particularly important to address in the context of the COVID-19 pandemic, in response to which there is a rising need for mental health care. The rise in telehealth use during the pandemic is likely due not only to safety issues associated with in-person care (due to needs for physical distancing to decrease transmission of the virus) but also to the increased incidence of mental disorders such as anxiety and depression [28]. In addition to the increase in common mental disorders, the changes brought about by the pandemic (such as stay-at-home orders) have also been associated with an increase in traumatic incidents, many of which involve or are witnessed by youth [29]. Thus, there is a need for delivery of trauma-informed EBPs to youth, particularly in CMH settings, where baseline rates of trauma in youth seeking treatment are high. One EBP that has been widely rolled out in the United States, trauma-focused cognitive behavioral therapy (TF-CBT), is particularly relevant. TF-CBT is an evidence-based, short-term intervention for youth exposed to trauma that typically involves weekly 60-minute sessions delivered over the course of 12-25 sessions and involves participation of caregivers [30]. TF-CBT involves collaboration among the clinician, client, and caregiver to provide the client with psychoeducation and skills in a supportive environment through which the client can process traumatic memories. TF-CBT, the core components of which are often referred to with the acronym "PRACTICE," includes psychoeducation and parenting skills, relaxation techniques, and support in affective expression, among other skills. Central to the intervention is the use of exposure to upsetting memories

(via the trauma narrative) and exposure to trauma reminders (via in vivo exposure) to support clients in becoming less fearful. Studies suggest that TF-CBT can be effectively delivered via telehealth with children at school and at home [14]. However, certain adaptations to TF-CBT are needed, particularly to components that fall within the “adaptable periphery” of the intervention (ie, elements of an intervention or how it is delivered that can be altered while maintaining treatment fidelity) rather than the “core components” (ie, the crucial and unexchangeable elements of the intervention that underlie its effectiveness) [31-33]. Particular consideration must be given to the trauma narrative, a core exposure-based treatment element wherein the client creates and shares a narrative of the traumatic event that occurred. Although the trauma narrative can take multiple forms, clients typically choose to create a written narrative. In the context of telehealth, clients may dictate the trauma narrative while the clinician types it and shares their screen. Clinicians have documented their adaptations to exposure-based treatments using telehealth [34].

Even when adaptations are made to facilitate delivery of TF-CBT via telehealth, additional challenges remain [35,36]. For example, clients may have attention difficulties that impair their ability to engage in therapy, or may struggle to secure a safe and private place to engage in therapy at home or school. These challenges may impair their ability to speak freely and may necessitate shorter sessions. Additionally, children and the adults supervising them may not have the skills to easily navigate digital platforms. The virtual format also presents particular challenges to the delivery of the trauma narrative. For example, clinicians may find it challenging to read clients’ body language and affect or to identify their dissociation over the screen, making it difficult to assess clients’ level of distress and to modulate exposure potency accordingly. Clinicians may also find it challenging to help clients regulate their affect via the telehealth format.

Although previous studies have illuminated some of the challenges associated with delivery of TF-CBT via telehealth, these studies were carried out in an academic medical setting and within a context that provided clients with access to technological devices and internet connectivity. Studies on clinician satisfaction with and ratings of telehealth acceptability have largely been conducted in private systems, which may differ substantially from community clinics given the higher resources, lower caseloads, and less complex clients compared with those of public systems [37]. Thus, little is known about CMH clinicians’ perspectives on delivering EBPs through a virtual platform within the context of usual care.

In this study, we focused on clinician perspectives on telehealth delivery of TF-CBT with a CMH population within the first 6 months of the COVID-19 pandemic. Given the widespread implementation of TF-CBT nationally and the similarity in implementation barriers faced across EBPs and across CMH settings, we view this study as a potential exemplar for understanding how clinicians delivering EBPs in CMH settings more broadly experienced this shift to telehealth [38-40]. We also view this survey as an opportunity to identify and highlight considerations for future directions in improving and sustaining telehealth delivery within the CMH context.

## Methods

### Study Setting

This study was conducted in the Community Behavioral Health (CBH) network of public behavioral health clinics in Philadelphia. CBH is a not-for-profit contracting organization that serves as the exclusive payer for Medicaid-funded services in Philadelphia, and has supported the implementation of EBPs in CMH organizations since 2007. As a response to high rates of youth trauma exposure, the Philadelphia Department of Behavioral Health and Intellectual Disability Services (DBHIDS) developed a comprehensive trauma-informed public behavioral health system in 2011, and in 2012, DBHIDS was awarded a National Child Traumatic Stress Initiative Community Treatment and Service Center grant to form the Philadelphia Alliance for Child Trauma Services (PACTS). This initiative is centered around increasing the number of children in Philadelphia receiving evidence-based trauma treatment such as TF-CBT [41]. To date, PACTS has trained 11 cohorts of clinicians in TF-CBT across both outpatient and residential CMH agencies.

### Study Procedures

Study procedures were approved by the City of Philadelphia Department of Public Health and the University of Pennsylvania Institutional Review Boards. As part of a survey to broadly assess TF-CBT clinicians’ experiences during the first 6 months of the COVID-19 pandemic, all clinicians who had been trained through the PACTS initiative (N=198) and were currently treating at least one youth (aged 3-21 years) using TF-CBT within the CBH clinic network were invited by email to participate, and if they chose to participate were asked a number of questions about their perspectives on telehealth [42]. Recruitment was carried out using a modified tailored design, which involved incorporating stakeholders into survey recruitment and providing a strong rationale for the utility of the survey data for clinicians and clients [43]. Clinicians received an email 1 week before the survey was distributed and were sent reminder emails 1 and 3 weeks after distribution. The survey was hosted on Qualtrics, a secure online service platform, and included an electronic informed consent form that stated that the survey would take approximately 30-40 minutes to complete. The survey was tested for usability on both computer and cellular platforms prior to distributing it to clinicians. Items appeared in the same order for each participant and all participants received the same questions. Survey items were distributed across multiple screens to decrease the number of questions per page and increase usability. At any time prior to submitting their responses, respondents could return to any previous screen and adjust their responses. To maintain anonymity, neither cookies nor IP addresses were used to identify duplicate responders, although upon revision of the completed surveys, there was no indication of duplicate survey entries by a single user. Clinicians completed the survey in July and August of 2020 and received a US \$25 gift card for participating.



## Measures

### *Perspectives on Telehealth*

Clinicians' ratings of telehealth were measured using a survey instrument developed by Becevic et al [44] measuring clinician satisfaction with telehealth, and through several short-answer open-ended questions added by the authors. The Provider Survey was developed based on a literature review and the analysis of the role of the provider in telehealth delivery, which included 12 items: the first item asked clinicians whether or not they use telehealth, and the following 11 items asked about the extent to which they agreed with statements about telehealth on a 5-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). In responding to the survey questions, clinicians were instructed to consider any telehealth sessions they were conducting with clients via phone or video conference. In our sample, internal consistency of the scale was high ( $\alpha=.89$ ). Following the 12 items, we included 4 open-ended questions that assessed clinicians' perspectives on how telehealth compares to in-person therapy ("What differences have you noticed in how you deliver treatment via telehealth compared to in-person?"), barriers to delivering treatment via telehealth ("Please report your top two barriers to delivering treatment via telehealth [ie, things that make it hard to deliver treatment via telehealth]"), facilitators to delivering treatment via telehealth ("Please report your top two facilitators to delivering treatment via telehealth [ie, things that make delivering telehealth easier]"), and how they could be supported in utilizing telehealth ("How can the PACTS team support you in delivering treatment via telehealth?"). Response rates to the 4 open-ended questions were high (range 36-45 respondents per question; total of 164 responses across questions).

### *Demographics*

Clinicians completed a brief demographic questionnaire that included questions about age, gender, race, licensure status, years at current organization, and number of clients. This questionnaire also asked clinicians whether they were a salaried full-time worker or an independent contractor (ie, clinicians who contract with an organization but are paid per session rather than salaried).

### *Analysis Plan*

#### *Quantitative Data*

Demographic data were analyzed using descriptive statistics. Survey items were analyzed individually as well as by using a mean score of the 11 items. We also carried out exploratory posthoc correlation analyses to examine relationships among

the mean score and the clinicians' age, employment status, and number of clients.

#### *Qualitative Data*

Open-ended responses were analyzed using thematic analysis based on best practices and guiding principles in qualitative coding, and involved categorization of responses and coding of response frequency [45-47]. Content from open-ended responses was imported into Microsoft Excel (version 16.55), with one response per cell, and was first mapped onto different categories of repeating ideas that were derived from the data that were then formed into subthemes. Each response was coded using an open coding procedure; there were no predetermined categories and more than one code could be applied if warranted. Through an iterative process, each of the subthemes were then grouped into larger themes, and themes were grouped into domains. Frequencies were calculated for each domain. Following recommended qualitative research practices, a second coder coded 20% of the data and percent agreement was calculated using the total number of agreements divided by the total number of possible agreements [48]. Percent agreement was very high (96%) and the two coders reviewed and discussed discrepant codes until consensus was reached.

#### *Reporting*

We use the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) to guide our reporting of survey characteristics and results [49].

## Results

### *Sample Characteristics*

We received responses from 67 of the 198 clinicians contacted (response rate 34%); the 18 surveys with less than 50% of the items complete were not included, leaving 49 respondents (completion rate 25%). Although we reviewed timestamps of survey responses, responses were not eliminated due to long timestamps as clinicians were not instructed to complete the survey in a single sitting. Four of the remaining 49 respondents had never used telehealth, leaving a total of 45 clinicians (including staff with multiple clinical, supervisory, and administrative roles) in the study. These respondents were predominantly female (82%), master's-level (93%) clinicians in their mid-30s (mean age 36 years); see Table 1 for detailed clinician demographics. They worked at 15 different agencies in Philadelphia (one agency had seven survey respondents, two had five respondents, two had four respondents, and the rest had three or less).

**Table 1.** Clinician demographics.

Characteristic	Respondents, n	Value
Age (years), mean (SD), range	42	36 (10), 25-64
<b>Gender, n (%)<sup>a</sup></b>	44	
Female		37 (82)
Male		6 (13)
Chose not to disclose		1 (2)
<b>Race, n (%)</b>	44	
White		35 (78)
Black		4 (9)
Asian		2 (4)
Mixed race or other race		2 (4)
Chose not to disclose		1 (2)
<b>Ethnicity, n (%)</b>	44	
Not Latinx		38 (84)
Latinx		3 (7)
Chose not to disclose		3 (7)
<b>Position type, n (%)</b>	44	
Master's-level clinician		25 (56)
Social worker		8 (18)
Other position		8 (18)
Marriage and family clinician		2 (4)
Psychologist		1 (2)
In a role with a supervisory or administrative component	45	18 (40)
<b>Employment status, n (%)</b>	45	
Salaried full-time		28 (62)
Independent contractor/fee-for-service		16 (36)
Other		1 (2)
<b>Highest degree completed, n (%)</b>	44	
Master's degree		42 (93)
Doctoral degree		2 (4)
<b>Licensure status, n (%)</b>		
Licensed		23 (51)
Not licensed		12 (27)
In process		9 (20)
Clients seen per week, mean (SD), range	45	14 (8), 1-30
Hours worked per week across all jobs, mean (SD), range	45	39 (11), 5-60
Years of experience in full-time human services work, mean (SD), range	44	10 (8), 2-30
Years of experience in role of clinician, mean (SD), range	44	9 (8), 1-30
Years worked at present agency, mean (SD), range	44	5 (4), 1-16

<sup>a</sup>Percentages were calculated using a denominator of the 45 clinicians who responded.

## Quantitative Results

All 45 clinicians completed each of the telehealth survey items; there were no missing data (see [Table 2](#)). Across items, clinicians tended to agree with the statements presented in the survey, with mean responses falling between “neutral” and “agree” on 7 (64%) items. Clinicians agreed more strongly with two statements in particular: “Telehealth helps me to converse with my clients” (mean 2.0, SD 0.7) and “For the moment, I am satisfied with the work I’ve done through telehealth” (mean 2.0, SD 0.6). Clinicians also responded with more neutrality to

one item (“The images and sounds of telehealth gear are clear and crisp”; mean 3.0, SD 1.0) and more disagreement to one item (“I prefer telehealth visits over visits that are in person”; mean 3.8, SD 1.0). Posthoc exploratory correlational analyses did not suggest a relationship between clinician telehealth ratings and their age or number of clients. However, clinician employment type appeared to be associated with the mean telehealth score, with independent contractors rating telehealth more positively compared to full-time salaried employees ( $B=-0.32$ , 95% CI  $-0.47$  to  $-0.02$ ;  $P=.03$ ).

**Table 2.** Clinicians’ ratings of telehealth (N=45)<sup>a</sup>.

Survey item	Mean (SD)	Mode (range)
It is easy to run and use the telehealth system	2.4 (0.9)	2 (1-4)
I am confident and feel at ease when I use the telehealth system	2.5 (1.0)	2 (1-5)
Telehealth gives me the chance to build and keep a personal bond with each of my clients	2.3 (0.9)	2 (1-5)
Telehealth fits well with each day’s workflow	2.3 (0.8)	2 (1-4)
The images and sounds of telehealth gear are clear and crisp	3.0 (1.0)	3 (1-5)
I get more done in my day when I see clients through telehealth	2.8 (1.1)	3 and 4 (1-5)
Telehealth helps me to converse with my clients	2.0 (0.7)	2 (1-4)
Telehealth allows me to see more clients	2.4 (1.1)	1 and 3 (1-4)
I am able to treat my clients’ needs well through telehealth	2.4 (0.8)	2 (1-4)
I prefer telehealth visits over visits that are in person	3.8 (1.0)	4 (1-5)
For the moment, I am satisfied with the work I’ve done through telehealth	2.0 (0.6)	2 (1-4)
Mean score	2.5 (0.6)	2.5 (1.1-3.8)

<sup>a</sup>1=strongly agree, 2=agree, 3=neutral, 4=disagree, and 5=strongly disagree.

## Qualitative Results

We developed five domains based on the data, each comprised of multiple themes and, within those themes, subthemes (see [Table 3](#) for domains, themes, and subthemes; see [Multimedia Appendix 1](#) for additional examples). The domain most frequently mentioned by clinicians (n=68 responses) was changes to therapy process and content, which involved clinicians’ observations about the ways in which telehealth has changed the process of carrying out therapy (ie, therapy process) as well as the nature of the therapy content itself (ie, therapy content). This domain included observations about the pros and cons to the virtual therapy process. Some clinicians noted that teletherapy offers an opportunity for more creativity and collaboration than in-person therapy, such as in jointly coming up with realistic plans for coping based on the clients’ home environment. However, they also noted risks associated with the shift to telehealth, including no longer sharing physical space with clients and a lack of nonverbal communication. Some clinicians also noted ways in which delivering treatment over telehealth appears to be slowing the pace of therapy. Clinicians also noted the need for adaptation of and modification to the therapeutic intervention being used. They also noted additional challenges, including difficulty with implementing core TF-CBT practice elements over telehealth (eg, trauma narrative), limitations in the use of physical tools and supplies that they typically rely upon (eg, games and physical books), changes to

the content of their sessions and the aspects most emphasized (eg, less emphasis on mindfulness), and changes to the format of therapy (eg, shorter sessions).

Clinicians’ responses also frequently fell into the domain of engagement, retention, and attendance (n=59 responses). Many clinicians noted changes in attendance and retention associated with the shift to telehealth, with most identifying an increase in attendance and retention, and greater ease of scheduling (although a few cited a decrease in attendance and retention with certain clients). Clinicians also noted differential engagement challenges across clients. Although across the board there were widespread challenges with engagement, some clients were particularly hard to engage (especially young children), whereas in select cases, clients were more engaged (eg, some teenagers, some children with higher anxiety). Additionally, respondents observed an increase in caregiver engagement, including more consistent involvement of caregivers in therapy and specific ways in which caregivers impacted client engagement.

We developed a third domain around technology (n=57 responses). Clinicians noted the indispensability of access to technological devices, the frequent problem of internet access, and the presence of digital disparities. Clinicians noted that it is essential that clients and clinicians have the devices needed to access telehealth, such as a computer with a webcam, and the platforms needed to carry out telehealth visits. Clinicians

also noted the frequency of internet connectivity issues and the ways in which these issues have an adverse effect on therapy. They also highlighted digital disparities that negatively impact low-income clients; in the context of telehealth, lack of access to crucial resources may mean inability to access mental health services altogether.

The importance of training, resources, and support was identified as a fourth domain (n=52 responses). Many clinicians highlighted the need for more guidance pertaining to telehealth, including didactic trainings and supervision and consultation. Clinicians also noted the need for resources and funding specific to telehealth, including provision of telehealth-compatible physical supplies, telehealth-specific funding and incentives, and provision of technological devices and internet access, particularly to low-income clients. Many also highlighted the value of shared telehealth information and tools through their organization or via email, including recommendations for creative online resources, distribution of telehealth tips between clinicians, and online materials shared with clients.

Finally, clinicians' responses highlighted a fifth domain pertaining to barriers and facilitators to telehealth (n=43 responses). Clinicians noted that the individual characteristics of clinicians, clients, and caregivers can serve to facilitate or hinder successful therapy. For example, clinicians who are creative and flexible may have an easier time implementing treatment over telehealth, as will those with greater motivation and greater bandwidth. Additionally, caregiver support of clients is impactful in facilitating success. Many responses also highlighted drawbacks and limitations of telehealth; even in the best of circumstances, telehealth increases certain burdens on clinicians and poses logistical limitations, leaving some clinicians feeling exhausted. Finally, telehealth is more acceptable to some clients and clinicians than to others. Many clients find telehealth to be convenient, although some may find it more challenging and uncomfortable. Additionally, clinicians suggested that the acceptability of telehealth is not a constant and may increase as time passes.

**Table 3.** Domains, themes, subthemes, and examples<sup>a</sup>.

Domains, themes, and subthemes	Examples
<b>Changes to therapy process and content</b>	
<b>Altered therapy process has pros and cons</b>	
Loss of shared physical space	Lack of in-person contact feels different
Hindered nonverbal communication	Can't read body language or body cues
Opportunity for creativity, collaboration, and cooperative planning	Easier identification of realistic plans for coping
Potential effect on pace of therapy	Progress moving slower
<b>Need for adaptation and modification of content for telehealth</b>	
Difficulty implementing core practice elements	Challenging to get child input in trauma narrative
Inability to use preferred tools and supplies	The therapy tools feasible over telehealth are less engaging
Changes in therapy content and technique	Using more visuals, discussion questions, and planned activities
Changes in therapy process, format, and structure	Clients want check-ins and not full sessions
<b>Engagement, retention, and attendance</b>	
<b>Changes in attendance and retention</b>	
General increase in attendance and retention	Decreased no-shows
Greater scheduling flexibility	Easier to reschedule if needed
Occasional negative impact on attendance and retention	Some clients are forgetful and need more reminders
<b>Differential engagement challenges across clients</b>	
Widespread challenges with engagement across many clients	Difficulty paying attention
Some groups particularly hard to engage	Particular difficulty engaging young clients
Small subset have increased engagement	Some clients able to open up more over telehealth compared to in person
<b>Caregiver engagement and involvement has generally increased</b>	
More direct and consistent contact with caregivers	Easier for caregivers to be involved
Caregivers can aid in client engagement	Caregivers can increase buy-
<b>Technology</b>	
<b>Access to and facility with technological devices and platforms is crucial</b>	
Need for appropriate devices and accessories	Both clients and clinicians require devices with video capabilities
Need for access to specific programs and capabilities	Access to HIPAA <sup>b</sup> -compliant video platforms (preferably with paid subscription) is essential
<b>Internet access is a problem</b>	
Many clients have connectivity issues	Access to stable internet not always available
Connectivity issues have adverse effect on therapy	Poor network connections (frequent glitches, bad lags) and internet interruptions (calls dropping in middle of session) are disruptive to therapy
<b>Digital disparities are undeniable</b>	
Technological issues disproportionately affect low-income clients	Access to technology limited among low-income clients
Those without access to telehealth may be unable to receive care	Without stable internet or phone connection, telehealth becomes inaccessible
<b>Training, resources, and support</b>	
<b>Clinicians want more training and support in telehealth</b>	
Clinicians want didactic trainings	Desire for webinars
Need for supervision and consultation	Support from colleagues and employer makes a difference
<b>Provision of resources, funding, and incentives is needed</b>	



Domains, themes, and subthemes	Examples
Physical supplies can still be used	Physical items can be sent to clients
Need for funding and incentives	Clinicians and clients can benefit from funds allocated toward supplies
Technological devices and internet access is a must	Clients need access to appropriate devices for telehealth
<b>Desire for continued sharing of information, suggestions, and tools for telehealth</b>	
Use online resources creatively	Make use of websites, apps, worksheets, books
Distribute telehealth tips between clinicians	Tips for how to support (young) children and parents using telehealth
Share materials with clients	Provide clients with interactive materials and worksheets
<b>Differential barriers, facilitators, and acceptability across clinicians and clients</b>	
<b>Individual characteristics of clinicians, clients, and caregivers can facilitate or hinder successful therapy</b>	
Creativity and flexibility are key	Clinician and client creativity are key to successful telehealth use
Motivation matters for clinicians, caregivers, and clients	High motivation and drive from client and family facilitates success
Logistics and bandwidth make a difference	Clinicians who have time to prepare in advance may find telehealth easier
Caregiver support and involvement in therapy is a huge facilitator	Caregivers can create a safe space for therapy
<b>Telehealth has drawbacks and limitations</b>	
Telehealth increases burden on clinicians	Increased preparation and planning required
Limitations exists even when done well	Many tangible tools and games cannot be used
<b>Differential acceptability of telehealth across clients and clinicians</b>	
Increased convenience and comfort for some clients and clinicians	Many clients and families find telehealth to be more convenient
Telehealth can be challenging and uncomfortable	Telehealth feels limited to many clinicians
Acceptability may change over time	Getting easier over time and clinicians getting better and more confident

<sup>a</sup>Additional examples of each subtheme can be found in [Multimedia Appendix 1](#).

<sup>b</sup>HIPAA: Health Insurance Portability and Accountability Act.

## Discussion

### Principal Findings

The perspectives shared by the clinicians in our sample highlight an array of insights that may reveal common challenges and benefits to EBP delivery via telehealth in CMH settings. They also point to the next steps for practice and directions for future research. Clinicians observed that telehealth has pros and cons, and may better fit some clients than others. They also made clear the distinction between access to telehealth and engagement in telehealth; while session attendance is important, it is only half the battle. In order for clients to benefit from therapy, they must also be engaged. Finally, although telehealth may be a more convenient option for families who can access it, there are many clients, particularly those from low-income families, for whom it is not available due to lack of internet access or lack of privacy, among other reasons. Given that TF-CBT is widely implemented on a national level and that the challenges to implementing TF-CBT in our sample may be similar to challenges that arise in implementing EBPs more broadly in other CMH settings, these findings may be useful in informing and facilitating implementation of EBPs across CMH settings nationally. Further, it is likely that the barriers faced by clinicians in our sample reflect those faced by clinicians in

other CMH settings where resources are limited, and caseloads and administrative burdens are relatively high. Suggestions made by clinicians in our sample may be useful in supporting clinicians in other CMH settings in delivering EBPs over telehealth.

### Telehealth May Be a Better Fit for Some Clients and Clinicians Than for Others

Our data suggest that clinicians do not view telehealth as a one-size-fits-all modality for treatment delivery. Clinicians broadly reported that telehealth can be a good option for many clients in that it is convenient, generally acceptable, and may even provide surprising benefits such as increased creativity and collaboration, increased parental involvement, and an ability for clinicians to gain a more intimate understanding of their clients' home environment (ie, more ecological validity), which can provide clinically important information that would not otherwise be available. These benefits are supported by other studies [50,51], and provide promising implications regarding the potential for the longstanding use of telehealth for clients who prefer this modality. Positive views about telehealth are also reflected in our quantitative data, which show relatively favorable ratings of telehealth, especially when considering the quick pivot and lack of preparation. It is unclear, however, whether these perspectives would be held outside of the context

of a pandemic or if clinicians are merely “finding a silver lining” in the midst of an otherwise difficult set of circumstances. Future research should investigate how acceptable and satisfactory telehealth-delivered EBPs are to clinicians and clients postpandemic. It may be that there is differential effectiveness of telehealth wherein individuals who find it more acceptable have better therapy outcomes than those who find it less acceptable. Future research should address this question.

Despite these positive elements of telehealth, clinicians noted additional challenges to both clients and clinicians. Some clinicians reported feeling more burdened and exhausted than when delivering therapy in person. Although clinicians tended to agree that telehealth is a good solution “for the moment,” the survey item with the greatest disagreement was “I prefer telehealth visits over visits that are in person.” It seems that clinicians may be accepting telehealth as a short-term solution without necessarily preferring it. This contrasts with findings within a sample of clinicians at a nonprofit hospital system serving predominantly privately insured clients, as roughly half indicated that they would like to continue using telehealth after the pandemic [37]. It may be that utilization of telehealth in a CMH clinic puts higher burdens on clinicians than in higher-resourced systems. More work is needed to identify how to best support CMH clinicians in delivering treatment via telehealth. It is also possible that there are individual differences across clinicians that determine the acceptability of telehealth, including differences in personality or differences in job characteristics. For example, in our sample, clinicians who were independent contractors rated telehealth more highly than did full-time salaried clinicians. We hypothesize that for independent contractors, the reduction in transportation time may make a greater difference than for salaried clinicians, particularly if they are accustomed to traveling between agencies. It may also be that the general flexibility and variability in independent contractor positions prepared these clinicians well to adapt to a novel situation. Future work harnessing their insights may be beneficial in identifying further ways to improve telehealth and to optimize the experience of salaried full-time workers.

Telehealth raises a number of challenges that may not be mutable even in the best of circumstances, such as the lack of confidentiality in households without a private space, the inability to read body language, and the fact that some clients may simply be too young to engage in telehealth. Future research should examine the question of what aspects of treatment can be best carried out using telehealth, and whether, analogous to the question of what forms of psychotherapy work best for which clients, we can gain greater insight into “personalized telehealth” and identify for whom telehealth is best suited [52,53]. It may be that at least some of the challenges highlighted in these data can be overcome through provision of supplies and through dissemination of information. This can come in various forms, including didactic webinars, shared resources, and consultation and supervision, all of which the clinicians in our sample highlighted as a desired form of support. For example, our system sponsored a webinar led by a clinical director at one of the agencies highlighting creative ways in which to enact telehealth. The APA has compiled a list of

telehealth resources, including other webinars and information about regulatory guidelines. There are also TF-CBT-specific resources about telehealth, such as the Telehealth Outreach Program [54] and the National Therapist Certification Program [55] from the Medical University of South Carolina. Similar telehealth resources for clinicians are available for a broad array of treatments and disorders. Previous work has also examined the ways in which training in delivering treatment via telehealth may be integrated into graduate training, which may be a proactive way to prepare future clinicians [56].

The challenges that clinicians reported with regard to burden may be due to the abrupt shift to telehealth and stage of maturation when clinicians were surveyed. Clinicians were surveyed within the first 6 months of the shift to telehealth, and their perspectives may have changed with further experience. Indeed, there is evidence to support the notion that telehealth gets easier with time. A systematic review of clinician attitudes toward telehealth revealed that those who had more experience with the modality felt more positively about it than those who did not use it or were new to it [57].

The extent to which telehealth continues to be utilized in the future will depend not only on how acceptable it is to clients and clinicians but also on regulatory factors such as reimbursement from payors and licensure restrictions [58]. Although it is unclear whether the temporary allowances made in the context of a global pandemic will continue, there is promising data to suggest that this time of increased telehealth use has resulted in a ramp-up in telehealth infrastructure and a decrease in some of the barriers that existed previously [59]. It may be that with sufficient interest and attention given to strengthening telehealth systems, and with research to support effectiveness of its use, sufficient pressure will be put on policymakers and payors to make this modality a sustainable long-term option.

### **Attendance Is Necessary but Not Sufficient**

Important questions remain with regard to engagement and parental involvement. Telehealth may reduce barriers in accessing care, such as transportation barriers, and our findings are consistent with previous work that noted less attrition with depressed clients when using telehealth [35,60,61]. Factoring in clients' busy schedules as well as the technological advances and relative accessibility of internet connection, telehealth may make it easier for many clients to attend sessions regularly. However, for these clients who find telehealth more convenient, the extent to which they successfully engaged in sessions remains unclear. Many clinicians noted that engagement in sessions remains a challenge, particularly for younger children. Future research should compare client attendance, engagement, and outcomes of in-person versus telehealth-delivered therapy sessions to better understand how telehealth influences these factors. Despite challenges with client engagement, there was unanimous agreement among the clinicians who commented on parental engagement that telehealth facilitates involvement of parents. Clinicians indicated that when parents are involved, therapy seems to go better. Even if telehealth does not remain the first-line mode of treatment, it may be worth investigating

whether, even within the context of the return to face-to-face therapy with clients, parents can continue to engage virtually.

### Digital Disparities Must Be Addressed

Even if the shift to telehealth increases access for some clients, attention must be paid to digital disparities. Clinicians noted the ways in which digital disparities create issues with access to therapy, and that among the clients who can access therapy, a subset may have impaired quality of connectivity. Disruptions in connectivity are not conducive to therapeutic progress, and in many cases make it more difficult to foster a strong therapeutic alliance. This was reflected in the clinicians' relatively low agreement on the quantitative survey that telehealth is "clean and crisp." Although families that are in a low-income category may benefit, in theory, from the elimination of transportation barriers in accessing care, if they do not have reliable internet access, then telehealth is not a solution. It is important to note that the challenges associated with digital disparities are rooted in far wider-reaching issues of inequity that must be addressed for longstanding change to occur. Recent work has focused on mitigating digital disparities through the lens of health equity. Future implementation of telehealth should be guided by consideration of how to reduce digital disparities across the individual, institutional, and broader social levels [62]. In the interim, there may be creative solutions to help reduce these disparities within existing systems, including allowing clients without home internet access to engage in therapy at school. Additional short-term solutions include leveraging auxiliary staff or community health workers to aid families in accessing telehealth, or in providing families with temporary devices and internet access to engage in care, as was successfully demonstrated in one study [13,63,64].

### Limitations

This study has several limitations. First, and most importantly, the shift to telehealth occurred within the context of a global pandemic, and therefore the generalizability of these observations to more typical circumstances is unknown. Second, the clinicians all belong to one public mental health system, and the extent to which their perspectives can be generalized to other settings is unclear. For example, there may be idiosyncrasies to the Philadelphia youth community behavioral health system that are unique, and the perspectives of these clinicians may not capture challenges in other settings such as rural areas. Of note, a recent study of clinician attitudes toward telehealth in a rural CMH setting found that clinicians' concerns were similar to those of clinicians in our sample [65]. Third, although our sample included therapists from a diverse set of agencies, some agencies were more represented than others and

we did not account for nesting in our analyses due to power limitations. Fourth, the response rate to the survey was low (although typical for online surveys), and the sample may be biased toward clinicians who were functioning more highly and thus not representative of the broader sample of clinicians invited to participate [66,67]. However, demographic characteristics of the clinicians in our sample were reflective of those of the broader public mental health workforce of Philadelphia, providing some support for generalizability [68]. Fifth, although our intention was to understand clinicians' perspectives and we see self-report as a strength, there are potential response biases, blind spots, and limitations associated with self-reporting. Although the anonymity of a survey may serve to reduce certain types of response biases, the data are not as extensive as those obtained with an in-depth interview. Nonetheless, we found a lot of overlap in clinicians' responses, suggesting that theoretical saturation had been reached. Sixth, the Provider Survey used to capture clinicians' ratings of telehealth has not yet been validated. We selected this measure due to the relative dearth of surveys on provider perspectives on telehealth; thus, we opted to use a published measure rather than creating our own. Finally, this study does not include client and family perspectives, and future qualitative work with these groups will be important, not only in understanding how much they like or dislike telehealth but also in allowing their views to help shape future developments in telehealth systems to increase acceptability.

### Conclusion

This study examined the perspectives of clinicians working in a public mental health system providing TF-CBT via telehealth. Our findings lend insight into the challenges and benefits associated with delivering EBP via telehealth in the context of a system that shifted rapidly into this new delivery modality. Future work should determine which clinicians and clients are best suited for telehealth, identify how to better engage clients, and reduce digital disparities. The future of telehealth delivery within public mental health systems will depend largely on reimbursement streams, and the extent to which these services will be utilized more permanently may be revealed once it becomes safe to resume in-person therapy. Although the long-term trajectory of telehealth is largely unknown and our findings are derived from a single sample of clinicians, there is likely some universality to their observations, particularly in urban CMH settings. The insights and recommendations of the clinicians in our sample may help to inform future research and strengthen telehealth services for youth in need of mental health care.

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### Conflicts of Interest

None declared.

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### Multimedia Appendix 1

Domains, themes, and subthemes with additional examples.

[[DOCX File, 22 KB - pediatrics\\_v5i1e29250\\_app1.docx](#) ]

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## Abbreviations

**APA:** American Psychological Association  
**CBH:** Community Behavioral Health  
**CHERRIES:** Checklist for Reporting Results of Internet E-Surveys  
**CMH:** community mental health  
**DBHIDS:** Department of Behavioral Health and Intellectual Disability Services  
**EBP:** evidence-based practice  
**OCD:** obsessive-compulsive disorder  
**PACTS:** Philadelphia Alliance for Child Trauma Services  
**PTSD:** posttraumatic stress disorder  
**TF-CBT:** trauma-focused cognitive behavioral therapy

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Original Paper

# Gender Differences and Associated Factors Influencing Problem Gambling in Adolescents in Sweden: Cross-sectional Investigation

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## Abstract

**Background:** Although gambling disorder is traditionally considered an adult phenomenon, the behavior usually begins in childhood or adolescence.

**Objective:** The aim of this study was to explore the frequency of problem gambling among Swedish adolescents and the suspected associated factors.

**Methods:** This study was based on data collected through a public health survey distributed in 2016 to pupils in ninth grade of primary school and in second grade of secondary school in Sweden. Bayesian binomial regression models, with weakly informative priors, were used to examine whether the frequency of the associated factors differed between those with and without problem gambling.

**Results:** Approximately 11.7% (469/4002) of the boys in ninth grade of primary school and 13.9% (472/3407) of the boys in second grade of secondary school were classified as problem gamblers. For girls, the corresponding frequencies were 1.2% (48/4167) and 0.7% (27/3634), respectively. The overall response rate was 77% (9143/11,868) among ninth grade pupils and 73.4% (7949/10,832) among second grade pupils, resulting in a total of 17,092 responses. Problem gambling was associated with poor sleep and having tried smoking, alcohol, and other substances among both boys and girls in ninth grade of primary school and boys in second grade of secondary school. Problem gambling among girls in second grade of secondary school was associated with an increased prevalence of having tried smoking and other substances and an increased prevalence of poor sleep.

**Conclusions:** Using a large representative sample of Swedish adolescents, we found that problem gambling was robustly associated with a substantially increased prevalence of poor sleep and having tried smoking, alcohol, and other substances among both boys and girls in ninth grade of primary school as well as among boys in second grade of secondary school. Our study adds important information for policy makers pointing at vulnerable groups to be considered in their work to prevent problem gambling.

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**KEYWORDS**

gambling; cross-sectional study; adolescents; sleep; alcohol; smoking; pediatrics; parenting; mental health; addiction; children

## Introduction

Behavioral or nonsubstance addictions have relatively been formally acknowledged recently [1,2]. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders includes a new diagnostic category “Substance-Related and Addictive Disorders,” listing not only alcohol and drug abuse but also gambling disorder [1]. Although gambling disorder is traditionally considered an adult phenomenon, the behavior usually begins in childhood or adolescence and more frequently in younger ages among males, in resemblance with both substance use disorders and pathological gaming [2]. Gambling disorder is the most established and most thoroughly investigated behavioral addiction based on a formal diagnosis and founded diagnostic criteria [1]. The research on gambling is rather extensive and includes literature focusing on the Swedish population [3,4], though mainly among adults. The severity of this behavior is currently uncontroversial, as this condition has been associated with negative psychological consequences, including an increased risk of suicide [4-6]. Previous research also demonstrates that gambling disorder shows great comorbidity with various psychiatric conditions such as depression, anxiety disorders, low impulse control, and bipolar disorder as well as alcohol, substance, and nicotine use [2,6,7]. Kessler et al [8] showed that nicotine, alcohol, and drug dependence elevated the odds of pathological gambling. The behavior is traditionally considered mainly an adult problem, but research has shown that problem gamblers debut in gambling at a younger age than nonproblem gamblers [8]. Additionally, previous research concerning comorbidity relies on treatment-seeking samples [4,6,7], and as little is known about gambling in a younger population, this study adds to the knowledge about gambling by addressing early debuting gambling among girls and boys in an ordinary school setting. The psychological health among adolescents is on the decline in the western world, and recent research suggests that this decline is associated with the digital technological development, known as “digital depression” [9,10]. A major study in the United States showed that about 22% of teenagers exhibit multiple symptoms of depression, whereas the lifetime overall US prevalence rate of a full clinical depressive episode is 5%-10% [9,10]. Psychological well-being among adolescents has been reported as poorer among those who spend more hours on electronic communication and in front of screens (eg, social media, gaming, internet, texting) [10].

Autism spectrum disorder (ASD) is an impairing and heterogeneous neurodevelopmental disorder with an early onset and a worldwide prevalence of 1%-3% [11]. This disorder is characterized by social impairments, communication difficulties, altered sensory processing, and repetitive and restricted behaviors [11]. Studies have shown possible social gains for online gamers, decreased feelings of loneliness, increased feelings of connectedness to friends, increased social capital between players, and increased social bridging between players [12]. Based on the design of the games with repetitions and immediate reinforcement, it can be assumed that patients with attention-deficit/hyperactivity disorder (ADHD)/ASD have an increased risk of developing problem gambling [13].

We wanted to explore the frequency of problem gambling among Swedish pupils and examine whether the frequency of the suspected associated factors outlined below differed among those with and without problem gambling. Specifically, using a large sample of Swedish pupils from primary and secondary school, we investigated whether those with and without problem gambling differed in the frequency of (1) often feeling low, (2) often feeling anxious, (3) self-reported ADHD, (4) self-reported 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

This study is based on data collected through a public health survey distributed in 2016 to pupils in ninth grade in primary school and in second grade of secondary school. The survey was distributed in all 33 municipalities in Skåne, a region in southern Sweden, with a response rate of 77% (9143/11,868) in ninth grade and 73.4% (7949/10,832) in second grade. Information about gender was missing for 86 respondents, resulting in a total sample size of 17,006. The purpose of the survey was to investigate the current health, way of life, health hazards, and social factors among teenagers and adolescents, and was provided by Region Skåne in cooperation with the municipal association of Skåne. The survey was answered anonymously on computers in classroom settings. Participation was voluntary, all measures were based on self-reports, and all questions were described as optional. In addition to answering questions about problem gambling, respondents were extensively asked about various life circumstances, physical and psychological health factors, and different risk-taking behaviors.

### Measures

#### Problem Gambling

The Lie/Bet questionnaire was used to identify respondents with gambling problems [14,15]. This brief yet diagnostically accurate screening instrument [16] contains only 2 questions (answers: “yes” or “no”): (1) having felt a need to gamble an increasing amount of money in the hopes of winning back what has been lost and (2) lying about the amount of gambling to people of personal importance. Problem gambling was defined as endorsing at least one of these 2 questions.

#### Associated Factors

Based on previous research and clinical experience, we wanted to examine a broad range of suspected associated factors related to overall well-being, mental health, and adverse behaviors. In order to examine the frequency of each factor, new binary variables were created from the available survey questions. Two items based on the Health Behavior in School-aged Children symptom checklist were used to assess respondents’ psychological health, both with separately verified satisfactory test-retest reliability [17]. Respondents rated how often they had “felt low” and “anxious/worried” during the past 6 months on a 5-point scale (about every day, more than once a week, about every week, about every month, rarely or never). Two new binary variables labelled “often feeling low” and “often



feeling anxious” were created, where those who answered “about every day” or “more than once a week” were categorized as “yes” and all others as “no.” The survey included several questions on long-term somatic or psychiatric disorders. Respondents were asked whether they had “ADHD or attention-deficit disorder” and “autism/Asperger syndrome.” Two new binary variables labelled ADHD and ASD were created, where those who affirmed ADHD/attention-deficit disorder or ASD were categorized as yes and all others as no. Respondents were asked to rate their general health status on a 5-point scale (very good, rather good, neither good nor poor, rather poor, poor) using the Self-Rated Health instrument [18]. A new binary variable labelled “satisfied with health” was created, with those answering “very good” or “rather good” classified as yes and all others as no. Respondents were asked to rate how many hours a night they usually sleep on weekdays on a 3-point scale (less than 7 hours, 7-9 hours, more than 9 hours). A new binary variable labelled “poor sleep” was created, with those answering “less than 7 hours” classified as yes and all others as no. Respondents were asked to rate on a 4-point scale (have no close friend, have one close friend, have two close friends, have several close friends) whether they presently have a close friend with whom they could talk in confidence about almost any personal matter. A new binary variable labelled “loneliness” was created, with those answering “have no close friend” classified as yes and all others as no. Respondents were asked several questions about smoking, alcohol habits, and illicit substances. Three new binary variables labelled “tried smoking,” “tried alcohol,” and “tried other substances” were created, with affirming of any kind of frequency classified as yes and all other responses as no.

### Statistical Analysis

All statistical analyses were carried out using the R statistical programming language, version 4.0.4 [19], and several functions from the R package tidyverse [20] were used during data processing. Owing to its many advantages over the traditional frequentist approach, including the possibility of making genuine probabilistic statements about estimated parameters [21], we opted for a fully Bayesian approach to statistical analysis. The

R package brms [22], which interfaces R with the Stan probabilistic programming language [23], was used to specify Bayesian models. Bayesian binomial regression models with weakly informative priors centered around zero, which should have minimal impact on the obtained estimates while still providing moderate regularization [24], were used to assess whether the frequency of a suspected associated factor was different among those with and without problem gambling. The R package emmeans [25] was used for postprocessing of results. Differences are presented as estimated median absolute percentage differences along with associated odds ratios, both with 95% highest density intervals (HDIs) presented within parentheses. An advantage of the HDI is that, in contrast to a frequentist confidence interval, a 95% HDI actually has a 95% probability of containing the values inside it [26]. Finally, since there is no notion of “statistical significance” in the Bayesian framework, we used the region of practical equivalence in conjunction with the 95% HDI as a decision boundary [26] in order to establish whether an estimated difference between those with and without problem gambling was of practical clinical importance. We considered an estimated difference of 5% (or -5%) as the minimal difference for “practical equivalence,” and if the 95% HDI was not beyond this cutoff, we deemed the results as uncertain in terms of practical importance.

## Results

### Frequency of Problem Gambling Among Swedish School Pupils

Approximately 11.7% (469/4002) of boys in ninth grade of primary school and 13.9% (472/3407) of the boys in second grade of secondary school were classified as problem gamblers. For girls, the corresponding frequencies were 1.2% (48/4167) and 0.7% (27/3634), respectively. Additional details, including the number of valid responses in each group, are presented in Table 1. Overall, 4 factors emerged as robustly more frequent among respondents with problem gambling (although the results varied depending on sex and grade): poor sleep and having tried smoking, alcohol, and other substances.

**Table 1.** Frequency of problem gambling among school pupils in southern Sweden based on data collected in 2016.

School grade and gender	Respondents (N)	Valid responses, n (%)	Problem gambling, n (%)	No problem gambling, n (%)
Boys in ninth grade of primary school	4609	4002 (86.8)	469 (11.7)	3533 (88.3)
Girls in ninth grade of primary school	4497	4167 (92.7)	48 (1.2)	4119 (98.8)
Boys in second grade of secondary school	3945	3407 (86.4)	472 (13.9)	2935 (86.1)
Girls in second grade of secondary school	3955	3634 (91.9)	27 (0.7)	3607 (99.3)

### Problem Gambling and Associated Factors Among Boys in Ninth Grade of Primary School

In ninth grade of primary school, 43.3% (202/466) of boys with problem gambling were classified as having poor sleep compared to 25.5% (897/3513) of those without problem gambling, with an estimated difference of 17.8% (14%-21.9%) and a corresponding odds ratio of 2.23 (95% CI 1.86-2.61). Findings were similar for having tried smoking, alcohol, and other substances. Almost half (226/458, 49.3%) of all boys with

problem gambling had tried smoking compared to about one-fourth (963/3482, 27.7%) of those without problem gambling, with an estimated difference of 21.7% (17.7%-25.8%) and a corresponding odds ratio of 2.55 (95% CI 2.14-2.98). As for having tried alcohol, this was true for 77.3% (357/462) of those with problem gambling and 52.8% (1857/3514) for those without, with an estimated difference of 24.5% (20.9%-27.9%) and a corresponding odds ratio of 3.04 (95% CI 2.49-3.66). Finally, 15.9% (73/459) of boys with problem gambling had



tried other substances compared to 4.9% (172/3480) of those without, with an estimated difference of 10.9% (8.1%-13.8%) and an associated odds ratio of 3.63 (95% CI 2.78-4.56). In addition, there was a robust although smaller group difference

for all remaining suspected associated factors except for ADHD and ASD, but the estimated differences were not robustly beyond 5%. Further details are presented in [Table 2](#) and [Figure 1A](#).

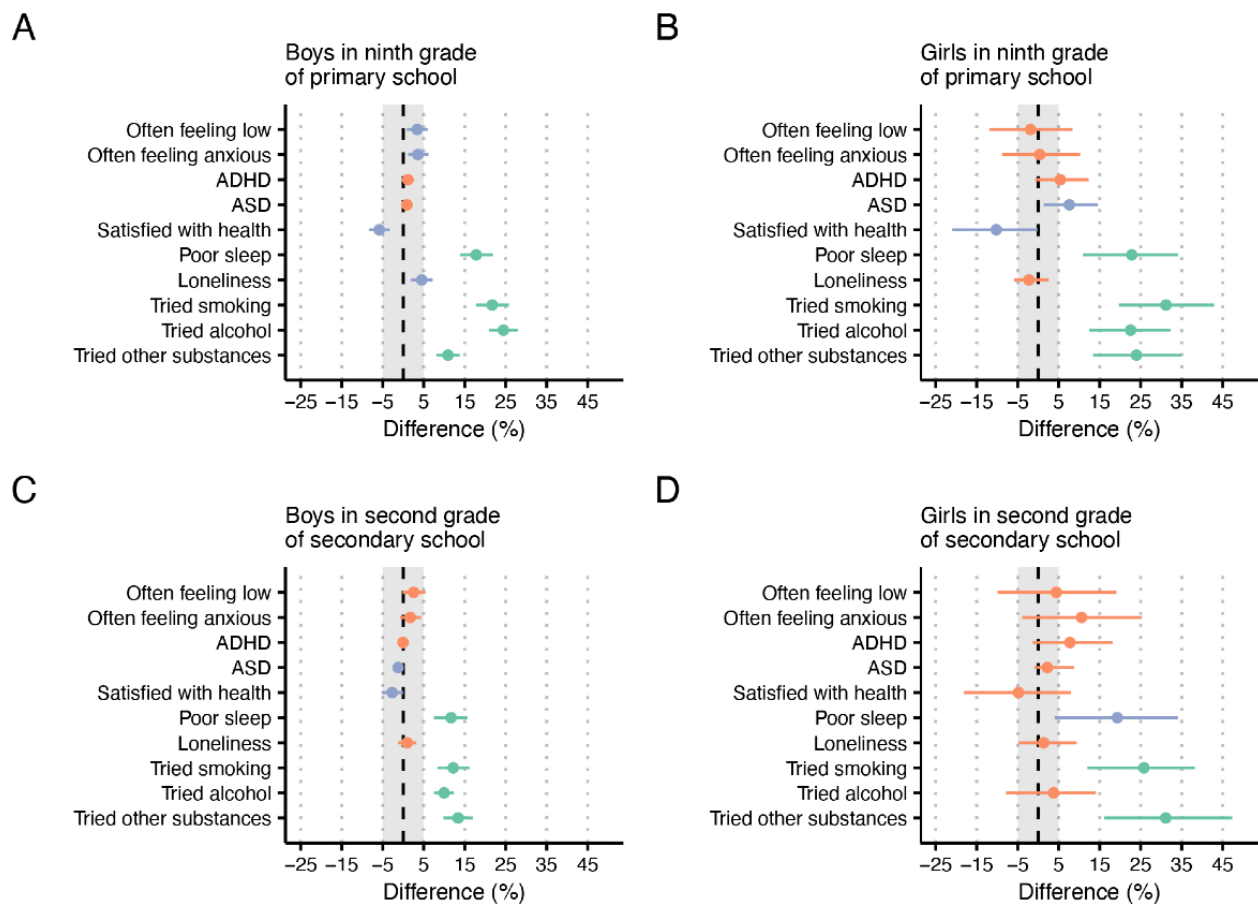
**Table 2.** Problem gambling and associated factors among boys in ninth grade of primary school based on data collected in southern Sweden in 2016.

Factors <sup>a</sup>	Boys (n)	Problem gambling, n (%)	No problem gambling, n (%)	Estimated difference in percent (95% highest density interval) <sup>b</sup>	Odds ratio (95% highest density interval)
Often feeling low	3855	52 (11.6)	278 (8.2)	3.4 (0.8 to 6.0)	1.47 (1.10 to 1.87)
Often feeling anxious	3845	46 (10.3)	225 (6.6)	3.6 (1.2 to 6.1)	1.61 (1.18 to 2.08)
Satisfied with health	3919	404 (88.2)	3257 (94.1)	-5.8 (-8.4 to -3.3)	0.47 (0.35 to 0.60)
Attention-deficit/hyperactivity disorder	3852	16 (3.6)	81 (2.4)	1.1 (-0.3 to 2.7)	1.50 (0.85 to 2.22)
Autism spectrum disorder	3853	13 (3)	67 (2)	0.9 (-0.4 to 2.3)	1.49 (0.79 to 2.30)
Poor sleep	3979	202 (43.3)	897 (25.5)	17.8 (14.0 to 21.9)	2.23 (1.86 to 2.61)
Loneliness	3964	58 (12.5)	276 (7.9)	4.5 (2.0 to 7.2)	1.66 (1.25 to 2.09)
Tried smoking	3940	226 (49.3)	963 (27.7)	21.7 (17.7 to 25.8)	2.55 (2.14 to 2.98)
Tried alcohol	3976	357 (77.3)	1857 (52.8)	24.5 (20.9 to 27.9)	3.04 (2.49 to 3.66)
Tried other substances	3939	73 (15.9)	172 (4.9)	10.9 (8.1 to 13.8)	3.63 (2.78 to 4.56)

<sup>a</sup>The number of respondents with problem gambling and no problem gambling differ for each factor owing to missing data. The number of respondents for each factor are provided in Table S1 of [Multimedia Appendix 1](#).

<sup>b</sup>Estimated differences and odds ratios with 95% probability that are above the prespecified cutoff for practical equivalence are in italics.

**Figure 1.** Estimated differences in prevalence of factors that may be associated with problem gambling. Dots represent the posterior median estimate, and bars represent 95% highest density intervals. Shaded regions indicate the region of practical equivalence (ie, a 5% difference in absolute terms). Estimates that with 95% probability are above the region of practical equivalence are shown in green, whereas estimates that with 95% probability are above zero, and estimates that are not, with 95% probability, above zero are shown in orange. Estimates are based on data collected among school pupils in southern Sweden in 2016. ADHD: attention-deficit/hyperactivity disorder; ASD: autism spectrum disorder.



### Problem Gambling and Associated Factors Among Girls in Ninth Grade of Primary School

Girls in ninth grade of primary school classified as problem gamblers had a higher frequency of poor sleep and having tried smoking and other substances than boys in ninth grade, although the frequency of having tried alcohol was similar. Approximately 58% (28/48) of girls with problem gambling were classified as having poor sleep compared to 35.7% (1460/4094) among those without, with an estimated difference of 22.8% (10.9%-34.1%) and an associated odds ratio of 2.54 (95% CI 1.42-3.9). Furthermore, 63% (29/46) of those with problem gambling had tried smoking compared to 31.7% (1306/4082) of those without, resulting in an estimated difference of 31.2% (19.7%-42.9%) and an associated odds ratio of 3.65 (95% CI 1.94-5.71). Almost 4 out of 5, 77% (37/48)

of girls with problem gambling had tried alcohol compared to a bit more than half (2252/4102, 54.9%) among girls without, with an estimated difference of 22.5% (12.5%-32.2%) and an associated odds ratio of 2.82 (95% CI 1.35-4.62). Finally, 28% (13/46) of girls with problem gambling had tried other substances compared to 4% (165/4078) of those without, with an estimated difference of 24% (13.4%-35%) and a corresponding odds ratio of 9.25 (95% CI 4.54-14.89). Note, however, that the HDIs presented here are wider than the corresponding HDIs among ninth grade boys owing to the lower number of girls reporting problem gambling. Thus, these estimates are more uncertain. Girls with problem gambling had a higher prevalence of ASD and were less satisfied with their health compared to girls without problem gambling, although these estimates were not robustly beyond 5%. Detailed results are presented in Table 3 and Figure 1B.

**Table 3.** Problem gambling and associated factors among girls in ninth grade of primary school based on data collected in southern Sweden in 2016.

Factors <sup>a</sup>	Girls (n)	Problem gambling, n (%)	No problem gambling, n (%)	Estimated difference in percent (95% highest density interval) <sup>b</sup>	Odds ratio (95% highest density interval)
Often feeling low	4076	10 (22.2)	955 (23.7)	-1.9 (-11.9 to 8.3)	0.9 (0.42 to 1.49)
Often feeling anxious	4071	9 (20)	770 (19.1)	0.4 (-8.8 to 10.2)	1.02 (0.45 to 1.70)
Satisfied with health	4104	35 (74.5)	3449 (85)	-10.2 (-21.0 to -0.2)	0.52 (0.26 to 0.86)
Attention-deficit/hyperactivity disorder	4047	4 (8.9)	118 (2.9)	5.4 (-0.7 to 12.3)	3 (0.69 to 5.92)
Autism spectrum disorder	4032	4 (9.1)	37 (0.9)	7.6 (1.3 to 14.6)	10.09 (2.21 to 20.3)
Poor sleep	4142	28 (58.3)	1460 (35.7)	22.8 (10.9 to 34.1)	2.54 (1.42 to 3.90)
Loneliness	4142	2 (4.3)	245 (6)	-2.2 (-5.9 to 2.5)	0.61 (0.04 to 1.46)
Tried smoking	4128	29 (63)	1306 (32)	31.2 (19.7 to 42.9)	3.65 (1.94 to 5.71)
Tried alcohol	4150	37 (77.1)	2252 (54.9)	22.5 (12.5 to 32.2)	2.82 (1.35 to 4.62)
Tried other substances	4124	13 (28.3)	165 (4)	24 (13.4 to 35)	9.25 (4.54 to 14.89)

<sup>a</sup>The number of respondents with problem gambling and no problem gambling differ for each factor owing to missing data. The number of respondents for each factor are provided in Table S2 of [Multimedia Appendix 1](#).

<sup>b</sup>Estimated differences and odds ratios with 95% probability that are above the prespecified cutoff for practical equivalence are in italics.

### Problem Gambling and Associated Factors Among Boys in Second Grade of Secondary School

Notably, differences between those with and without problem gambling were smaller for poor sleep and having tried smoking and alcohol among boys in second grade of secondary school than among boys in ninth grade of primary school, while the difference for having tried other substances stayed more or less the same. Approximately 51.6% (241/467) of boys with problem gambling were classified as having poor sleep compared to 39.9% (1167/2924) of those without, with an estimated difference of 11.7% (7.5%-15.7%) and a corresponding odds ratio of 1.61 (95% CI 1.34-1.87). Furthermore, 66.2% (307/464)

of boys with gambling problems had tried smoking, while the same was true for 53.3% (1564/2897) of those without, with an estimated difference of 12.2% (8.4%-16.2%) and a corresponding odds ratio of 1.67 (95% CI 1.38-1.96). The vast majority of boys with (425/464, 91.6%) and without (2380/2915, 81.6%) problem gambling had tried alcohol, with an estimated difference of 10% (7.5%-12.3%) and an associated odds ratio of 2.46 (95% CI 1.78-3.2). Finally, 28.2% (130/461) of those with problem gambling had tried other substances compared to 14.8% (428/2895) of those without, with an estimated difference of 13.4% (9.8%-17%) and an associated odds ratio of 2.26 (95% CI 1.85-2.71). Detailed results are presented in [Table 4](#) and [Figure 1C](#).

**Table 4.** Problem gambling and associated factors among boys in second grade of secondary school based on data collected in southern Sweden in 2016.

Factors <sup>a</sup>	Boys (n)	Problem gambling, n (%)	No problem gambling, n (%)	Estimated difference in percent (95% highest density interval) <sup>b</sup>	Odds ratio (95% highest density interval)
Often feeling low	3308	63 (13.8)	318 (11.2)	2.5 (0.1 to 5.5)	1.27 (0.97 to 1.59)
Often feeling anxious	3313	50 (11)	263 (9.2)	1.7 (-0.8 to 4.4)	1.21 (0.9 to 1.55)
Satisfied with health	3351	406 (88.3)	2630 (91)	-2.7 (-5.2 to 0.0)	0.75 (0.56 to 0.95)
Attention-deficit/hyperactivity disorder	3309	12 (2.7)	76 (2.7)	-0.1 (-1.3 to 1.3)	0.98 (0.49 to 1.5)
Autism spectrum disorder	3311	7 (1.5)	78 (2.7)	-1.2 (-2.2 to -0.1)	0.54 (0.22 to 0.92)
Poor sleep	3391	241 (51.6)	1167 (39.9)	<i>11.7 (7.5 to 15.7)</i>	1.61 (1.34 to 1.87)
Loneliness	3381	39 (8.3)	212 (7.3)	1 (-1.3 to 3.2)	1.15 (0.81 to 1.5)
Tried smoking	3361	307 (66.2)	1564 (54)	<i>12.2 (8.4 to 16.2)</i>	1.67 (1.38 to 1.96)
Tried alcohol	3379	425 (91.6)	2380 (81.6)	<i>10 (7.5 to 12.3)</i>	2.46 (1.78 to 3.2)
Tried other substances	3356	130 (28.2)	428 (14.8)	<i>13.4 (9.8 to 17.0)</i>	2.26 (1.85 to 2.71)

<sup>a</sup>The number of respondents with problem gambling and no problem gambling differ for each factor owing to missing data. The number of respondents for each factor are provided in Table S3 of [Multimedia Appendix 1](#).

<sup>b</sup>Estimated differences and odds ratios with 95% probability that are above the prespecified cutoff for practical equivalence are in italics.

### Problem Gambling and Associated Factors Among Girls in Second Grade of Secondary School

Again, owing to the low number of girls with problem gambling in second grade of secondary school, several estimates were uncertain. For instance, while 63% (17/27) of girls with problem gambling and 43.7% (1578/3590) without were classified as having poor sleep, the estimated difference of 19.3% (4%-34%) was not, with 95% probability, above the prespecified cutoff for practical equivalence (although the estimated difference was, with 95% probability, still above zero). As for having tried

smoking, this was affirmed by 77% (20/26) of girls with and 51.8% (1857/3585) of girls without problem gambling, with an estimated difference of 25.8% (12%-38.3%) and an associated odds ratio of 3.23 (95% CI 1.09-6.28). Notably, the difference in having tried alcohol was negligible, while 42% (11/26) of girls with and 10.9% (393/3574) of girls without problem gambling had tried other substances, with an estimated difference of 31.1% (16.1%-47.3%) and an associated odds ratio of 5.9 (95% CI 2.5-10.36). Detailed results are presented in [Table 5](#) and [Figure 1D](#).

**Table 5.** Problem gambling and associated factors among girls in second grade of secondary school based on data collected in southern Sweden in 2016.

Factors <sup>a</sup>	Girls (n)	Problem gambling, n (%)	No problem gambling, n (%)	Estimated difference in percent (95% highest density interval) <sup>b</sup>	Odds ratio (95% highest density interval)
Often feeling low	3579	9 (33.3)	1011 (28.5)	4.4 (-9.9 to 19.1)	1.23 (0.49 to 2.15)
Often feeling anxious	3585	9 (33.3)	795 (22.3)	10.6 (-3.9 to 25.3)	1.71 (0.66 to 2.96)
Satisfied with health	3570	20 (76.9)	2918 (82.3)	-4.8 (-18.2 to 8.1)	0.74 (0.26 to 1.46)
Attention-deficit/hyperactivity disorder	3560	3 (12)	118 (3.3)	7.7 (-1.4 to 18.1)	3.61 (0.48 to 7.9)
Autism spectrum disorder	3560	1 (4)	28 (0.8)	2.2 (-1.0 to 8.7)	3.94 (0 to 13.63)
Poor sleep	3617	17 (63)	1578 (44)	19.3 (4 to 34)	2.19 (0.88 to 3.84)
Loneliness	3629	2 (7.4)	186 (5.2)	1.3 (-4.8 to 9.4)	1.27 (0.05 to 3.09)
Tried smoking	3611	20 (76.9)	1857 (51.8)	<i>25.8 (12 to 38.3)</i>	3.23 (1.09 to 6.28)
Tried alcohol	3620	22 (84.6)	2935 (81.7)	3.8 (-7.8 to 14)	1.32 (0.38 to 2.96)
Tried other substances	3600	11 (42.3)	393 (11)	<i>31.1 (16.1 to 47.3)</i>	5.9 (2.5 to 10.36)

<sup>a</sup>The number of respondents with problem gambling and no problem gambling differ for each factor owing to missing data. The number of respondents for each factor are provided in Table S4 of [Multimedia Appendix 1](#).

<sup>b</sup>Estimated differences and odds ratios with 95% probability that are above the prespecified cutoff for practical equivalence are in italics.

## Discussion

### Principal Findings

Given the increasing interest in behavioral addictions and alarming reports on consequences of screen time and adolescents increasing psychological complaints [2,9,10], this study aimed to describe problem gambling and suspected associated factors within a population of Swedish pupils in an ordinary school setting, targeting adolescents in ninth grade of primary school and in second grade of secondary school. Our study adds to the knowledge of pathological gambling by investigating male and female characteristics. The interest in behavioral addiction is increasing, but there are still gaps to be filled. Gambling addiction is the most established and researched behavioral addiction, but the phenomenon is mainly investigated among adults or within populations of care-seeking gamblers [4,6,7]. Games with or without money constitute adjacent phenomena in the sense that monetary elements such as so-called loot boxes are common in computer games or through more computer-game-like virtual environments where games about money take place. One possibility for affirmation of gambling among adolescents younger than 18 years of age could be that the participants meant games containing such monetary elements when endorsing items on gambling in the questionnaire. The difference in the frequency between girls with and without problem gambling was notably larger than the difference between boys with and without problem gambling for several variables. For instance, the estimated difference in having tried other substances was 11% among boys in ninth grade and 24%, more than double, among girls in ninth grade (see Tables 2 and 3). This might be explained by the fact that girls with problem gambling are fewer but exhibit more severe psychiatric health problems [27,28].

Behavioral and substance addictions have previously been reported as robustly related [2]. Correspondingly, we observed that both male and female problem gamblers in ninth grade displayed a disproportionately high prevalence of having tried cigarettes, alcohol, and illicit drugs. The overrepresentation was seen among male and female problem gamblers in second grade of secondary school, with the exception of the female experience of alcohol. This is well in line with previous research showing that male gamblers drink more and female gamblers less [29]. Owing to legal regulations on gambling, most of the studies were conducted on adult populations, but several studies—some as early as those in 1998 [30]—showed that adolescent gamblers were more likely to drink alcohol, smoke tobacco, and take drugs compared to nongamblers [31]. Theories regarding the relationship between gambling and experience of cigarettes, alcohol, and illicit drugs have been suggested to be excitement-seeking and risk-taking personalities having similar social, environmental, neurobiological, and genetic features [31-34]. Petruzelka et al [35] suggest that the socioeconomic status plays an important role in this bad marriage. Díaz and Pérez [34] found that tobacco and alcohol users are more likely to gamble and spend more on gambling products. Further research is needed to increase the understanding of the causality.

ASD is an impairing and heterogeneous neurodevelopmental disorder with an early onset, which affects 1%-3% of the population [11]. ASD is characterized by social impairments, communication difficulties, altered sensory processing, and repetitive and restricted behaviors [11]. Studies have shown the following possible social gains for online gamers: decreased feelings of loneliness, increased feelings of connectedness to friends, increased social capital between players, and increased social bridging between players [12]. Based on previous research [36,37], we had expected a higher prevalence of gambling in the ASD group but we only found such a relationship among girls in ninth grade. This group had a higher prevalence of ASD and were less satisfied with their health compared to girls without problem gambling. In our study, the total number of participants with ASD was too small ( $n=20$ ) to draw any conclusions. There is a notable comorbidity between ADHD and ASD [38] and as we only logged the main diagnosis, there might be a possibility that there are some participants with ASD among participants with ADHD and vice versa. Looking at neurodevelopmental disorders from the ESSENCE (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations) perspective, we could have created a group consisting of participants with ASD plus ADHD to obtain a more realistic picture [39]. ASD does not belong to the most frequent conditions investigated in the relationship to a problem or addictive gambling and even less to a potential gender discrepancy. Our results warrant a more thorough investigation of the potential link between neuropsychiatric conditions and problem gambling among female adolescents.

Previous research reports on a relationship between problem gambling and both bad sleeping habits and sleeping difficulties [40]. The association between screen time and sleeping difficulties is established and highly clinically relevant since previous research describes how insufficient sleep is associated with both mental health problems and poor academic performance [41,42]. Concordantly, respondents in our material with problem gambling showed a positive association with  $<7$  hours of sleep per night among female and male ninth graders and among male second graders. Girls with problem gambling showed the same tendency, and it cannot be ruled out that an association would have been seen in a larger data material.

### Strengths and Limitations

Among the strengths of this study are the large, representative sample size, the fact that the study is population-based, and the use of a Bayesian statistical approach, which allowed us to make genuine probabilistic statements about our obtained estimates. However, notwithstanding the strengths of a fully Bayesian approach, the number of girls with problem gambling was relatively small ( $n=75$ ), and thus, the number of girls with both problem gambling and the presence of an associated factor was even smaller. As indicated by the wider HDIs, our findings pertaining to girls are therefore less robust than those pertaining to boys.

This study has several limitations. First, all measures used were based on self-report, which entails a risk for recall bias that could influence our findings. This study also shows considerable strengths. The survey was population-based and included a large



number of individuals and a relatively high response rate, which reduces the risk of selection bias. The only question regarding sleep was “How many hours do you sleep during a weekday?” with 3 fixed alternatives “less than 7 hours,” “7-9 hours,” and “more than 9 hours.” This item might have specified whether the sleep was continuous or intermittent, and a continuous scale for the numbers of hours of sleep during a normal weekday might have been included. However, the sleep item is part of a general public health questionnaire for adolescents in schools in southern Sweden with the aim of reporting the general public health status of this group regarding school, family, demographic, socioeconomic, social capital, social cohesion, social support, social participation/social networks, bullying (physical and cyber bullying), health behavior, somatic health status, psychological health status, exposure to crime, sex habits, and beliefs about the future in a comprehensive and reasonably short questionnaire. Furthermore, to the best of our knowledge, this is the first study to highlight problem gambling and associated factors among Swedish teenagers.

## Conclusion

Using a large representative sample of Swedish adolescents, we found that problem gambling was robustly associated with a substantially increased prevalence of poor sleep and having tried smoking, alcohol, and other substances among both boys and girls in ninth grade of primary school as well as among boys in second grade of secondary school. Owing to the small number of girls with problem gambling in second grade of secondary school, our estimates were less certain, but problem gambling was nevertheless robustly associated with a substantially increased prevalence of having tried smoking and having tried other substances, as well as (less robustly) with an increased prevalence of poor sleep. Furthermore, teenagers with ASD should possibly be considered as more likely to engage in problem gambling, specifically girls. Important and clinically relevant questions have been revealed for future studies to answer. Our study adds important information for policy makers pointing at vulnerable groups to be considered in their work to prevent problem gambling.

## Conflicts of Interest

AH has a researcher position at Lund University, which is sponsored by the gambling operator AB Svenska Spel. AB Svenska Spel is entirely owned by the Swedish state and is a part of that body’s responsible gambling policies. AH also has funding from the independent research council of Svenska Spel and the research council of the Swedish alcohol monopoly Systembolaget. These organizations are not involved in this project in any aspect.

## Multimedia Appendix 1

Supplementary data for tables.

[[DOCX File, 17 KB - pediatrics\\_v5i1e35207\\_app1.docx](#)]

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## Abbreviations

**ADHD:** attention-deficit/hyperactivity disorder

**ASD:** autism spectrum disorder

**ESSENCE:** Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations

**HDI:** highest density interval

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Original Paper

# Immersive Reality Experience Technology for Reducing Social Isolation and Improving Social Connectedness and Well-being of Children and Young People Who Are Hospitalized: Open Trial

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## Abstract

**Background:** Children and young people who are hospitalized can feel disconnected from their peers and families, which can, in turn, predispose them to psychological problems, including anxiety and depression. Immersive reality experience technology, recently developed by the New Zealand Patience Project Charitable Trust, may help to overcome these issues. Immersive reality experience technology uses immersive 360° live streaming and a virtual reality headset to enable children and young people who are hospitalized to connect through cameras located in either their school or home environment and via SMS text messaging with a designated buddy.

**Objective:** This trial aims to expand qualitative findings from a previous smaller *proof of concept* trial to ascertain the views of New Zealand children and young people who are hospitalized, their caregivers, and teachers regarding immersive reality experience technology and quantitatively evaluate the effectiveness of immersive reality experience technology in reducing social isolation and improving social connectedness and well-being using validated outcome measures.

**Methods:** An open trial of immersive reality experience technology was conducted between December 2019 and December 2020 for which 19 New Zealand children and young people aged 13 to 18 years who had been hospitalized at Starship Hospital—a specialist pediatric hospital in Auckland—for at least 2 weeks were recruited. All young people completed the Short Warwick–Edinburgh Mental Well-Being Scale, an abbreviated version of the Social Connectedness Scale, and the Social Inclusion Scale at baseline. Of the 19 participants, 10 (53%) used immersive reality experience technology as often as they wished over a 6-week period and completed postintervention measures. Semistructured interviews with a subset of the 10 young people, 4 caregivers, and 6 teachers were conducted immediately after the intervention.

**Results:** Participants reported improvements in social inclusion (mean change 3.9, SD 2.8;  $P=.06$ ), social connectedness (mean change 14.2, SD 10.0;  $P=.002$ ), and well-being (mean change 5.7, SD 4.0;  $P=.001$ ). Key themes from interviews with participants, caregivers, and teachers were the importance of support for using immersive reality experience technology, connecting versus connectedness, choice and connection, and the value of setting it up and getting it right. Recommendations for improving connectedness via immersive reality experience and related technologies were also provided.

**Conclusions:** Immersive reality experience technology can improve the social inclusion, social connectedness, and well-being of New Zealand children and young people who are hospitalized. With some technological modifications and simplified implementation, immersive reality experience and related technology could become part of standard care and support children and young people who are hospitalized in New Zealand and elsewhere to sustain family and peer cohesion, experience fewer psychological problems, and more easily return to normal life following the completion of treatment.



**Trial Registration:** Australian New Zealand Clinical Trials Network Registry ACTRN12619000252112; <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=376837&isReview=true>

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## KEYWORDS

immersive reality experiences; social isolation; hospitalized children; well-being; social connectedness; immersive reality; virtual reality; serious games; pediatrics; mental health; isolation; hospitalized patients; adolescents

## Introduction

### Background

Between 10% and 12% of children and young people worldwide, and up to 22% of New Zealand Māori taitamariki (children and young people), experience long-term physical conditions (chronic illnesses) such as cancer, diabetes, and cystic fibrosis [1]. Many spend weeks or months in hospitals, disconnected from their wider families, peers, and schools [2]. Social disruption and exclusion may be related to psychological problems, including anxiety and depression, and may be associated with reduced academic achievement [3-5]. Conversely, social inclusion during treatment may be associated with improved psychosocial functioning [6]. Psychosocial support offered to children and young people who are hospitalized varies widely [7]. For example, many rural institutions or those in lower income countries offer minimal formal support, whereas specialist pediatric centers in others have access to multiple resources (eg, on-site consultation liaison, mental health teams, play specialists, and volunteer organizations). Despite the support available in more developed countries, resources are usually focused on supporting medical treatment rather than improving social connections [8].

Over the past few decades, advances in technology have led to the development of a wide array of eHealth interventions, including websites, self-help apps, health games, and devices that provide immersive reality experiences [9]. A number of these were developed for, or trialed with, children and young people with long-term physical conditions [10]. Immersive reality experience technology engages users in an alternate, real environment, virtual environment, or a combination of real and virtual environments [11]. Immersive reality experience technology has been shown to reduce psychological stress and improve mental health in adults [12,13], children with disabilities [14], and older adults [15]. In some cases, immersive reality experience technology has been shown to enhance engagement in schoolwork and improve emotional well-being in children and young people with long-term physical conditions [14-17]. However, factors affecting the use of immersive reality experience technology by this group, such as hardware issues, privacy concerns, and the impact of health status and hospitalization, are not well-described in the literature.

In 2018, the Patience Project, a New Zealand charitable organization headed by one of the members of our research group (BM), developed a virtual reality (VR) environment-based system of immersive reality experience technology to connect children who are hospitalized with peers at home and school. Two-way communication was possible through the young person using the immersive reality experience

technology texting a designated buddy in their school environment to ask questions to the teacher on behalf of the absent young person or strike up a conversation with their peers. This was the first intervention of its kind in New Zealand. A formative assessment of the Patience Project was conducted with 15 participants in 2018 [18] and aimed at developing an understanding of the perceived strengths and weaknesses of the project to inform future directions. A total of 5 children receiving oncological treatment at Starship Hospital, a tertiary pediatric hospital in Auckland, New Zealand, along with their teachers and caregivers, comprised the sample. Despite the small sample, the formative assessment elicited valuable information about young people who experience social disruption and the potential for immersive technology to facilitate and sustain connectedness to familiar environments and to peers. This exploratory investigation supported the viability of undertaking a more formal open trial described in this paper.

### Objectives

This trial was conceptualized by two authors (HT and CF) with the following aims:

1. To investigate the acceptability of immersive reality experience technology for children who are hospitalized, families, and school staff
2. To examine the effectiveness of this technology in improving social connectedness, reducing social isolation, and improving the well-being of children who are hospitalized
3. To provide information regarding the feasibility of a more definitive randomized controlled trial (RCT)

## Methods

### Recruitment and Sample

A mixed methods trial design was used. We aimed to recruit a convenience sample of up to 40 children and young people admitted to Starship Hospital, a tertiary pediatric hospital in Auckland, New Zealand, between December 2019 and December 2020. However, because of the COVID-19 pandemic and its potential risks to the young people in our sample who already have compromised immune systems, we were unable to recruit all 40 potential participants for 6 months between March and September 2020. This led to the final recruitment of 19 young people to trial the immersive reality experience technology, 10 (53%) of whom felt well enough to complete the intervention. In addition to the study participants, we also aimed to recruit up to 10 caregivers and 10 school staff who supported the young person's participation in the classroom to take part in semistructured interviews after the intervention. Of these 10 young people, 4 (40%) young people and their



respective caregivers, together with 7 teachers, provided in-depth feedback. Fortunately, this number was sufficient for us to obtain rich qualitative data regarding the acceptability of immersive reality experience technology and some quantitative data regarding its effectiveness.

The participants were provided with information about the trial via their clinical teams. Participating teachers were actively recruited by a research assistant. All other participants learned about the project through waiting room conversations at the hospital with a physician or nurse or, in one case, a television advertisement. The required inclusion criteria for young people to participate in this trial were as follows: (1) aged 13 to 18 years, (2) presence of any medical condition, and (3) admitted to Starship Hospital for more than a 2-week period or intermittently over a 6-month time frame. Three exclusion criteria were set as follows: (1) children aged <13 years or adults aged >18 years, (2) individuals with a physical or mental health issue that prevented exposure to immersive reality experience technology (eg, severe seizures), and (3) those not able to provide informed consent (or assent with caregiver consent). All participants received a US \$25 gift voucher for their participation.

A total of 19 young people were recruited via their usual clinicians at Starship Hospital, of which 10 (53%) used the intervention. Of the 9 young people who did not use immersive reality experience technology, 2 (22%) reportedly found it too difficult to use, 1 (11%) was too unwell for the duration of the trial, 1 (11%) left the hospital sooner than expected, 1 (11%) did not provide a reason, and the schools of 4 (44%) other young people declined to allow immersive reality experience technology to be used in their classrooms despite ethics committee approval of the project and personal explanation by a research assistant.

All 19 young people completed preintervention questionnaires at the time of recruitment, and the 10 young people who completed the intervention filled out postintervention questionnaires. Only 40% (4/10) of young people took part in semistructured interviews; thus, their data were analyzed alongside those of caregivers and teachers. Characteristics of all the recruited young people are further described in Table 1. To maximize confidentiality, no data were collected regarding the type of long-term physical condition or conditions participants were experiencing.

**Table 1.** Characteristics of participants.

Characteristics	All participants			Participants who completed the intervention			Participants who completed interviews		
	Young people (n=19)	Caregivers (n=4)	Teachers (n=6)	Young people (n=10)	Caregivers	Teachers	Young people (n=4)	Caregivers (n=4)	Teachers (n=6)
Age (years), mean (SD; range)	14.3 (1.3; 12-17)	N/A <sup>a</sup>	N/A	14.2 (1.0; 13-16)	N/A	N/A	14.3 (1.0; 13-15)	N/R <sup>b</sup>	N/R
<b>Sex, n (%)</b>									
Male	9 (45)	0 (0)	3 (50)	5 (50)	N/A	N/A	1 (25)	0 (0)	3 (50)
Female	10 (50)	4 (100)	3 (50)	5 (50)	N/A	N/A	3 (75)	4 (100)	(50)
<b>Ethnicity, n (%)</b>									
New Zealand European	5 (26)	3 (75)	6 (100)	3 (30)	N/A	N/A	3 (75)	3 (75)	6 (100)
New Zealand Māori	5 (26)	0 (0)	0 (0)	1 (10)	N/A	N/A	0 (0)	0 (0)	0 (0)
Pacific Islander	5 (26)	0 (0)	0 (0)	3 (30)	N/A	N/A	0 (0)	0 (0)	0 (0)
Asian	3 (16)	1 (25)	0 (0)	3 (30)	N/A	N/A	1 (25)	1 (25)	0 (0)
Other	1 (5)	0 (0)	0 (0)	0 (0)	N/A	N/A	0 (0)	0 (0)	0 (0)

<sup>a</sup>N/A: not applicable.

<sup>b</sup>N/R: not recorded.

## Intervention

The used immersive reality experience hardware included an Oculus Go (Meta Platforms) all-in-one VR headset and laptop, either of which could be used by children who are hospitalized to see and hear others, and an Insta 360 Pro 360° revolving camera and screen that could be situated in homes or schools for a young person who was absent from that environment to virtually see and move around the environment. In addition, the intervention included a buddy system, whereby a designated individual could communicate with the young person who is hospitalized via text. The young person who is hospitalized would contact the teacher in advance of a scheduled lesson.

Cameras were turned on by the teacher at the start of the class and left on until the young person no longer felt like participating. The equipment had no recording capability.

## Data Collection

Following the completion of consent procedures and paper-based outcome measures, for the quantitative portion of this study, young people were given access to immersive reality experience technology for a 6-week period, and then the outcome measures were repeated. We used the following outcome measures: the Short Warwick–Edinburgh Mental Well-Being Scale (SWEMWBS), Social Connectedness Scale, and Social Inclusion Scale. The SWEMWBS is a short version of the

14-item Warwick–Edinburgh Mental Well-Being Scale, which comprises positively worded items measuring different aspects of positive mental health [19,20]. The SWEMWBS is a 7-item scale that asks participants to rate their experience of a range of thoughts and feelings (eg, “I’ve been dealing with problems well”) over the past 2 weeks on a 5-point Likert scale ranging from 1 (*none of the time*) to 5 (*all of the time*). The score is calculated by summing the individual ratings and transforming the total into a metric score using a transformation provided by the scale authors. Scores range from 7 to 35, with higher scores indicating greater positive mental well-being. The original scale has demonstrated good content validity and is correlated with other mental health and well-being measures [19]. The short version has demonstrated similar reliability and validity to the full version ( $\alpha=.84$ ) and is suitable for use by adolescents [21,22]. The Social Connectedness Scale is a 20-item scale measuring the degree of interpersonal closeness that individuals feel between themselves and other people, both friends and society. Sample items include *I feel disconnected from the world around me* and *I don’t feel related to anyone*. Items are rated from 0 to 6, with higher scores representing a stronger sense of belonging. The scale has been shown to have good internal and test–retest reliability [23,24]. We used an abbreviated version of the scale, comprising the first 8 positively framed items, with a total score of 48. The Social Inclusion Scale is a 22-item scale for measuring social inclusion that has been validated in young adults and contains three subscales for social isolation, relations, and acceptance [25]. We adapted some of the language for use with our adolescent population but did not change any of the actual items.

Qualitative data were collected through separate semistructured interviews, lasting between 30 and 45 minutes each, and were then undertaken by two members of the research team (CF and LAC) with 16 participants, including 4 (25%) young people (3, 75% female and 1, 25% male), 4 (25%) caregivers (all mothers), and 7 teachers (4, 57% female and 1, 43% male), as well as the project custodian. The aim of the interviews was to understand views on the acceptability and usefulness of the immersive reality experience technology. Interviewees reported that the number of engagements (ie, times the young person connected to their classroom via immersive reality experience technology) varied between 3 and 12 sessions. The typical length of each engagement was between 30 and 60 minutes. Engagements were usually shorter when students were in the hospital and received treatment on the day.

### Data Analysis

Quantitative data were analyzed by two members of the research team (HT and HK) using Microsoft Excel (version 16) and IBM SPSS (version 25). Quantitative analyses included basic descriptive statistics (eg, changes in scores on validated scales and demographic characteristics of the sample), and changes in

social connectedness, well-being, and social inclusion were evaluated using the nonparametric Wilcoxon signed-rank test. A  $P$  value of  $<.05$  was taken to indicate statistical significance, and 95% CIs were used to establish the extent of any difference between before and after measures. A sample size of 40 was calculated a priori using Strata (version 15) software to enable detection of changes of 0.5 SD in the primary measure of well-being (using the SWEMWBS) with 80% power. Interviews were audiotaped using a Phillips VoiceTracer digital recorder. The recordings were transcribed, and the transcripts were deidentified by a registered transcriber who had signed a confidentiality agreement with the University of Auckland. To analyze the data, individual transcripts were coded thematically using a 6-step coding process using NVivo 12 software (QSR International) [26]. After transcript familiarization, separate codes were linked to one of three separate case groupings distinguished as either caregiver, teacher, or young people’s reflections on the project. Under each of these groups, the codes were arranged into categories based on the relationships established among them. The initial categories and subcategories were refined by 2 authors (CF and LAC), only including codes in a category if  $\geq 2$  interviewees referred to the idea. Any differences were resolved by consensus. All authors were involved in drafting and reviewing the manuscript.

### Ethical Issues

The study received ethical approval from the New Zealand Health and Disability Ethics Committee in December 2018 (reference: 18/NTB/241). Participants were approached via their clinical teams rather than directly by the research team to minimize coercion. Consent for participation was obtained directly for those aged  $>16$  years and via caregivers with participant assent for those aged  $<16$  years. Consent for participation in semistructured interviews by young people, caregivers, and teachers was obtained separately. School principals provided signed consent for their teachers and students to be involved in the trial. Participants were informed that they were free to depart from the trial at any stage. All data were deidentified before analysis and publication.

## Results

### Quantitative Results

At baseline, participants reported moderate levels of well-being, social connectedness, and social inclusion. Following the use of immersive reality experience technology, 70% (7/10) of participants reported improved social inclusion, 80% (8/10) of participants reported improved well-being, and all participants reported improvement in social connectedness. Changes in social connectedness ( $P<.05$ ) were statistically significant, as described in Table 2.

**Table 2.** Changes in social isolation, social connectedness, and well-being following the use of immersive reality experience technology (N=10).

Measures	SWEMWBS <sup>a</sup>		SCS <sup>b</sup>		SIS <sup>c</sup>	
	Before	After	Before	After	Before	After
Values, mean (SD; range)	22.4 (5.2; 17-32)	28.1 (4.5; 20-35)	27.6 (11.2; 10-45)	41.8 (6.9; 29-48)	42.1 (4.8; 34-49)	46 (4.2; 40-54)
Values, mean difference (SD)	N/A <sup>d</sup>	5.7 (4.0)	N/A	14.2 (10.0)	N/A	3.9 (2.8)
<b>Wilcoxon signed-rank test</b>						
Negative ranks	N/A	0 <sup>e</sup>	N/A	0 <sup>e</sup>	N/A	3 <sup>e</sup>
Positive ranks	N/A	8 <sup>f</sup>	N/A	10 <sup>f</sup>	N/A	7 <sup>f</sup>
Ties	N/A	2 <sup>g</sup>	N/A	0 <sup>g</sup>	N/A	0 <sup>g</sup>
Total	N/A	10	N/A	10	N/A	10
P value	N/A	.12	N/A	.01	N/A	.07

<sup>a</sup>SWEMWBS: Short Warwick–Edinburgh Mental Well-being Scale.

<sup>b</sup>SCS: Social Connectedness Scale.

<sup>c</sup>SIS: Social Inclusion Scale.

<sup>d</sup>N/A: not applicable.

<sup>e</sup>Post-immersive reality experience scores lesser than pre-immersive reality experience scores.

<sup>f</sup>Post-immersive reality experience scores greater than pre-immersive reality experience scores.

<sup>g</sup>Post-immersive reality experience scores equal to pre-immersive reality experience scores.

## Qualitative Results

Four major themes were derived from the experiences of young people, caregivers, and teachers involved in the trial:

1. Support for immersive reality experience technology
2. Connecting versus connectedness
3. Choice and connection
4. Setting it up and getting it right

All participant quotes are distinguished by the following: young person, caregiver, and teacher.

### Support for Immersive Reality Experience Technology

Young people in this project echoed the sentiments of those who trialed the equipment assessment in 2018 in terms of their support for the technology [18]. Immersive feelings of *being there (in the chosen environment)* and the project as *cool* were still prevalent descriptors about the appeal of the technology by young people:

*It feels like you're kind of there, so I think that was really cool, when you think about it...I was fascinated about the idea, you know? On the headset...you could watch things...there were games and stuff. So, it was pretty cool doing that. [young person 4]*

*I talked to my friends, and they said that it was pretty cool, and they would love to do it. [young person 19]*

Caregivers also expressed the same enthusiasm for the technology:

*Funnily enough at parent interviews lots of parents have said, "hey my daughter had come home" even though she wasn't in that particular Year 9 maths class, "and talked about this camera. I think it's*

*amazing that your school has taken this on board!" [teacher 18]*

Contributing specifically to the appeal of the technology was its ease of setup, as noted by different teachers:

*It would take all of about a minute to get going and I didn't feel that was too time-consuming. [teacher 24]*

*The camera is easy, it was all plugged in, you just had to press the button. [teacher 13]*

*The camera obviously was very unobtrusive, so it created no real difficulties for me in the classroom. It's just a very small device on a stand that we positioned in the middle of the class...it gave no real concerns about us getting around it. [teacher 18]*

Barriers to support for the technology in schools were initially encountered in terms of the ethical concerns related to recording children. However, this was resolved swiftly once permissions were obtained, and staff were briefed on how the technology would function:

*Other than the fact that the school had to sort permissions and stuff, but once they realized classes won't be recorded, there were no problems. [teacher 3]*

Several teachers noted the capacity of the technology in the classroom to generate opportunities for improved understanding about fellow students who were homebound or hospitalized. A teacher recalled a discussion about inclusion and isolation with her students:

*The biggest thing is that I saw it as a learning opportunity for the other students in the class. We had some really nice conversations about inclusion...When they see it there, they think, oh is*

that [name of young person who is home or hospital-bound]? And then my other students would notice the camera, particularly Year 12 or Year 10 and it's like, "what's that?" I'd explain to them what it is, and they're like, "What? So, she still has to do her homework?...Like oh that's ridiculous, you can't even escape it in hospital." I'm like, no—I explained it's not for learning. They're like "Oh Wow." And then they realize the real reason...That opens up conversations about isolation and how fortunate they are to be in school, healthy, with their friends, all that stuff. [teacher 6]

All caregivers and teachers acknowledged that they would not hesitate to tell other families about the Patience Project as it helps young people retain a sense of familiarity with the learning environment and their peers. Young people echoed these sentiments, as best exemplified by the following participant:

*Everyone who's in hospital and going through the same thing, just to catch up with your friends and feel*

*like you're kind of connected in the same way. It's just good... 'cause you don't wanna miss out on being with your friends [young person 4]*

### Connecting Versus Connectedness

Although the immersive reality experience technology enabled young people to connect to their chosen environments, connecting did not always result in the sense of connectedness. Caregivers shared mixed perceptions (Textbox 1) on whether the technology had significantly affected the young person's connectedness to their peers or made or was making their ability to return to school easier. Some caregivers concluded that there was no significant impact in these areas and suggested there might even be an increase in stress because of a sense of obligation to participate. Others described the connections made to the classroom as beneficial to break up the monotony of hospital and recovery days. In a few instances, the same caregiver noted that the connectedness capacity felt a little superficial from their perception but also acknowledged the joy experienced through participating.

**Textbox 1.** Caregivers' mixed perceptions of participation benefits for the young person.

#### Participation as beneficial for connectedness

- "My opinion is that even if you're [the YP] just there in the lesson it's better than not being there, because you'll pick up something rather than nothing." [caregiver 20]
- "I was in tears, tears of joy rather. Not sadness, joy. Thinking wow, there's something for kids who really do feel isolated. Because [she] was having a really tough time. And the first time when she connected I think I had the biggest smile on my face, seeing her smile." [caregiver 5]
- "I guess with the camera, the kids hadn't forgotten him." [caregiver 29]
- "I think there's been one child, one or two children who came and met her at hospital, which means that this connection does help. Because in the past we've really never had many people come and visit from school." [caregiver 5]

#### Participation as nonsignificant for connectedness

- "You know they may have anxiety about, 'well I'm on this and I'm supposed to be doing this so many times a week. And it's not happening'. So yeah, I guess in some ways it could add to a bit of stress, feeling like they have to make sure they're on it." [caregiver 2]
- "I don't think that it built...any new friendships or anything like that. I don't think that the camera would have helped him feel like he can fit in again...I think it's superficial and I also think it's a huge novelty at the start." [caregiver 29]
- "I don't think it's really made a major significant difference to be honest." [caregiver 2]
- "She was excited the first time. The second time she was like 'Mum, it's boring. Cause English is boring.' She was only connecting because she had friends in that class. And the thing is, because the class is still going, you're not able to have a specific conversation with your friend, right?" [caregiver 5]

Caregivers predominantly held a help-more-than-hinder attitude toward the technology. However, the acknowledgment that some aspects of the experience and the context within which it was engaged might be limiting is an important reminder that technology might interrupt or reduce feelings of isolation but not always incite a sense of connection. Two young people also reiterated the fact that the novelty of participating wears off, as exemplified by the following quote:

*I kind of just got used to it. Turned it on, texted me just through text for a bit. And then when class started, they'd get back into it, they would be doing their work and I would be doing nothing much. [young person 19]*

These connecting experiences were also influenced by a number of factors, including whether the connection was stable, whether

the young person's buddy was reliable, the effectiveness of the interaction loop (ie, between the young person, their buddy, and the teacher), and whether the young person was feeling unwell on the day they chose to connect. Despite these factors, and in light of the insights regarding participation as potentially nonsignificant for connectedness, future adaptations of the project should consider actions to enhance the formation of strong connections, as shared by the following young person:

*It would've been nice to be able to shift classes and maybe even be able to participate a bit more or something like that. Maybe even be able to have like a virtual worksheet or something that I could do along with the class. Instead of sitting there watching them do the work. [young person 28]*



The need for more interactive participation was stated by all the young people.

Although not producing a sense of connectedness in all instances, all participants in semistructured interviews acknowledged that using the immersive reality experience technology was beneficial as a means of maintaining a connection with the school environment, which is best represented by the following quote:

*I was able to connect with my teachers a bit more. And about who they are a bit and understand what their expectations or something are. They can get to know me and everything too. So, it was much more comforting than showing up to the first day of class and just being shocked because some teacher might yell at you for using the wrong kind of pencil or something like that. [young person 28]*

Caregivers also saw gaining familiarity with the school environment through the camera as facilitating the return to school:

*I think it would help her in the sense that she knows what's been going on. So, you know you'd hope that she'd be able to slot back in quite easily. [caregiver 2]*

Building on the idea of maintaining a connection, teachers noted the technology as a good way of easing back into school life after extended periods away through maintenance of connections with peers:

*The girls were very engaging with the camera, they would talk to her in the camera, I would call her name out on the role every day. We'd all wave to her...She couldn't talk back to the girls, but they would say, hey what are you doing? How's it going? We're doing this in class. Oh, we've got a mufti (casual attire) day today because of da, da, da. All that type of thing and then occasionally she'd message the buddy back on her computer and just say, hey, nice to see everyone, wish I was there, say hello to everyone for me. But instantly there was that connection going backwards and forwards, which was fantastic. [teacher 18]*

Another teacher noted that education was a secondary benefit of using the technology:

*I think some of these kids are so sick, who cares if they're not doing the work...it's a connectedness, the feeling of belonging, able to see their peers through that lens, able to feel like they're part of that classroom again. It might just be a little, you know, half an hour of their day which they feel like a normal teenager. [teacher 18]*

Caregivers shared similar sentiments about the purpose of the technology to be more about peer connections than education:

*It's not about learning English. It's more about connecting with your friends and being able to, as I said, go back and find it easier to go back. [caregiver 5]*

## Choice and Connection

For the young person, connecting and building connectedness was centered on choice (ie, who, what, when, where, and how of their choices).

### When and Where to Connect?

Timing is crucial for young people wanting to and feeling physically able to connect. Young people predominantly made a choice to connect to the classroom where they could spend the most time (ie, choosing English, as that class was also the young person's homeroom where they could have informal conversations). However, sometimes the choice of room or timing did not equate to a satisfying participation experience, as noted by the following young person:

*It was a very hit or miss sort of deal. Because, of course, if I had social studies in first period, I needed to make sure that I was up, like, by 9 o'clock, get on everything, do all that, especially considering when I first woke up, I would get, yeah, nausea, just a bit of sort of, like, not feeling great. And then you hop into virtual reality and you're surrounded by all this noise, and it's just sort of hard, yeah. [young person 28]*

A caregiver reiterated this young person's sentiment in describing her daughters' hit or miss experience:

*When you've got a sick child it's actually day by day. So the practicality of it—we'd wake up some days and she would be like yeah, I'm good to go...other days she'd wake up and go no, I'm not getting out of bed today..., it's one of those things. [caregiver 20]*

Having increased possibilities for when to connect may foster a sense of control or power over aspects of daily life that have been lost with the illness.

### How and With Whom to Connect?

Considering the social nature of the Patience Project, it is imperative to understand the different types of dynamics at play, including the fact that there is a buddy system. In particular, it is important to consider how decisions about the buddy system are determined and perceptions of friendships are formed by other students. Some participants described very positive experiences with their buddy, whereas others noted jealousy arising among peers in the classroom, who assumed they should be the designated buddy, with some disturbances arising in the friendships:

*At one stage, one was definitely on the outer. But I'm not sure. I wondered if it was because [the buddy] had been chosen as [the young person's] buddy. I even wondered if there was a little bit of jealousy there, I'll be honest...I did alert the dean to it just in case she could have a quiet word. [teacher 21]*

Other disturbances to friendships were also expressed. A young person noted their disappointment after their chosen buddies stopped communicating frequently:

*My close friends...didn't come and I was just really upset about that. I didn't really wanna talk to all of*



*them then, and I was just really upset because I would always put it in the group chat and be like, “hey guys, you wanna come over?”...My friends that were really nice and wanted to come are on my headset thing. And none of my other friends really knew about it. But when I tried to tell them...it felt like their lives just kept going and they didn't really care about me.*  
[young person 4]

This young person's experience is an important reminder to not underestimate the fact that when young people have choices with technology, it may come with risks.

### **Why Connect?**

All caregivers and young people similarly stressed the need to view the project as noncompulsory, as conveyed in the following statement:

*I do recommend it to someone for socialisation. But I would probably stress to them, like, heavily stress to them it's not compulsory, it's not for education, it's for socialisation.* [young person 28]

However, some caregivers and young people conveyed difficulty in engaging out of a sense of obligation because of the opportunity versus genuine motivation on the day:

*This is purely from us and not from [project custodian] because I think she goes through so much trouble having it all set up and this camera couriering around the country, and the school setting it up and all of that. I think that you feel “I really should [connect].” Like all this trouble's happened for me. Not that there's any pressure at all put on from the Patience Project end. But I think that's just natural human nature, that if somebody's done something for you—you want to make the most of it.* [caregiver 29]

## **Setting It Up and Getting It Right**

### **Overview**

When it comes to enhancing the experience of using the immersive reality experience technology to connect and build connectedness, participants asserted the need to get it fully right from the initial setup. Otherwise, it may become *a bridge too far*. A young person's ability to engage was conveyed as hinging on three important factors:

1. The technology must work well every time.  
Participants in all groups recalled technical glitches in terms of noise, connection difficulties, and inability to see the board or teacher effectively at some points.
2. To maximize the use of technology, it needs to be easily movable.  
This factor builds on the findings previously mentioned and aims to put power back into the hands of the young person, allowing them to facilitate choice over the environment for the camera. Teachers communicated that the increased mobility of the camera might enhance the educational capacity of the technology.
3. The ease of use for all parties involved is imperative.

Participants indicated that if they had to struggle with any part of the process of connecting, they would give up and consider trying another time.

Participants across all groups suggested ideas concerning these three factors, which they viewed as potentially enhancing the experience from the start, each fitting within one of the five categories:

1. Connecting participating teachers
2. Formation of bonds
3. Mock sessions before participation
4. Device mobility
5. Education about virtual connections

### **Connecting Participating Teachers**

This involves a channel to share specifics of the process and any inclusive activities to engage students on the other side of the camera.

### **Formation of Bonds**

Bonds with the teacher and a buddy were central to the project's success and moved it from the aforementioned *a bridge too far*. From the young person's perspective, when a buddy was unreliable, their connecting experience was compromised. Young people reported mixed experiences in this regard:

*Because my buddy just really wasn't in touch at all. And then I couldn't find when my class.* [young person 1]

versus

*She turned it on and she turned it off. She was fun. She was a lot of fun in the class, so she could text me and I could text her.* [young person 19]

Two caregivers suggested that it might be best for the teacher to choose someone they perceive would be a reliable buddy so as to not risk existing friendships and create opportunities to build new connections. Caregivers indicated that an individual such as the project custodian is imperative to young people's engagement and ensuring that buddies and teachers fulfill their roles. Both caregivers and young people were appreciative of the participating teachers, specifically those who embraced a new way for young people to connect to the classroom. Participants deemed it essential to have a competent teacher who will make the most of the technology and use the experience to educate other students about illness and isolation. Gauging this enthusiasm early may be a good indication of the type of interaction loop that will arise between the young person, the buddy, and their teacher.

### **Mock Sessions Before Participation**

Having an understanding of what the young person could see on the other side of the camera was described as an important consideration for teachers to understand the experience more holistically so that they can serve the students' learning and connecting needs more effectively (ie, is board work clear? Is the camera close enough to see the content?). The idea of participating in mock sessions was also proposed as a support to help the chosen buddy grasp the importance of the session.

### Device Mobility

It was unanimously suggested that if the device were easily mobile, the number of engagements would be far greater, and the student's experience would perhaps be increasingly meaningful.

### Education About Virtual Connection

Participants referred to the need for education about the project and education about virtual inclusion initiatives. A teacher described their future tips for class education as being central to getting it right from the beginning:

*...the teacher needs to spend the time explaining the meaning behind it, why has it been designed, if you were in the students shoes do you think it would be helpful for you? Show the clip, Ben explaining his reasons for developing it...when the kids have full context they engage with it, they're completely on your side, they engage with the participant and then I think they get 100 times more out of it. Being totally honest and upfront with the class from the beginning I think gives you the best possible outcome. [teacher 18]*

Two teachers described how in parent-teacher interviews, caregivers said, "I think it's amazing that your school's taken this onboard" after expressing their child had come home describing the technology and its purpose. Young people also highlighted the need for further training on how to use the technology:

*There was a bit of a problem with the VR set...because I didn't know how to make it 360, I couldn't find the setting. So it was just on a big screen. I was on my laptop. So, yeah. But it was fine other than that. [young person 19]*

Both teachers and caregivers noted initial concerns about who else would see into the classroom, whether the sessions were being recorded, and whether the teacher was being judged by onlookers. The Patience Project was designed for the child's eyes only, and after speaking with the project custodian, teachers and students in the classroom felt assured that privacy would be upheld.

Adding to a need for education, encouraging the heads of schools to use the project as a tool to bridge unmet needs was also described by a caregiver. Helping teachers and heads of school move beyond *the too hard basket* mentality when it comes to children who are home and hospital bound was a significant concern of a few caregivers who struggled to find support for their children upon initial diagnosis. Thus, the Patience Project helped with connection to educational and social environments, even if only for familiarity purposes—a need not previously met, as described by a caregiver:

*About October she was feeling better and she goes "mum, can you get me some work?" ...I contacted her teacher and no one would get back to us. It was in the too hard basket for them. I asked, "Can these kids not Skype into their classrooms? We Skype all the*

*time and you're telling me we can't do this?" [caregiver 2]*

Educating the staff (head teachers to classroom teachers) was also noted as a way of fostering supportive environments for the immersive reality experience technology for schools:

*I spoke at a staff afterschool meeting, talked about it and showed how it worked...did some photos, did a little video clip of how it works in my general day to day class room and explained it to our staff of 120. And at the end they were...blown away! I guess, by the technology and the opportunity that students like [she] could get by having that camera in the class. [teacher 18]*

These education sessions often turned into curiosity about the technology, as another teacher noted the following:

*I obviously briefed all the teachers; told them about the camera in my class and the reason for it etcetera. They thought it was a worthwhile initiative and some came round to have a look at how it worked. [teacher 3]*

Aside from one teacher who was respecting the privacy of the participant, all participants described sharing with staff and students as a positive experience, and all stated that they would happily be involved again.

## Discussion

### Principal Findings

Our results provide valuable information regarding the acceptability of immersive reality experience technology and what might be required for its successful implementation. The technology appealed to many of our trial participants, and there was an acknowledgment of its potential to facilitate learning and ease the transition back to normal life, particularly school following an illness. Our findings also provide a preliminary indication of its effectiveness at improving well-being and social connectedness and, to a lesser extent, improving social inclusion and disrupting social isolation for young people with long-term physical conditions.

A handful of other devices and web-based and text-, audio-, and video-based technologies have been trialed over the past couple of decades to connect children who are hospitalized with schools and meet their academic and social needs in international contexts outside New Zealand [27]. These include a communication app for young people with cystic fibrosis [28], an ambient technology-based orb in the classroom [29], and the Presence app [30]. To date, no studies have used virtual or immersive reality. Most previously studied interventions demonstrated similar qualitative acceptability to that of immersive reality experience technology [14,31]. Only one open trial of the 2-way, web-based Bednet tool [32] demonstrated improved social connectedness using a Likert scale, and a nonrandomized trial of a CareRabbit robot that helps children stay in touch with family and friends [33] has demonstrated nonsignificant differences in well-being between groups. Thus, our study is the first trial of a hospital to school communication

system to demonstrate improvements in both social connectedness and well-being.

A number of participants in our trial experienced personal, health-related, technological challenges and school-related barriers to its use. Some simply did not find the technology engaging enough to continue using it. Others experienced challenges in getting the equipment to work. Duration and frequency of use were often related to users' state of health or treatment schedules, with greater use on days when they were feeling well or not attending medical appointments. Acceptance of cameras in classrooms, knowing how to use them, and socializing classroom buddies and fellow students also proved difficult for some schools. These issues have all been experienced by the developers of similar interventions [27] and, rather than being reasons for their disuse, are probably key barriers to target during implementations. They are also issues to consider during the design of a more definitive RCT. Allowing greater time, sourcing participants from a larger catchment, and engaging schools in advance of participant recruitment would be useful.

Young people's sense of connectedness appeared to be dependent on everyone else's connection and ability to foster connectedness (eg, the buddy connecting, friends continuing to engage with them through the device, family or whanau communicating with teachers when a child is unwell, and teachers communicating classroom activities and checking in via the device). For some, the social connectedness they experienced was superficial; however, they still embraced the moments of interrupted isolation the technology offered. For others, it worked exceptionally well, indicating that all the dependent factors functioned in cohesion. It was reassuring that most caregivers and teachers supported the use of the immersive reality experience technology. Although some caregivers were focused on the educational benefits of connection between hospitals and schools, most appreciated the value of social connectedness for their children's well-being. Teachers were also positive about the child's right to inclusivity and the formation of new, and maintenance of old, friendships between students in the classroom and young people who are hospitalized. This may be attributed to the fact that they were witnessing (at least in part) what the young person was seeing on the other side of the camera in terms of peers in the classroom speaking to the camera, asking questions about the situation, and seeing the 2-way communication loop (ie, texting) between the buddy and young person occur. Effective education regarding the purpose of the trial and training in how to use immersive reality experience equipment were key parts of this process.

VR-based technology is not new. It has been shown to be useful for distraction, pain reduction, and relaxation during the treatment of children and young people who are hospitalized and has improved in quality over the past decade [34,35]. Illness or treatment-related nausea reportedly detracts a subset from fully engaging with the immersive reality experience technology. A future trial that includes VR and non-VR arms would help clarify the additive value of VR headsets. Having a reliable *buddy* at the other end of the connection was a more relevant issue for most participants. Being able to connect in a flexible

manner, including being able to choose between the use of VR and non-VR methods, also probably helped to foster a sense of control or power over aspects of daily life that have been lost with illness. The reliability of technology appeared to be especially important for participants, with connection difficulties and inability to see the teacher or board and inability to move the camera sometimes proving to be *a bridge too far*. Although the COVID-19 pandemic significantly affected recruitment, it may also have normalized children's access to educational environments through virtual media. Evident from the increasing openness of teachers to immersive reality experience technology toward the end of the trial, this phenomenon deserves greater investigation.

The strengths of this trial include participation by young people with a range of long-term physical conditions, the collection of both quantitative and qualitative data with which to better understand the experience of individuals using immersive reality experience technology, and triangulation of participant views with those of their caregivers and teachers. Low recruitment because of COVID-19-related restrictions in access to patients who are hospitalized and the consequent absence of any participants aged 17 to 18 years were the main limitations of this trial, as was the absence of any qualitative data from participants who did not use the intervention and those who were too unwell or elected not to be interviewed, which might have provided less favorable perspectives. Nonetheless, we were pleased to observe qualitative evidence of acceptability and improvement in all quantitative outcomes. The generalization of trial results to other settings cannot be assumed from our findings, nor can effectiveness and acceptability to individuals from different cultural backgrounds. A larger trial is needed to confirm our preliminary quantitative results. It would also be useful to collect objective data regarding the actual time spent using the immersive reality experience technology. A more in-depth analysis of hospital and school-related factors affecting engagement and setup; the impact of COVID-19 on openness to virtual communication between hospitals and schools; the use of e-mentors, as suggested by Ellis et al [36]; and the value of liaison workers in schools (eg, health school staff and health school teachers) [37] would be useful to augment the effective use of immersive reality experience. Considering feedback to date, immersive reality experience technology is being adapted and integrated into lower cost, multimodal communication by the Patience Project Charitable Trust. This should improve its portability and applicability to a greater number of users.

## Conclusions

This trial demonstrates that immersive reality experience technology has the potential to improve the well-being, social connectedness, and social inclusion of New Zealand children and young people who are hospitalized. It also provides valuable information regarding the feasibility of a more definitive RCT. With some technological modifications and simplified implementation, immersive reality experience and related communication technology could become part of standard care and support children and young people who are hospitalized in New Zealand and elsewhere to sustain family and peer cohesion,



experience fewer psychological problems, and more easily return to school and normal life following completion of treatment.

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## Conflicts of Interest

None declared.

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## Abbreviations

**RCT:** randomized controlled trial

**SWEMWBS:** Short Warwick-Edinburgh Mental Well-Being Scale

**VR:** virtual reality



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Original Paper

# The Development of an mHealth Tool for Children With Long-term Illness to Enable Person-Centered Communication: User-Centered Design Approach

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## Abstract

**Background:** Children with long-term illnesses frequently experience symptoms that could negatively affect their daily lives. These symptoms are often underreported in health care. Despite a large number of mobile health (mHealth) tools, few are based on a theoretical framework or supported by scientific knowledge. Incorporating universal design when developing a product can promote accessibility and facilitate person-centered communication.

**Objective:** The aim of this study is to identify the symptom-reporting needs of children with cancer and congenital heart defects that could be satisfied by using a mobile app. Another aim is to evaluate how the child might interact with the app by considering universal design principles and to identify parents' views and health care professionals' expectations and requirements for an mHealth tool.

**Methods:** User-centered design is an iterative process that focuses on an understanding of the users. The adapted user-centered design process includes 2 phases with 4 stages. Phase 1 involved interviews with 7 children with long-term illnesses, 8 parents, and 19 health care professionals to determine their needs and wishes for support; a workshop with 19 researchers to deepen our understanding of the needs; and a workshop with developers to establish a preliminary tool to further investigate needs and

behaviors. Phase 2 involved interviews with 10 children with long-term illnesses, 9 parents, and 21 health care professionals to evaluate the mock-up (prototype) of the mHealth tool. Data were synthesized using the interpretive description technique.

**Results:** A total of 4 aspects of needs emerged from the synthesis of the data, as follows: different perspectives on provided and perceived support; the need for an easy-to-use, non-clinic-based tool to self-report symptoms and to facilitate communication; the need for safety by being in control and reaching the child's voice; and a way of mapping the illness journey to facilitate recall and improve diagnostics. The children with long-term illnesses expressed a need to not only communicate about pain but also communicate about anxiety, fatigue, fear, and nausea.

**Conclusions:** The findings of this study indicated that the PicPecc (Pictorial Support in Person-Centered Care for Children) app is a potential solution for providing communicative support to children with long-term illnesses dealing with multiple symptoms and conditions. The interview data also highlighted symptoms that are at risk of being overlooked if they are not included in the mobile app. Further studies are needed to include usability testing and evaluation in hospitals and home care settings.

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## KEYWORDS

children; communication; long-term illness; mHealth; pediatric care; person-centered care; symptom assessment; universal design

## Introduction

### Background

Children with long-term illnesses such as cancer [1] and congenital heart defects [2] have multiple symptoms that cause discomfort and negatively affect their daily lives. These children have a significantly lower health-related quality of life (HrQoL) than that of healthy controls [3,4]. Children experiencing multiple symptoms also have lower HrQoL than that of children with fewer symptoms [5]. Parents of children with long-term illnesses, such as cancer, confirmed that they experience challenges in identifying symptoms—specifically pain-related symptoms—in their children [6,7]. As a result, these symptoms are often underreported and not identified [8,9], treated, or relieved [10], causing children unnecessary distress and pain.

Symptom assessment is a key to symptom relief, and children should have the opportunity to self-assess and report their symptoms. However, such reporting may be limited by the children's ability to measure and describe distinct cancer-related symptoms, which can further affect the ability of parents or health care professionals to provide the necessary supportive care [11]. Evidence to show that exclusive use of rating scales makes a difference in the management of symptoms, such as pediatric pain, is limited [12]. More knowledge is needed about how symptom assessment could be combined with other measures to reduce symptom intensity and improve function [12]. There is also a need to ensure valuable apps continue to be used by children and are usable by providing access to maintenance and updates [13,14]. Therefore, finding an appropriate means of facilitating children's self-reported communication of symptoms is important. Bernier Carney et al [15] and Wesley and Fizur [16] proposed the use of mobile health (mHealth) tools such as mobile gamified apps that include creative approaches to symptom assessment to enable health care professionals and parents to capture self-reported data of children's symptoms.

In existing apps, pain is often considered as a core symptom to be monitored via self-report [15]. Apps can even help to significantly reduce cancer-related pain scores, especially when

they offer instant messaging modules [17]. Besides pain, other symptoms such as changes in appetite, cough, dizziness, nausea, fatigue, difficulty sleeping, vomiting, and well-being are also represented in apps [18-20]. In general, the willingness to use these apps is high because of developmentally appropriate interfaces and features that ensure child-centered self-reporting [17-21]. No specific symptom management app was found for children with congenital heart defects.

When developing an mHealth supportive tool or app for children, it is important to consider children's diagnoses and their cognitive, developmental, and language levels [22,23]. It is also necessary to take into account children's experiences and suggestions. However, children are rarely invited to participate in the development of such tools [24]. According to a qualitative evaluation of existing apps for pain management (n=36), it was stated that most apps were developed without end user and clinician involvement. In addition, the apps had security problems, lacked graphical data visualization, and did not include instruments used in clinical settings [25]. Moreover, measures are generally created for adults and simplified at a later stage to accommodate use by children under the assumption that children and adults share the same concerns [26].

To ensure that children's preferences and needs are incorporated in the mHealth tool, it is important to include children, as well as other stakeholders, in its development. This process is referred to as user-centered design (UCD) and involves all stakeholders working together as equal partners to contribute to the design of a new product (eg, mHealth tool) in an attempt to develop an efficient and feasible tool for a specific population [27,28]. When designing an app that can be used by various people in different situations, it is important to take human abilities, needs, and requirements into account. As such, universal design (UD) or *inclusive design* aims to facilitate accessibility for users with all kinds of abilities and needs [29]. Accessibility could be provided through the use of pictures, audio, and easy-to-read texts [30-32].

Three different approaches to centeredness exist in pediatric health care: child, family, or person [33]. This study focuses on person-centeredness, as this closely follows the caring process

and includes the child and the family [34]. In pediatric symptom assessment, a person-centered approach could help in selecting and providing optimal treatments [26,35]. In health care, the need to implement person-centered care is growing [36,37]. Person-centered care aims to create partnerships among patients, families, carers, and health care professionals [34,37]. As defined by the Gothenburg model for person-centered care, the three routines of this approach are as follows: (1) initiating a partnership by eliciting the patient's narrative, including goals, capabilities, and limitations; (2) building the partnership through the cocreation of a health plan promoting the patient's self-efficacy and self-care; and (3) safeguarding the partnership by documenting the patient's story and health plan to support the continuity of care [37,38]. A European Union standard for patient involvement has recently been launched to facilitate pediatric person-centered care [34,39].

## Objective

This study is based on the child's perspective, meaning that the child's needs and experiences are central. It strives for a child-centered approach by listening to the child's preferences and taking into account the adults' views on what is in the best interests of the child [34,39,40]. Research shows that parent-centered communication styles can feel disempowering for children, whereas communication tailored to child-centric communicative and developmental needs gives them a sense of respect, safety, and control. In turn, empowering children and promoting their autonomy and partnership may be beneficial for their quality of care, health outcomes, and well-being [1].

First, our study aims to identify the symptom-reporting needs of children with cancer and congenital heart defects, with and without communication challenges, to inform the design of a tool that could be used in a mobile app to meet the child's requirements in order for them to feel safe in its use to communicate their symptoms. As most apps are focused on pain and not necessarily on other symptoms such as anxiety, nausea, and fear, this study aims to describe the initial development of a person-centered communication support mHealth tool (ie, PicPecc [Pictorial Support in Person-Centered Care for Children]) intended for use as a self-report device by children with long-term illnesses to report and manage their symptoms at a hospital or at home. Children with cancer and children with congenital heart defects were chosen as they often experience multiple symptoms, which would test the functionality of the app. The subsequently developed app is called PicPecc.

Second, this study aims to evaluate how the child might interact with the app, considering UD principles, and to identify parents' views and health care professionals' expectations and requirements for an mHealth tool.

## Methods

### The Adapted UCD Process

UCD is an iterative process that focuses on an understanding of the users and their context in all stages of design and

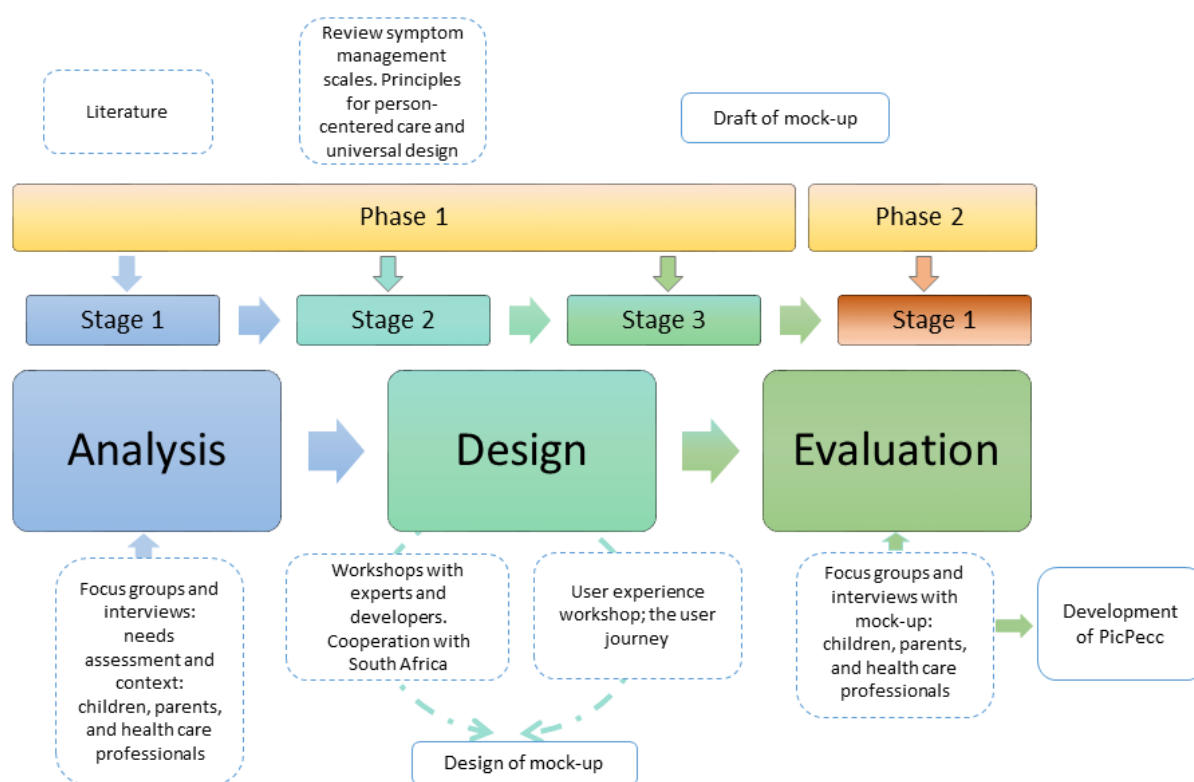
development. In UCD, the design project is based on an explicit understanding of the users, tasks, and environments. Therefore, the team involved in the design process should include a range of professionals across multiple disciplines, as well as domain experts, stakeholders, and the users themselves [41,42]. This is a way of increasing the impact of mHealth tool usability for children and adolescents [27,28]. During the development process of PicPecc, a set of key principles were in focus: dynamism, iteration, creativity, openness to change, and a look forward toward future evaluation and implementation [43].

From a user-centered perspective, it is central to not only involve the user but also to have a point of departure in the existing practice where the artifact is intended to be used [44]. Thus, being user-centered means having a focus on multiple users and on the context in which the use takes place. Thus, in a care situation involving children, it is central to weave in the experiences of children, their parents, and health care professionals [41]. In addition to users, UCD stresses the importance of having different types of experts in the design process. We are not referring primarily to information technology experts but to experts in the areas that the design process may affect.

From a UCD perspective, design is not just the activities conducted together with a user or activities for which the digital artifact is developed. A central part of the process is to set the framework for the project and define its starting point. It is said that design is vision driven and intentional, meaning it is consciously aimed toward change [45]. Thus, the design process starts as soon as the principles for the project are defined and data are collected and lasts beyond the implementation of the artifact in the practice it was designed for.

In this study, the starting point was a design approach that departs from 3 child-centered standpoints. The first is to design a solution that solves the problem of children's symptoms being underreported and not identified [8,9], treated, or relieved [10], causing children to experience unnecessary distress. The second is symptom assessment being key to symptom relief, whereby children should have the opportunity to self-assess and report their symptoms. Thus, this study centers on children's ability to self-report their symptoms. The third standpoint was to follow the principles of UD to identify the expectations and requirements of the health care professionals who would analyze the data and the parents' attitude toward using the app and, finally, to use a mock-up of the app to evaluate how children from different backgrounds, speaking different languages, and with different long-term illnesses benefit from the app.

Inspired by previous research, the UCD process included feedback, suggestions, and observations from a multidisciplinary research team, children, parents, and health care professionals in 2 phases [46]. Figure 1 shows a visual presentation of the 2 phases.

**Figure 1.** A visual presentation of the two phases of the study. PicPecc: Pictorial Support in Person-Centered Care for Children.

Children with cancer could not participate in all stages of UCD for medical and ethical reasons. An adapted version of UCD was used where the children's, parents', and health care professionals' voices were represented in stages 2 and 3 via interview data. Subsequently, the adapted UCD was followed in the development of the PicPecc mHealth tool, comprising 2 sequential phases.

Phase 1 involved 3 stages. For example, in stage 1 of phase 1, interviews with children with long-term illnesses and their parents were conducted, with participants sharing their lived experiences to guide the development of the PicPecc app. Health care professionals who worked within the system also provided input on their needs and the perceived needs of the children when caring for them. The children's needs and wishes were the departure points for all the following design activities, followed by the results from the parents and health care professionals.

Stage 2 of phase 1 involved a workshop where researchers with theoretical and clinical intervention knowledge presented information on person-centered care, UD, and evidence-based practices on the use of mHealth tools in various settings, such as high-, low-, and middle-income countries, to inform the development needs of the specific intervention (PicPecc).

In stage 3 of phase 1, a workshop was held with the design team (information technology personnel). These designers provided valuable input in terms of which electronic platforms might best

suit the needs of the specific tool (PicPecc). In addition, this stage involved using the analyzed data from the first 2 stages as guidance for the development of PicPecc. The task of the experts and developers was to highlight existing evidence and indicate what technical possibilities were available to meet the children's requirements. The design of the app was decided along with experts in UD [47] to facilitate accessibility for all users, regardless of their ability and needs.

In phase 2, we followed principles from previous research and included a pilot test with children, parents, and health care professionals who tested our ideas for the first time with a mock-up (prototype) of the developed PicPecc [48]. Stage 1 (forming part of phase 2) involved interviews with children, parents, and health care professionals to evaluate the PicPecc app (Figure 1). The participants tested the ideas and reflected on the flow of the PicPecc app, commenting on whether the app was easy or fun to use. The participants also described whether the app was adaptable to their individual needs.

The Shier [49] Pathway to Participation model (2001) is often used to assess commitment to youth participation. The model contains 5 levels of participation, where level 5 means that children share power and responsibility in the development of an intervention. The present adapted UCD reaches level 3 on the Shier [49] model; that is, children's voices are taken into account in the process of developing the intervention.



## Ethical Approval

After ethical approval was obtained from the Swedish Ethical Review Authority (reference 2019-02392; 2020-02601; 2020-06226), children and parents were contacted and informed about the study through assigned persons working in the pediatric wards where the children were treated. Each assigned person was informed about the study by the researchers.

## Phase 1

### Stage 1 Semistructured Interviews and a Focus Group

#### Research Question

How do children with long-term illnesses, their parents, and health care professionals prefer to communicate about symptoms and symptom relief, and what symptoms are important to talk about?

## Participants

Participants were recruited from 5 different hospitals in Sweden. Purposive sampling of children, parents, and health care professionals was used according to the following eligibility criteria: (1) an understanding of Swedish or English, (2) an age of 5 to 17 years, (3) a cancer or congenital heart defects diagnosis, and (4) an experience of illness. We chose to include children with an expected experience of a range of symptoms. Children in need of end-of-life care were excluded. Parents of children diagnosed with cancer or congenital heart defects, as well as health care professionals working with children with these diagnoses, were also involved in this study. Health care professionals with <6 months of work experience in pediatrics were excluded. Participants in this first stage of phase 1 included 7 children with cancer, 8 parents, and 19 health care professionals (Table 1).

**Table 1.** Characteristics of participants in phase 1 (stage 1) and phase 2 (stage 1).

Characteristics of health care professionals	Phase 1 (stage 1), n/N (%)	Phase 2 (stage 1), n/N (%)	Participants who participated in both phases, n/N (%)
<b>Health care professionals</b>			
<b>Gender</b>			
Female	15/19 (79)	18/21 (86)	9/11 (82)
Male	4/19 (21)	3/21 (14)	2/11 (18)
Registered nurse	11/19 (58)	17/21 (81)	7/11 (64)
Assistant nurse	3/19 (16)	1/21 (5)	1/11 (9)
Physician	5/19 (26)	3/21 (14)	3/11 (27)
<b>Working years in the same workplace</b>			
0-5	4/19 (21)	9/21 (43)	3/11 (27)
6-15	6/19 (32)	2/21 (10)	1/11 (9)
≥16	9/19 (47)	10/21 (48)	7/11 (64)
<b>Children and parents</b>			
Children	7/15 (47)	10/19 (53)	6/11 (55)
Parents	8/15 (53)	9/19 (47)	5/11 (45)
<b>Age (years) of the child during the time of data collection</b>			
7-11	2/7 (29)	4/10 (40)	2/6 (33)
12-14	4/7 (57)	5/10 (50)	3/6 (50)
≥15	1/7 (14)	1/10 (10)	1/6 (17)
<b>Diagnosis of the child at the time of data collection</b>			
Leukemia (ALL <sup>a</sup> or AML <sup>b</sup> )	5/7 (71)	6/10 (60)	5/6 (83)
Solid tumor	2/7 (29)	2/10 (20)	1/6 (17)
Congenital heart defects	0/7 (0)	2/10 (20)	0/6 (0)
<b>Time since diagnosis at the time of data collection (months)</b>			
0-3	2/7 (29)	0/10 (0)	0/6 (0)
4-8	4/7 (57)	1/10 (10)	0/6 (0)
≥9	1/7 (14)	9/10 (90)	6/6 (100)

<sup>a</sup>ALL: acute lymphoblastic leukemia.

<sup>b</sup>AML: acute myeloid leukemia.

## Procedure

The health care professionals were contacted by the last author (SN) and invited to participate. Interviews were conducted with children and parents at the hospital where the child had a scheduled appointment for treatment. Written consent was obtained from health care professionals and parents, and assent was obtained from each child. The interviews were conducted by the first (AW) and last authors (SN) and were audio recorded or video recorded (Textbox 1). The young children were given the option to be interviewed together with their parents or to be interviewed alone. To hear the child's own voice, the child was asked to answer the question first, after which the parent could

answer the question to add depth to what the child said and to add the parents' view. Some health care professionals also chose to do their interviews in dyads, as they often worked together. Upon receiving consent, a suitable time and a meeting place were decided. The health care professionals' interviews were conducted at their workplace. A focus group with 4 health care professionals was also conducted, where the first author (AW) was the moderator and the last author (SN) was an observer. At the end of each interview, all participants were asked to prioritize the different symptoms according to their importance on a 5-point Likert scale (Table 2). The symptoms were identified as important, in accordance with previous literature [50].

**Textbox 1.** Topics and questions of the semistructured interviews.

Data collection	
•	Stage 1 (phase 1)
Topics	
•	Existing support, existing scales, and experiences of symptoms and conditions
•	A communicative support tool as support when dealing with multiple symptoms and conditions
Questions	
•	Tell me about a good and a bad care situation?
•	What symptoms have you experienced (children), and which symptoms do you see (adults)?
•	How do you measure what the child feels (adults)?
•	What kind of support is there when dealing with multiple symptoms and conditions?

**Table 2.** Prioritization of symptoms that need to be assessed in a new way (N=27).

Symptoms	Strongly disagree (1), n (%)	Disagree (2), n (%)	Neutral (3), n (%)	Agree (4), n (%)	Strongly agree (5), n (%)	Values, mean (SD)
Anxiety	0 (0)	0 (0)	1 (4)	10 (37)	16 (59)	4.56 (0.57)
Fatigue	0 (0)	3 (11)	8 (30)	11 (41)	5 (19)	3.67 (0.90)
Fear	0 (0)	0 (0)	1 (4)	14 (52)	12 (44)	4.41 (0.56)
Nausea	1 (4)	5 (19)	5 (19)	6 (22)	10 (37)	3.70 (1.24)
Pain	2 (7)	5 (19)	6 (22)	8 (30)	6 (22)	3.41 (1.23)
Well-being	0 (0)	1 (4)	4 (15)	16 (59)	6 (22)	4 (0.72)

Multi-perspective data with children, parents, and health care professionals were collected through semistructured interviews—one-on-one children–parent, parent–parent, and health care professional dyads and in a focus group. Multiple data collection approaches were a viable option to ensure different perspectives [51]. Multi-perspective data also enabled us to compare different participants' perspectives and feelings regarding symptom relief and explore the possible underlying reasons for differences.

The individual interviews with the children (4/7, 57%) lasted between 17 and 44 minutes (mean 35, SD 10.56 minutes) and interviews with the parents (5/8, 63%) lasted between 26 and 37 minutes (mean 30.40, SD 5.39 minutes), one of the interviews were a dyad interview with a mom and a dad. The dyad interviews with the child and parent (3/12, 25%) lasted between

29 and 60 minutes (mean 45.33, SD 12.71 minutes). The individual interviews with health care professionals (11/19, 58%) varied in length from 28 to 53 minutes (mean 38.36, SD 8.16 minutes). The health care professionals' dyad interviews were 53 minutes and 58 minutes long (mean 55.50, SD 2.5 minutes), respectively. A focus group was conducted with 21% (4/19) of the health care professionals to generate more variation and multiple perspectives in the collected data. The length of the focus group interview was 66 minutes.

## Data Analysis: Qualitative Data

All audio data were transcribed verbatim and complemented with video recorded information. The qualitative analysis software NVivo 12 Pro (QSR International) was used to arrange and rearrange the codes into patterns and relationships.

The analysis process started with the transcribed interviews being read intensely by the first (AW) and third (VC) authors to obtain a sense of the whole, in accordance with interpretive description [51]. During the preliminary reading, words and sentences that corresponded to the aim of the analysis were underlined according to a broad inductive coding. The different groups of participants were first coded sequentially, starting with the children's interviews, followed by the parents, and finally, the health care professionals. The initial coding was used as a basis for subsequent coding; however, new codes were added for parents' and health care professionals' interview data. Tentative patterns and relationships were identified. A broader analysis was subsequently made where questions such as, "What does it mean?" and "What are they talking about?" were asked. Continued synthesis of the tentative patterns facilitated the understanding of various interpretations of the topic. The data reflected not only common patterns but also ideas and beliefs. The final step of the analysis was the definition of themes [52].

During the analytical process, the researchers were mindful that their preunderstanding could affect the data and, therefore, returned to the data repeatedly for confirmation of the emerging patterns and relationships. These patterns and relationships were discussed within the research team to reach a consensus about relevant findings and to ask, "What are we not seeing?" The analytical process from the first phase gave us an understanding of the unmet needs and wishes mentioned by participants when dealing with multiple symptoms.

Member checking was conducted with the participants as an important step to improve qualitative validity [51].

Interpretive description supports a credible and transparent process in qualitative research [52,53]. The researchers need to make their preconceptions regarding the research topic transparent; that is, recognize that these preconceptions can influence data collection or data analysis. This was performed in an interdisciplinary research group with members who had several years of experience in interaction design, information systems, nursing sciences, pediatric oncology care, psychology, communication, and UD. We strove to be as open as possible to the participants' perspectives and experiences.

### **Data Analysis: Quantitative Data**

All assessments from the participants were described using descriptive statistics; that is, with numbers, percentages, and means.

### **Stage 2 Workshop**

The project team arranged a workshop to ensure theoretical relevance and anchoring regarding relevant clinical, person-centered, and design-related perspectives.

### **Research Question**

Which theoretical knowledge and findings from the research are relevant to consider in the development and research of the app?

The workshop was designed explicitly to prevent such shortcomings from occurring in this project. To ensure that our app of UD principles was acceptable in a different societal context, a collaboration was established with university partners

in South Africa. We wanted to investigate whether our app based on the principles of UD was acceptable in a completely different context. This context also includes a multilingual and multicultural environment that poses additional challenges.

### **Participants**

The workshop was attended by 19 researchers, 12 health care professionals, and 8 postgraduate students from Sweden and South Africa in areas related to the project.

### **Procedures**

Topics of discussion involved person-centered care, communication of children in health care settings, principles of UD and communication support, and the design and development of mHealth tools.

The workshop was video recorded, and notes were taken; mapping of relevant theoretical perspectives and patterns were conducted.

### **Data Analysis**

The data collected from the workshop were analyzed using manifest analysis [54]. In the analysis process, important areas were selected to be used in stage 3. This workshop provided knowledge of the conditions for using an app in low- and middle-income countries. The workshop also mapped existing apps and in-depth knowledge of person-centered care and UD.

### **Stage 3 Workshop**

We determined the possible user journey for the PicPecc app by means of a user experience (UX) workshop.

### **Research Question**

What is a possible user journey for the PicPecc app?

### **Participants**

Throughout the project, the children were included in the research and design whenever possible. However, these children had decreased immune function and experienced fatigue. This made it difficult to include them in design events such as workshops. However, other users of the mHealth tool (eg, nurses) participated in the design workshop. Web-based participation was considered and can be of value [55,56]. However, some activities were not suited for web-based settings, and web-based participatory design settings have proved to be challenging [57].

A total of 3 UX specialists, 2 speech and language therapists (a PhD and an associate professor), 3 pediatric nurses (a PhD student, a PhD, and an associate professor), 2 researchers in information systems (both PhDs), and a health psychologist specialist (an associate professor) participated in stage 3.

### **Procedures**

A full day, face-to-face interprofessional workshop was held in Gothenburg, Sweden, to collate the assumptions of the different researchers into a design report. The workshop had a structured agenda comprising 3 distinct parts. The first part comprised a value proposition canvas with the purpose of pinpointing the value offering [58]. The second part focused on impact mapping with the purpose of tracing how and who created the impact [59]. Finally, a user journey was undertaken to create a

visualization of a user's possible interaction with the app over time [60].

### Data Analysis

This workshop provided knowledge for the developers and gave them a basis for developing a mock-up.

### Phase 2—Stage 1 Semistructured Interviews and Focus Groups

Phase 2 involved only 1 stage where children with cancer or congenital heart defects, their parents, and health care professionals provided input on the mock-up version of the PicPecc app.

### Research Question

How can the PicPecc app provide children, parents, and health care professionals support when communicating about symptoms and symptom relief?

**Textbox 2.** Topics and questions of the semistructured interviews.

#### Data collection

- Stage 1 (phase 2)

#### Topics

- Process of engaging with the communicative support tool
- Existing websites for support and tips when dealing with symptoms and conditions

#### Questions

- What do you want to know from the support tool?
- What do you want help with?
- What motivations do you and the children need to use it?
- When can it be useful?
- Did you understand everything?

The individual interviews with the children (7/10, 70%) varied from 18 to 57 minutes (mean 37.29, SD 11.80 minutes), the individual interviews with the parents (6/9, 67%) varied from 19 to 62 minutes (mean 37.67, SD 13.77 minutes), and the dyad interviews with a child and a parent (3/16, 19%) were between 23 and 41 minutes (mean 32.33, SD 7.36 minutes). The individual interviews with the health care professionals (11/21, 52%) varied from 26 to 71 minutes (mean 44.82, SD 10.60 minutes) and the 2 focus group interviews with health care professionals (10/21, 48%) lasted between 37 and 75 minutes (mean 56, SD 19 minutes). In the 2 focus groups, 30% (3/10) of participants took part in the first focus group, and 70% (7/10) of participants took part in the second focus group.

### Data Analysis: Qualitative Data

In stage 1 of phase 2, all participants were presented with the prototype of the mHealth tool that was developed according to the key findings of the first phase.

We followed the same data analysis procedures as in stage 1 of phase 1.

### Participants

Participants were recruited from 5 different hospitals in Sweden. The recruitment process was similar to stage 1 of phase 1. These participants were also invited to participate in phase 2, resulting in 6 children, 5 parents, and 11 health care professionals (Table 1) taking part in both phases. Additional recruitment of participants was conducted. Finally, the sample comprised 10 children with cancer or congenital heart defects, 9 parents, and 21 health care professionals (Table 1).

### Procedure

The procedure was similar to stage 1 (phase 1), apart from using the mock-up as stimuli material (Textbox 2).

## Results

### Phase 1

#### Stage 1—Qualitative Findings

The results are presented with quotations, which are presented with a unique code and general information about the speaker.

#### Significant Standpoints to Address

Children and parents emphasized a need to address both the positive and negative sides of daily life. Health care professionals focused to a higher degree on symptoms in need of treatment and requested valid instruments. Participants stressed highlighting symptoms beyond pain; for example, anxiety or fear.

All participants talked about the ways in which symptoms interrupt the child's life. Self-care strategies are needed to help children cope:

*Not meeting friends and not even doing...video games make them feel sick. That's it. And some of them feel*

*ill as long as the therapy lasts.* [310; female pediatrician]

### Different Perspectives on Provided and Perceived Support

Children expressed a wish to receive support for self-care; however, there seems to be a disparity between what children want and what health care professionals provide. Parents experienced a lack of support from health care professionals who worked closely with the child. Health care professionals focused more on physiological symptoms, whereas children and parents indicated that they also needed psychosocial support. Children and parents also appreciated when the nurses provided emotional support and took time and stayed a little longer to talk about entertaining topics such as movies or books:

*For me it was most useful and valuable when the nurses stayed for a bit and just talked. I saw that some of the nurses had an easy way of talking with my daughter about movies and...they were more open for conversations.* [202; mother of a 14-year-old girl]

### Need for an Easy Tool to Assess Symptoms and Facilitate Communication

Children, parents, and health care professionals expressed a need for an easy way of assessing the child's symptoms in a reliable manner based on multimodal strategies. For example, health care professionals were satisfied with existing pain scales but at the same time stated that these scales were not used as often as they could be. Health care professionals needed an easy way of assessing pain or other symptoms, as they sometimes doubted the assessment given by the child, based on the signs and behavior they could observe. Parents wished that they could facilitate the children's expression of how tired or how much pain they experienced in different ways, such as via visual support. The children wanted to use an easy tool that helped them explain how they felt, sometimes even without having to talk because of feeling tired or experiencing pain:

*It would be easier, instead of talking all the time, you could just show them.* [104; boy, 16 years]

*If you have a bad day, then you may not want someone to ask how you feel. Then you can write it in the app. That would be a smart thing.* [102; girl, 14 years]

### Creating Safety and Reaching the Child's Voice

All participants stressed the importance of safety in the situation. From the child's perspective, this was expressed as a need to feel that they have control over the situation. Parents and health care professionals described wanting to access the child's needs and wishes; that is, get to the primary source. Children wanted to feel safe and have a sense of control over the situation. When they knew what to expect, children could handle their treatment-related procedures better. Health care professionals felt they were able to listen to the child's needs and wishes and, thereby, provide appropriate help:

*I believe in the visual for a child...That the child has a way to show and express, so that you don't lean too much on the parent's interpretation.* [309; female pediatrician]

### Mapping the Journey to Facilitate Recall

The ability to visualize and thereby easily remember the child's journey was emphasized. Children, parents, and health care professionals wanted to measure the aspects of well-being and not only the negative experiences, as described by the following adolescent:

*It would have been good to have a positive thing, so that you can see that sometimes you feel well, so you can see which days during the week are the better ones.* [104; boy, 16 years]

Another perspective mentioned by health care professionals was the need to retrieve information with the purpose of providing appropriate symptom relief to the individual child.

Parents stressed the need to strengthen their child's self-efficacy using an mHealth tool to prompt and support the child in symptom relief.

### Quantitative Results

All symptoms were found to be important, as shown in [Table 2](#).

#### Stage 2

The presentations and the following discussion created a common ground regarding four areas. (1) The discussion resulted in a mutual understanding of the most relevant symptoms (anxiety, fatigue, fear, nausea, and pain), the assessment of symptoms (Visual Analog Scale, Numerical Rating Scale, Faces Pain Scale–revised, and Wong–Baker Faces Pain Rating Scale), and management of symptoms. Regarding the assessment of symptoms, for instance, the project identified a need for digital assessment of pain that aligned with the current assessment method at different hospitals. (2) There was also a focus on children's rights, person-centered care, and UD from an augmentative and alternative communication perspective. This discussion emphasized the development of an mHealth tool with communication support and illustrations of specific actions and text-augmented communication for children of different ages, cultures, and cognitive capabilities. The idea of a UD perspective focused on alternative communication became a central thesis for this project. (3) Another outcome was a deeper understanding of UCD, where the focus is on the use situation and how the mHealth tool also must fit into a larger context of information systems to stay relevant beyond the study phase. (4) Finally, there was a slightly different discussion on how to measure the effect of the intervention from a neurochemistry perspective; that is, the possibility to measure the effects of the intervention in blood samples.

A meta outcome of the second phase acknowledged the complexity of the intervention at hand. Designing a research-anchored mHealth tool from a UD perspective is a great challenge in itself. Designing something that fits into the existing care practices and information systems at different locations increased the complexity even further.

#### Stage 3

Although the children did not participate in this stage, their perspectives were central throughout the workshop. From stage



1, the children's needs and wishes were fundamental to each part of this study.

The value proposition canvas summarized the different stakeholders and their pains, gains, and actions. For instance, from the child's perspective, a typical symptom would be fear in relation to the disease. A typical gain would be a visualization of their symptom journey, and a typical action would be to assess their well-being. This was followed by detailing the possible impacts of the app.

The outcome from the workshop was translated into a number of user stories (participant journeys); that is, a set of requirements based on different actions that different users want to perform with the system to fulfill certain goals. These user stories were grouped into themes. These themes could be general; for example, *user management* and *calendar*. More specific ones were *gamification*, *my pets*, *avatar system*, and an *assessment system*. *My pets* and the *avatar system* are related to the personalization of the system. *Gamification* is related to motivating the child to perform the assessments ([Multimedia Appendix 1](#)).

## Phase 2

### Stage 1

In stage 1 (also referred to as phase 2), children, their parents, and health care professionals provided input on the mock-up version of the PicPecc app.

### Different Perspectives on Provided and Perceived Support

Health care professionals in this phase also focused more on physiological symptoms, whereas children and parents indicated that they also needed psychosocial support ([Multimedia Appendix 2](#)). The children talked about how the PicPecc app could be a way of communicating without having to speak to either their parents or health care professionals. Children also said that this could help them express how they feel and help them manage their symptoms:

*It helps you to say how you feel, and the tips on what you can do to lessen the pain or lessen the nausea; it's good to get help with that because sometimes it feels like nothing works. But if you have tips, maybe you will find one that works for you. [101; girl, 14 years]*

Health care professionals also emphasized the child's self-care and further wanted the PicPecc app to provide professional support, such as the next dose of medication, preparations for procedures, and information about possible side effects.

The health care professionals thought they could see the PicPecc app being useful during medical rounds to follow up on symptoms to guide treatment and prepare the child for treatment and procedures. This was facilitated by a function in the app; that is, diagrams.

### Need for an Easy Tool to Assess Symptoms and Facilitate Communication

Children thought that gamification (eg, in PicPecc, the use of the app enabled collection of pets) could motivate the use of the app. Health care professionals were also of the opinion that

a reward system was a positive motivator for children to use the app. Older children stated that the app was an easy way of informing health care professionals and parents about how they felt. The children also felt that their parents might ask fewer questions if they (the parents) could have access to the information on how their child assessed his or her symptoms in PicPecc:

*This app could make mum and dad stop asking how I feel all the time; instead I can go in here and press from time to time how I feel, so they can see. [101; girl, 14 years]*

Health care professionals and older children thought the calendar or schedule was also a motivator as it would help the children during hospital visits. This was also verified by a parent:

*I've been giving my child medicine now at two o'clock and the next one comes at eight o'clock. And she wanted to know that because then she knew she'll feel better then. [201; mother of a 14-year-old girl]*

The health care professionals mentioned that PicPecc might clarify their communication with the children and especially envisioned using it with children who found expressing their opinions challenging. The PicPecc app can also facilitate understanding of the child:

*It will probably be easier to ask the child than...Now you ask the parents, even if the child can talk. So, you don't reach the child, it's the parents. Here I think I can reach them. [316; focus group, nurse in pediatric cardiology]*

The colors and faces added to the thermometer in PicPecc helped with the understanding of the thermometer scale. Most symptoms were easy to assess, ranging from feeling good (green and smiley face) to worse (red, sad, and crying face), except for the symbol *appetite*, where the participants found this kind of scale difficult to use.

The health care professionals liked that the mock-up included a page called *my page*, where the child could write their requests and wishes for their care. However, some parents doubted that their child would use that function. Nevertheless, the health care professionals saw it as a means of helping the child to become more involved in their own care.

Parents appreciated the diagram function and the possibility for the child to assess symptoms using the body figure. The feedback provided by PicPecc could help the child to realize that they need help with symptom management. The feedback option may also offer a way for the parent to help explain feelings that the child might find difficult to express clearly.

The word *anxiety* was not problematic for the children. However, health care professionals and parents were unsure if the word *anxiety* was the correct term to use, although they highlighted the children's need for psychosocial support in the first phase. The adults were of the opinion that the word *anxiety* may be too strong a term to use when talking to young children and that they might find it challenging to understand the meaning of anxiety:

*No, I don't know. But anxiety is one of those adult words. "Oh, I have anxiety". But it's almost like a...anxiety, it should be classified as anxiety, but worry is something...I think children will recognize.* [209; mother of a 12-year-old boy]

### Mapping the Journey to Facilitate Recall

The children liked features such as the schedule and the calendar that could help them remember what was planned, how the treatment worked, and how they felt each day. The schedule was regarded as a way of offering the children and parents a simple overview of the week:

*You can see what's going on and that the doctor can put in, yes, but around this time I'll come in and talk to you, and around this time you'll change the infusion (drip) or something.* [101; girl, 14 years]

The health care professionals were positive about the additional notes feature, as it was a way of getting to know the child and allowed them to tell their narrative. Meanwhile, parents saw it as a personal space for their child to make short notes that he or she could remember and write questions. They also saw the notes feature as a possibility for the child to document their treatment journey and write down things they were looking forward to.

The children proposed features that, in their opinion, were lacking in the design, such as being able to check off parts that had been completed on the schedule. The children also suggested the inclusion of information about their disease, common symptoms, and a treatment plan, so that they could understand themselves how their bodies are going to change and easily explain this to their friends:

*Friends ask day in, day out, day in, day out. And it's really hard because it's so hard to explain.* [110; girl, 7 years]

### Design of the Mock-up

The health care professionals and the parents wondered if the PicPecc app needed to be age adjusted; for example, if the pets and pictures were too childish for older children. Some parents thought it was too childish for adolescents, whereas others thought it looked good. The children themselves thought the design was simple and easy to understand but not childish:

*I think it's very nicely laid out and looks good etc. It's not too difficult for five-year-olds and not too childish then for those who are older.* [102; girl, 14 years]

The health care professionals and parents felt that the design of the PicPecc app facilitated user-friendliness and appreciated the read-aloud feature.

The children wanted different ways of personalizing their avatars and pets, with both real and fantasy animals in the pet section. They also talked about being able to name and change different features of their pets.

All groups commented on the chosen symbols, as they found them difficult to interpret and thought that if pictures and picture schedules were used, they needed to be accurate. The children

needed to see what was going to happen to feel safe. They also had difficulty in understanding some of the words used in the mock-up version of PicPecc; for example, care plan and estimates.

A part of the mock-up included creating a care plan. Children and parents found it difficult to understand the usefulness of this part. Children struggled with the word *estimates* and suggested that *estimates* be rewritten as *how do you feel?*

### The PicPecc App

The mobile PicPecc app comprises a number of pages where children can describe how they are feeling using icons and a faces thermometer scale. On the home page, there are three options—record symptoms, access the gaming function (collecting animal icons that can be included in the child's profile), and access an area where the data are displayed in the form of customizable statistics. A setting function also allows for customization of the sounds, spoken text, or notifications. The child is represented in the app by an avatar of their choice. Symptom location can be described on a body outline. There is a support and help page where the child can obtain information about their condition and tips and ideas about how to feel better. This can be linked to an external webpage.

## Discussion

### Principal Findings

There were 2 phases in this study. In the first phase, information from participants in stage 1 and experts from stage 2 formed a PicPecc mock-up in collaboration with UX specialists in stage 3. Both participants from stage 1 (phase 1) and new participants tested the mock-up in phase 2. The participants in phase 2 stated that the mock-up was accessible, affordable (in this case, the value of spending personal resources and time with the app), and acceptable. The results generally emphasized that the potential to support symptom management was a beneficial aspect of PicPecc and that children can find symptom relief within the app. Symptom relief is an important aspect of pediatric care and an essential part of the care process [61].

In stage 1, the children with long-term illness wanted to describe symptoms beyond pain, and parents and health care professionals confirmed the relevance of including anxiety, fatigue, fear, and nausea. This is consistent with previous work examining symptom distress in children with cancer [8]. The most frequently prioritized symptom assessed by the participants was anxiety, followed by fear. Similar findings have been highlighted in previous research [8,62]. PicPecc aims to support the child and the parents in discussing distressing issues and support the health care professionals in raising issues other than pain and nausea. PicPecc strives to facilitate communication and has the potential to be a tool that helps health care professionals listen to the child.

In stages 2 and 3 of phase 1, researchers cooperated with the participants to innovatively translate their needs into the PicPecc mock-up. Adaptations were made based on UD and person-centered care. The participants suggested that digitalization may facilitate the assessment of symptoms using a faces thermometer scale, which the participants described as

useful in assessment, ranging from feeling good (green and smiley face) to worse (red, sad, and crying face). This type of traffic light system has previously been described to manage symptoms such as pain on a scale of 0 to 10 but is sometimes not enough to reflect the intensity level [63].

In stage 1 (phase 2), the children commented that the PicPecc mock-up was not too childish. This is in line with previous research identifying determinants that might have an impact on access to health care [64]. The design of the mock-up was accessible and acceptable to all children; it was simple and easy to use. UD might improve accessibility by adding sound, easy-to-read texts, and pictures that could facilitate communication across languages, cognitive developmental stages, or disabilities. This corresponds well with a study by Rodgers et al [22], stating that the method of assessing symptoms needs to be on a level that equals the child's cognitive and developmental level. However, some of the parents and health care professionals in our study were concerned that the design was too childish. UD is a design that should not present an obstacle but rather use symbols and pictures to make the content more accessible for all people. Adults may see symbols and pictures as something for young children; however, as the results show, children of various ages can see the benefits of visualization.

In this study, a person-centered approach was adapted to pediatric care, which emphasizes the purpose of accessing the child's stories [34]. The goal of such an approach is to empower the child to become more independent in their own care. Lin et al [1] stated a need for tools to enhance communication with health care professionals as children value empathic and respectful communication. Feelings of powerlessness and anxiety may arise when communication is perceived to be parent-centered or paternalistic [1]. PicPecc may have the potential to bridge the gap and open a dialog between the child and health care professionals. This dialog might help the child feel more independent, relieving the parents of the responsibility of being that bridge. Information and communication technologies can be a bridge between users who do not know the culture or language and the health care professionals [65]. The children in our study generally expressed a wish for autonomy and a possibility for communicating directly with the health care professionals about symptoms through mHealth tools.

In PicPecc, the story is told through the child's own estimations and the note function, which can hopefully help the health care professionals recognize the child's symptoms and focus on them. PicPecc intends to facilitate a supportive approach, which may enable more person-centered care. In addition, PicPecc is

an attempt to create a digital tool that supports the child in expressing what they are feeling and provides information that may help them manage some of their symptoms. Symptom relief is a prerequisite for reducing long-term problems. For example, chronic pain in adulthood can progress from acute pain in childhood [26]. Thus, there is a need for a tool that helps children with symptom relief early and that is immediately available when a symptom occurs.

### Limitations

Six main limitations can be identified in this study. First, there is a risk of population selection bias, as the children and parents were recruited by the health care professionals who were treating them. Second, no child with congenital heart defects participated in phase 1 (stage 1). Third, the parents could have influenced the children's answers, and fourth, it would have been valuable to have had a wider range of ages, as most of the participants were adolescents. Fifth, it is a limitation that the end users (ie, children, parents, and health care professionals) did not themselves participate in stages 2 and 3. Finally, the sixth limitation is that this is a description and mock-up of an app, and we have not yet been able to test the final version of PicPecc.

### Conclusions

The results from our study reveal a need for a tool that facilitates communication between children and health care professionals. Both parents and children stressed the importance of communication about feelings beyond symptoms of pain. With the potential to facilitate person-centered communication through UD, PicPecc is an advanced first attempt on how to provide support when dealing with multiple symptoms and conditions. PicPecc has the potential to open a dialog between the child and the health care professionals and addresses symptoms that may otherwise be overlooked. Over the past decade, the use of digitalization has expanded within health care. This study demonstrated the potential for using PicPecc as a digital support in clinical practice. Future phases should include usability testing and evaluation of the effects in hospitals and in home care settings.

The effectiveness of PicPecc to communicate symptoms and lead to symptom alleviation, thereby improving well-being and HrQoL, will be assessed in the next phase of the project. Representative populations of children in Sweden and South Africa will be identified through a randomization method and invited to participate in an evaluation study. In addition to PicPecc, standardized instruments for measuring symptoms and well-being will be administered to a group using PicPecc and a control group.

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### Conflicts of Interest

None declared.

### Multimedia Appendix 1

Parts of the mock-up.

[[DOCX File , 669 KB - pediatrics\\_v5i1e30364\\_app1.docx](#) ]

### Multimedia Appendix 2

Results of stage 1, phase 2.

[[DOCX File , 520 KB - pediatrics\\_v5i1e30364\\_app2.docx](#) ]

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## Abbreviations

**HrQoL:** health-related quality of life

**mHealth:** mobile health

**PicPecc:** Pictorial Support in Person-Centered Care for Children

**UCD:** user-centered design

**UD:** universal design

**UX:** user experience

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Original Paper

# A Digital Health Program Targeting Physical Activity Among Adolescents With Overweight or Obesity: Open Trial

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## Abstract

**Background:** Prior studies suggest that mobile health physical activity programs that provide only weekly or daily text-based health coaching evidence limit the efficacy in improving physical activity in adolescents with overweight or obesity. It is possible that incentives, combined with health coaching and daily feedback on goal success, may increase program efficacy; however, such programs have not yet been tested with adolescents with overweight and obesity.

**Objective:** This study aims to examine the feasibility and acceptability of a 12-week, incentive-based, mobile health physical activity program with text-based health coaching, goal setting, and self-monitoring for adolescents with overweight or obesity. Program adherence and changes in tracked physical activity (ie, steps and active minutes while wearing a Fitbit [Google LLC]), body mass, and body fat are assessed.

**Methods:** A total of 28 adolescents aged 13 to 18 years with a BMI  $\geq$ 90th percentile participated in the program. Of the 28 participants, 2 (7%) were lost to follow-up; thus, data from 26 (93%) participants were used in analyses.

**Results:** Participant-reported acceptability was high, with all mean ratings of text-based coaching, Fitbit use, and the overall program being  $>5$  on a 7-point scale. In addition, 85% (23/26) of participants reported that they would like to continue to wear the Fitbit. Program adherence was also high, as participants wore the Fitbit on 91.1% (SD 12.6%) of days on average and met their weekly goals for an average of 7 (SD 3.5) of 11 possible weeks. There were no demographic (ie, sex, age, and baseline body mass) differences in the percentage of days participants wore their Fitbit. Across the 12-week study, there were significant improvements in tracked daily active minutes ( $P=.006$ ) and steps ( $P<.001$ ) and significant pre- to posttest improvements in body fat percentage ( $P=.04$ ).

**Conclusions:** The pilot program improved adolescent physical activity and physical health. A larger factorial design trial with adaptive daily goals may clarify the role of each program component in driving physical activity.

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**KEYWORDS**

mHealth program; physical activity; adolescent overweight; adolescent obesity; incentives; mobile phone

## Introduction

Adolescence is a high-risk period to have overweight and obesity [1], which may be in part attributable to a decline in physical activity found in this age group. Addressing having overweight and obesity during adolescence is imperative to reduce the risk of continued overweight and obesity—and their common comorbid health conditions—into adulthood [2]. Fewer than 40% of adolescent girls and 30% of adolescent boys meet physical activity recommendations, yielding <10,000 steps per day or 60 minutes of moderate to vigorous physical activity [3]. Traditionally, physical activity intervention programs targeting overweight or obesity among adolescents include in-person, scheduled, activity-based intervention programs to support physical activity habit formation and demonstrate notable downstream improvements in body fat [4] and equivocal efficacy in improving body mass [5-7]. However, despite the general successes of physical activity intervention programs, adolescents with overweight or obesity and their families struggle with accessing and completing such intervention programs, limiting treatment benefits [8,9]. The two major reasons for attrition are a lack of motivation or interest in increasing physical activity and a lack of time to dedicate to participating in a physical activity intervention [10]. Thus, there is a need to test highly scalable intervention programs designed to promote physical activity in adolescents with overweight and obesity, which may also produce secondary effects on body mass and body fat. Importantly, considerations of how to motivate physical activity change must be made during the program development process to reduce the risk of attrition. This study included the pilot-testing of a mobile health (mHealth) program that incentivizes an increase in tracked physical activity in adolescents with overweight or obesity. Program acceptability, program adherence, and changes in physical activity (ie, increase in tracked active minutes and steps) were assessed. A series of exploratory analyses assessed possible changes in body mass and body fat from baseline to after the intervention.

mHealth physical activity intervention programs can reduce the cost and time burden for participants [11], and the inclusion of electronic feedback with goal setting may further improve intervention effects. mHealth programs are uniquely suited to improve adolescent health behavior, as a high percentage of adolescents have access to mobile technologies and report a preference for mHealth programs [12]. Within mHealth physical activity programs, specifically, there is a reliance on an array of remote components, including passive sensing to track behavior (eg, momentary feedback via a pedometer) [13-15] and text-based coaching with goal setting [16,17]. Unfortunately, mHealth physical activity programs that provide only weekly or daily text-delivered messages to adolescents evidence limited efficacy in improving physical activity [16,17]. In contrast, in adult samples, physical activity-promoting mHealth programs that use adaptive goal setting and incentives are efficacious in increasing physical activity [13]. In addition to electronic tracking and feedback, the application of incentives within an mHealth program may further enhance physical activity goal achievement in adolescents with overweight and obesity.

Incentives may be an effective method of increasing engagement in health behaviors in adolescents [18], and incentives for meeting adaptive goals may support improved physical activity in adolescents with overweight and obesity. Incentives that are tied to an individual's success in meeting a specific behavioral goal are hypothesized to be a more effective method than incentives delivered for intervention participation alone [18]. Incentives have been effective in facilitating health behavior change in adolescents with chronic health conditions, such as type 1 diabetes [19,20]. A recent meta-analysis found that incentives also promote improved physical activity goal achievement for adults participating in a physical activity intervention program [21]. On the basis of behavioral principles (ie, operant conditioning), researchers theorize that incentives support immediate improvements in physical activity through the use of positive reinforcement (ie, provision of monetary rewards) that is provided with high frequency (ie, daily or weekly) and predictability (ie, always after a set number of times the individual meets the physical activity goal) [22]. Moreover, the provision of incentives for meeting adaptive rather than static goals has been shown to yield the greatest improvements in physical activity [13], although a decline in activity may be found in the later phases of an intervention [23]. Therefore, to generate robust physical activity change that persists across a program, there may need to be two key features—(1) a shaping phase to incrementally establish a physical activity habit by providing immediate rewards in response to meeting increasingly challenging behavioral goals and (2) continued support for short-term and long-term preservation of habitual physical activity engagement through providing immediate rewards for continued goal success (ie, maintenance phase) and then delayed rewards for continued goal success (ie, fading phase) [24]. However, the provision of incentives in response to physical activity goal success within a scalable, mHealth physical activity program has not yet been tested with a sample of adolescents with overweight and obesity.

This manuscript describes the pilot-testing of a 12-week mHealth incentive program, which targets increased physical activity in adolescents with overweight or obesity. This study is a single group, pre-post pilot of a physical activity program with fixed daily and adaptive weekly physical activity goals, incentives for meeting goals, daily text-based feedback about goal success, and weekly text-based supportive coaching. The primary aim is to examine program acceptability (ie, perceived helpfulness of the text-based coaching, enjoyment of Fitbit (Google LLC) use, and overall program impressions). Secondary aims are to examine (1) program adherence (ie, goal attainment and incentive earnings), including demographic factors related to Fitbit use, and (2) changes in physical activity (ie, increase in tracked active minutes and steps). Finally, an exploratory aim is to identify the possible benefits of this program on body mass and body fat.

## Methods

### Participants

Participants included (N=28) adolescents with overweight or obesity (15/27, 54% male; mean age 14.81, SD 1.59; mean BMI



percentile 97.07, SD 1.85; 26/27, 93% White). Most participants (21/27, 78%) reported having private health insurance. Inclusion criteria included the following: age 13 to 18 years; BMI percentile >90; having broadband wireless internet at home; living at home; and permission from the pediatrician to engage in a physical activity program (eg, physical education or sports), which was noted in electronic health records. Although the 85th and 95th percentile are the standard cutoffs for having overweight and obesity [25], respectively, criteria were modified to include those participants who had obesity or who were at least at moderate or high risk of obesity (ie, at or above the top half of the BMI percentile range for having overweight). Participation in this study also included neuroimaging; thus, exclusion criteria included the following: contraindicated metallic objects in their bodies, psychiatric medication, pregnancy, neurological or health problems (other than obesity), morbid obesity that prevented entering scanner, and visual acuity that could not be corrected to normal.

### Ethics Approval

Ethics approval was received from the Dartmouth Hitchcock Medical Center institutional review board (study ID 29591). The pilot trial protocol is available by contacting the corresponding author. At the time of the study, a registry of pilot trials was not required. In addition, this was an open trial; thus, preregistration did not occur.

### Procedures

A partial Health Insurance Portability and Accountability Act waiver was obtained, which allowed for the recruitment of participants from a general pediatric clinic at Dartmouth Hitchcock Medical Center using data from electronic medical records to identify potentially eligible adolescents based on age and BMI. Letters were sent to parents of potentially eligible adolescents, which provided instructions on how to opt out of the recruitment process (by calling a study coordinator within 2 weeks). After the 2-week opt-out period, research staff called families to tell them more about the study, assess their interest in participating, and determine eligibility (see Figure 1 for participant flow). Briefly, out of 100 adolescents who completed a phone screen, 28 (28%) adolescents enrolled in the study. Study recruitment took place between November 2016 and March 2017. Recruitment ended once 30% (30/100) of adolescents either enrolled or expressed strong interest in doing so. Intakes were conducted between December 2016 and March 2017. Participants completed the program on a rolling basis between winter 2016 and spring 2017. Follow-up assessments occurred throughout June 2017. Of the 28 participants, 26 (93%) completed their follow-up visits, 1 (3%) was lost to follow-up, and 1 (3%) withdrew from the study.

Informed consent and assent were obtained from parents and adolescents, respectively. All participants completed a baseline, in-person assessment that included a body composition assessment, web-based questionnaires, and computer tasks. Next, participants were provided a Fitbit Charge HR (Google LLC) to self-monitor their activity levels throughout the program. Participants then downloaded the Fitbit mobile application on their smartphone and created a Fitbit account, the credentials of which were shared with study staff for

monitoring. The staff ensured that the Fitbit was set to track daily goals of 60 moderate to vigorous minutes, as recommended by the Centers for Disease Control and Prevention [26] and American Heart Association [27]. Although there is a lack of consistent activity guidelines, some prior studies have indicated that there is a correlation between 60 active minutes and a minimum of 10,000 steps in adolescents [3]. Therefore, step counts ( $\geq 10,000$  steps) were included in the adolescents' daily goals. Moreover, consistent with the self-determination theory, adolescent engagement in physical activity programs can be improved through supporting the basic psychological needs of adolescents, including autonomy [28]. Accordingly, the adolescents were given the opportunity to select whether to work toward their active minutes goal or their step goal each day. Adolescents were instructed on how to view daily progress toward exercise goals and incentives. Families were provided information on how to charge and wear the Fitbit (eg, wearing the device at all times when awake except when showering or otherwise exposed to water). Approximately 11% (3/28) of adolescents were loaned an iPod Touch as they did not have a smartphone on which to track their active minutes or receive daily text and email reminders.

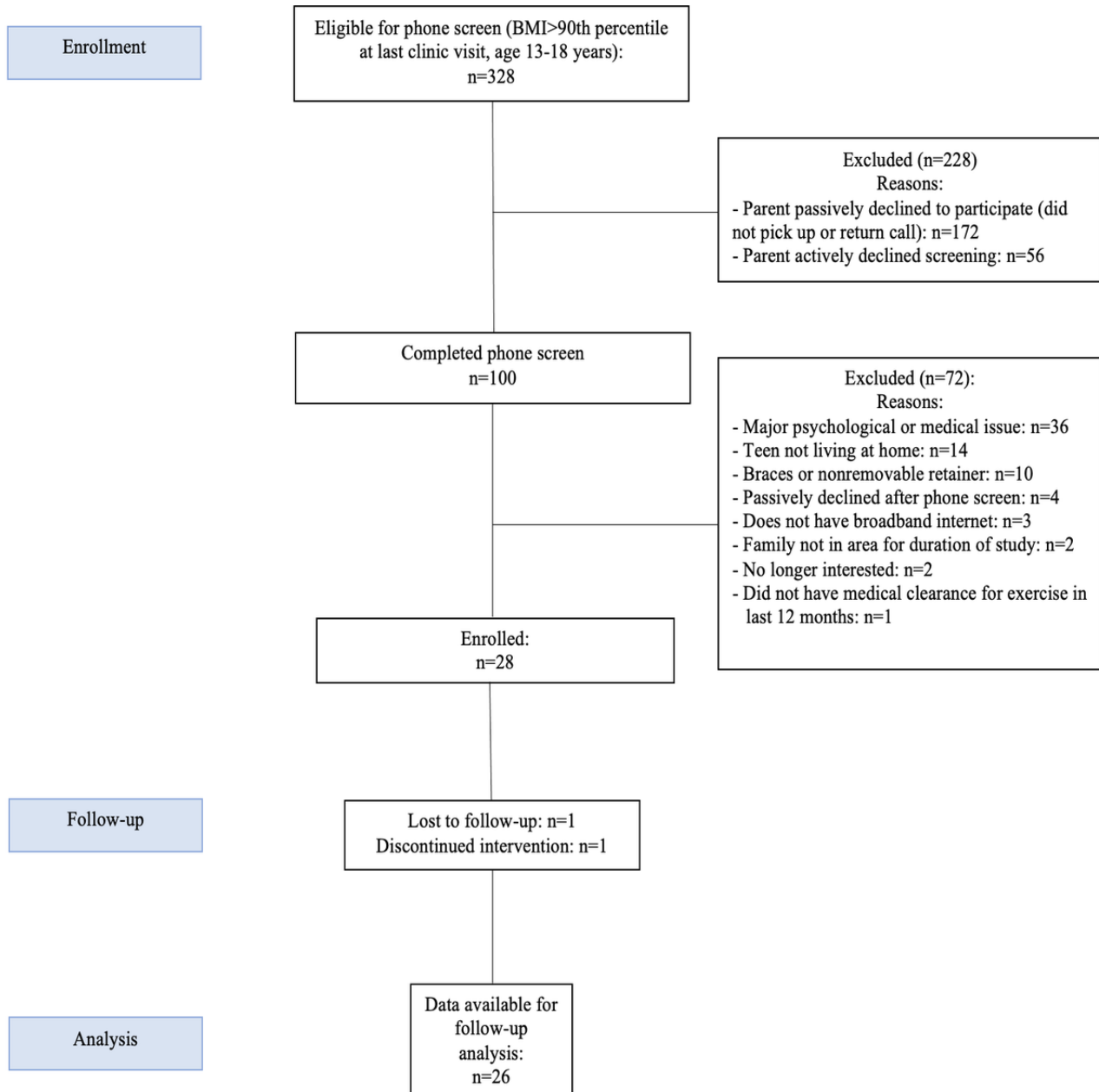
An incentive program commenced on the first Monday following completion of the baseline visit to ensure consistency of feedback across participants. Table 1 shows program phases, weekly goals, and maximum incentives. Briefly, adolescents were provided a daily goal of >60 active minutes or 10,000 steps of exercise per day and weekly goals that depended upon the level of activity in the prior weeks. Adolescents were asked to sync their Fitbits at least once daily (either in the morning or at the end of the day) so that research staff could view their steps or active minutes from the previous day and to prevent loss of data (Fitbits store 30 days of data). Tuesday through Friday, texts informed adolescents about whether they met their active minute or step goal the previous day and praised them if they met their goal; if adolescents did not meet their goal or sync their Fitbit the previous day, texts reminded them to do so. In this pilot research phase, coaches only worked on weekdays; thus, feedback regarding goal success on Friday, Saturday, and Sunday were not delivered until the following Monday. Once per week texts on Monday informed adolescents about whether they met their *weekly* goal, praising them if they did and providing encouragement if they did not; these texts also informed adolescents of the amount of incentives earned that week, if applicable, and the goal for the upcoming week. SMS text message content was standardized and focused specifically on activity goals. However, if technical problems emerged with using or syncing the Fitbit, coaches provided support to adolescents and parents in navigating the technology. To provide immediate monetary reinforcement during the baseline and shaping phases, incentives for adherence to program weekly goals were loaded onto a reloadable debit card once per week for the first 9 weeks. To assess whether physical activity habits were formed rather than activity levels being contingent upon immediate monetary reinforcement, incentives for adherence to program weekly goals were only loaded at the end of the final week for the last 3 weeks in the program (ie, week 12, using a fading strategy).



Following the program, adolescents and parents attended a poststudy assessment and returned the Fitbit and Fitbit charger and iPod Touch if distributed. Adolescents earned US \$100 for completing each assessment that included a lengthy functional

magnetic resonance imaging session (US \$200 total for baseline and poststudy assessment), although functional magnetic resonance imaging data were not analyzed in this study.

Figure 1. Participant Flow Chart.



**Table 1.** Program phases, weekly goals, and maximum incentives (total US \$510).

Week	Phase	Goal	Incentive if goal is met (US \$)	Incentive if goal is exceeded (US \$)	Incentives (US \$ per week)	Total incentives paid (US \$)
1	Baseline	Sync Fitbit $\geq 5$ of 7 days to establish starting level for weekly goals	10	— <sup>a</sup>	10	10
2	Shaping	Individualized exercise goal: meet daily goal 1 day more than the prior week (maximum 5 days)	20	10	30	30
3	Shaping	If goal met, goal for next week increases by 1 day (maximum 5 days); if goal not met, new goal is to match prior week	25	10	35	35
4	Shaping	If goal met, goal for next week increases by 1 day (maximum 5 days); if goal not met, a new goal is to match prior week	30	10	40	40
5	Shaping	If goal met, goal for next week increases by 1 day (maximum 5 days); if goal not met, a new goal is to match prior week	35	10	45	45
6	Shaping	If goal met, goal for next week increases by 1 day (maximum 5 days); if goal not met, a new goal is to match prior week	40	10	50	50
7	Maintenance	$\geq 60$ minutes of exercise (or 10,000 steps), 5 days per week	40	10	50	50
8	Maintenance	$\geq 60$ minutes of exercise (or 10,000 steps), 5 days per week	40	10	50	50
9	Maintenance	$\geq 60$ minutes of exercise (or 10,000 steps), 5 days per week	40	10	50	50
10	Fading	$\geq 60$ minutes of exercise (or 10,000 steps), 5 days per week; incentives paid at the end of 3-week period	40	10	50	—
11	Fading	$\geq 60$ minutes of exercise (or 10,000 steps), 5 days per week; incentives paid at the end of 3-week period	40	10	50	—
12	Fading	$\geq 60$ minutes of exercise (or 10,000 steps), 5 days per week; incentives paid at the end of 3-week period	40	10	50	150

<sup>a</sup>Not available (weeks in which there was no weekly goal bonus or incentives were not delivered).

## Measures

### Program Acceptability

Program acceptability was assessed via participant report of the helpfulness of the text-based coaching (ie, “How helpful did you find our texts?”), experience of using the Fitbit (ie, “How much did you enjoy wearing the Fitbit?”) and overall experience with the program (ie, “How did you like the program?”). Participants rated each question on a 7-item scale, with higher scores indicating more positive experiences. In addition, participants were given a Fitbit Charge HR to track their activity, including active minutes and steps. At the end of the intervention, participants indicated whether they would like to continue wearing the Fitbit after the end of the program.

### Program Adherence

Program adherence was assessed via the percentage of days participants wore their Fitbit (ie, Fitbit adherence) and the number of weeks each participant met their goals and obtained bonuses. Accordingly, participants’ earning totals were considered as indicators of program adherence.

### Physical Activity

As described above, all participants were provided with a Fitbit Charge HR as part of the program. Steps and active minutes were tracked while the Fitbit was worn. Fitbit’s algorithm considers active minutes to be those with  $\geq 3$  metabolic equivalents and only calculates active minutes after 10 minutes of continuous activity. Steps and active minutes were automatically summed daily. The Fitbit Charge has been used in prior studies to measure tracked activity, and a *valid* day of Fitbit use is often characterized as having at least 1500 steps tracked [29,30]. On the basis of this metric, in this study, with 2184 possible data points (26 participants  $\times$  84 days), 1989 (91.1%) days of activity tracking met this criterion.

### Body Mass and Body Fat

A Tanita TBF-300A scale was used to measure body fat and weight at baseline and after the program. The Tanita scale uses bioelectrical impedance analysis, or gentle electric signals through the body, to measure body fat. The Tanita TBF-300A scale has been shown to be a reliable and valid measure of body fat [31,32] and weight [33]. Height was measured using a

stadiometer. Data were collected by research staff once at the initial intake and once at the follow-up (post program) session. Data were manually documented in participants' study records. According to the Freeman et al [34] equation, BMI and Centers for Disease Control and Prevention growth charts were used to compute the percentage of the 95th BMI percentile for age and sex.

### Analysis Plan

First, descriptive statistics were used to examine program acceptability and adherence. Second, to further characterize adherence to daily Fitbit use, correlations and two-tailed *t* tests were also used and compared the percentage of days participants wore their Fitbit based on sex, age, and percentage of the 95th BMI percentile for age and sex. Third, program adherence subgroups were identified, as determined by participants' weekly activity goal success during the first and second half of the program. Fourth, to assess changes in tracked daily active minutes (dependent variable) and steps taken (dependent variable) during participation in the program, multilevel growth modeling was used. Time (ie, day 1 to day 84) was included as an independent variable. Due to the small sample size,

demographic covariates were not included in the multilevel models. A separate model was computed for active minutes and steps. To improve model fit, for the model with steps as the dependent variable, the step count variable was transformed, with participants' daily step count divided by 100. Full information maximum likelihood estimation was used to account for missing data (<10%). Finally, paired-sample *t* tests were used to examine changes in body mass (ie, percentage of the 95th BMI percentile for age and sex) and body fat from baseline to after the intervention. Change scores were used (ie, week 12 – week 1), with negative change scores indicating decreases in body mass and body fat.

## Results

### Program Acceptability

Full descriptive statistics of program acceptability are documented in Table 2. Briefly, participants rated the text-based coaching, Fitbit enjoyment, and overall program highly. In addition, out of 26 participants, 23 (85%) reported that they would like to continue to wear the Fitbit.

**Table 2.** Program acceptability and adherence.

Measures	Values, mean (SD)
How helpful were the SMS text messages? (scale of 1 to 7)	5.8 (1.3)
How much did you enjoy wearing the Fitbit? (scale of 1 to 7)	6.2 (1.3)
How did you like the program? (scale of 1 to 7)	6.6 (0.7)
Weeks (maximum of 11) that participants met the weekly goal	7.2 (3.5)
Weeks (maximum of 11) that participants met the weekly bonus	5.3 (3.8)
Total incentives (US \$) earned during the program (maximum of US \$500)	302.04 (163.85)

### Program Adherence

Full descriptive statistics of program adherence are documented in Table 2. Briefly, participants wore the Fitbit on 91.1% (SD 12.6%) of days on average, with a range of 85.2% (week 11) to 95.6% (week 4) and no notable decreases in Fitbit adherence from week 1 (92.9%) to week 12 (86.6%). There were no differences in the average percentage of days the Fitbit was worn based on sex (female: mean 87.99, SD 13.78; male: mean 93.33, SD 11.55; 2-tailed *t* test  $t_{24}=-1.08$ ;  $P=.29$ ), age ( $r=-0.01$ ;  $P=.97$ ), or percentage of the 95th BMI percentile for age and sex ( $r=0.08$ ;  $P=.72$ ). Participants also met their weekly goals and bonus goals for an average of 7 (SD=3.5) and 5 (SD=3.8) of 11 possible weeks, respectively, each earning an average of approximately US \$300 of the US \$510 maximum.

Three program adherence subgroups were identified: sustained program adherence, nonsustained program adherence, and limited program adherence. Participants categorized as exhibiting sustained program adherence (11/26, 42%) included participants who met at least 80% of their weekly goals across the full program period (ie, weeks 2 to 12). Participants categorized as demonstrating nonsustained program adherence

(7/26, 27%) included participants who met 80% of their weekly goals in the first half of the program during shaping (ie, weeks 2 to 6) but not during maintenance and fading (ie, weeks 7 to 12). Participants categorized as showing limited program adherence (7/26, 27%) included participants who did not meet 80% of their weekly goals during either half of the program. Of the 28 participants, 1 (4%) exhibited delayed program adherence (ie, met 80% of weekly goals only during maintenance and fading).

### Physical Activity

Findings demonstrated a significant increase in tracked daily active minutes ( $P=.006$ ) and steps ( $P<.001$ ), with an average increase of 20.41 (SD 34.27) tracked active minutes per day and 924.00 (SD 2141.59) tracked steps per day found across the entire intervention. There was also a significant intercept by slope effect in the daily active minutes multilevel model ( $P=.005$ ), indicating that adolescents who demonstrated greater active minutes per day at the start of the intervention also demonstrated the greatest increases in active minutes per day over the full intervention period. Full test statistics are presented in Tables 3-6.

**Table 3.** Changes in daily active minutes (fixed effects).

Fixed effects	<i>b</i> (SE; 95% CI)	<i>t</i> test	<i>P</i> value
Intercept	54.80 (6.28; 67.10-42.50)	8.73	<.001
<b>Within-subjects (level 1)</b>			
Time	0.24 (0.08; 0.40-0.08)	2.96	.003

**Table 4.** Changes in daily active minutes (random effects).

Random effects (covariances)	<i>b</i> (SE; 95% CI)	Wald <i>Z</i>	<i>P</i> value
<b>Within-subjects</b>			
Residual	3113.47 (100.04; 3309.56-2917.39)	31.12	<.001
<b>Between-subjects</b>			
Intercept	859.48 (283.12; 1414.39-304.57)	3.04	.002
Time	0.10 (0.05; 0.20-0.01)	2.15	.03
Intercept and time	7.98 (2.82; 13.51-2.45)	2.83	.005

**Table 5.** Changes in daily steps (fixed effects).

Fixed effects	<i>b</i> (SE; 95% CI)	<i>t</i> test	<i>P</i> value
Intercept	93.13 (3.84; 100.64-85.61)	24.28	<.001
<b>Within-subjects (level 1)</b>			
Time	0.11 (0.05; 0.22- 0.01)	2.05	.04

**Table 6.** Changes in daily steps (random effects).

Random effects (covariances)	<i>b</i> (SE; 95% CI)	Wald <i>Z</i>	<i>P</i> value
<b>Within-subjects</b>			
Residual	1129.73 (36.32; 1200.91 to 1058.55)	31.11	<.001
<b>Between-subjects</b>			
Intercept	322.18 (106.89; 531.69 to 112.68 )	3.01	.003
Time	0.05 (0.02; 0.09 to 0.01)	2.30	.02
Intercept and time	0.42 (0.10; 2.57 to -1.74)	0.38	.71

## Body Mass and Body Fat

Findings demonstrated a significant decrease in body fat percentage from week 1 to week 12 ( $P=.04$ ). Change in

percentage of the 95th BMI percentile for age and sex was nonsignificant ( $P>.05$ ). Full test statistics are documented in [Table 7](#).

**Table 7.** Descriptive statistics for physical health outcomes at baseline to 12-week follow-up for the entire sample.

Outcomes	Baseline, mean (SD)	Follow-up, mean (SD)	<i>t</i> test	<i>P</i> value
Percentage of the 95th percentile for age and sex	110.20 (11.42)	110.46 (10.33)	-0.26	.80
Body fat (%)	35.54 (7.79)	34.61 (8.46)	2.17	.04

## Discussion

### Principal Findings

This was a single group pre–post pilot study testing a novel mHealth physical activity program for adolescents with overweight and obesity. Despite the lack of a control group, this study provides preliminary support that an mHealth program

with incentives and text-delivered support and feedback may be an effective nonintensive alternative for increasing tracked physical activity and reducing body fat in adolescents with overweight and obesity. Adolescents reported a positive experience with each program component (ie, text-based coaching and use of Fitbit) and with the program as a whole. There was a low attrition rate (2/28, 7%). These indicators of program acceptability were consistent with program adherence

data that showed that participants wore their Fitbit over 90% of program days, and Fitbit adherence was consistent across sex, age, and percentage of the 95th BMI percentile for age and sex groups. In addition, most participants regularly met their weekly goals, especially in the shaping period of the program from weeks 1 to 6, during which 64.3% (18/28) of participants met at least 80% of their weekly goals. In addition, participants acquired bonuses for exceeding their predetermined goals in about half of the total weeks (5.3 of 11 possible weeks), suggesting positive program outcomes. Across all enrolled participants, the program led to significant improvements in tracked time spent engaging in daily active minutes with metabolic equivalents  $\geq 3$  and steps, as well as significant reductions in body fat percentage, although no significant changes in body mass were noted. Notably, these changes in health and health behavior were achieved with minimal human resources (eg, human contact involved 1 brief in-person *start-up* meeting with a bachelor's level coach and then 5 brief SMS text messages each week, with incentives delivered electronically).

Intensive, multi-component behavior modification studies for health behavior change have faced challenges in achieving high adolescent adherence and have struggled to maintain adolescent motivation throughout the program [9,35]. However, within this study, we had limited attrition, and participants reported favorable opinions of the program, including Fitbit use. Participants were also highly engaged, often meeting their activity goals—especially in the first half of the intervention—and wearing their Fitbit regularly. A reason for the promising level of adherence found within this program may be the low burden of participation combined with incentives. In addition, the use of sensor data collection, in lieu of self-report measures of physical activity, is likely less burdensome and provides a more objective and continuous measure of physical activity [36]. This low level of burden can be contrasted with multi-component intervention programs for treating overweight or obesity, which often involve parental engagement, family therapy, and nutritional changes [11,37]. The findings of the study are promising in that they suggest that an mHealth program with remote incentives, goal setting, and text-delivered support is acceptable within an adolescent sample.

Significant improvements in tracked daily active minutes and steps were also found, highlighting the promise of the program in facilitating relatively immediate health behavior change to support adolescents to manage overweight and obesity. Notably, participants demonstrated an average increase of  $>20$  tracked active minutes per day and 924 tracked steps per day over the course of the 12-week program. Recent research suggests a 20-minute increase in activity per day in adults would lead to a 13% decrease in the number of deaths per year [38]. Therefore, the demonstrated physical activity improvements in response to this novel program are noteworthy and further underscore the feasibility of the program in evoking health behavior change in this high-risk population.

Although some research has shown that increased physical activity predicts decreased body mass [39], this study observed no change in percentage of the 95th BMI percentile for age and sex. This finding is more consistent with well-established weight

loss research indicating that dietary changes rather than physical activity alone drive weight loss among individuals with overweight and obesity [40,41]. Nevertheless, participants demonstrated an overall decrease in body fat, underscoring the ways in which improved tracked physical activity improves physical health [42]. Dissemination of this type of physical activity program may reduce the risk of overweight and obesity, as well as of endocrine and cardiovascular diseases [43], in adulthood.

### Limitations

The findings of the study should be interpreted in the context of its limitations. There was no control group in the study; thus, the effects found in the program cannot be attributed to the program alone. In addition, the sample size was small, and there were subgroups with varying mean levels of adherence, highlighting the need to further modify the program to address nonresponse in some participants. In addition, the reduction in body fat, although statistically significant, may not be clinically significant. In addition, participants were primarily White, and only a paucity of participants reported having public insurance, of which the latter is a strong indicator of low socioeconomic status (SES); thus, the findings might not be generalizable to racially or ethnically diverse samples and adolescents from low SES backgrounds. In addition, the sample includes adolescents at or above the 90th BMI percentile, such that the generalizability of findings to those adolescents with overweight but between the 85th and 89.9th BMI percentile is unknown. Although there was an even distribution of girls and boys, an assessment of differences in changes in physical activity and physical health based on sex could not be conducted. Notably, pubertal status was not assessed in this study, and pubertal changes over the course of the program may have affected physical health results.

In addition, it is possible that participants who enrolled in the study were more motivated to increase physical activity than those who declined. Nonetheless, we used universal outreach (ie, completed a chart review to identify potentially eligible participants) to identify those individuals who may be eligible but otherwise were not seeking behavioral care for the management of overweight or obesity. In addition, owing to the novelty of the Fitbit and monitoring of activity by the text-based health coach, there may have been an increase in activity during the baseline period relative to *usual* activity levels, and the true baseline level of activity before receiving the Fitbit was unknown. However, such an impact would lessen the increase in activity over the course of the intervention.

There also may have been measurement errors, as a recent meta-analysis indicated that Fitbit estimates of step count and moderate to vigorous active minutes might be less accurate than research-grade accelerometers [44], and there was no blinded research-grade measurement of activity before, during, and after the intervention. Regarding the physical health measures, there may have been measurement error in the body mass and body fat calculations, as participants were not given specific instructions to fast or avoid fluid intake before the physical health assessments, and all measurements were taken only once at each study time point.



There are also limitations in the program structure. First, owing to the lack of a universal guideline, participants were given a 10,000 daily step goal, which is lower than the physical activity recommendations used in other studies (eg, 12,000 daily step count, which is more strongly correlated with 60 active minutes) [45]. Second, long-term follow-up assessments were not conducted. In addition, as there were multiple treatment components, it is unknown which specific components guided program effects and whether the program would be as effective with even fewer components. Finally, participants were eligible to receive up to US \$510 in incentives, which may limit implementation by some health systems. It is important to note that participants had an average weekly earning of US \$25.34, which equated to only approximately 59% of the maximum possible incentive earnings (ie, average incentives earned per participant was only US \$302.04 across the entire 12-week program). The scalable program yielded a more optimal cost-effectiveness ratio than traditional, multi-component in-person interventions [46].

### Conclusions and Future Directions

This pilot study provides preliminary support of the acceptability and feasibility of a remote, mHealth program comprising tracked physical activity goals, incentives, and text-based support from health coaches to improve tracked physical activity and reduce body fat in adolescents with overweight and obesity. Replication of findings in a randomized trial by involving a larger, more diverse sample is warranted, including youth with BMI percentiles >85th, and may further clarify the utility of the program in addressing the pediatric overweight and obesity epidemic. Importantly, future studies should explore individual-level factors (eg, sex, cultural background, SES, motivation to lose weight, and pubertal status) that may predict program adherence and changes in tracked activity levels, as well as examine whether program effects are *clinically* significant. To allow for comparison of findings across studies, it should also be a priority to establish a universal cutoff for Fitbit wear time (or adherence), including the minimum number of steps and minutes required to be considered a full day of wear time, as well as universal guidelines for daily step and active minutes for adolescents, specifically. Future studies could investigate the incremental efficacy of each program component using a factorial design to compare the efficacy of an SMS text

message only program, incentives only program, and SMS text message plus incentives program in increasing physical activity among adolescents with overweight or obesity. Researchers might also consider investigating the differential effects of varying incentive magnitudes on changes in tracked physical activity. Given that health insurers are poised to deliver incentives for health behavior change, a randomized trial of this program could advance the evidence-based use of incentives by health insurers. Researchers may also examine whether other incentive types, including parent-led behavior contracting and provision of rewards other than incentives (eg, time with peers and low-cost books or games), may evoke similar results. An adaptive program might also be tested, in which participants are initially offered smaller incentives for a brief period, with participants who demonstrate limited program adherence switching to a more intensive program (eg, parental involvement and larger incentives). In addition, the text-based mHealth program used in this study could be automated by using technology such as the Fitbit application programming interface to automate goal setting and deploy reinforcing SMS text messages every day. The program could also be lengthened to support greater reductions in body fat, as well as be modified to target only increased active minutes or only step counts. Importantly, all future iterations of the program should implement an intervention mapping framework [47].

Future research may also consider assessing mediators and moderators of change. Other adaptations that might be tested include personalized daily adaptive goals (in addition to weekly goals) and incentives for meeting daily goals to increase the number of adolescents meeting weekly goals. In addition, a longer fading period (eg, 12 weeks of weekly incentives, followed by 4-6 weeks of more gradual fading) may support sustained physical activity improvements and long-term program response. Finally, future research should investigate whether participation in an incentive program may increase motivation for additional lifestyle behavior changes (eg, diet and sleep patterns) associated with overweight and obesity, as well as guide the long-term prevention of having overweight and obesity and their common comorbidities during adulthood. Combined, such avenues for future program development may allow for a highly scalable, accessible, and sustainable program for adolescents with overweight and obesity.

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### Conflicts of Interest

None declared.

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## Abbreviations

**mHealth:** mobile health

**PI:** principal investigator

**SES:** socioeconomic status

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Original Paper

# Parents' Experience With a Mobile Health Intervention to Influence Human Papillomavirus Vaccination Decision Making: Mixed Methods Study

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## Abstract

**Background:** Human papillomavirus (HPV)-attributed cancers are preventable, yet HPV vaccination rates severely lag behind other adolescent vaccinations. HPVcancerFree (HPVCF) is a mobile health (mHealth) intervention developed to influence parental HPV vaccination decision making by raising awareness of HPV, reducing HPV vaccination barriers, and enabling HPV vaccination scheduling and reminders through a smartphone app. Evaluating the user experience of mHealth interventions is a vital component in assessing their quality and success but tends to be underreported in mHealth intervention evaluation.

**Objective:** We aimed to evaluate the user experience of HPVCF, an HPV cancer prevention app designed for a pediatric clinic network, using mixed methods data collected from log files, survey measures, and qualitative feedback.

**Methods:** Study data were evaluated from parents in a large US pediatric clinic network using HPVCF in the treatment study condition of a group randomized controlled trial. Log data captured HPVCF retention and use. Postintervention rating scales and items assessed HPVCF utility, usefulness, understandability, appeal, credibility, and perceived impact. Overall quality was evaluated using the user version of the Mobile Application Rating Scale (uMars). Open-ended responses assessed parent recommendations for HPVCF enhancement.

**Results:** The 98 parents were mainly female (n=94, 96%), 41 (5.67) years of age, college educated (n=55, 56%), and White and non-Hispanic (n=55, 56%) and had private health insurance for their children (n=75, 77%). Parents used HPVCF 197 times, with the average visit duration approximating 3.5 minutes. The uMARS app quality score was positively skewed (4.2/5.0). Mean ratings were highest for information (4.46 [SD 0.53]) and lowest for engagement (3.74 [SD 0.69]). In addition, of 95 parents, 45 (47%) rated HPVCF as helpful in HPV vaccination decision making and 16 (17%) attributed HPV vaccine initiation to HPVCF. Parents reported that HPVCF increased their awareness (84/95, 88%), knowledge (84/95, 88%), and HPV vaccination intentions (64/95, 67%). Most of the 98 parents rated the 4 HPVCF components as useful (72-92 [73%-94%]). Parents also agreed that HPVCF is clear (86/95, 91%), accurate (86/95, 91%), and more helpful than other HPV vaccine information they had received (89/95, 94%) and that they would recommend it to others (81/95, 85%). In addition, parents suggested ways to increase awareness and engagement with the app, along with opportunities to enhance the content and functionality.

**Conclusions:** HPVCF was well received by parents and performed well on indicators of quality, usefulness, utility, credibility, and perceived impact. This study contributes a multimethod and multimeasure evaluation to the growing body of literature focused on assessing the user experience of patient-focused technology-mediated applications for HPV education.

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**KEYWORDS**

human papillomavirus; vaccination; user experience; parent; mHealth; HPV; vaccine; HPV vaccine; parenting; pediatrics; sexual health; cervical cancer; adolescents; mHealth; app; application

## Introduction

### Background

Human papillomavirus (HPV) is a sexually transmitted infection that causes anogenital cancers and oropharyngeal cancers in men and women [1]. HPV is attributed to 630,000 new cancer cases per year worldwide [2] and 44,000 cases per year in the United States [3]. The majority of HPV-attributed cancers can be prevented with a 2-dose 9-valent HPV vaccine [4]. HPV vaccination is recommended for adolescents 11-12 years old, but rates severely lag behind other adolescent vaccinations, such as Tdap and meningococcal vaccines [5]. The Healthy People 2030 goal for HPV series completion is 80% of youth; however, only 60% of 13-17-year-olds have initiated and 40% have completed the HPV series in the United States [6].

National samples in the United States have found that 28% of parents have refused or decided not to get the HPV vaccine for their child and 8% of parents have delayed or put off getting the vaccine [7]. Refusal is associated with parental perceptions that the HPV vaccine is ineffective and harmful, and delay is associated with the parental need for more information [7]. Frequent reasons for HPV vaccine hesitancy also include perceptions that the vaccination is not necessary, a lack of provider recommendation, and a lack of parental knowledge [8]. Despite this, parent intervention can persuade HPV vaccination initiation, as over 85% of parents with a history of delay have reported initiating HPV vaccination or intending to do so after continued counseling and recommendation [7].

Factors at the individual, provider, and clinic levels have been positively associated with HPV vaccination outcomes. Interventions that address parental psychosocial factors (ie, knowledge, beliefs, and outcome expectations), provider behavior (ie, HPV vaccine recommendation), patient-targeted systems (ie, reminder systems), and provider-targeted systems (ie, assessment and feedback) can positively influence HPV vaccination rates [9]. Multimethod strategies demonstrate the highest rates of maintaining increases in HPV vaccination [10].

The use of parent- and patient-focused apps to promote HPV education and vaccination is on the rise [11-14]. Mobile health (mHealth) is rapidly becoming a dominant mode to deliver health education and health promotion interventions [15]. Evaluating the user experience of mHealth interventions is important in assessing their quality, acceptability to users, and application in real-world clinical settings [16-20] but is often underreported [21-23]. User experience is broadly defined as a person's perceptions and responses resulting from the use or anticipated use of a product, system, or service [24]. There is a lack of consensus on the best methods, measures, or scales to use when assessing mHealth user experience, although this field is maturing, and a number of scales have been developed that focus exclusively on usability [25,26], quality [27,28], and clinically meaningful risks and benefits [29]. The most frequently evaluated domains in assessments of commercially

available mHealth apps include the scientific and clinical basis, functionality, usability, accountability, impact, and popularity [23]. Nouri et al's [30] systematic review of mHealth evaluation criteria found 7 domains that are commonly used: design, content, usability, functionality, ethical issues, security and privacy, and user-perceived value. In addition, government bodies, such as the UK National Health Service, have developed their own mHealth evaluation standards, which include usability and accessibility to ensure they meet the needs of a diverse set of users, including people with disabilities or those with limited technical knowledge, for their health app marketplace [31]. Of 18 scales developed to evaluate the quality of mHealth apps, the Mobile Application Rating Scale (MARS) is the most frequently applied and is the only scale that has a user version for evaluation by nonhealth professionals [32]. A few studies have evaluated the aspects of user experience for patient-focused technology-mediated HPV interventions, including evaluating the usability of a conversational agent for HPV vaccine counseling of parents and college students using a Wizard of Oz methodology [11,33]; evaluating the feasibility, acceptability, and usability of a cervical cancer and HPV educational virtual agent for Hispanic women [34]; and evaluating the usability of a HPV information website for parents and adolescents [35]. These usability evaluations were done as part of the formative design process and did not include users enrolled in a randomized controlled trial (RCT), using the intervention longitudinally on their own. As HPV vaccination misinformation remains a significant public health problem, there is a need for HPV education apps that are usable, useful, and scalable to motivate parents to vaccinate their adolescent children.

### mHealth Intervention: HPVcancerFree

HPVcancerFree (HPVCF) is an iOS- and Android-compatible smartphone app designed for parents of patients aged 10-17 years who have not initiated HPV vaccination. HPVCF is part of a multilevel intervention aimed at increasing HPV vaccination initiation and completion rates in a large US pediatric clinic network [36]. HPVCF was designed to (1) raise awareness of HPV and its prevention, (2) reduce barriers to HPV vaccination, and (3) enable parents to initiate HPV vaccination scheduling and reminders through their smartphone. Preliminary findings have demonstrated potential of HPVCF in changing parental knowledge and perceptions of HPV vaccination [37].

HPVCF was created using user-centered design principles and Intervention Mapping, an evidence- and theory-based systematic framework for developing behavior change interventions [38]. The design steps included (1) literature review and online synchronous text-based focus groups with parents from the pediatric clinic network to assess HPV attitudes, barriers, beliefs, and needs related to a digital behavior change solution [39]; (2) matrices describing target behaviors, psychosocial determinants of behavior, and change objectives; (3) delineation of theoretical methods and practical applications; (4) prototype build; (5) heuristic evaluation and in-house alpha testing; and (6) iterative user testing to assess app content, function, delivery channel,

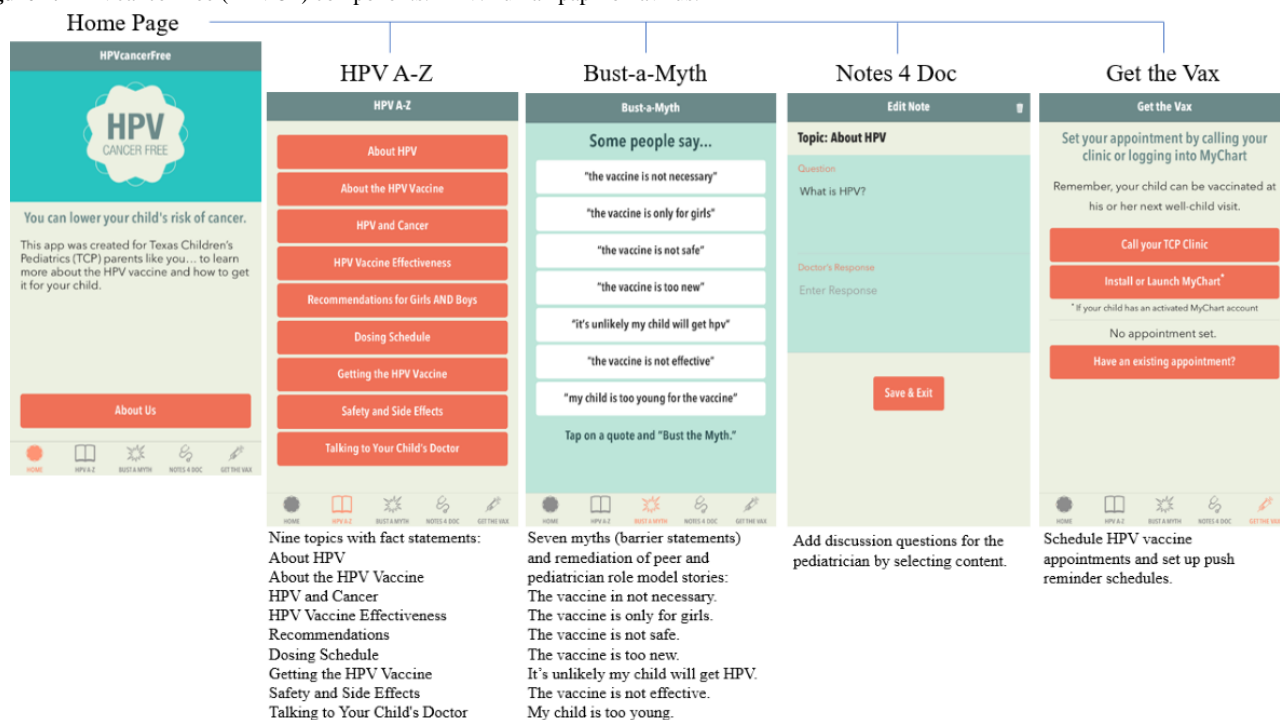
usability, value, desirability, and adoptability for both design and content.

HPVCF contains 4 self-tailored components: (1) HPV A-Z, a compendium of 9 content domains providing facts about HPV and the HPV vaccine; (2) Bust-a-Myth, 7 educational modules, including peer and health care provider testimonials addressing the most salient HPV vaccination barriers; (3) Notes 4 Doc, a medium to facilitate communication with health care providers about the HPV vaccine; and (4) Get the Vax, a feature to

schedule HPV vaccination appointments and receive tailored reminders (Figure 1). There were 77 app pages and links that parents had unlimited access to. HPVCF was designed for user-centric navigation and so did not prescribe an intended user path.

The purpose of this study is to evaluate the user experience of HPVCF, an HPV cancer prevention app designed for a pediatric clinic network, using mixed methods data collected from log files, survey measures, and qualitative feedback.

**Figure 1.** HPVcancerFree (HPVCF) components. HPV: human papillomavirus.



## Methods

### Study Design and Ethics Approval

Study data were drawn from parents who used HPVCF in a group RCT assessing HPVCF effectiveness within a large pediatric clinic network in Texas, USA, and completed a postintervention experience survey [37]. The study occurred between September 2017 and March 2019, where the 51 network clinics were randomized to either the treatment (HPVCF with usual care) or a comparison (usual care only) study condition. Parents in the 26 treatment clinics represented the analytic sample for this user experience evaluation. These parents were given instruction and links to download HPVCF from the Apple App Store (iPhone users) or Google Play Store (Android users). They were given a personal ID to enter the first time they launched HPVCF for tracking purposes. Study protocols were approved by the institutional review board at the University of Texas Health Science Center at Houston (HSC-SPH-15-0202).

### Study Inclusion Criteria and Recruitment

Eligibility for the study included (1) having a 10-to-17-year-old child who was a patient in the clinic network, (2) having a child that had not initiated HPV vaccination, and (3) the ability to speak and write in English. Parents who had an eligible child

were invited to participate in the study via patient health record portal invitations, flyers in the clinic waiting rooms, and posts on the clinic network Facebook page. Recruitment for the study took place on a rolling basis from September 2017 to September 2018. Each parent participated in the intervention for 5 months between September 2017 and March 2019, depending on when they were recruited and enrolled. Parent completed a presurvey before they were given access to the intervention and a postsurvey, which included an experience assessment, at the conclusion of their intervention time frame.

### HPVCF Onboarding, Use, and Retention

HPVCF use data were gathered over the course of the 5-month intervention from log files, including total number of visits, number of visits per participant, actions (viewing an app page or link) per visit, and visit duration. A back-end data capture system (Matomo) [40] collected time-stamped use by participant. Actions were triggered when the parent visited a new app page.

### Experience

HPVCF user experience was assessed with a postintervention survey using a quality rating scale, survey items, and an open-ended response item for recommended enhancements.

The survey items included utility, perceived impact, component usefulness, clarity, credibility, and motivational appeal.

### **App Quality**

App quality was assessed by the user version of the Mobile Application Rating Scale (uMARS) [28]. uMARS is a reliable mHealth quality measure comprising 3 separate components: an app quality mean score, an app subjective quality scale, and perceived impact items. The app quality mean score contains 16 items evaluating 4 subscales: engagement (5 items), functionality (4 items), aesthetics (3 items), and information (4 items) on a 5-point response from 1 for “inadequate” to 5 for “excellent” and N/A if an app component is not used. uMARS has consistent internal consistency (Cronbach  $\alpha=.90$ ) for all subscales (engagement  $\alpha=.80$ ; functionality  $\alpha=.70$ ; aesthetics  $\alpha=.71$ ; information  $\alpha=.78$ ) [28]. The app quality score was calculated by averaging the combined scores for each of the 4 subscales (engagement, functionality, aesthetics, and information).

### **Survey Items**

#### **Utility**

Two utility items assessed whether HPVCF information helped parents decide to get the HPV vaccine for their child (no, yes, no opinion) and whether parents got their child the HPV vaccine as a result of using HPVCF (no, yes, no opinion). These items were adapted from prior surveys used with patient-focused digital behavior change interventions in clinic and school settings [41-43].

#### **Perceived Impact**

Perceived impact was assessed with 5 items on user perceptions of HPVCF. These modified perceived impact uMARS items measured perceptions of change in awareness of HPV and the HPV vaccine, knowledge of HPV and the HPV vaccine, attitudes of HPV and the HPV vaccine, intentions to get their child the HPV vaccine, and communication with the child’s pediatrician about the HPV vaccine. These items were evaluated on a 4-point scale with response options “strongly disagree,” “somewhat disagree,” “somewhat agree,” and “strongly agree” [28]. For analysis, “somewhat agree” and “strongly agree” response options were collapsed into an “agreement” category.

#### **Usefulness**

Usefulness was assessed using ratings of 4 HPVCF components (HPV A-Z, Bust-a-Myth, Notes 4 Doc, and Get the Vax) with response options “did not use,” “not very useful,” “somewhat useful,” “very useful,” and “do not recall.” For analysis, “very useful” and “somewhat useful” were collapsed into an “agreement” category.

#### **Clarity**

Clarity was assessed with a single item on whether the goal of HPVCF was clear (no, yes, no opinion).

#### **Credibility**

Credibility was assessed using 1 rating of accuracy of HPVCF content (inaccurate, accurate, no opinion) and 1 rating of

trustworthiness of HPVCF information (cannot be trusted, can be trusted, no opinion).

### **Motivational Appeal**

Motivational appeal was assessed using 3 ratings: whether parents would use HPVCF again (no, yes, no opinion), a comparison of the helpfulness of HPVCF content against other HPV content received (less helpful, as helpful, more helpful), and the extent to which parents would recommend HPVCF to others who might benefit from it (few people, several people, many people, everyone). These items were adapted from prior surveys used with patient-focused digital behavior change interventions in clinic and school settings [41-43].

### **Recommended Enhancements**

Recommended enhancements were solicited from an open-ended question, “What would make the HPVCF app more appealing so that parents would want to use it?” adapted from prior surveys used with patient-focused digital behavior change interventions in clinic and school settings [41-43].

### **Demographics**

Parent sociodemographic variables were gathered from preintervention survey items at the start of the 5-month intervention. The parent sociodemographic variables included age, number of adolescent children, sex, race, ethnicity, education, child’s health insurance status, and baseline HPV vaccination intention.

## **Results**

### **HPVCF Onboarding, Use, and Retention**

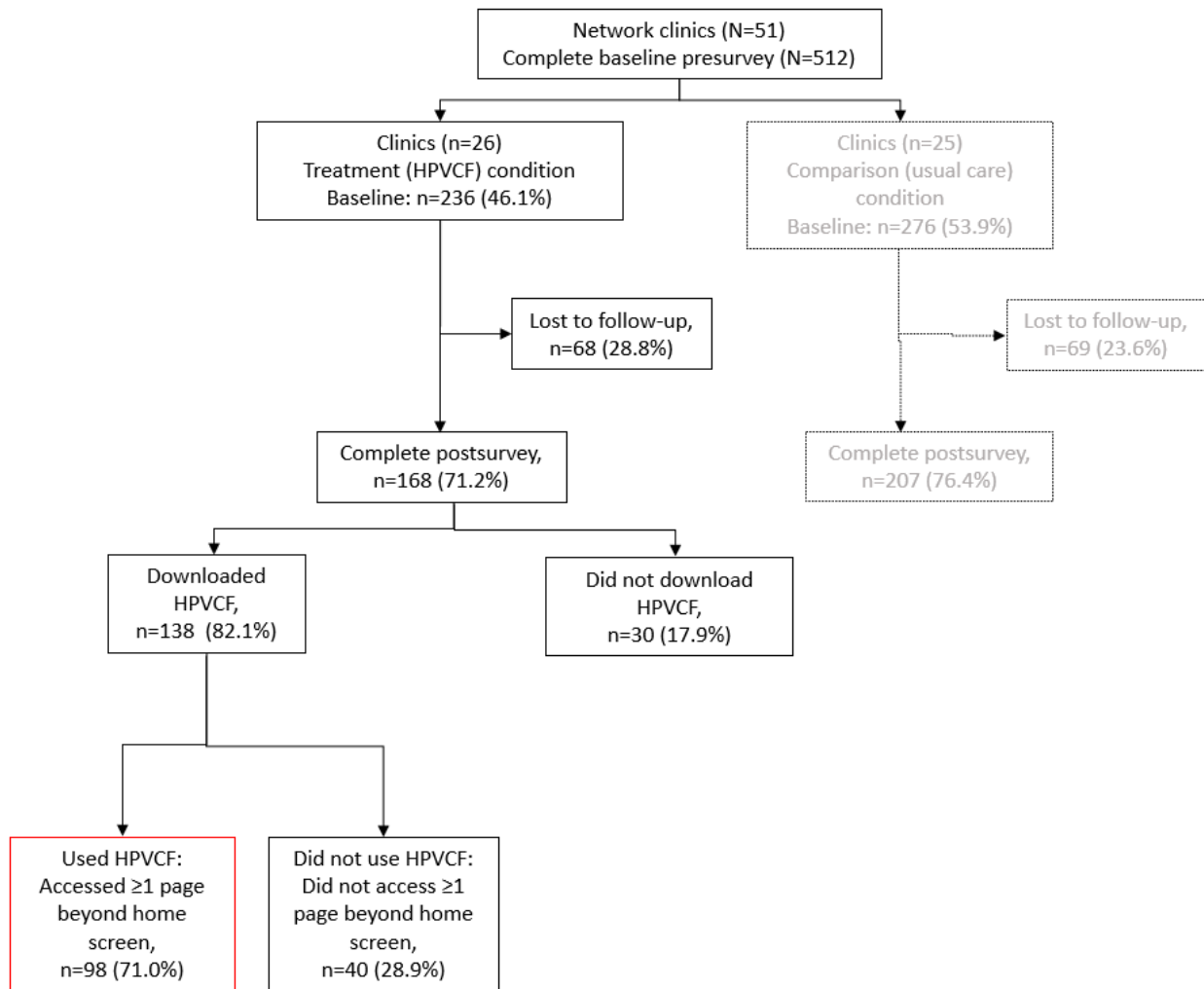
In total, 168 parents completed the postintervention survey, of whom 98 (58.3%) were included in this experience analysis as they also downloaded and used the intervention (viewed at least 1 page past the home screen on any visit; Figure 2).

Parents had a mean age of 41 years, and the majority were female (94/98, 96%), college graduates (55/98, 56%), and White and non-Hispanic (55/98, 56%) and had private health insurance for their children (75/98, 77%); see Table 1. Most parents had 1 child between 10 and 17 years of age, with a range of 1-4 children in that age group. At baseline, of 98 parents, 12 (12%) reported that they “don’t intend” to vaccinate their child for HPV, 40 (41%) “definitely” planned to, and 46 (46%) were unsure (“haven’t thought of it,” “considering,” and “will probably get”). These demographics reflected the RCT sample where parents had a mean age of 41 years, were majority female (358/375, 95.5%), were college graduates (233/375, 62.1%), and identified as White and non-Hispanic (210/375, 56%). Further, these results approximate the demographic characteristics of the clinic network population where among children 10-17 years old, 45% are White and non-Hispanic and 80% have private health insurance.

Parents visited HPVCF 197 times during the study period (Table 2). Most parents used HPVCF once (45/98, 46%) or twice (28/98, 29%) with a range of 1-8 visits. During a single visit, 2-84 actions occurred with a mode of 3 actions. The average visit duration was 3 minutes and 27 seconds with a mode of 24

seconds and a range from 3 seconds to just under 27 minutes. (273 views), Get the Vax (173 views), and Notes 4 Doc (110 views). Of the 4 HPVCF main component pages, HPV A-Z (370 views) was visited most often by parents, followed by Bust-a-Myth

**Figure 2.** Recruitment and retention. HPV: human papillomavirus; HPVCF: HPVcancerFree.



**Table 1.** Parent demographics (N=98).

Characteristic	Value
<b>Age (years), mean (SD); range</b>	41.23 (5.67); 26-54
<b>Number of adolescent children<sup>a</sup>, mean (SD); range; mode</b>	1.42 (0.62); 1-4; 1
<b>Parent sex, n (%)</b>	
Male	4 (4)
Female	94 (96)
<b>Parent race and ethnicity, n (%)</b>	
White, non-Hispanic	55 (56)
Black or African American, non-Hispanic	7 (7)
Hispanic	30 (31)
Asian	4 (4)
Other	2 (2)
<b>Parent education, n (%)</b>	
Some high school	1 (1)
High school graduate or General Educational Development (GED)	7 (7)
Some college	35 (36)
College graduate	25 (25)
Graduate or professional degree	30 (31)
<b>Child/children's health insurance status<sup>b</sup>, n (%)</b>	
Private health insurance	75 (77)
Medicaid/Medicare/State Children's Health Insurance Program	20 (20)
Uninsured; no coverage of any type	3 (3)
<b>Parent baseline HPV<sup>c</sup> vaccination intention, n (%)</b>	
Haven't thought of it	8 (8)
Considering	19 (19)
Will probably get	19 (19)
Definitely	40 (41)
Don't intend	12 (12)

<sup>a</sup>10-17 years old.

<sup>b</sup>Response options are inclusive.

<sup>c</sup>HPV: human papillomavirus.



**Table 2.** HPVcancerFree (HPVCF) use (N=98).

Visit details	Value
<b>Total number of separate visits<sup>a</sup> (all parents)</b>	197
<b>Number of visits<sup>a</sup> per parent, mean (SD); range</b>	2 (1.25); 1-8
<b>Distribution of parent visits, n (%)</b>	
1 visit	45 (46)
2 visits	28 (29)
3 visits	13 (13)
4 visits	10 (10)
5 visits	2 (2)
8 visits	1 (1)
<b>Actions<sup>b</sup> per visit, mean (SD); range; mode</b>	11 (10); 2-84; 3
<b>Visit duration (seconds), mean (SD); range; mode</b>	207 (249); 3-1601; 24
<b>Total views by main component page<sup>c</sup>, n</b>	
HPV <sup>d</sup> A-Z	370
Bust-a-Myth	273
Notes 4 Doc	110
Get the Vax	173

<sup>a</sup>A visit was defined as viewing at least 1 page past the home screen.

<sup>b</sup>An action was defined as viewing an app page or link. There were 77 app pages and links in total, which could be viewed unlimited times.

<sup>c</sup>The main component pages could be visited unlimited times while visiting the app.

<sup>d</sup>HPV: human papillomavirus.

### App Quality

The uMARS app quality rating was 4.2/5.0 (Table 3). The uMARS information subscale had the highest mean rating (4.46

[SD 0.53]), followed by functionality (4.32 [SD 0.65]), aesthetics (4.30 [SD 0.57]), and engagement (3.74 [SD 0.69]).

**Table 3.** User version of the Mobile Application Rating Scale (uMARS) mean scores (N=95).

Subscale <sup>a</sup>	Mean (SD)
Engagement (5 items)	3.74 (0.69)
Functionality (4 items)	4.32 (0.65)
Aesthetics (3 items)	4.30 (0.57)
Information (4 items)	4.46 (0.53)
Overall quality <sup>b</sup> (from subscales)	4.20 (0.48)

<sup>a</sup>Items in the subscale measured on a 5-point response scale from 1 for “inadequate” to 5 for “excellent” and N/A if an app component was not used.

<sup>b</sup>Calculated by averaging the combined scores for each of the 4 subscales (engagement, functionality, aesthetics, and information).

### Utility, Perceived Impact, Usefulness, Clarity, Credibility, and Appeal

#### Utility

Overall, 45 (47%) of 95 parents rated HPVCF as helping them decide to get their child the HPV vaccine, and 16 (17%)

responded that they got their child the HPV vaccine as a result of HPVCF (Table 4).

**Table 4.** Parent agreement on utility, perceived impact, usefulness, clarity, credibility, and appeal (N=95).

User experience survey parameter	Agreement, n (%)
<b>Utility<sup>a</sup></b>	
The information I got from HPVCF <sup>b</sup> helped me decide to get my child the HPV <sup>c</sup> vaccine.	45 (47)
I got my child the HPV vaccine as a result of using the HPVCF app.	16 (17)
<b>Perceived impact of HPVCF<sup>d</sup></b>	
Increased my awareness of HPV and HPV vaccine.	84 (88)
Increased my knowledge of HPV and HPV vaccine.	84 (88)
Changed my attitudes of HPV and HPV vaccine.	54 (57)
Increased my intentions to get my child the HPV vaccine.	64 (67)
Encouraged me to talk to my child's pediatrician about the HPV vaccine.	65 (68)
<b>Usefulness by component<sup>e</sup></b>	
HPV A-Z	92 (94)
Bust-a-Myth	88 (90)
Notes 4 Doc	72 (73)
Get the Vax	73 (75)
<b>Clarity<sup>c</sup></b>	
The goal/purpose of the HPVCF app was clear.	86 (91)
<b>Credibility</b>	
I think information I got from the HPVCF app was accurate. <sup>f</sup>	86 (91)
I think the information I got from the HPVCF app can be trusted. <sup>g</sup>	85 (90)
<b>Appeal</b>	
I would use HPVCF again. <sup>c</sup>	63 (66)
Compared to other information I have seen about the HPV the HPVCF app is as or more helpful. <sup>h</sup>	89 (94)
I would recommend HPVCF to others. <sup>d</sup>	81 (85)

<sup>a</sup>Responded "yes" as opposed to "no" or "no opinion."

<sup>b</sup>HPVCF: HPVcancerFree.

<sup>c</sup>HPV: human papillomavirus.

<sup>d</sup>Includes "somewhat agree" and "strongly agree" response options.

<sup>e</sup>N=98; combined responses of "very useful" and "somewhat useful." Combined percentage responses of "did not use" and "do not recall" were as follows: HPV A-Z (5/98, 5%), Bust-a-Myth (5/98, 5%), Notes 4 Doc (19/98, 19%), and Get the Vax (20/98, 20%).

<sup>f</sup>Rated as "accurate" as opposed to "inaccurate" or "no opinion."

<sup>g</sup>Rated as "can be trusted" as opposed to "cannot be trusted" or "no opinion."

<sup>h</sup>Rated as "as helpful" or "more helpful" as opposed to "less helpful."

### Perceived Impact

Most parents (64/95, 67%) agreed that HPVCF increased their intentions to get their child the HPV vaccine. Parents reported that HPVCF positively impacted their awareness (84/95, 88%), knowledge (84/95, 88%), and attitudes (54/95, 57%) about HPV and the HPV vaccine and encouraged them to discuss the HPV vaccine with their child's pediatrician (65/95, 68%); see [Table 4](#).

### Component Usefulness

Most parents rated the 4 HPVCF components as useful ([Table 4](#)). HPV A-Z (92/98, 94%) scored the highest, followed by

Bust-a-Myth (88/98, 90%), Get the Vax (73/98, 75%), and Notes 4 Doc (72/98, 73%). Most parents used Bust-a-Myth and HPV A-Z (both  $\geq 95\%$ ); however, 20 (20%) and 19 (19%) of 98 parents reported not using the Get the Vax and Notes 4 Doc components, respectively.

### Clarity, Credibility, and Appeal

The majority of parents rated the purpose of HPVCF as clear (86/95, 91%) and that the information in HPVCF was accurate (86/95, 91%) and can be trusted (85/95, 89%). Parents also agreed that they would use HPVCF again (63/95, 66%), that it was more helpful than other information they had seen about

HPV and the HPV vaccine (89/95, 94%), and that they would recommend HPVCF to others (81/95, 85%); see [Table 4](#).

### Recommended Enhancements

Qualitative feedback gathered on how to improve HPVCF included themes of increasing awareness and engagement with the app and enhancing the content and functionality.

#### *Increasing Awareness and Engagement*

Parents commented that they forgot to use the app after the initial download and needed a reminder from the app, pediatrician, or clinic to use HPVCF:

*It's been a long time since I used the app, so I don't remember if there was a function to remind the user in the future to make an appointment etc. That would prompt the user to reopen the app. I read all the information the first time I opened it and didn't open it again, so I've forgotten much of it now.*

Due to a lack of repeated engagement, some parents reported they had forgotten much of the information they had originally reviewed. Parents suggested improving engagement by having push notifications with HPV facts instead of having to open and use the app to obtain information. Further, to improve marketability, one parent recommended incorporating HPVCF content into a broader app that included topics outside of HPV.

Parents also suggested making HPVCF more interactive and entertaining, especially by providing opportunities to engage and speak with adolescents about HPV and sexual health. To make HPVCF more adolescent friendly, parents suggested adding animations and games.

#### *Enhancing Content and Functionality*

To improve the content, parents suggested offering parent testimonials highlighting their struggle to decide to vaccinate and how they used HPVCF to make an informed decision:

*I think offering parent testimonials about their struggle to decide to vaccinate and how they used the info offered to help make an educated decision.*

Some parents were dissatisfied with the presentation of HPV's long-term effects, expecting to see more in-depth information and studies about complications and side effects of the vaccine:

*This app, as a parent, did not give me the type of information I would want and need about HPV. I would prefer more information on the age of the vaccine. Credible studies completed. New research and side effects. More of that information would help. If the vaccine is less than 10 years old, I want more information on studies.*

Parents wanted a tailored reminder system that conveyed information regarding their child's HPV vaccination status and recommendation:

*[I would suggest] some type of electronic reminder from the doctor to review the app. I downloaded the app for the survey, reviewed it, but then forgot about it. Maybe the doctor's office can send email to parents of 9-, 10-, and 11-year-old patients. Also, [a]*

*reminder should have information on [the] child's status (ie, for informational purposes only; needs first dose; received first dose, time for second; etc).*

Parents noted some issues with the available functionality, such as the app not storing their appointment information caused by usability issues with the design. For future iterations, parents suggested the ability to share information in the app with existing social media outlets:

*[It would be helpful if the app would] allow for flagging/sharing individual items to foster organic awareness through existing social outlets?*

## Discussion

### Principal Findings, Strengths, and Limitations

This study evaluated the user experience of HPVCF, an HPV cancer prevention app designed for parents with children belonging to a large urban pediatric clinic network in the United States. Parents viewed HPVCF as having high quality, utility, and perceived impact. HPVCF quality ratings were robust (4.2) compared to quality scores of 2.4–4.6 for mHealth apps focused on prostate cancer risk [44], Alzheimer disease [45], alcohol use [46], occupational therapy [47], orthopedic rehabilitation [48], and medication adherence [49]. HPVCF quality was rated the highest for information and lowest for engagement subscales. This is consistent with the parents' perceptions of HPVCF information as accurate and trustworthy, while also acknowledging the need to enhance functions and features. The positively skewed quality rating is consistent with a considerable number of parents (16/95, 17%) attributing their child's HPV vaccination to HPVCF and the majority of parents (64/95, 67%) attributing HPVCF to increasing their intentions to vaccinate their child. This is promising, considering that the period of participation in the study was only 5 months, which is inadequate to fully track vaccinations through annual well visits. The study design was insufficient to determine whether these perceptions and vaccinations were significantly different from trends in parents not exposed to HPVCF, but it does appear that HPVCF was sufficiently persuasive to move at least a sample of parents to action. It is also unclear whether, in these instances, HPVCF was directly associated with vaccination or mediated through greater pediatrician dialogue that promoted vaccination.

Interestingly, 63 (66%) of 95 parents reported that they would use the app again, but log data indicated that 45 (46%) of 98 parents only used the app once. Triangulating these findings with information obtained in the qualitative feedback suggests possible reasons for this, including forgetting about the app after initial download, only using HPVCF on an as-needed basis, or no longer needing the app since it fulfilled its intended use after a single visit. Future iterations could be strengthened to help parents reengage by utilizing pediatricians and clinic staff to incorporate reminders as part of their standard communication. Exploring adjunct functionality that offers HPVCF information in more compact ways (ie, push notifications, text messages) may prove beneficial as most parents only looked at a few pages or links for a brief time (under 3.5 minutes).

Parents perceived HPVCF as more impactful for increasing awareness and knowledge than in changing attitudes about HPV. Knowledge is necessary but not necessarily sufficient to elicit behavior change. Negative attitudes around HPV vaccine safety are particularly pervasive [9], and strategies that are personalized, tailored, and require engagement beyond passive education may be needed to modify attitudes [50]. Concerns about HPV vaccination may have extended to HPVCF itself, with some parents feeling that HPVCF is biased in its portrayal of the long-term risks and safety of the HPV vaccine, despite high credibility ratings. A further behavioral impact was that the majority of parents also reported that HPVCF prompts greater communication with their pediatrician. This is an important adjunct function that helps the parent engage more competently with the pediatrician and provides the pediatrician with an opportunity to educate the parent during “teachable moments” at the clinic visit.

Importantly, parent engagement with the intervention was low, with about 70 (41.7%) of 168 parents choosing not to use HPVCF, making it difficult to generalize results to the clinic network. The low engagement is partially a reflection of the real-world nature of the study and accompanying challenges of competing for attention in an open market. Future iterations might adopt a more assertive approach by having parents download HPVCF during clinic visits and having clinic staff be more involved in providing reminders for its use. Future studies can explore promotional strategies to motivate parents to use HPVCF.

Additional limitations of this study should be considered. The intervention timeline did not include the back-to-school vaccination period (generally June-September) for many adolescent children, as the intervention took place on a 5-month rolling basis over the course of 1.5 years. This may have affected

the parents’ decision to get their adolescents vaccinated. The 5-month intervention timeline also meant that some parents answered postintervention questions weeks after using HPVCF, possibly affecting their ability to accurately recall and report on some survey measures. A further limitation of the study was that the English-only content and the smartphone-based application may have excluded participation from parents with lower socioeconomic status or those who do not speak English. Although smartphone ownership among Americans is high (85% White, 85% Hispanic, 83% Black), there are disparities between Americans who are college educated (93%) and those with a high school diploma or less (75%) [51], and health app usage among low-income, racial minority, and ethnic minority patients in Texas remains low [52]. Future research addressing non-English-speaking and populations with a lower socioeconomic status is recommended. Finally, this analysis did not examine user experience by participant characteristics. However, subsequent analyses explored content-specific patterns of use that underlie psychosocial characteristics of parents [53].

As digital technologies continue to evolve, they stand to provide a paradigmatic shift in how health education and health behavior research are conducted [54], but doing so will require them to be perceived by users as being usable and useful applications. This study contributes a multimethod and multimeasure evaluation to the growing body of literature focused on assessing the user experience of patient-focused technology-mediated applications for HPV education [11,33-35].

### Conclusion

HPVCF was well received by parents and performed well on indicators of quality, usefulness, utility, credibility, and perceived impact. HPVCF contributes to a multimethod and multimeasure evaluation strategy for user experience, which remains underreported in mHealth apps.

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### Conflicts of Interest

None declared.

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## Abbreviations

**HPV:** human papillomavirus

**HPVCF:** HPVcancerFree

**mHealth:** mobile health

**RCT:** randomized controlled trial

**uMARS:** user version of the Mobile Application Rating Scale

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Original Paper

# Social Media–Driven Routes to Positive Mental Health Among Youth: Qualitative Enquiry and Concept Mapping Study

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## Abstract

**Background:** Social media influence almost every aspect of our lives by facilitating instant many-to-many communication and self-expression. Recent research suggests strong negative and positive impacts of social media exposure on youth mental health; however, there has been more emphasis on harmful relationships.

**Objective:** Given the limited research on the benefits of social media for mental health, this qualitative study explored the lived experiences of youth to understand how social media use can contribute to positive mental health among youth.

**Methods:** Using an interpretivist epistemological approach, 25 semistructured interviews and 11 focus group discussions were conducted with male and female youth of different ethnicities (aged 15 to 24 years) residing in Singapore, who were recruited through purposive sampling from the community. We conducted inductive thematic analysis and concept mapping to address the research aims.

**Results:** We found that youth engaged in a wide range of activities on social media from connecting with family and friends to participating in global movements, and these served as avenues for building positive mental health. Based on participants' narratives, our analysis suggested that positive mental health among youth could be influenced by 3 features of social media consumption (connection with friends and their global community, engagement with social media content, and the value of social media as an outlet for expression). Through these, pathways leading to the following 5 positive mental health components were identified: (1) positive relationships and social capital, (2) self-concept, (3) coping, (4) happiness, and (5) other relevant aspects of mental health (for example, positivity and personal growth).

**Conclusions:** The study results highlight the integral role of social media in the lives of today's youth and indicate that they can offer opportunities for positive influence, personal expression, and social support, thus contributing to positive mental health among youth. The findings of our research can be applied to optimize engagement with youth through social media and enhance the digital modes of mental health promotion.

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**KEYWORDS**

teens; young adults; concept mapping; mental well-being; digital media; social media; mental health; social support; mental health promotion; self-expression

## Introduction

Rapid developments in smartphone and internet use have broadened people's opportunities for the production and consumption of online content. Platforms and apps collectively termed social media, facilitate many-to-many communication in contrast to traditional one-to-one personal communication and one-to-many media communication [1]. Over the last decade, youth have been one of the biggest groups online [2]. In the United States, the proportion of adolescents who have a smartphone is estimated to be 89%, which has doubled over a 6-year period from 2012 to 2018; moreover, 70% of teenagers use social media multiple times per day, which is up from 30% in 2012 [3]. In Australia, a longitudinal study found that over 86% of students owned smartphones in grade 8, which increased to 93% by grade 11, with a marked increase in social media communication from teenage to early adulthood [4].

With this surge of online activity among youth, research into the relationship between social media use and health, especially among those in critical stages of development, such as the transition from teenage years to young adulthood, has gained importance [5]. Popular social media sites, such as Facebook, YouTube, Instagram, and Snapchat, provide extensive opportunities to youth to connect with others, express their creativity, and assert their self-identity through pictures, text, audio, or videos [6]. While the functionality and popularity of each platform varies, they are now well established as avenues for identity and self-presentation [7], building social capital [8], and participation in social activism [9] among youth.

Internet use and excessive social media engagement have, however, been linked to cyberbullying, social isolation, stress, and depression [10]. Frequent social media activity is also linked to harmful behaviors, such as addictions, self-harm, and suicidality that can be detrimental to mental health [11]. Although much of the narrative on social media implies an adverse effect on mental health, more recent research findings have been mixed. For instance, a review indicated that some uses of social media, such as suicide prevention [12] and authentic self-presentation, are associated with mental well-being in adolescents [5]. Mental well-being refers to several positive aspects of mental health, such as happiness, life satisfaction, positive relationships, positive outlook, and personal growth [13]. The positive impacts of social media are attributed to increased access to social capital and useful information that present various easy modes of social support in a virtual world [8]. These are of particular relevance among youth experiencing emotional problems who reportedly prefer anonymity offered by social media to in-person interactions [14].

Considering the centrality of social media in forming close connections, which contribute to positive youth development [15], and the high exposure to social media use among youth, understanding how social media influences positive mental health would be beneficial in improving youth mental health. However, the benefits of social media to youth mental health are not fully recognized. A scoping review of 79 studies investigating the association of social media use with mental health and well-being among adolescents found that

three-quarters of the studies focused on psychopathology, with limited data on positive outcomes, such as well-being, happiness, and quality of life [11]. The authors also identified a gap in the understanding of "how youth themselves experience and perceive relationships between social media and mental health" and thus highlighted the value of qualitative research in gaining a deeper understanding into this relationship from youths' perspectives. A recently proposed multidimensional model of social media use (MMSMU) explains the role of social media in relation to both beneficial and adverse effects on youth mental health but emphasizes the need for furthering research into its complex psychological implications [16]. In addition, given the disparate patterns of social media use and impacts among different age and racial groups, it is recommended to consider the unique psychological perspectives among target populations and sociocultural settings [6].

Singapore is a high-income nation in Southeast Asia with a population of 5.70 million, of which 4.03 million are citizens or permanent residents comprising Chinese (76.2%), Malays (15.1%), Indians (7.4%), and other ethnic groups (1.4%). Youth (age 15-24 years) constitute 11% of the local population. The 2016 National Youth Survey found that 42% of youth spent 10 hours or more daily on online activities [17]. The daily consumption of social media for networking, news, and entertainment also grew from an average of 65% in 2013 to 80% in 2016 in this population. The survey also found that the levels of life satisfaction and happiness have remained stable despite the increase in social media consumption. In Singapore, youth engagement in social media has been previously investigated in relation to psychological stress [18], suicidality [19], body esteem [20], daytime sleepiness [21], online bullying [22], and social activism [23]. However, to the best of our knowledge, the role of social media in positive mental health among youth is underexplored.

Given the lack of knowledge on the potentially beneficial links between social media and youth mental health in Singapore, this study explored lived experiences of youth on how social media contribute to positive mental health. Specially, we aimed to understand the components of and pathways to acquiring positive mental health from youths' perspectives through thematic analysis and concept mapping.

## Methods

### Study Design

Following an interpretivist approach [24], we used qualitative semistructured interviews and focus group discussions (FGDs) to explore youths' perspectives on the role of social media in positive mental health. This method enabled a deeper understanding into the subjective view and perceptions of youth.

### Ethics Approval

Ethical approval was obtained from the National Healthcare Group's Domain-Specific Review Board (DSRB Reference 2020/00228). After discussing the aim of the study and the processes for safeguarding data and participants' identities, all participants and parents of those under 21 years of age provided written informed consent.



## Sample

A purposive sample of youth, aged 15 to 24 years, was selected for the study. This age group was selected to reflect the age range for youth specified by the United Nations [25]. Including this age group was of particular interest to this study because these are critical transitional life stages (from teenage to adulthood and from being a student to being employed) and are the best periods to introduce mental health interventions. Table 1 contains information on the participants' backgrounds. The sample was designed to include equivalent proportions of male and female participants, youth in the age ranges of 15 to 19 years and 20 to 24 years, and those belonging to the 3 main ethnic groups in Singapore (Chinese, Malay, and Indian), along

with a smaller number of youth from other ethnic groups. This allowed collection of rich and balanced information from a diverse group of youth. Efforts were also taken to include participants with experiences of psychological distress, school drop-out, or risky behaviors, such as gang participation or substance use and incarceration, so that the findings represent a wider community of youth, who may not be in the academic setting, which seems to be the population in the majority of past research on youth mental health [11]. In order to recruit youth, the first few referrals were sought from colleagues and acquaintances, and the participants were provided with study brochures to disseminate to others and initiate snowball recruitment. Referrals were also sought from community-based youth welfare services.

**Table 1.** Participant background.

Variable	Focus group discussions (11 discussions; n=70)	Semistructured interviews (n=25)	Total (n=95)
Age (years), mean	20	21	20
<b>Gender, n (%)</b>			
Female	37 (52.9)	14 (56.0)	51 (53.7)
Male	33 (47.1)	11 (44.0)	44 (46.3)
<b>Ethnicity, n (%)</b>			
Chinese	25 (35.7)	7 (28.0)	32 (33.7)
Indian	20 (28.6)	7 (28.0)	27 (28.4)
Malay	21 (30.0)	7 (28.0)	28 (29.5)
Others	4 (5.7)	4 (16.0)	8 (8.4)
<b>Highest education level attained, n (%)</b>			
Primary	1 (1.4)	2 (8.0)	3 (3.2)
Secondary	32 (45.7)	4 (16.0)	36 (37.9)
Junior college	13 (18.6)	10 (40.0)	23 (24.2)
Diploma	12 (17.1)	4 (16.0)	16 (16.8)
Institute of Technical Education	6 (8.6)	2 (8.0)	8 (8.4)
Tertiary (graduate/postgraduate degree)	6 (8.6)	3 (12.0)	9 (9.5)
<b>Employment, n (%)</b>			
Employed, full time	4 (5.7)	3 (12.0)	7 (7.4)
Employed, part time	6 (8.6)	6 (24.0)	12 (12.6)
Unemployed, never worked	18 (25.7)	4 (16.0)	22 (23.2)
Unemployed, past work/internship experience	42 (60.0)	12 (48.0)	54 (56.8)

## Data Collection

Data were collected through online videoconferencing using the Zoom platform for all FGDs and 21 interviews. The other 4 interviews were conducted in person. Data used in this study belonged to a larger study exploring the meaning and pathways to positive mental health among youth. Participants were also specifically asked about their experiences with social media use and how social media had benefitted their mental health. For this study, "social media" broadly referred to any social networking website or app that enabled them to share and access

information in the form of posts, photos, videos, messages, news, comments, etc [26]. Participants were encouraged to share experiences with any sites and platforms if they considered them to be relevant to positive mental health. This provided adequate flexibility in the content generated through the study. Key probes included in the interview/discussion guide are listed in Textbox 1. In addition, FGD participants were asked to provide multiple single-word responses to the question "When I use social media, I feel..." to act as quick starting points for the discussion. The interviews lasted for approximately 1.5 hours, while FGDs took 2 hours on average.



**Textbox 1.** Interview guide to understand the beneficial role of social media for youth mental health.

#### Interview guide

- Thinking about places and practices youngsters are most exposed to nowadays, what are some of these that can influence their mental health?
- Which of these are beneficial to them/their mental health? And how?
- What about social media? How can social media benefit youth mental health?
- What about yourself? For example, in relation to social media how has this improved your mental health? Thinking about the past 1 year, can you give me some examples?
- What about your friends? Any pleasant or unpleasant experiences/incidents that you can recall in relation to social media? How does it make them feel?
- Activity (only for focus group discussions): “When I use social media, I feel...”
- When have you/your friends felt (experience/emotion)? Can you/someone describe any such incident or experience? How did it influence your/their mental health?
- Which aspects or components of positive/good mental health does social media influence? How?

These discussions were audio recorded with participants' permission, transcribed verbatim, and anonymized. The content of the discussions was regularly reviewed by the research team to assess adequate data saturation and allow for identification of key themes. Data collection was discontinued after 11 FGDs and 25 interviews. Data from interviews and FGDs were combined to conduct pooled analysis.

#### Data Analysis

Coding and data were managed with the NVivo 11 software [27]. In the initial stage, thematic analysis was undertaken through inductive coding, constructing categories, and continuously comparing codes between the transcripts and coders [28]. Preliminary codes representing broad categories on how social media benefitted mental health were created from the first 6 transcripts and discussed between coders, and based on their relevance to the research aims, refinements were incorporated. Codes were then grouped into wider categories to produce a coding framework [29], which was applied to the rest of the transcripts. The current analysis focused on positive influences of social media on youth mental health. The categories were reviewed, and key themes were generated from participants' narratives on positive experiences with social media and their relation to positive mental health. Qualitative concept mapping [30] was conducted using the transcripts to identify short statements or phrases that were then linked in unrestricted “chain” sequences [31] to generate interpretable pathways to positive mental health in youth. This method has been previously used to conceptualize information relating to mental health from a public health perspective [32,33] and has been found to be useful “as an evidence-gathering tool” in research [34].

## Results

### Participant Background and Social Media Use

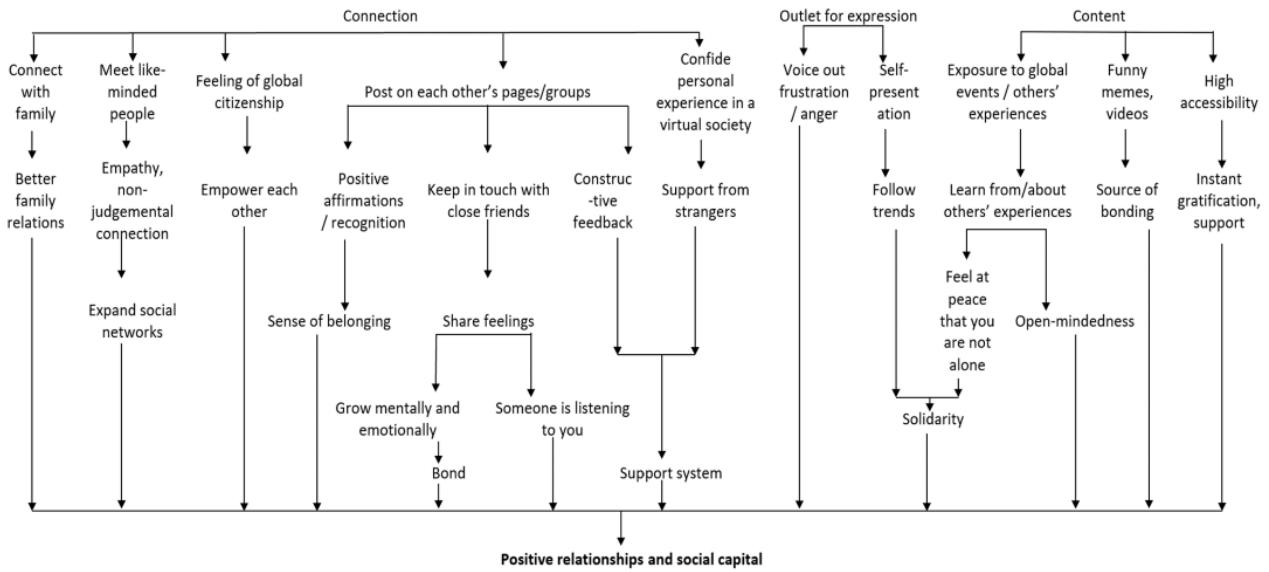
A total of 36 data units were included in this study, comprising 25 interviews and 11 FGDs. Participants' details are presented in Table 1. There were 51 female participants and 44 male participants, and almost equal proportions of Chinese, Malay, and Indian participants, with a small number belonging to other ethnicities, such as Filipino and Burmese. Our participants included 8 youth with a history of psychological distress, school drop-out, or risky behaviors, such as gang participation, substance use, and incarceration.

All the participants had access to smartphones, and they used a wide array of social media platforms regardless of their demographic characteristics. These platforms included Instagram, TikTok, WhatsApp, Twitter, YouTube, Reddit, LinkedIn, Facebook, and others, with the first 3 being the most commonly quoted online platforms. They used social media platforms to create and follow online identities, communicate with friends and family, build social networks, and access information resources relating to news, fashion, hobbies, sports, health, and employment.

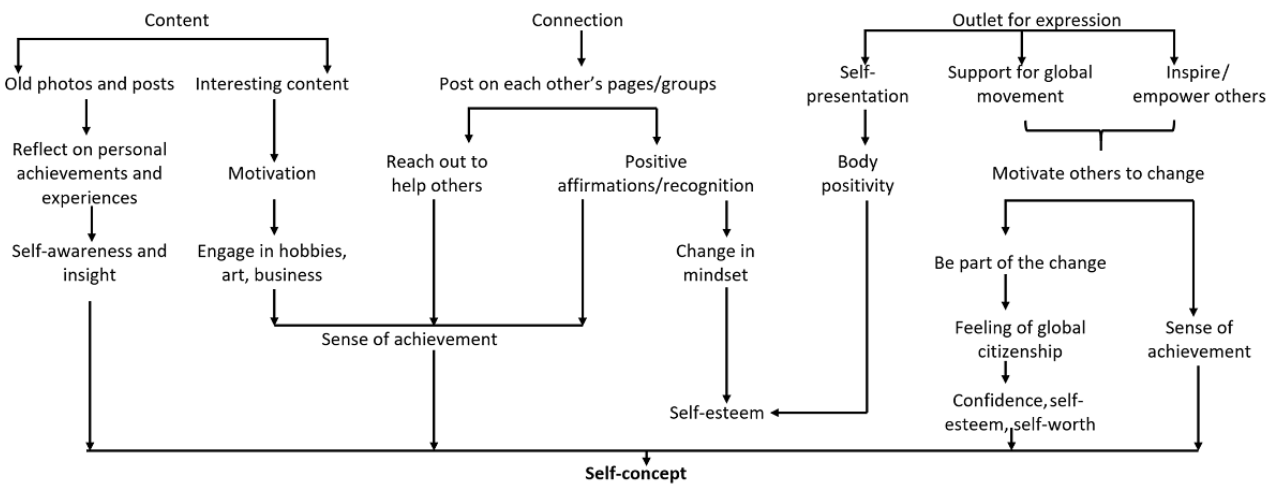
### Role of Social Media in Attaining Positive Mental Health

Based on participants' narratives, our analysis suggested 3 features of social media consumption, namely, connection, content, and outlet for expression, with each influencing multiple aspects of positive mental health. These pathways contributed to the following 5 positive mental health components: (1) positive relationships and social capital (Figure 1), (2) self-concept (Figure 2), (3) coping (Figure 3), (4) happiness (Figure 4), and (5) other relevant aspects of mental health (positivity, personal growth, and psychological well-being) (Figure 5).

**Figure 1.** Social media as a way to build positive relationships and social capital.



**Figure 2.** Enriching self-concept through social media.



**Figure 3.** Social media improve the coping process.

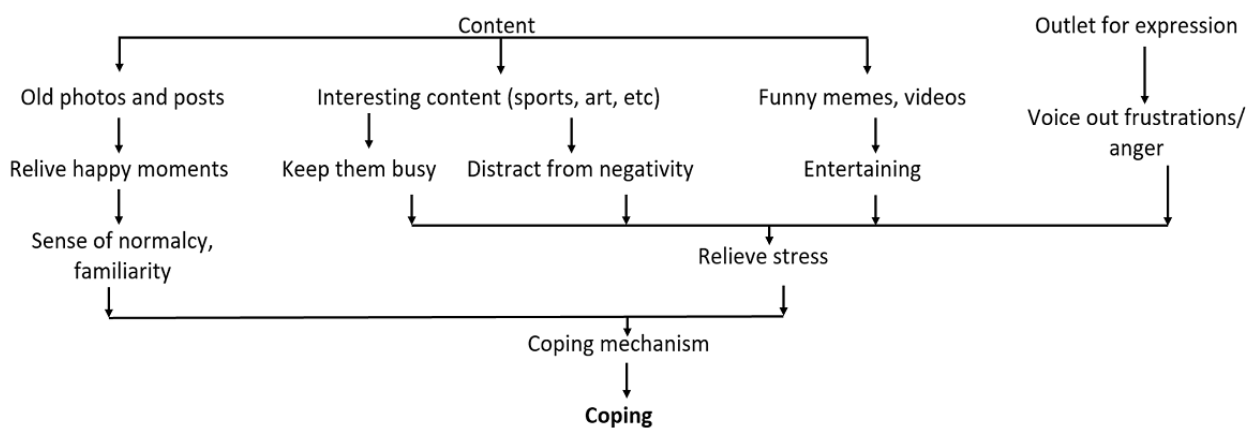


Figure 4. Feeling happy through social media.

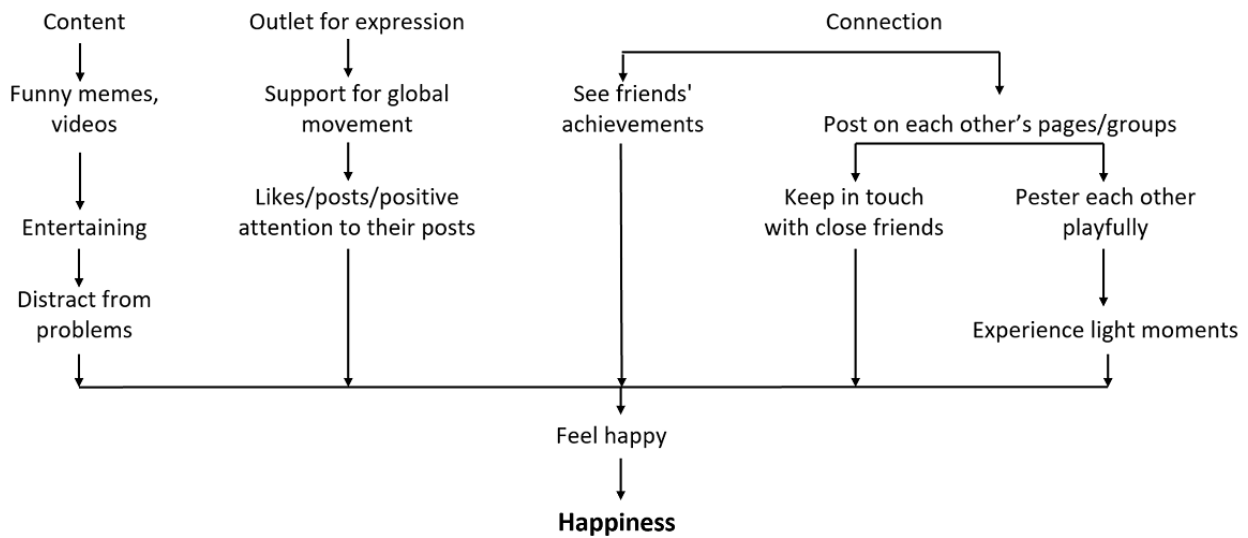
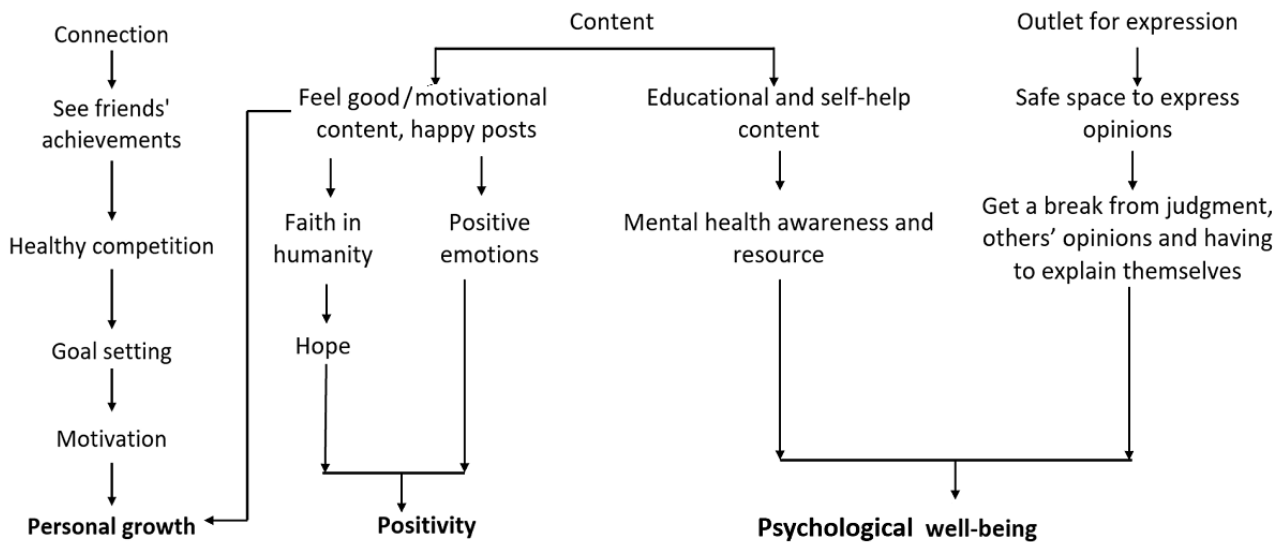


Figure 5. Influence of social media on other positive mental health aspects.



**Theme 1: Social Media as a Way to Build Positive Relationships and Social Capital**

Reflecting on the potential of social media as a mode to connect with others, participants discussed how they used different platforms to stay in touch with their family and communicate with friends virtually by posting messages on each other’s pages. These actions often resulted in developing close relationships with mutual trust, recognition, and a sense of belonging.

*I guess when my friends tagged me in a photo and all that. Some of my friends, they're more appreciative and expressive on Instagram posts, so they will have this long message, especially after Uni camps or like Poly camps everyone will start like appreciation posts and all that. I guess that's the sense I feel included or appreciated, in that sense, though it's not extremely significant for me lah, but I guess in that sense being tagged in that message or on a photo on Instagram,*

*on social media, it does make me feel included. [FGD participant #08]*

The participants often used social media as a channel to share feelings with their friends and felt that they always had someone out there who was listening to them and willing to provide constructive feedback and support.

*I use Instagram to be very cathartic, so when I'm feeling very angry or stressed, Instagram has this feature where you can have a close friends' group. So in that close friends group, I tend to rant and express my emotions, and then it's good because it's also another layer of a support system. [FGD participant #02]*

*If I Tweet out, "I'm sad," she can immediately send me ten memes rather than having to come directly over to my house or even like telephoning me by like being-- asking me directly, saying, "How are you*

feeling?” Like it's a-- sorry, no. I think it's also another way-- instead of calling me on the phone, which is also effective, it's an alternative also, another immediate alternative. [Semistructured interview participant #13]

The youth also offered support and empathy to others who needed help. Through these, the participants narrated how they were able to grow close emotionally and bond with their peers.

*I think apart from getting inspired or getting educated from other people, it gives ourselves a platform to do the same, as well. So for example... I also during the COVID [referring to Covid-19 pandemic] period, I also started out like a small business with my friend that... inspired [to donate] the profit... to donate it to other people. So that's kind of one of the positive change that we are trying to do, as well. So apart from getting educated from other people, we also are kind of inspired to do the same for others, as well. [FGD participant #02]*

For our participants, social media provided opportunities to expand their social network and meet like-minded people beyond their family and friends. Furthermore, they considered how they were able to confide their personal experiences in their virtual network and derive a feeling of support and global citizenship.

*Social media is a platform like how you can find other people, like-minded people, you can see, if they're trying to connect with people who have the same beliefs, ideas, or struggles that you have, so you can connect with them and talk with them. You can share with them your beliefs without being heavily judged. [FGD participant #06]*

By expressing their feelings and preferences either anonymously or openly in the relatively nonjudgmental environment of social media platforms, our participants were able to bond with others who shared their values or sentiments, participated in popular trends, and showed solidarity with global movements, such as “Black Lives Matter” and climate change activism. They also often derived helpful knowledge from others’ experiences and felt that they were not alone when encountering difficulties.

*I have seen opportunities across the spectrum where people empower one another and support good causes and stuff. So relating back to this question, I guess seeing the way people can empower and help one another, like the recent Black Lives Matter stuff, I've seen how people will help one another, linking donation links and stuff. [FGD participant #02]*

Besides the aspect of interaction that improved relationships between the youth and their local and global counterparts, our participants highlighted how social media were accessible 24/7 if they needed support or access to content such as memes, which they could share with their friends to bond with them and expand their social capital.

*Memes...[where] people just put their words and stuff, and you need to have that context behind it. But it feels it's like a whole bonding thing for all the*

*people in that age group. Everyone kind of has that similar experience or relatable stuffs. So it's kind of like everyone coming together. Yeah. They'll be, “I'm not alone in all of these things that we are going through.” It's a way for us to come together, despite the distance. It's not just people in a friend group, like 4 or 5 people. It's literally millions of teenagers around the world, who are all coming together like, “Yeah. Okay. Life sucks, but we're doing it together.” [FGD participant #05]*

## **Theme 2: Enriching Self-concept Through Social Media**

Many of the participants narrated how they evaluated and perceived themselves while using social media platforms. It appeared to both reinforce and provide avenues for self-awareness and self-esteem. Some expressed how reviewing their older posts helped them gain insight into themselves, while others explained how presenting themselves in the way they truly were increased their self-acceptance, body positivity, and eventually self-esteem.

*I think that's always very nice to be reconnected with someone and to kind of like start to share more about yourself. Like you say you've been up to and by doing that you kind of like also reflect on the achievements and things that have been happening in your life to see whether-- it kind of helps me kind of like have a little more insight on what I'm doing and how has that been helping me. [FGD participant #11]*

Self-esteem was also gained through their social connections who provided encouragement and recognition due to which some participants were able to appraise themselves more positively and gain confidence.

*At one point, I felt pressured to create things that was basic or simple so that more people can buy it. But then I felt frustrated because that was not the reason why I started the business in the first place. So I posted about that on my Instagram, ...[.]...I was really actually speechless because I didn't even know these people and they showed me so much love. And it felt really good. Yeah. It helped me improve. Because I was feeling really down at that time, so it helped me become more confident and assured that I can do this. [FGD participant #07]*

Our participants described how social media helped them gain a sense of achievement through accessing positive content that motivated them to achieve more, be it pursuing their interests or growing their careers. Some participants shared how they derived confidence and self-worth by being able to motivate their friends or lend support to others or events happening around the world.

*I felt confident and good knowing that I do care about world issues in my own perspective because I care about world issues. So it made me felt good as a citizen. It made me felt good as someone as part of this world, that I don't not care about the world, but I care about the world. So it kind of made me feel better as a person. [FGD participant #10]*



### Theme 3: Social Media Improve the Coping Process

From the narratives in our study, youth seemed to use social media to relieve stress in various ways. By being able to engage in relaxing activities or by expressing their frustrations or anger without being judged or shamed, our participants argued that it was a simple way to destress from problems.

*I believe some of us are sacred to go to our parents and talk through some issues with our parents. So we choose instead to post on social media ... Because you get to rant it out on your [page]-- you get to rant it out either way. You get to express what you feel on a platform where you know you won't be judged. You know people won't shoot you down for it. At least you feel secure that-- you also feel secure that, one, they get to rant out their emotions. Two, they know that there are people who really care for them and want to know what's on their minds instead of just keeping it all in. [FGD participant #09]*

Participants also recognized that they benefited from the content available on social media that involved reliving happy memories or spending time entertaining themselves through watching light and humorous videos. These provided them with a sense of normalcy and familiarity in a changing world and helped relieve their stress. The youth often used these techniques to cope, rest, and recharge.

*I started realizing that a lot of people started to look back at the memories. So for Instagram there's this archive feature, ...where you can look back at your post like, years back. And whatnot. A lot of people started throwing back all these pictures so I don't know where did that sense of familiarity or rather, that sense of normalcy, kind of helped them cope. [Semistructured interview participant #10]*

Young people also frequently accessed content related to their personal interests, such as sports and hobbies. The content helped them to engage actively and stay busy, distracting them from negativity and acting as a coping mechanism.

*I think like itself as a platform for me to kind of distract myself because when I'm watching a video, I'm invested in what's going with video instead of whatever negativity that may be happening in life. [FGD participant #03]*

### Theme 4: Feeling Happy Through Social Media

The participants identified social media as a source of happiness in their daily routines. While describing instances when participants felt happy, they indicated how it could be rooted in meaningful relationships they had built with their social networks. Having a positive self-image or experiencing positive affirmation through “likes” from friends or when they supported popular global causes promoted their happiness. Participants' happiness was also enhanced when they cherished happy moments with their friends or participated in appreciating their friends' successes.

*I guess when my best friend posts her baking videos on her stories right, I always react very excitedly. I'd*

*be like, “Oh my God. the buns look good.” Yeah, that kind of thing. So yeah. I don't know why but her baking and showing everyone the end product makes me very happy, not only just looking at food but really happy that she's finding something that she really enjoys doing. So yeah. That gets me excited. [FGD participant #01]*

Many of the participants used social media to distract themselves from stressors by consuming memes and funny videos on social media to feel happy. Our participants also often accessed motivational content to enhance their happiness.

*TikTok videos for humor, I guess, it really helps you feel more happy. Recently discovered TikTok and there was 1 point of time, I think 2 months ago, I was pretty upset. So I downloaded TikTok, and I wasn't expecting much. I was just thinking it's some stupid app, stupid videos. But then I realized it was pretty funny and I was laughing for like 1 hour straight, and that made me feel happy. So I guess that's the good thing about social media. [Semistructured interview participant #08]*

*I think last year on Instagram, I started following a lot of these quotes pages and inspirational pages. And sometimes, every morning when I wake up, right, and before I see all the other celebrity posts or my friends going out and everything, sometimes I see these inspiring and really like motivational quotes. And I don't know. When I think about it and then I start my day off with something like that, then it just makes me happier, I guess. It just gives me that little boost to go about my day. [FGD participant #06]*

### Theme 5: Influence of Social Media on Other Positive Mental Health Aspects

Given that youth spend a considerable amount of time using social media, they described how the materials they access are beneficial to their overall mental health and well-being. Our participants viewed social media as a safe space that facilitated open expression of their emotions and experiences. This allowed them to take a break from others' judgement and avoid feeling the need to constantly explain themselves, unlike what might be expected of them in environments under adults' command.

*I think the aspect of open-mindedness is much more influenced by social media. Because I think since social media is very-- it's very large. And it basically is exposed to-- I mean, almost all youth, right? And I think social media in itself is-- it's basically giving people the voice to speak up. So it's very unrelenting in that way because it accepts everyone's opinions, everyone's views, on topics and stuff like that. And it just exposes everyone to that. And I think being exposed to various topics and viewpoints and opinions, it sort of creates that open-mindedness quality in youth where they think where now it's more the norm to just accept other people's opinions I would say. Because it just become more normal to listen to other people's opinions and be*



*nonjudgmental about it I would say.* [Semistructured interview participant #15]

Few participants also shared how seeing their friends' growth presented them with an opportunity for healthy competition and motivated them to raise their personal goals. This was deemed important as setting goals for themselves was recognized as an important aspect of positive mental health among youth. Others also shared how they grew their skills through coaching and educational content accessed on their social media platforms.

*The competitive side, yes, is good, ...there is positive competition to outdo yourself, like outdo your friends.* [FGD participant #06]

*People learn a lot of tips and tricks online, something like, how to cook, how to make this, how to solve this, how to do financial stuff in Singapore (be)cause we are not taught to do that in school. So we learn it online and we educate ourselves online.* [FGD participant #06]

Another benefit of using social media was access to feel-good and motivational content that could promote mental well-being by introducing participants to resources, which some participants mentioned improved awareness on their personal mental health. Specifically, through access to happy posts and motivational content, some participants were able to experience more positive emotions, hope, and positivity.

*I think that's one thing about social media like, okay, you can also spread negativity, but at the same time, you can use that platform to spread positivity also. ...- so I have these friends who also post small happiness, like small bundles of joy that they experience and it could be like some aunty smiling at them when they are crossing the road or all those kind of small things. And sometimes, when you see those, then your faith in humanity is just restored. You're like, "Okay, maybe life is quite good." And there are lots to look forward to. So in that way, that's also another way of how social media is so hard to give up. Because sometimes a lot of people also focus on the negativity of social media. There's also so much of positivity that comes with it. It all depends on how you view it.* [FGD participant #06]

## Discussion

Increasing levels of internet and social media penetration in the daily lives of youth have resulted in significant influences of social media practices and culture on mental health among youth. Our study provides new insights into the ways youth can achieve and experience positive mental health through social media. Our analysis suggested 3 features (content, connectivity, and modes of expression) offered by social media as beneficial to positive mental health among youth. Five main themes were identified, namely, positive relationships and social capital, self-concept, coping, happiness, and other relevant aspects of mental health, such as positivity and personal growth, offering an in-depth understanding into the different pathways through which social media can affect positive mental health.

These routes are partly consistent with the MMSMU of Yang et al that proposed pathways to youth well-being resulting from their activities, motivators, and communication on social media [16]. The MMSMU was theoretically developed from past cross-sectional quantitative research. Thus, our qualitative study sheds further light on the important links between social media use and positive mental health using the lived experiences of youth contemporary to a generation of heightened technology users. Specifically, our study showed how attributes of social media, such as the content available on them, social connections formed on social media, and outlet for self-expression, lead to positive mental health through multiple interconnected pathways.

The relevance of positive mental health to positive relationships, social support, and social networks, often referred to as social capital, has been well established. According to the model of psychological well-being by Ryff [35], positive relationships with others relate to the establishment of close, trusting, and meaningful bonds with others, and being able to reciprocate by showing empathy and support to others. Research has shown that good relationships with friends and family in adolescence buffer the stresses of teenage life [36] and serve as early sources of emotional support and coping that can have long lasting impacts on the life course [37]. Our results indicate that social media can improve relationships and enhance youths' social capital, likely through mutually satisfying and close interactions with peers and by expressing their support on every day and global matters. The concept of solidarity, in combination with the aspects of social cohesion and capital, has gained prominence with the increase in social media-related activism [23]. Social activism can form integration, identity, and ties in a community, be it physical or virtual, and bind people to one another. It can also influence psychosocial processes by providing youth with a source of meaningful connection and mutual respect, thus increasing their sense of belonging and purpose in life [38]. Our results lend further support to this notion and indicate that social media can serve as a tool to enable youth to connect with a social community, thereby benefiting psychologically from the gained social capital.

Based on the experiences of our participants, we uncovered several mechanisms that develop and strengthen self-concept among youth. Self-concept refers to how people perceive themselves physically, socially, academically, or professionally. Youth is a critical age for the development of positive self-concept, which has shown long-term benefits to individuals [39]. Constructing profiles and receiving social feedback on social networking sites were associated with adolescents' self-esteem and achievement of self-concept clarity, which in turn were related to positive self-appraisal and a strong sense of personal identity [40]. Clarity of self-concept is also associated with better self-knowledge, personal goals, and relationships [41]. It is also considered vital to psychological well-being, particularly of young people, as people who feel good about themselves and their abilities are known to be more happy, motivated, and successful and have lower risks of depression and anxiety [42]. Social media sites empower users to take an active role in constructing their own self-identity [43]. Authentic self-disclosures can produce greater intimacy among

peers [44] and lead to social support and autonomy [16]. Research has also shown that self-disclosure helps by getting feedback from peers and develops a sense of self [45]. Our study supported these results strongly and found that youth partake in self-disclosures through posts to show solidarity with global causes and seek support from their friends. Through social media, they also aim to receive attention from a broad spectrum of people in their virtual community in direct or indirect ways, and in doing so, enhance their self-worth and self-esteem. In addition, our study identified the value placed on older posts that can help youth reflect on their personal achievements and gain self-awareness, which has not been previously reported in research.

Coping involves a collection of behavioral and cognitive responses aimed at minimizing the effect of stressors [46]. Recent research on the physiology of stress mechanisms has shown the potential of social media in reducing biological stress responses, such as heart rate and cortisol production, with exposure to social media immediately after acute stress induction compared to other activities such as reading [47]. Studies also indicate that social support obtained from online relationships can be beneficial in coping. For example, youth are likely to discuss their mental health problems on social media [48] or connect with strangers who may be enduring similar problems [49]. Similarly, a recent study found that support from virtual communities is as effective as face-to-face support in terms of coping with stress [50]. There is also evidence that when adolescents received “likes” and positive affirmation for their posts, it resulted in reward processing that could help modulate brain areas involved in stress responses [51]. Our findings developed through qualitative enquiry are consistent with the findings from these previous studies and provide a single framework on how social media could benefit individuals seeking support and avenues for relaxation from stressors. The results from this study thus add to the literature on social media influence on coping mechanisms among youth and provide potential anchors for assessing and reducing the stress they experience.

In this study, our participants narrated several instances when they felt happy while using social media or used social media to feel happier. Happiness or subjective well-being is defined as a positive evaluation of how one’s life is progressing [52]. It is associated with higher life satisfaction, quality of life, and self-esteem, and better academic outcomes in adolescents and young adults [52,53]. In relation to social media and the culture of self-presentation on popular platforms among youth, such as Instagram [3], it is believed that happiness is dependent on the cognitive and affective processes involved in drawing social comparisons with peers [54]. Comparisons on social media are more often associated with a negative body image and poor life satisfaction than positive mental health [5]. The relationship between social media and happiness can thus vary. However, a recent study found that the impact of social comparison through social media on happiness depends on the type of platform or the activities engaged by youth [54]. For example, platforms that relied heavily on visual appeal, such as Facebook, were found to reduce happiness, while writing or reading blogs was found to have a positive effect on life satisfaction and

overall happiness. Contrary to the current literature on the adverse impact of comparing with peers [54], our study participants mentioned that they felt happy to see their friends’ achievements. It is possible that they were only referring to close friends, and it made them appraise their own life positively. In fact, much of the experiences relating to happiness were linked to close friends or community bonding, sharing light moments, and entertainment associated with social media, and it is possible that in an Asian setting, positive relationships influence the experience of happiness on social media. Future quantitative research should investigate our framework statistically to further understand the process of happiness in relation to social media.

Our participants also alluded to other components of positive mental health where social media featured prominently. These were related to deriving a sense of positivity, avenues for personal development and growth, and other ways in which social media were generally beneficial for participants’ mental health and well-being. Creating environments with positive experiences and increasing competence have been indicated as relevant to positive youth development [15]. In relation to social media, positivity can result from news feeds and posts that make individuals feel good and inspire them to achieve more. Strategies to get into the habit of being motivated to embrace positive change and being able to contribute to others’ motivation have been widely adopted lately by youth to tackle the negativity associated with social media [53]. Research findings also indicate that prioritizing positivity as opposed to the pursuit of happiness is associated with more positive emotions, self-compassion, resilience, and less depressive symptoms [55]. Given the limited research in this area, our findings provide a foundation for understanding the role of social media in youth positivity and mental well-being.

The strengths of this study include the generation of rich qualitative data with a large purposively selected sample of youth and the use of an online activity within the FGDs to prompt reflection on social media experiences and facilitate a rich discussion. This is also the first study to have exclusively investigated positive mental health among youth in a community sample comprising a population of teenagers and young adults, thus reflecting their experiences at important developmental milestones. However, the study also has some limitations. Our research does not provide a detailed account of the ways in which different social media platforms are experienced by youth in relation to their mental health or whether the frequency of use and patterns of use have any bearing on their experiences. Our study also lacks a deeper exploration of the negative context and experiences with social media that are often associated with depression and anxiety in youth [56]. In addition, participants’ reflections on specific social media sites and online practices were grounded in their day-to-day experiences, which may be subject to rapid development in preferences and platforms. It is therefore necessary to review the findings in the context of technological developments in the future. Finally, our study sample mainly consisted of Asian ethnic groups living in a high-income country with high internet and smartphone access. The findings may therefore not be generalizable to youth residing in low-income and non-Asian settings.

In conclusion, our study results highlight the integral role of social media in the lives of today's youth and indicate that social media can offer opportunities for positive influence, personal expression, and social support, thus contributing to positive mental health among youth. Among Singapore's youth, improved positive relationships and social capital, self-concept, coping, happiness, and other aspects, such as positivity and personal growth, are linked to self-expression, connections, and content on social media platforms that youth are exposed to. Our study indicates that social media have been used by youth for increasing connectivity, broadening social networks, and increasing knowledge, and for entertainment purposes. Advancements in digital and health technology have also prompted interest in social media as a potentially inexpensive

way to implement mental health promotion, impart psychoeducation, and reduce stigma [57]. Our study findings could inform public health policies or mental health promotion measures focusing on interventions in youth who are connected to social media use in schools or other settings. Specifically, interventions can promote the ways in which social media engagement could bring about positive mental health, such as improving self-esteem and supportive social networks among adolescents and young adults. Furthermore, information on social media can be tailored to youth based on their priorities and value systems [58]. Our findings can thus be applied to inform and optimize engagement with youth through social media, and enhance digital modes for mental health promotion and intervention.

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### Conflicts of Interest

None declared.

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## Abbreviations

**FGD:** focus group discussion

**MMSMU:** multidimensional model of social media use

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Review

# Understanding Information Needs and Barriers to Accessing Health Information Across All Stages of Pregnancy: Systematic Review

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## Abstract

**Background:** Understanding consumers' health information needs across all stages of the pregnancy trajectory is crucial to the development of mechanisms that allow them to retrieve high-quality, customized, and layperson-friendly health information.

**Objective:** The objective of this study was to identify research gaps in pregnancy-related consumer information needs and available information from different sources.

**Methods:** We conducted a systematic review of CINAHL, Cochrane, PubMed, and Web of Science for relevant articles that were published from 2009 to 2019. The quality of the included articles was assessed using the Critical Appraisal Skills Program. A descriptive data analysis was performed on these articles. Based on the review result, we developed the Pregnancy Information Needs Ontology (PINO) and made it publicly available in GitHub and BioPortal.

**Results:** A total of 33 articles from 9 countries met the inclusion criteria for this review, of which the majority were published no earlier than 2016. Most studies were either descriptive (9/33, 27%), interviews (7/33, 21%), or surveys/questionnaires (7/33, 21%); 20 articles mentioned consumers' pregnancy-related information needs. Half (9/18, 50%) of the human-subject studies were conducted in the United States. More than a third (13/33, 39%) of all studies focused on during-pregnancy stage; only one study (1/33, 3%) was about all stages of pregnancy. The most frequent consumer information needs were related to labor delivery (9/20, 45%), medication in pregnancy (6/20, 30%), newborn care (5/20, 25%), and lab tests (6/20, 30%). The most frequently available source of information was the internet (15/24, 63%). PINO consists of 267 classes, 555 axioms, and 271 subclass relationships.

**Conclusions:** Only a few articles assessed the barriers to access to pregnancy-related information and the quality of each source of information; further work is needed. Future work is also needed to address the gaps between the information needed and the information available.

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**KEYWORDS**

pregnancy; information needs; ontology; systematic review; fertility; parenting; pregnancy information; online information; health database

## Introduction

As a widely discussed topic in women's health, pregnancy is an important phase of women's lives, a period in which women experience biological changes and gain a new identity at the same time [1]. Importantly, pregnancy is often accompanied by various complications. According to the Blue Cross Blue Shield Association [2], pregnancy complications occurred in 1 in 5 pregnancies among prospective mothers aged 18 to 44 years (2014-2018). Even though regular medical monitoring and prenatal testing are essential to ensure healthy pregnancy, they may provoke anxiety, especially for those who experience complications in their pregnancy. Besides pregnancy, infertility presents a concerning issue since 1 in 8 couples have experienced fertility problems [3]. The Centers of Disease Control and Prevention reported that about 6% of married women aged 15 to 44 years in the United States experience infertility after 1 year of trying [4]. The internet has been an important source of information that can help women deal with doubts and make pregnancy-related decisions [5]. According to a nationwide survey in the United States, more than 75% of childbearing women searched for information related to pregnancy and childbirth on the internet [6]. However, resources related to pregnancy are often scattered, conflicting, and hard to appraise and understand [7]. It was found that patients with limited health literacy often have difficulties finding useful medical information online that is contextualized to their conditions [8]. The emergence of Web 2.0 health technologies, such as blogs, smartphone apps, and online health communities, provides ways for pregnant women to proactively interact with the community by posting questions with detailed information, sharing their experiences, and providing answers to others pregnancy-related questions [9,10].

Previously, researchers have attempted to understand the consumer information needs related to pregnancy and infertility [11,12]. Moreover, systematic reviews have assessed the use of the internet, health information needs, sources of information, and barriers to accessing health information among pregnant women [13,14]. For example, Sayakhov and Carolan-Olah [14] reported that pregnant women often search the internet for different topics such as medication, nutrition, and fetal development during their pregnancy. Ghiasi [13] found that women expressed various information needs during their pregnancy. However, these reviews mostly focused on a certain stage of pregnancy. In reality, consumer information needs

across different stages are correlated with each other and certain needs may span all stages of pregnancy. Hence, a study that systematically organizes pregnancy-related information is necessary yet unavailable to date. Such a study would allow us to better understand the consumer information needs across the span of pregnancy and find opportunities to better meet these needs.

To fill this gap, we performed a systematic review of the published literature related to consumer information needs and sources across all stages of pregnancy: including prepregnancy, which refers to the stage prior to pregnancy [15]; pregnancy, the condition of being pregnant [15]; and postpartum, the period following childbirth [16]. To support subsequent development of pregnancy apps such as websites, mobile apps, and patient portals, we also created a taxonomy of pregnancy information. This has helped us to identify a number of important research gaps and opportunities.

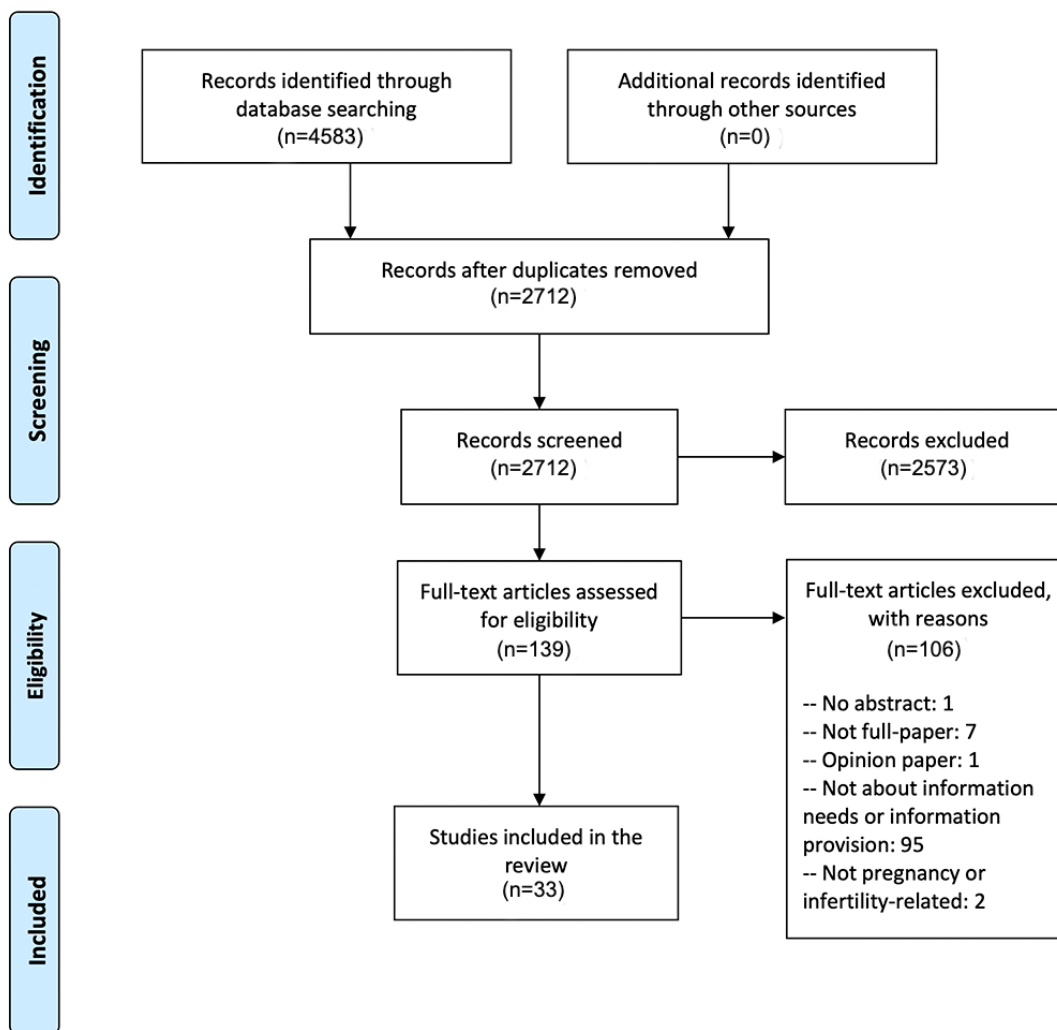
## Methods

### Literature Search Strategy

In this study, following the Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) guideline [17], we performed a systematic review of the literature regarding pregnancy-related consumer information needs from 2009 to 2019 from 4 major databases: CINAHL, Cochrane Reviews, PubMed, and Web of Science using the search queries "health information" and (pregnan\* or fertility or infertility or conception or mother\* or matern\* or prenat\* or pre-nat\* or antenat\* or ante-nat\* or perinat\* or peri-nat\* or pre-pregnancy or pre-pregna\* or gestation\*).

In total, we found 4583 articles. After removing duplicates, 2712 articles remained. We excluded 2573 articles after the title and abstract screening. Then we performed full-text review on the remaining 139 articles, including articles about pregnancy information needs or sources, pregnancy- or infertility-related, that were published in English from 2009 to 2019 and excluding articles that were not full papers, were opinion papers, or did not contain an abstract. The remaining 33 articles were evaluated using the Critical Appraisal Skills Program (CASP) [18] for quality assurance and were determined to have adequate quality to be included in the final full-text extraction. The detailed information about CASP review can be found in the [Multimedia Appendix 1](#). The PRISMA workflow is shown in [Figure 1](#).

Figure 1. PRISMA flowchart of paper selection process.



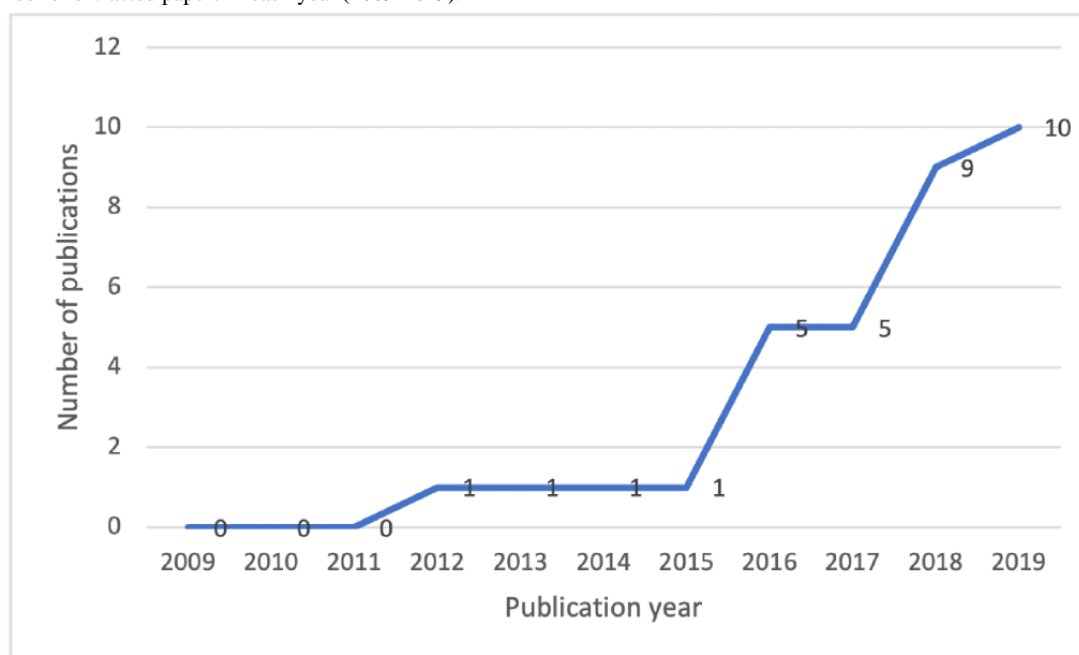
### Data Extraction

In the evaluation of the full text of the 33 articles, we identified the following aspects of information: (1) year when the article was published, (2) topic of the study, (3) research method of the study, (4) sample size of the study (if human subjects were used), (5) sources of the health information, (6) stages of pregnancy on which the study focused, (7) target population, (8) country, and (9) consumer information needs.

## Results

### Overall Trends

The trend of the number of the included articles is shown in Figure 2. Between 2009 and 2015, there was a small number of studies about pregnancy-related consumer information needs and sources. Since 2015, there has been a surge in the number of studies published.

**Figure 2.** Number of extracted papers in each year (2009-2019).

## Methods, Sample Sizes, Health Information Sources, and the Stages of Pregnancy

### Characteristics of Included Papers

The characteristics (eg, topic, study type, sample size, health information source, stage of pregnancy, and target population) of all included studies are presented in [Multimedia Appendix 2](#).

### Methods Used for Data Collection in Included Studies

Among all methods, secondary data (11/33, 33%), interview (7/33, 21%), and survey/questionnaire (8/33, 24%) were the most frequently adopted methods, followed by systematic review (4/33, 12%), participatory design (1/33, 3%), randomized controlled trials (1/33, 3%), and focus group (1/33, 3%). We present these data collection methods as follows.

### Secondary Data

Studies that leveraged secondary data assessed various population groups' consumer information needs about different aspects of pregnancy. For instance, Kallem et al [19] investigated new mothers' information needs related to newborn health. The results suggested that sleep and the appropriate use of screen time or media for infants were 2 topics that women commonly posted practices that were inconsistent with expert recommendations. Holton et al [20] analyzed group discussions of women with polycystic ovary syndrome on Facebook to assess their fertility-related consumer information needs. The results suggested that evidence-based information in various formats (eg, fact sheets, trusted websites, and podcasts) could help women with polycystic ovary syndrome make informed decisions about childbearing and achieve their reproductive goals. Van De Belt et al [12] analyzed questions in online forums and phone consultations to examine the gaps in information provision to infertile Dutch patients. The results showed that infertile patients demand high-quality health information and the information from health care providers did

not cover all reported consumer information needs. Hence providers should explore new means of health information creation that involve the patient perspective [12].

### Interview

Among the interview studies, Rotich and Wolvaardt [21] interviewed 15 pregnant women to assess Kenyan women's pregnancy-related consumer information needs. The results suggested that pregnant women sought information about the expected changes after delivery and health care providers did not provide enough explanations of routine activities for newborns (eg, drawing blood from babies). Owusu-Addo et al [22] performed interviews to assess the information-seeking behavior of pregnant teenagers in rural Ghana. The interviews revealed that participants generally relied on traditional sources, such as family and neighbors; thus, health promotion interventions should target both the expecting teenagers and the family/community. Zhu et al [10] interviewed 20 Chinese women who had conceived and were currently in any stage of pregnancy. The interviews were recorded and used in a thematic analysis to identify major themes of participants' information seeking and sharing via social media. The results suggested that participants' information needs spanned all stages of pregnancy (prepregnancy, during pregnancy, and postpartum) and most of them were moderately or highly satisfied with the current provision of pregnancy-related information. Pang et al [23] conducted semistructured interviews to investigate online health information-seeking behavior among women who had experienced miscarriage. The results demonstrated that women sought information about miscarriage, miscarriage prevention, and current research advances, along with online support through peer experience and support from family and friends.

### Survey/Questionnaire

Among the survey studies, Song et al [24] conducted a survey to assess consumer information needs, information-seeking behavior, and family support among low-income expectant



mothers. The results indicated that information obtained from family can lead to the most positive difference in supporting women who are expecting or preparing to have a baby. Ceulemans et al [25] conducted a survey in Belgium to assess pregnant women's information needs and beliefs about medications in general. The results suggested that pregnant women generally showed positive attitudes toward medications and high education levels suggest high thresholds to use medications during pregnancy. Cramer [26] performed a survey study to investigate expectant fathers' health information-seeking behavior during pregnancy. The results suggested that paternal information needs were diverse and could change across stages of child development, interpersonal sources of information were important both before and after childbirth, and a close relationship between the expectant/new father and his partner is the key predictor of paternal health information seeking. Some studies used both survey and interview to assess pregnancy-related needs. For instance, Robinson et al [11] surveyed pregnant women and their caregivers about their demographic information; and then conducted interviews with the participants about their pregnancy-related consumer information needs. The results of the study suggested that consumers required pregnancy-related information about prognosis, health management, tests, interventions, logistics, and psychological support. Guerra-Reyes et al [27] used a survey and interviews to understand the postpartum health information-seeking behavior of low-income women using mobile apps. They found that mobile apps were used mostly during pregnancy but not postpartum, although low-income postpartum women do rely on mobile apps for infant care and personal health information.

### ***Systematic Review of Websites, Apps, and Papers***

Cannon et al [28] assessed pregnancy-related information on nutrition and physical activity websites and found that the nutrition-related information provided by those websites did not align with the guidelines. Brown et al [29] assessed nutrition-related information provided by mobile apps to pregnant women and found that these apps provided information about topics such as food safety, alcohol consumption, seafood consumption, caffeine consumption, and the recommended number of daily servings from key food groups for pregnant women. Ghiasi [13] conducted a systematic review of published papers to assess the health information needs of pregnant women and found that they often sought information about prenatal care, managing discomforts, environmental cleanliness, personal hygiene, sexual activity during pregnancy, medicine use, nutrition, and the development of fetus. Postpartum women often searched for information related to self-care after childbirth, breastfeeding, physical and mental complications after childbirth, newborn care, and family planning.

### ***Focus Group***

Arcia et al [30] conducted a focus group study to assess how low-income pregnant women characterize their information needs and found that this population's needs span a wide range of topics, including pregnancy discomforts, environmental exposures, cloth diapering, and treating anemia.

### ***Participatory Design***

Linden et al [31] performed a participatory design and evaluation to assess the web-based provision of information to pregnant women with diabetes. The design proved to be a functional way of creating appropriate health information for the target group.

### ***Randomized Controlled Trial***

Kallem et al [19] conducted a randomized controlled trial to assess low-income urban mothers' Facebook posts about infant health. They found that peers' answers to mothers' question posts generally did not contradict with the American Academy of Pediatrics guidelines.

### ***Countries From Which Participants Were Recruited***

Half of the studies which recruited human subjects recruited participants in the United States (9), followed by Australia (2), and 1 each from Canada, Belgium, China, Ghana, Iran, Kenya, and the Netherlands.

### ***Sample Size***

Over half of all human-subject studies had a sample size less than 50 (10/19, 53%), following by sample size of 51-100 (2/19, 11%), and 351-400 (2/19, 11%). Only a few studies (4/19) had a sample size over 400. We summarize the findings of the studies with over 100 participants as follows. Narasimulu et al [32] conducted a cross-sectional study of 503 pregnant/postpartum women to assess their patterns of eHealth use. The findings implied that pregnant women frequently use eHealth resources but do not routinely share their findings with their providers. Kamali et al [33] performed a descriptive study on 400 women to assess their consumer information needs during pregnancy and childbirth. The main finding was that most women searched for information when they are suffering from a disease or pregnancy complication. Cramer [26] surveyed 186 expectant and recent fathers to investigate their health information behavior during pregnancy. The results suggested that paternal information needs were diverse and could change across stages of child development. Kriss et al [34] surveyed a total of 486 pregnant women to assess disparities in Tdap vaccination (tetanus toxoid, reduced diphtheria toxoid, and acellular pertussis) among pregnant women in the United States. They found that provider recommendation was one of the most important factors in Tdap vaccination. Brochu et al [35] surveyed 567 participants (men and women) to determine whether web-based sources met their consumer information needs related to infertility. The results implied that certain infertility-related consumer information needs were not always met and that patients may benefit from alternative sources. Ceulemans et al [25] investigated beliefs and consumer information needs about medicines among 372 pregnant women in Belgium. The results suggested that providers should be aware of pregnant women's beliefs about medicine and guide them toward reliable sources.

### ***Stages of Pregnancy***

A large proportion of the included articles only focused on during pregnancy (13/33, 39%), followed by during pregnancy and postpartum (8/33, 24%) and postpartum only (7/33, 21%). Other studies also assessed consumer information needs only

at the prepregnancy stage (4/33, 12%), and across all stages (1/33, 3%).

### **Consumer Information Needs**

Out of the 33 articles, 20 mentioned pregnancy-related information. During prepregnancy stage, the most frequently raised topics was infertility (3/20, 15%), such as the cause of infertility and treatment information and options. During pregnancy, the most frequently mentioned consumer information needs included lifestyle in pregnancy (9/20, 45%), such as nutrition for pregnant women and daily activities in pregnancy; labor/delivery (9/20, 45%), such as labor analgesia and labor pain and relief methods; prenatal care (8/20, 40%), such as the development and safety of the fetus; medication during pregnancy (6/20, 30%), such as the safety of medications; and vaccination during pregnancy (5/20, 25%), such as side effects of vaccines. At the postpartum stage, information about newborn care (5/20, 25%) was frequently sought, such as neonatal complications and newborn feeding. Across all stages of pregnancy, consumers often sought information about lab tests (6/20, 30%; eg, interpreting test results and DNA testing); and mental health (4/20, 20%; eg, preexisting or postpartum anxiety or depression and stress management).

### **Health Information Sources**

We analyzed the percentage of health information sources in all applicable included studies (24). The most frequent health information source is the internet (15/24, 63%), followed by mobile apps (3/24, 13%), and health care providers (2/24, 8%). Some studies (2/24, 8%) used both the internet and health care providers as information sources. Another study mentioned using health care providers, family and friends, and the internet as sources (2/24, 8%). Some papers in this review described the sources of information they used [36,37]. For example, the World Health Organization [36], National Health and Medical Research Council of Australia [36], United Nations Children's Fund [36], Australian Society of Clinical Immunology and Allergy [36], AmericanPregnancy.org [37], WebMD [37], BabyCenter.com [37], BreastfeedingUSA.org [37], NHS.uk [37].

### **Types of Pregnancy-Related Information Available in Each Source**

We noticed that although all sources of information (including the internet, mobile apps, and health care providers) provided information related to pregnancy symptoms [33,38], nutrition and physical activity [28,29,31,33,38], labor [31,33,38], and postpartum care [33,37,38]. However, each of these sources also provided various types of information about pregnancy that were not available in the other 2 sources. The internet often provided information related to preconception [37], fertility preservation options [39], maternal diet [36], sleep [28], and congenital heart defects [40]. Mobile apps often provided information related to body changes during pregnancy [38], weight gain [38], finding a doctor or midwife [38], planning for a newborn [38], and mental health [27]. Health care providers often provided information related to body changes during pregnancy [33], vaccines [33], tests [33], prenatal education [33], medication [12], infertility treatment [12],

abortion [33], personal hygiene [33], sexual activity in pregnancy [33], newborn feeding [33], newborn care [33], and physical/psychological complications after delivery [33].

### **Barriers to Access**

Two articles pointed out that consumers face certain barriers to accessing pregnancy-related information [13,33]. Kamali et al [33] found that lack of knowledge and ignorance regarding existing resources are 2 frequent barriers to accessing health information among pregnant women. In addition, the systematic literature review by Ghiasi [13] classified the barriers to accessing health information into 7 categories: (1) affective barrier included feeling ashamed or embarrassed to talk about pregnancy-related issues; (2) cognitive barrier included negative attitudes of health care providers, lack of familiarity with the internet for information seeking, poor patient-provider communication, reliance on self, underestimation of the risks of pregnancy complications, and unawareness of relevant information sources; (3) cultural barrier mainly referred to the social stigma related to pregnancy; (4) availability barrier included long wait times to see a doctor in clinic, lack of adequate information sources, and inadequate information from health care providers; (5) accessibility barrier referred to lack of time; (6) affordability barrier included high cost of information sources; and (7) infrastructure barrier referred to erratic power supply to access electronic information.

In addition, as shown in the reviewed papers, there were 3 scenarios regarding the accessibility of information: (1) needed information does not exist [12,41], (2) needed information exists but is not easily accessible (eg, consumers do not know how to find it or it is not easily readable) [32,39,42], and (3) needed information exists but in an incomprehensible or inconsistent manner [12].

### **Quality of Information**

Several studies also assessed the quality of information provided by these sources. For example, Brown et al [29] investigated the quality of information provided by iPhone apps for pregnancy and nutrition using the Mobile Application Rating Scale tool; the Coventry, Aberdeen and London–Refined taxonomy; and expert review. The results showed that the included apps were generally of moderate quality. De Man et al [39] assessed the availability and quality of online health information about fertility in the cancer setting using the DISCERN instrument, the Minervation validation instrument for health care websites, and a readability test. The results suggested that the included websites had moderate scores in readability and usability. However, the readability test did not consider medical jargon. Carlsson et al [40] assessed the quality of online information related to congenital heart defect following a prenatal diagnosis. The results showed that the majority of included websites scored poor in quality and readability with respect to the various themes about congenital heart defects.

### **Pregnancy Information Needs Ontology**

A secondary contribution of this study is an ontology about pregnancy information needs that contains information across all stages of pregnancy (pregnancy, during pregnancy, and postpartum). To develop the preliminary version of Pregnancy

Information Needs Ontology (PINO), one researcher (YL) first enumerated important terms about pregnancy information needs based on all reviewed papers. The goal of the enumeration was to obtain a comprehensive list of the terms. As certain terms may overlap with others in the meaning they represent, the researcher then synthesized terms that convey similar meanings. In the next step, the researcher developed a class hierarchy using a top-down approach, with the resulting hierarchy organizing information into themes and subnodes. The last step defined

the properties of terms. PINO consists of 267 classes, 555 axioms, and 271 subclass relationships. In future work, we will evaluate both the intrinsic aspects (eg, concept orientation, consistency, soundness) and extrinsic aspects with the support of tools [43,44]. Table 1, 2, 3, and 4 present subtaxonomies of PINO for each stage of the pregnancy trajectory, including prepregnancy, during pregnancy, postpartum, and across all stages.

**Table 1.** Taxonomy of pregnancy-related information: prepregnancy stage.

Theme and subnodes	N	Source
Preconception	1	[37]
Confirming pregnancy	1	[22]
Foster parenting	1	[35]
<b>Infertility</b>	3	[10,35,41]
Causes of infertility	1	[10]
Treatment information/options	1	[35]
Diagnosis of infertility	1	[35]
Medications used in treatment	1	[35]
Side effects of infertility treatment	1	[35]
Using donor sperm or eggs	1	[35]
Surrogacy	1	[35]
Foster parenting	1	[35]
Fertility preservation/infertility treatment options	1	[35,39]
<b>Provider for infertility treatment</b>	— <sup>a</sup>	—
Success rates	1	[35,39]
Surrogacy	1	[35]

<sup>a</sup>Not applicable.

**Table 2.** Taxonomy of pregnancy-related information: during pregnancy stage.

Theme and subnodes	N	Source
<b>Transmittable disease</b>	2	[24,26]
STI <sup>a</sup>	2	[24,26]
<b>Nutrition, physical exercise, or lifestyle in pregnancy</b>	9	[10,13,14,22,25,28,29,33,45]
Nutrition in pregnancy	7	[10,13,14,28,33,40,45]
Personal hygiene	2	[33,38]
Mother weight	1	[38]
Quality of oocyte, embryo, or semen	1	[12]
Food safety	2	[24,29]
Alcohol consumption during pregnancy	1	[29]
Fish and mercury consumption	1	[29]
Caffeine consumption	1	[29]
Daily activities in pregnancy	4	[28,31,33,38]
Sexual activity in pregnancy	2	[13,33]
<b>Risk behavior in pregnancy</b>	1	[10]
<b>Maternal complication</b>	1	[38]
Nausea or vomiting	1	[38]
Morning sickness	2	[24,38]
Maternal fatigue	1	[38]
Constipation	1	[38]
Heartburn	1	[38]
Bloating	1	[38]
Lower extremity edema	1	[38]
Increased urinary frequency	1	[38]
Difficulty sleeping	1	[38]
Gestational diabetes	2	[25,31]
<b>Fetal complication</b>	1	[40]
Congenital abnormality	1	[40]
<b>Other concerns</b>	— <sup>b</sup>	—
Hospital and doctor choices	1	[10]
Birth control	1	[24]
Environmental exposures	1	[30]
Adoption or abortion	3	[24,26,33]
<b>Prenatal care</b>	8	[10,22,24,25,30,33,38,40]
Coping with minor discomforts during prenatal care	1	[13]
Physiology of pregnancy	1	[13]
Personal care and hygiene	1	[13]
Development, safety of the fetus	5	[10,14,22,25,33]
Hospital choices	1	[32]
Finding a doctor or midwife	1	[38]
<b>Prenatal diagnostic and screening methods</b>	1	[40]
Fetal echocardiography	1	[40]

Theme and subnodes	N	Source
Amniocentesis	1	[40]
Chorionic villus sampling	1	[40]
Nuchal translucency scan	1	[40]
Blood tests	1	[40]
Risks of invasive methods	1	[40]
Umbilical cord sampling	1	[40]
Fetal magnetic resonance imaging	1	[40]
Anatomy scan	1	[11]
Issues related to prenatal visits	1	[38]
What to expect at prenatal visits	1	[38]
Facts about pregnancy	1	[38]
Rhogam	1	[38]
Dietary supplements during prenatal care	1	[38]
Suggestion to wait for labor at or >39 weeks	1	[38]
Information about disease in pregnancy	1	[38]
<b>Expected body changes and how to handle them</b>	2	[33,38]
Effects of pregnancy on mother's body	1	[33]
Effect of pregnancy on work	1	[33]
<b>Medication in pregnancy</b>	6	[13,24,25,28,33,35]
Side effects	1	[12]
Use or application of medication	1	[12]
Interaction with other medication	1	[12]
<b>Vaccination during pregnancy</b>	5	[19,25,33,34,38]
Vaccine safety	1	[34]
Pertussis disease	1	[34]
Effectiveness of vaccination during pregnancy	1	[34]
When to get Tdap <sup>c</sup>	1	[34]
Who else should get Tdap	1	[34]
Insurance coverage for Tdap	1	[34]
Where to get Tdap	1	[34]
Cost of Tdap	1	[34]
<b>Health care products</b>	2	[35,38]
Maternal product safety and product recalls	2	[35,38]
<b>Insurance</b>	1	[38]
Private health care coverage	1	[35]
<b>Labor/delivery</b>	9	[10,22,24,25,31-33,37,38]
Methods of delivery	1	[33]
<b>Induction</b>	1	[46]
Indications of induction	1	[46]
Oxytocin	1	[46]
Cervical ripening	1	[46]
Amniotomy	1	[46]



Theme and subnodes	N	Source
Outpatient methods	1	[46]
Side effects of induction	1	[46]
Failed induction	1	[46]
<b>Preparation for delivery</b>	1	[10]
Common labor fears	1	[38]
Pack hospital bag	1	[38]
Obtaining a labor doula	1	[38]
Mode and process of delivery	1	[10]
Delivery stories	1	[10]
Due date	1	[24]
Peer experience of delivery	1	[32]
<b>Labor pain relief methods</b>	1	[32,33]
Opioids	1	[46]
Nitrous oxide	1	[46]
Relaxation techniques	1	[38]
Spinal anesthesia	1	[46]
Continuous labor support	1	[46]
Water immersion	1	[46]
Sterile water injection	1	[46]
Touch and massage	1	[46]
Acupuncture and acupressure	1	[46]
Hypnosis	1	[46]
Transcutaneous electrical stimulation unit	1	[46]
Heat and cold	1	[46]
Music and audioanalgesia	1	[46]
Aromatherapy	1	[46]
Biofeedback	1	[46]
Labor analgesia	1	[47]
Oral health	1	[38]
Maternal diet	1	[36]
Diagnostic information	1	[24]
<b>Miscarriage</b>	1	[23]
Causes of miscarriage	1	[23]
Frequency of miscarriage	1	[23]
Symptoms of miscarriage	1	[23]
Research and breakthroughs on miscarriage	1	[23]

<sup>a</sup>STI: sexually transmitted disease.

<sup>b</sup>Not applicable.

<sup>c</sup>Tdap: tetanus toxoid, reduced diphtheria toxoid, and acellular pertussis.

**Table 3.** Taxonomy of pregnancy-related information: postpartum stage.

Theme and subnodes	N	Source
Maternal recovery	2	[10,32]
Parenting	1	[38]
<b>Postpartum planning</b>	1	[38]
Applying for baby's social security	1	[38]
Newborn jaundice checks	1	[38]
Swaddling	1	[38]
Nursing pillow	1	[38]
Cord blood banking	1	[38]
<b>Newborn care</b>	5	[13,24,33,37,38]
Finding pediatrician	1	[38]
Immunization	1	[40]
Side effect of vaccine	1	[34]
Newborn developmental milestones	1	[19]
Sleep	1	[19]
Fever	1	[19]
Outdoors	1	[19]
Stooling	1	[19]
Newborn coughs and colds	1	[19]
Newborn gas and burping	1	[19]
Newborn bathing	1	[19]
Newborn circumcision	1	[19]
Newborn growth	1	[19]
Pacifier	1	[19]
Teething	1	[19]
Neonatal complications	1	[32]
Health issues of newborn	1	[24]
<b>Milk feeding</b>	3	[13,19,24,27,31,33,36-38]
Bottle feeding	1	[27]
Breastfeeding	8	[19,24,27,31,36-38]
Continued breastfeeding	1	[36]
Breast milk substitutes	1	[36]
Formula feeding	1	[19]
<b>Solid food</b>	1	[36]
Solid foods–timing	1	[36]
First foods to introduce	2	[19,36]
Foods to avoid	1	[36]
Food allergens	1	[36]
Spacing of new foods	2	[10,45]
<b>Postpartum care</b>	1	[33]
Physical and psychological complications after delivery	1	[33]
Self-care after birth	1	[13]

Theme and subnodes	N	Source
<b>Miscarriage</b>	1	[23]
Causes of miscarriage	1	[23]
Frequency of miscarriage	1	[23]
Symptoms of miscarriage	1	[23]
Research and breakthroughs on miscarriage	1	[23]

**Table 4.** Taxonomy of pregnancy-related information: all-stage.

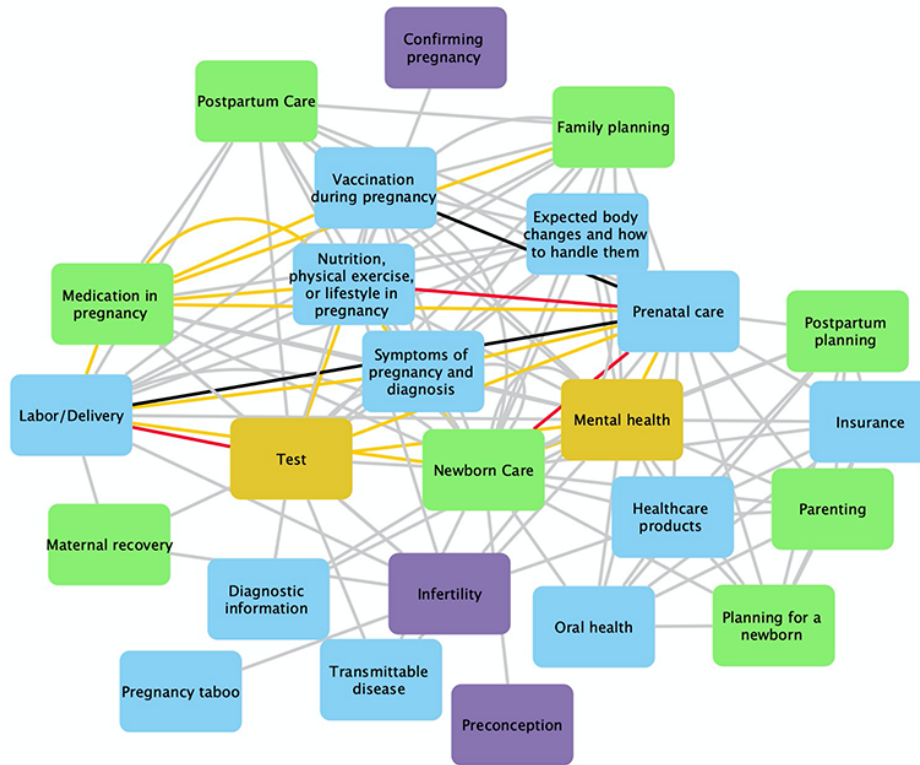
Theme and subnode	N	Source
<b>Test</b>	6	[11,24,32,33,35,40]
Special tests during pregnancy	1	[33]
DNA testing	1	[24]
Interpreting results of diagnostic tests	1	[35]
Blood sugar test	1	[31]
Family planning	1	[33]
Planning for a newborn	1	[38]
Preparing for a new pregnancy	1	[23]
<b>Mental health</b>	4	[24,27,33,38]
Preexisting or antepartum/postpartum anxiety or depression	1	[38]
Seeking support with friends, family, your doctor	1	[38]
Emotions in pregnancy	1	[38]
Establishing support network, including checking in with a friend, reaching out to other moms	1	[38]
Stress management	1	[38]
Relaxation techniques	1	[38]
Management	1	[38]
Genetic screening, amniocentesis, or chorionic villus sampling	1	[38]
Ultrasounds	1	[38]

### Co-Occurrence of Consumer Information Needs

Figure 3 presents the network graph for the co-occurrence of consumer information needs in all 33 articles. Purple, blue, green, and yellow nodes refer to prepregnancy, during pregnancy, postpartum, and multistage, respectively. Gray, orange, red, and black edges refer to the co-occurrence of 1, 2, 3, and 4 times, respectively. For example, consumer information needs related to infertility co-occur with medication in pregnancy, health care products, lab test, nutrition, physical

exercise, or lifestyle in pregnancy, pregnancy taboo, prenatal care, labor/delivery, and maternal recovery once, respectively. Consumer information needs about labor/delivery co-occur with maternal recovery once, symptoms of pregnancy and diagnosis twice, test 3 times, and prenatal care 4 times. Consumer information needs about family planning co-occur with newborn care, postpartum care, and mental health once, respectively. Consumer information needs about mental health co-occur with health care products, insurance, oral health, parenting, planning for a newborn, and postpartum planning, respectively.

Figure 3. Network graph of co-occurring information needs in articles.



### Intersection of Consumer Information Needs and Countries of Participants

For all human-subject studies in this review, Figure 4 presents the network graph for intersections between consumer information needs and countries of participants. For example, participants in Ghana sought information related to confirming

pregnancy, labor/delivery, nutrition, physical exercise, and lifestyle in pregnancy, while information about medication in pregnancy was sought by participants in Belgium, Canada, Iran, Netherlands, and the United States. This figure only represents the demographics of needs of participants by country in all reviewed articles and could not be generalized to describe the needs of consumers in each of these countries.

Figure 4. Network graph of information needs in countries of participants.



## Discussion

### Summary

Pregnancy is a major life-changing event and is considered one of the most sensitive periods of a women's life. Special care and various types of information are required during this period. However, due to reasons like health literacy and technology proficiency [32,37,38], women feel pregnancy-related information is insufficient and not well organized. Therefore, it is important to organize such information in a systematic way to meet the consumer information needs of this population. In this study, we assessed pregnancy-related consumer information needs and available information from different sources through the review of relevant articles. To the best of our knowledge, this is the first study to systematically assess consumers' pregnancy-related consumer information needs across all stages of the pregnancy trajectory. It is also the first study to derive a taxonomy of pregnancy-related information through a systematic literature review. Existing taxonomies of pregnancy-related needs in the included articles mainly focused on one or two stages of pregnancy [10,13,21,22,24,27,30,33,41] or a facet of pregnancy (eg, female infertility [12], nutrition [28,29,42], physical activity [28,48], vaccines [34], medications [25], labor analgesia [47], congenital heart defects [40], infant feeding [36], or miscarriage [23]). Our study systematically assessed consumer information needs and sources across the entire pregnancy trajectory, including preconception, during pregnancy, and postpartum.

In the last 50 years, the role of the patient has changed. Previously medical professionals were seen as the sole decision makers and information providers. Now patients are more responsible for decision making and personal information seeking. Given the nature of pregnancy decisions, this has definitely impacted this population. Consumers' online information seeking about pregnancy could be to obtain a sense of empowerment and preparedness in interacting with health care providers [49]. They also need to be able to understand the information presented by health care providers and better monitor decisions made with doctors [49]. High-quality information on the internet is often appreciated by consumers so that they can also use this information for decision making [50].

There are many theories that have been developed to provide a framework to examine information behaviors. One theory that applies to pregnancy information seeking is Dervin's sense-making theory [51]. The goal of sense-making may not always be finding relevant information but may include finding people in similar situations and avoiding bad information. Sense-making is not new and not limited to the information fields. It has also been seen in organization, communication, education, and human-computer interaction. In health care, it has been used in diabetes management [52], tumor contouring [53], and Down syndrome diagnosis [54]. One premise of this theory is the connection between how someone looks at a situation and how they are able to understand or make sense of this situation. Think about the gap between what you know and what you need or want to know. In pregnancy, this gap is almost

guaranteed even in individuals who have had successful pregnancies in the past. This gap can be influenced by many personal factors including history, previous education, adaptability, and skill at building connections with information. Ultimately, these factors are more individual and personal than situational. This moves the assumptions that are made from the individual to the instances of information seeking. This allows for studies like this to focus on the differences in the information and group the population together even though there are many differences in this population.

Traditional information sources (eg, health care providers) often provide critical and general information about pregnancy. However, such information is often not contextualized in personal situations. In addition, the medical jargon used in the information presented in traditional sources makes it difficult for consumers to understand [55]. As a result, the internet has become an alternative source of information. During the online information-seeking process, health literacy plays an important role. Prior studies found that consumers with low health literacy tend to use the internet less frequently [56,57] and find it challenging to retrieve and appraise online health information about pregnancy, which could in turn impair their ability in decision making and achieving better pregnancy outcomes [58]. Furthermore, our study found that only 2 out of the 33 articles about consumer information needs and sources assessed the barrier to accessing pregnancy-related information online and no article investigated the impact of health literacy on consumer information needs related to pregnancy. Therefore, future work should carefully examine consumers' health literacy so that information can be provided to consumers based on their different levels of health literacy.

We also found that most studies in this review assessed consumers' pregnancy-related information needs and the available information from different sources. However, only a few studies examined the quality of the information provided by these sources, which is consistent with the finding of the previous review [14]. Among the information quality criteria, readability was one of the most frequently cited issues [59]. Berland et al [7] found that English and Spanish websites required high levels of reading ability. Also, consumers often find that online health information contains a high level of technicality with lots of medical jargon [60]. To make better use of the internet, the readability of the content should be presented at or below a 5th grade reading level to accommodate people of all health literacy levels [61]. Last, the booming production of online health information has resulted in information overload [62]. To address these issues, it is important that health care providers and supportive technologies develop ways to direct consumers to high-quality sources that are layperson-friendly and pertinent to their situation.

In this review, we also intended to identify the types of information that are needed by consumers but have not been provided by different sources including websites, mobile apps, and health care providers. However, there are a few reasons why this goal could not be achieved. First, most of the articles are about consumer information needs but only a limited number of articles are about information sources. Also, the focus and ways of organizing information in these articles are different.



For example, some articles focused on a specific stage of pregnancy while others focused on a specific disease or complication related to pregnancy, and thus there were not many common themes of information provided. Second, the included articles about information sources could not represent the comprehensive types of information available in different platforms. Hence, future work can consider using systematic approaches to assess themes of information about pregnancy available on all the different platforms.

In addition, our study resulted in a taxonomy of pregnancy-related information. This taxonomy can be implemented into supportive technologies (eg, webpages, smartphone apps, and patient portals) so that consumers can easily access and retrieve a structured body of information about pregnancy regardless of the stage of their pregnancy. We have uploaded our PINO taxonomy to our GitHub repository [63] and BioPortal [64]. Currently, PINO only includes 267 classes and 271 hierarchical relationships. In the future, we will improve PINO by adding more concepts and semantic relationships between concepts to further express the conceptual domain space across all stages of pregnancy—prepregnancy, during pregnancy, and postpartum.

### Research Gaps

The result of this review suggested several research gaps. First, only a few studies assessed information quality of the sources of pregnancy-related information. Furthermore, these studies suggested that the quality of the provided information is questionable. Given that prior work has proposed a model for assessing consumer health information quality [65], future work can systematically extract and assess the quality of pregnancy-related information from all available sources (eg, providers' webpages, online health forums, mobile apps).

In addition, this review suggests that very little is known about how much consumer information needs about pregnancy have been satisfied and what needs are not yet met. Future work can consider comprehensively examining both consumer satisfaction and unmet consumer information needs about pregnancy.

Last, given the overwhelming amount of available health information online and the filter failure of existing information retrieval systems [62], future work could explore ways to help consumers retrieve high-quality, customized, and layperson-friendly health information.

### Limitations

This review has limitations. First, we only systematically assessed articles about pregnancy-related consumer information needs and sources published from 2009 to 2019. Second, articles in this study have different focuses and organization of pregnancy-related information themes. Neither consumer information needs nor available information could be generalized to all pregnant women or sources. Hence, conclusions regarding which consumer information needs have been met could not be made.

### Conclusions

In this study, we reviewed 33 articles published from 2009 to 2019 about pregnancy-related consumer information needs and available information from different sources. The resulting taxonomy comprehensively covered and provided hierarchal themes of pregnancy-related consumer information needs across the stages of pregnancy. Last, findings of this study suggested several future research directions: systematically assessing the quality of pregnancy-related information from all available sources, comprehensively examining both consumer satisfaction and unmet consumer information needs about pregnancy, and exploring ways to help consumers retrieve high-quality, customized, and layperson-friendly health information.

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### Authors' Contributions

ZH conceived and designed the study. LAB performed the initial database search of the related articles. LAB, YL, and ZH performed the screening of the articles. YL and ZH reviewed the articles and developed the PINO ontology. RZL, MA, CT, and ZH evaluated the PINO ontology. YL and ZH wrote the first draft of the manuscript. All the authors edited the manuscript. ZH supervised the entire project.

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### Conflicts of Interest

None declared.

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### Multimedia Appendix 1

Detailed information about the Critical Appraisal Skills Program (CASP) review of the included papers.

[[XLSX File \(Microsoft Excel File\), 11 KB - pediatrics\\_v5i1e32235\\_app1.xlsx](#)]

## Multimedia Appendix 2

Characteristics of the included papers.

[\[PDF File \(Adobe PDF File\), 118 KB - \*pediatrics\\_v5i1e32235\\_app2.pdf\*\]](#)**References**

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## Abbreviations

**CASP:** Critical Appraisal Skills Program

**PINO:** Pregnancy Information Needs Ontology

**PRISMA:** Preferred Reporting Items for Systematic Review and Meta-analysis

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Original Paper

# COVID-19 and Pregnancy: Citation Network Analysis and Evidence Synthesis

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## Abstract

**Background:** COVID-19 spread quickly around the world shortly after the first outbreaks of the new coronavirus disease at the end of December 2019, affecting all populations, including pregnant women.

**Objective:** The aim of this study was to analyze the relationship between different publications on COVID-19 in pregnancy and their authors through citation networks, as well as to identify the research areas and to determine the publication that has been the most highly cited.

**Methods:** The search for publications was carried out through the Web of Science database using terms such as “pregnancy,” “SARS-CoV-2,” “pregnant,” and “COVID-19” for the period between January and December 2020. Citation Network Explorer software was used for publication analysis and VOSviewer software was used to construct the figures. This approach enabled an in-depth network analysis to visualize the connections between the related elements and explain their network structure.

**Results:** A total of 1330 publications and 5531 citation networks were identified in the search, with July being the month with the largest number of publications, and the United States, China, and England as the countries with the greatest number of publications. The most cited publication was “Clinical characteristics and intrauterine vertical transmission potential of COVID-19 infection in nine pregnant women: a retrospective review of medical records” by Chen and colleagues, which was published in March 2020. Six groups identified as being close in the citation network reflect multidisciplinary research, including clinical characteristics and outcomes in pregnancy, vertical transmission, delivery mode, and psychological impacts of the pandemic on pregnant women.

**Conclusions:** Thousands of articles on COVID-19 have been published in several journals since the disease first emerged. Identifying relevant publications and obtaining a global view of the main papers published on COVID-19 and pregnancy can lead to a better understanding of the topic. With the accumulation of scientific knowledge, we now know that the clinical features of COVID-19 during pregnancy are generally similar to those of infected nonpregnant women. There is a small increase in frequency of preterm birth and cesarean birth, related to severe maternal illness. Vaccination for all pregnant women is recommended. Several agents are being evaluated for the treatment of COVID-19, but with minimal or no information on safety in pregnancy. These results could form the basis for further research. Future bibliometric and scientometric studies on COVID-19 should provide updated information to analyze other relevant indicators in this field.

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## KEYWORDS

pandemic; COVID-19; SARS-CoV-2; pregnancy; perinatal; citation; bibliometric; network analysis; women; maternal health; fetal health; research; literature; transmission; delivery; impact

## Introduction

In late December 2019, a cluster of novel human pneumonia cases in Wuhan City, China, were reported. Shortly after, on January 12, 2020, the World Health Organization temporarily termed the new virus “2019 novel coronavirus” (2019-nCoV) and then officially named this infectious disease COVID-19 on February 12, 2020, becoming the fifth pandemic after the 1918 flu pandemic, affecting people all over the world [1]. As of December 12, 2021, nearly 269 million confirmed cases and nearly 5.3 million deaths were reported globally. Recent reports of different variants of SARS-CoV-2 have raised concern and interest in the impact of viral changes [2].

Coronaviruses (Coronaviridae) are a family of viruses that cause infections in humans and animals. That is, coronavirus infections are considered to be zoonotic diseases that can be transmitted from animals to humans through direct contact with infected animals or their secretions. SARS-CoV-2, which causes COVID-19, exhibits human-to-human transmission by multiple means, namely by droplets, aerosols, and fomites [3]. Knowledge on COVID-19 in pregnant women has evolved tremendously; earlier reports from China considered the possibility of vertical transmission, but subsequent reports depicted a theoretical risk, and increased prevalence of preterm deliveries was also noticed [4].

The most frequent clinical characteristics of COVID-19 consist of fever, cough, fatigue or myalgia, sputum production, and headache [5]. Although viral pneumonia is an important cause of morbidity and mortality among pregnant women, the most common manifestations of COVID-19 during pregnancy are similar to those of infected nonpregnant women. However, infected mothers may be at increased risk for more severe respiratory complications [6,7].

Besides affecting the respiratory tract, COVID-19 has a remarkable impact on the mental health of pregnant women, since they are already at increased risk of developing mental health problems such as depression, anxiety, and posttraumatic stress symptoms [8]. This should be taken into account since it is proposed that the psychological stress of the COVID-19 pandemic during pregnancy can increase the risk of neurodevelopmental disorders in offspring [9]. Hence, it is important to proactively develop appropriate strategies to alleviate stress by screening, identifying, and managing perinatal mental health disorders during the pandemic.

Regarding the treatment of COVID-19, most guidelines include oxygen therapy, antiviral therapy, and supportive treatment. To date, dexamethasone is the only proven and recommended experimental treatment for pregnant patients with COVID-19 who are mechanically ventilated or who require supplemental oxygen [10]. Several other drugs are being used in research studies (eg, antiviral drugs, monoclonal antibodies, immunomodulators), but very few trials include pregnant people.

Citation networks enable searching for scientific literature on a specific topic. That is, by means of a publication, other relevant publications can be sought to demonstrate, qualitatively and quantitatively, the relationships between articles and authors through the creation of groups [11]. This approach further enables quantifying the most cited publications in each group and studying the development of a research area or focusing the bibliographic search on a specific topic [12,13].

Great efforts in knowledge production about the COVID-19 pandemic caused by the SARS-CoV-2 virus have been made from the beginning of the outbreak. In early 2020, studies about the scientific literature on COVID-19 and bibliometric analyses were published to summarize the research hotspots and offer a review of the topic to provide a reference for researchers. From inception (ie, the beginning of the pandemic) to March 1, 2020, the first authors of these publications were from 20 different countries and the papers were published in 80 different journals [14]. A bibliometric analysis of publications in five high-impact journals indexed to the Web of Science Core Collection's Science Citation Index Expanded (SCI-EXPANDED) database was also published [15]. By June 2020, China, the United States, and the United Kingdom were the most represented countries, and *The Lancet* was the journal with the highest number of contributions on the topic [15,16]. In Italy, a systematic review and bibliometric analysis of the scientific literature on the early phase of COVID-19 was conducted, but with limited international impact [17]. Furthermore, citation networks were used to investigate the strategic themes, thematic evolution structure, and trends of publications during the first 8 months of the COVID-19 pandemic in the Web of Science database in 2020, providing new perspectives of the field [18]. This tool has also been used in the pediatrics literature to identify publication trends and topic dissemination, showing the relevance of the publishing authors, institutions, and countries [19]. Most recently, the interdisciplinary status of coronavirus-related fields was investigated via the COVID-19 Open Research Dataset (CORD-19). To this end, bibliometric indicators of interdisciplinarity were calculated and a cooccurrence analysis method was applied [20]. Interdisciplinary research can provide an effective solution to complex issues in the related field of coronavirus research.

Taking into account the significant increase in the number of publications on COVID-19 and pregnancy, the aim of this study was to analyze the relationship between different publications and their authors through citation networks, as well as to identify the research areas and determine which publication has been the most highly cited. For this purpose, the analysis was carried out using Citation Network Explorer (CitNetExplorer) software.

## Methods

### Database

The following search terms were used to search the publications in the Web of Science database: “pregnancy,” “SARS-CoV-2,”

“pregnant,” and “COVID-19.” These terms were selected according to the main objective of this study because they are the most common terms in all related research fields.

Given that the search results contained articles in common, the Boolean operators NOT and AND, along with the “\*” character, were used to find the singular and plural forms of the words. In this way, the terms used were ([COVID-19 OR SARS-CoV-2] AND [pregnancy OR pregnant]). Likewise, the search field was selected by topic, thereby limiting the search by abstract, title, and keywords. The selected time interval was from January 2020 to December 2020.

In turn, Web of Science also makes it possible to add references to your library while performing bibliographic searches directly in external databases or library catalogs. With regard to the citation index, the Social Sciences Citation Index, SCI-EXPANDED, and Emerging Sources Citation Index were used. However, because of the different citation methods used by various authors and organizations, CiteSpace software was used to standardize the data. The publications were searched and downloaded on November 23, 2020.

### Network Analysis

The publications were analyzed using CitNetExplorer software. This software allows for the analysis and visualization of the citation networks of scientific publications, and further allows for citation networks to be downloaded directly from Web of Science. It is also possible to manage citation networks including thousands of interrelated publications and citations. As such, researchers can use a citation network consisting of thousands of publications as the starting point, before going on to perform a deeper analysis of the most relevant publications to generate a small subnetwork containing ~100 publications on the same topic. The Citation Score attribute was used to perform quantitative analysis on the most cited publications within a specific time frame. In this way, both internal connections within the Web of Science database and external connections were quantified, meaning that other databases were also considered [13].

CitNetExplorer offers several techniques for analyzing the different citation networks. The *clustering function* is achieved using the formula developed by Van Eck and Waltman [13] in 2021. The clustering function was used to assign a group to each publication. As a result, the most interrelated publications tended to be within the same group based on the citation networks [13].

Finally, the main publications were analyzed using the *identifying core publications* function. This function is based on identifying the publications that are considered as the core of a citation network (ie, those with a minimum number of connections with other core publications), making it possible to eliminate publications that are considered unimportant. The number of connections is established by the researchers, so that a higher value of this parameter indicates a lower number of core publications [13]. Thus, in this study, the publications with four or more citations within the citation network were taken into account. The *drilling down* function was used since it allows for a deeper analysis of each group at different levels.

VOSviewer software (version 1.6.9) was used for generating figures [21,22].

With this approach, it was possible to carry out an in-depth network analysis to visualize the connections between the related elements and explain their network structure. We considered three main subnetworks: a country coauthorship network, cited references cocitation network, and author keyword cooccurrence network.

The coauthorship analysis allowed for the identification of collaboration networks between countries in this field of research. The nodes correspond to the countries participating in this field of research and the links between the elements imply cooperative relationships. The size of the node increases in parallel with an increase in the number of articles published by an individual country. The number of links shows the number of times that a given country shared coauthorship with others. Therefore, the strength of the link increases as the number of coauthors increases.

In the cocitation network, nodes represent scientific references and the size of the nodes represents the number of times a reference is cited. The correlation of the articles according to the cocitation links was represented according to the distance between two references. Self-citations were not considered for analysis.

In the author keyword cooccurrence network, nodes represent the most frequently cited author keywords, and the size of an individual node represents how many times that keyword is cited. The strength of the link between two nodes indicated the number of articles in which two keywords appeared together [21,22].

Each group is determined by a resolution value, which ranges from 1.0 to 0.50 [21,22].

### Scientometric Analysis

CiteSpace (5.6.R2) software was used to perform the scientometric analysis. This software, developed by Chen Chaomei, is Java-based and is comprised of five basic theoretical aspects: Kuhn’s model of scientific revolutions, Price’s scientific frontier theory, the organization of ideas, the best information-foraging theory of scientific communication, and the theory of discrete and reorganized knowledge units [23,24]. In the scientometric analysis process, there are also some parameter indicators to carry out a specific assessment. The H-index is a mixed quantitative index, suggested by George Hirsch from the University of California, which is used to evaluate the quantity and level of the academic output of researchers and institutions. The H-index indicates that  $h$  out of  $N$  published articles in a journal have been cited at least  $h$  times [25]. The degree indicates the number of connections that exist among the authors (organizations, countries) in the cooccurrence knowledge graph. A higher degree value indicates a greater level of communication and collaboration between the authors (organizations, countries). The centrality value measures the importance of the nodes within the research cooperation network. Intermediary centrality is a measure of the number of times a node acts as a waypoint along the shortest path between two other nodes, according to the geodetic distance. The half-life

is a parameter that represents the continuity of institutional research from a time perspective [23], which is defined as the number of years a publication receives half of its citations since it was published. A low citation half-life suggests citation activity that peaks and declines rapidly. A high half-life suggests citation activity that peaks and then declines more slowly.

## Results

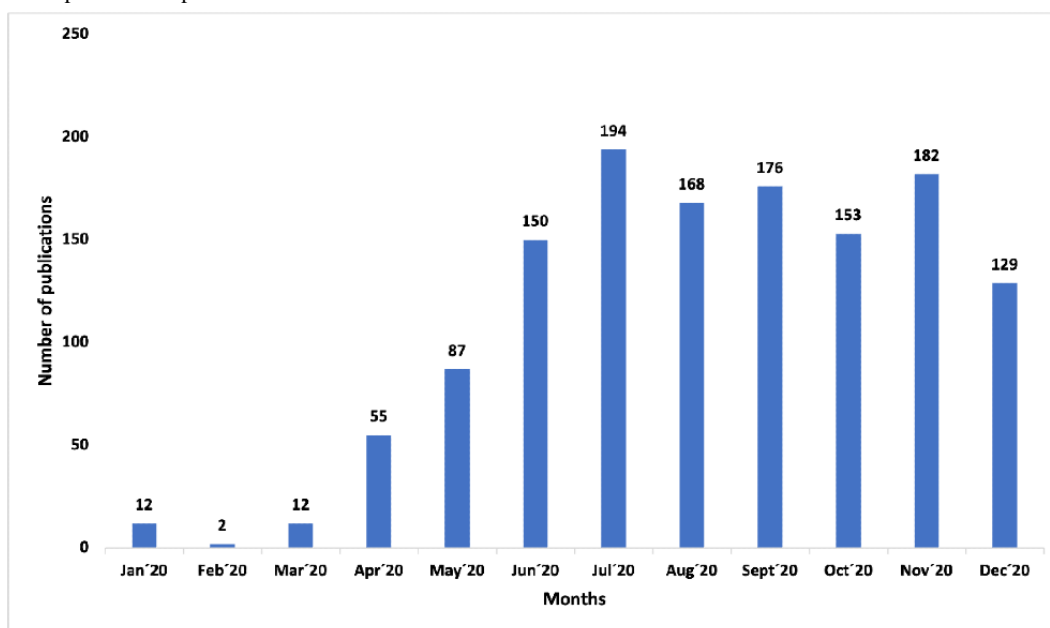
### Publication Trend

Since the first articles on COVID-19 were published at the beginning of 2020, the period of time selected for this analysis was from January 2020 to December 2020. A total of 1330 publications and 5531 citation networks were found in the search

in all fields on Web of Science. Among all 1330 publications, 721 (54.21%) were articles, 268 (20.15%) were letters to the editor, 185 (13.91%) were reviews, 121 (9.10%) were letters, 17 (1.28%) were meeting abstracts, 9 (0.68%) were news items, 5 (0.38%) were corrections, and 4 (0.30%) were proceedings papers.

The number of publications on COVID-19 has increased since May 2020 (January to April 2020: 9.26% of the total publications; May to December 2020: 90.74% of the total publications). July was the month with the largest number of publications, with 194 publications and 27 citation networks (Figure 1). A detailed description of the publications is provided in Multimedia Appendix 1.

**Figure 1.** Number of publications per month.



### Most Cited Publications

The most cited article was that of Chen et al [26], published in March 2020, with a citation index of 279. The aim of their study was to evaluate the clinical characteristics of COVID-19 in pregnancy and the potential for the vertical intrauterine transmission of COVID-19 infection. To this end, clinical records, laboratory results, and chest computed tomography (CT) scans of nine pregnant women with COVID pneumonia who were admitted to Zhongnan Hospital of Wuhan University, Wuhan, China, from January 20 to 31, 2020, were reviewed retrospectively. Evidence of vertical intrauterine transmission was evaluated by testing for SARS-CoV-2 in amniotic fluid, cord blood, and neonatal pharyngeal smear samples. Breastmilk samples were also collected and analyzed from patients after the first breastfeeding. The results showed that all nine patients had a cesarean section in their third trimester. Seven patients presented with fever. Other symptoms were also observed, including cough (in four of the nine patients), myalgia (in three patients), sore throat (in two patients), and malaise (in two patients). Fetal distress was controlled in two cases. Five of the

nine patients had lymphopenia and three patients had increased aminotransferase concentrations. However, none of the patients developed severe pneumonia from COVID-19. Nine live births were recorded and no neonatal asphyxia was observed in newborns. All nine live births had an Apgar score of 8 to 9 at 1 minute and an Apgar score of 9 to 10 at 5 minutes. The clinical characteristics of COVID-19 pneumonia in pregnant women were similar to those reported for pregnant patients who did not develop COVID-19 pneumonia. In conclusion, the findings suggest that there is no evidence of intrauterine infection caused by vertical transmission in women with COVID-19 in late pregnancy.

Among the 20 most cited articles (Table 1), 18 address the clinical manifestations, and obstetric and neonatal outcomes of pregnant patients with COVID-19. They also refer to the vertical transmission of COVID-19 in late pregnancy, including vaginal delivery. The remaining 2 articles deal with how to evaluate the management and safety of epidural or general anesthesia for cesarean delivery in women with COVID-19 and their newborns, and evaluation of standardized procedures for the protection of medical staff.



**Table 1.** Top 20 most cited articles about COVID-19 and pregnancy (January to December 2020).

Author	Title	Journal	Citation index
Chen et al [26]	Clinical characteristics and intrauterine vertical transmission potential of COVID-19 infection in nine pregnant women: a retrospective review of medical records	The Lancet	436
Rasmussen et al [27]	Coronavirus Disease 2019 (COVID-19) and pregnancy: what obstetricians need to know	American Journal of Obstetrics and Gynecology	159
Schwartz et al [28]	Potential maternal and infant outcomes from (Wuhan) coronavirus 2019-nCoV infecting pregnant women: lessons from SARS, MERS, and other human coronavirus infections	Viruses	154
Breslin et al [29]	Coronavirus disease 2019 infection among asymptomatic and symptomatic pregnant women: two weeks of confirmed presentations to an affiliated pair of New York City hospitals	American Journal of Obstetrics and Gynecology	144
Yu et al [30]	Clinical features and obstetric and neonatal outcomes of pregnant patients with COVID-19 in Wuhan, China: a retrospective, single-centre, descriptive study	Lancet Infectious Diseases	130
Schwartz [31]	An analysis of 38 pregnant women with COVID-19, their newborn infants, and maternal-fetal transmission of SARS-CoV-2: maternal coronavirus infections and pregnancy outcomes	Archives of Pathology & Laboratory Medicine	123
Dashraath et al [32]	Coronavirus disease 2019 (COVID-19) pandemic and pregnancy	American Journal of Obstetrics and Gynecology	118
Zaigham et al [33]	Maternal and perinatal outcomes with COVID-19: A systematic review of 108 pregnancies	Acta Obstetrica et Gynecologica Scandinavica	107
Di Mascio et al [34]	Outcome of coronavirus spectrum infections (SARS, MERS, COVID-19) during pregnancy: a systematic review and meta-analysis	American Journal of Obstetrics and Gynecology	92
Mullins et al [35]	Coronavirus in pregnancy and delivery: rapid review	Ultrasound in Obstetrics & Gynecology	87
Yan et al [36]	Coronavirus disease 2019 in pregnant women: a report based on 116 cases	American Journal Obstetrics and Gynecology	80
Alzamora et al [37]	Severe COVID-19 during pregnancy and possible vertical transmission	American Journal of Perinatology	78
Wang et al [38]	A case report of neonatal 2019 coronavirus disease in China	Clinical Infectious Diseases	75
Qiao et al [39]	What are the risks of COVID-19 infection in pregnant women?	The Lancet	74
Wang et al [40]	A case of 2019 novel coronavirus in a pregnant woman with preterm delivery	Clinical Infectious Diseases	74
Knight et al [41]	Characteristics and outcomes of pregnant women admitted to hospital with confirmed SARS-CoV-2 infection in UK: national population based cohort study	BMJ	74
Hantoushzadeh et al [42]	Maternal death due to COVID-19	American Journal of Obstetrics and Gynecology	74
Baud et al [43]	Second-trimester miscarriage in a pregnant woman with SARS-CoV-2 infection	JAMA	65
Liang et al [44]	Novel corona virus disease (COVID-19) in pregnancy: what clinical recommendations to follow?	Acta Obstetrica et Gynecologica Scandinavica	61
Ellington et al [45]	Characteristics of women of reproductive age with laboratory-confirmed SARS-CoV-2 infection by pregnancy status - United States, January 22-June 7, 2020	Morbidity and Mortality Weekly Report	61

## Clustering Function

Using the clustering function, each publication in the citation network is assigned to a group, which means that publications that are close in the citation network must belong to the same group. Consequently, each of these groups consists of

publications that are strongly connected through their citations. In this way, it could be interpreted that every group represents a different topic in the scientific literature. To differentiate among groups, each group was assigned a specific color. Additionally, the links between groups have been marked using colored lines. The clustering function identified 6 groups, 4 of



which contained a significant number of articles; however, the remaining groups only accounted for 5.72% of the total number of citations (Figure 2). The citation networks show the publications with the highest weight and the group to which they belong. The size of the circle increases with the increase in the number of citations. The color of an article represents its group and the lines that connect the elements represent links. Table 2 shows the information of the citation networks regarding the 4 main groups, listed from the largest to the smallest according to their size.

In group 1, 757 articles and 4407 citations were identified throughout the network. The most cited publication was that of Chen et al [26], published in March 2020 in *The Lancet*, which also ranked first among the 20 most cited publications. The publications of this group are focused on describing the clinical manifestations, and the obstetric and neonatal outcomes of pregnant patients with COVID-19. They also address the vertical transmission topic of COVID-19 in late pregnancy, including vaginal delivery (Figure 3) and treatment with chloroquine and hydroxychloroquine in pregnant women.

In group 2, 106 publications and 192 citations were identified throughout the network. The most cited publication was that of

Zaigham et al [33], published in April 2020 in *Acta Obstetrica et Gynecologica Scandinavica*. The aim of this study was to summarize the clinical manifestations, and maternal and perinatal outcomes of COVID-19 during pregnancy. To accomplish this, the databases were searched using multiple terms and combinations: COVID-19, pregnancy, maternal mortality, maternal morbidity, complications, clinical manifestations, neonatal morbidity, intrauterine fetal death, neonatal mortality, and SARS-CoV-2. The results showed that most reports describe pregnant women in the third trimester with fever (68%) and cough (34%). Lymphocytopenia (59%) with elevated C-reactive protein (70%) was also observed, and 91% of the women delivered by cesarean section. One neonatal death and one intrauterine death were also found. Therefore, it is necessary to monitor pregnant women with COVID-19 and try to prevent neonatal infection. This group’s publications also address how to evaluate the management and safety of epidural or general anesthesia for cesarean delivery in the context of COVID-19, and how to evaluate standardized procedures for the protection of medical staff. Besides avoiding nosocomial infections, recommendations for testing for gestational diabetes mellitus and the presence of sickle cell disease in patients with COVID-19 are provided (Figure 4).

Figure 2. Clustering function in the citation network on COVID-19 and pregnancy.

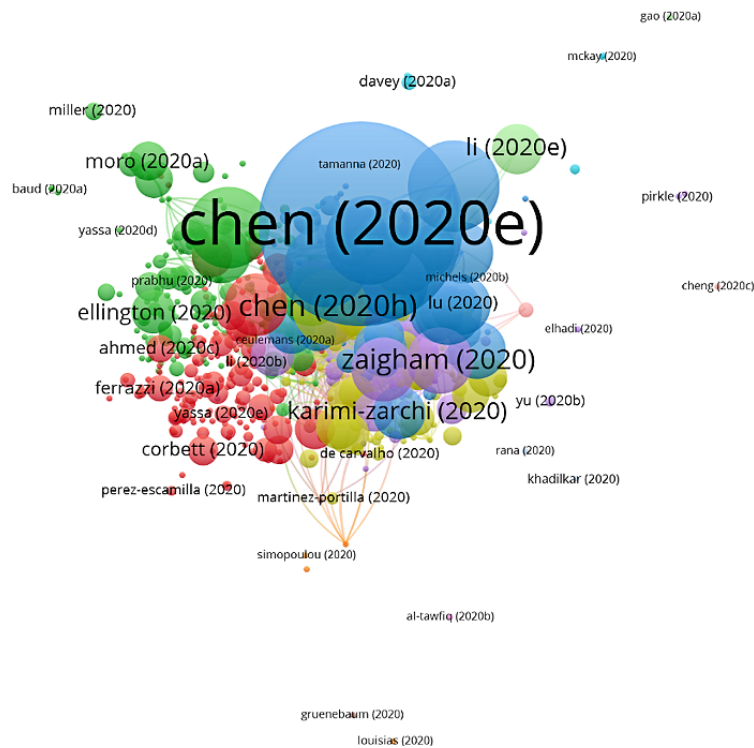


Table 2. Information on the citation network of the 4 main groups.

Main cluster	Number of publications	Number of citation links	Number of citations, median (range)	Number of publications with ≥4 citations	Number of publications in 100 most cited publications
Group 1	757	4407	0 (0-436)	506	91
Group 2	106	192	0 (0-107)	23	4
Group 3	32	56	0 (0-51)	9	4
Group 4	29	30	0 (0-25)	4	1

Figure 3. Citation network for Group 1.

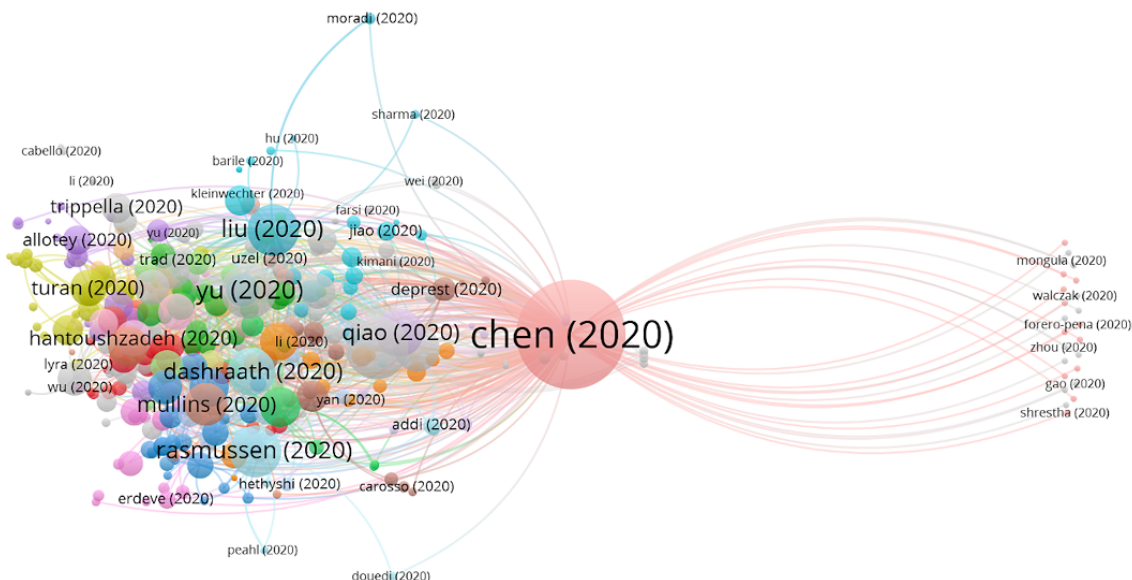
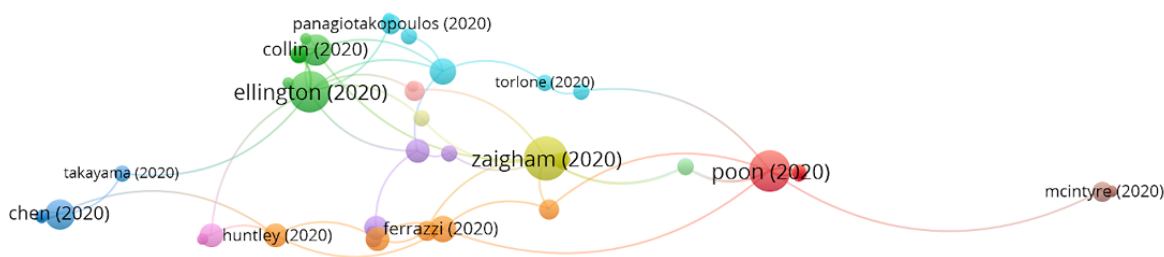


Figure 4. Citation network for Group 2.



In group 3, 32 publications and 56 citations were identified throughout the network. The most cited publication was Della et al [46], published in July 2020 in *American Journal of Obstetrics and Gynecology*. The aim of this study was to perform a systematic review of reported clinical outcomes for pregnant patients with COVID-19. All studies of pregnant women who received a diagnosis of COVID-19 through a nucleic acid test, with reported data on pregnancy and delivery cases, were included. Among 51 pregnant women, 3 pregnancies were in progress. Of the remaining 48 pregnant women, 46 delivered by cesarean section and 2 delivered vaginally. In turn, 1 stillbirth and 1 neonatal death were reported in this study. In conclusion, although vertical transmission of COVID-19 infection has been excluded to date, and the outcome for mothers and newborns has been generally good, the high rate of premature cesarean deliveries is a cause for concern. Cesarean delivery was typically an elective surgical intervention, and it is reasonable to question whether cesarean delivery for pregnant patients with COVID-19 was justified. COVID-19 and respiratory failure association in late pregnancy certainly creates a complex clinical scenario. The publications of this group address the significant increase in the rate of cesarean deliveries (>90%) and whether the mode of delivery is associated with maternal complications or neonatal transmission. These studies also emphasize the importance of imaging modalities in the treatment of patients suspected of having COVID-19, highlighting pulmonary ultrasound. This can be a valid alternative to chest CT, especially for pregnant women, since it presents certain advantages: the ultrasound can be performed

directly at the bedside by only one professional, which reduces the risk of spreading the disease. In addition, it is a test without radiation, which makes it safer and easier when monitoring patients who require a series of tests (Figure 5).

In group 4, 29 publications and 30 citations were identified throughout the network. The most cited publication was that of Corbett et al [47], published in August 2020 in *American Journal of Obstetrics and Gynecology*. The aim of this study was to examine the influence of COVID-19 on the prevalence of symptoms of depression and anxiety, as well as the corresponding risk factors among pregnant women in China. The results showed that pregnant women after the declaration of a pandemic had a higher rate of depressive symptoms than women evaluated previous to the appearance of COVID-19. These women are also at higher risk of thoughts of self-harm. It should be noted that women who were underweight before pregnancy, primiparous, under 35 years of age, and employed full time had a greater risk of developing depressive and anxiety symptoms during the disease. In conclusion, major life-threatening public health events such as COVID-19 increase mental health problems during pregnancy. Therefore, communication and the provision of psychological first aid can be useful to prevent negative results. Publications from this group assess the psychological impact of the COVID-19 pandemic on pregnant women (Figure 6).

When analyzing the relationship between groups, a connection was found between groups 1, 2, and 3. Therefore, these groups analyze topics that are clearly related to each other (Figure 7).

Figure 5. Citation network for Group 3.

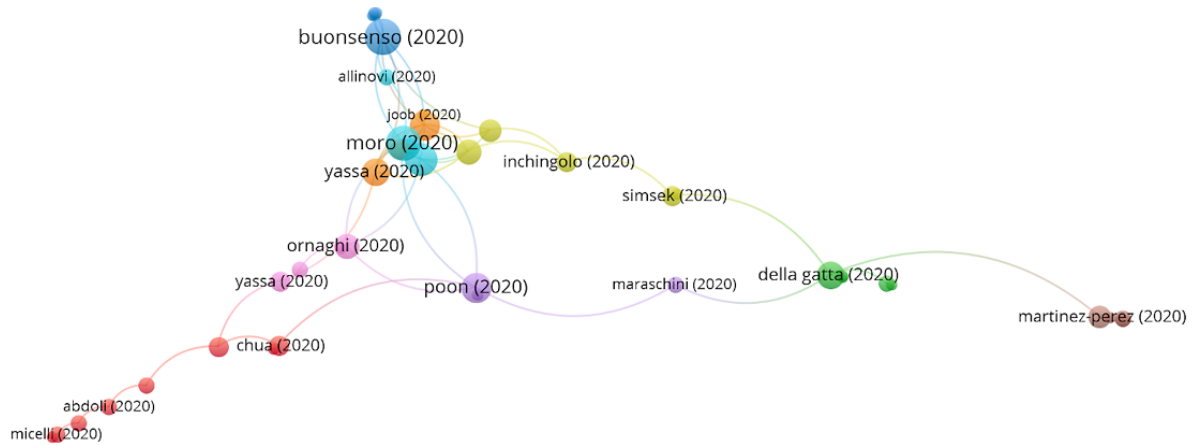


Figure 6. Citation network for Group 4.



Figure 7. Relation among the 4 main groups in the citation network.



Subclusters in Group 1

Six subclusters were found in group 1, three of which have a significant number of publications (Table 3). The rest of the

groups are relatively small, with fewer than 82 publications and 138 citation networks.

Table 3. Main citation network groups from the subclusters of Group 1.

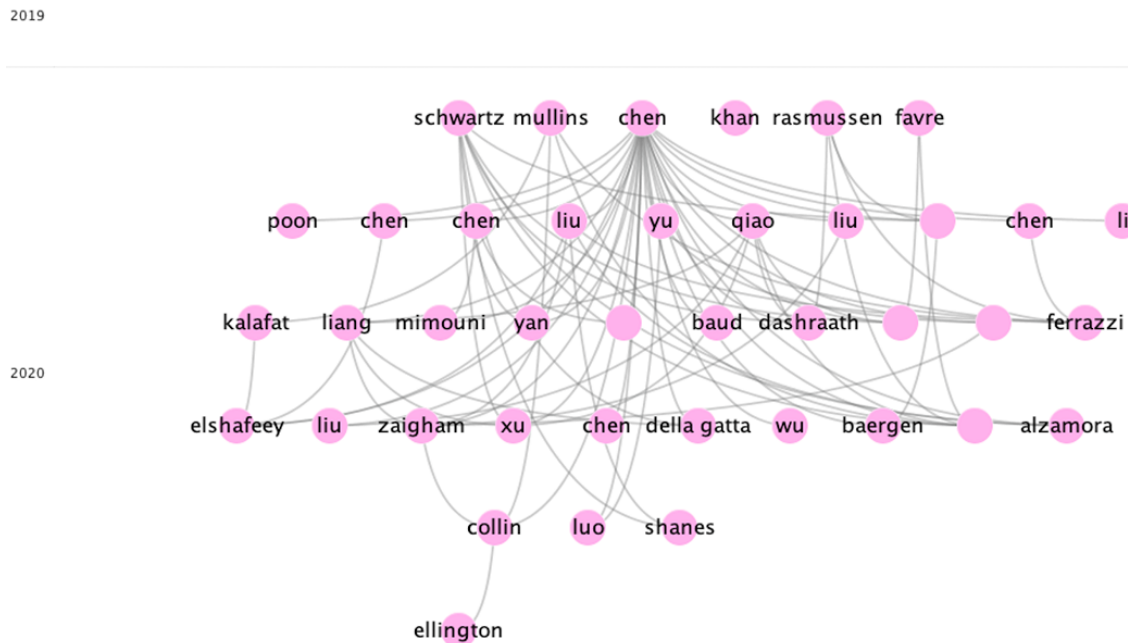
Characteristic	Subcluster 1	Subcluster 2	Subcluster 3
Number of publications	430	241	35
Number of citation links	2002	979	36
Most cited publication	Chen et al [26]	Ferrazi et al [48]	Li et al [49]
Main keywords	COVID-19, vertical transmission, infection	neonatal, virus, labor	SARS-CoV-2, pregnancy, prenatal care
Topic of discussion	Assess clinical characteristics and outcomes in pregnancy and the potential for vertical transmission of COVID-19 infection	Report vaginal delivery or cesarean section and immediate neonatal outcome in women infected with COVID-19	Impact of SARS-CoV-2 on male reproduction and pregnancy outcomes
Conclusion	COVID-19 infection during pregnancy is not associated with an increased risk of miscarriage or premature spontaneous birth. There is no evidence of vertical transmission of COVID-19 infection when it occurs during the third trimester of pregnancy.	Although postpartum infection cannot be excluded with 100% certainty, these findings suggest that vaginal delivery is associated with a low risk of intrapartum transmission of SARS-Cov-2 to the newborn. In addition, SARS-CoV-2 has been found in breastmilk.	Male gonads may be potentially vulnerable to SARS-CoV-2 infection, so caution is advised for pregnant women and couples planning a natural pregnancy or assisted reproduction.

## Core Publications

We found 610 publications with 4 or more citations and the citation network included 4726 citations, representing 45.86% of the 1330 total publications retrieved. This indicates the diversity of the research topic, showing that many research topics are analyzed. However, there is a clear focus in scientific

investigation carried out in this field. In this analysis, the main topic was to describe the clinical manifestations, and the obstetric and neonatal outcomes of pregnant patients with COVID-19, along with the vertical transmission of COVID-19 in the late stage of pregnancy and at the time of delivery (Figure 8).

**Figure 8.** Core publications in the citation network of COVID-19 and pregnancy.



## Discussion

### Principal Findings

The main databases such as Web of Science or Scopus allow for the creation of citation networks. On the one hand, Scopus includes a greater variety of publications compared to PubMed and Web of Science. On the other hand, the citation analysis presented by Web of Science offers better graphics and is more detailed than that performed by Scopus. This is likely because Web of Science was developed for the purpose of analyzing citations. PubMed focuses on the clinical and biomedical literature, whereas Web of Science is interdisciplinary, and includes journals of the highest quality in each subject area [13]. However, the usefulness of some of these databases is limited to conducting a systematic review of the literature, since they fail to offer an overview of the connections between citations in a group of publications. This is the main reason that we used CitNetExplorer and CiteSpace software in this study, since these tools enable visualizing, analyzing, and exploring citation networks in scientific publications [13]. In this way, CitNetExplorer obtains a more detailed analysis through the creation of dating networks (ie, networks based on the date of publication) compared to other databases.

Web of Science is one of the most extensive databases, beginning its search framework in 1900. However, as a limitation of this study, Web of Science only accepts international journals and its selection process is exhaustive,

which means that some publications that are not in Web of Science could have been excluded from this analysis.

The main goal of this study was to analyze the existing literature on COVID-19 and pregnancy. To identify relevant publications, the Web of Science database was used, and then connections between the fields of study and different research groups were analyzed. To obtain the results, the *clustering* function was used. This function allows for publications to be grouped according to the relationships that exist among citations. The *drilling down* function was also used to perform a more in-depth analysis of the existing bibliography for each group. The *core publications* function shows the main publications (ie, those with a minimum number of citations). Therefore, these functions make it possible for a complete analysis of the research in the field of interest.

Most of the knowledge about how a coronavirus infection might affect pregnant patients comes from the previous severe acute respiratory syndrome (SARS) and Middle Eastern respiratory syndrome (MERS) epidemics. These experiences showed that coronavirus infections could increase the risk of life-threatening maternal illness, intrauterine growth restriction, preterm delivery, miscarriage, and perinatal death [28]. Since the SARS-CoV-2 pandemic was declared, numerous case reports and reviews have been published regarding this new pathogen and its role in the course of pregnancy. The month with the largest number of publications on “COVID-19 and pregnancy” was July, which was only 1 month later in comparison to articles issued on “COVID-19” [50]. The article with the highest citation index was published by Chen et al [26] in March 2020. The



countries with the largest number of research articles published on the topic are the United States, China, and England. It is logical that most articles written at the beginning of the pandemic were by Chinese researchers. However, this has been a cause of major concern among frontline health workers and politicians due to the language barrier. Currently, the English language and high investment in research likely justifies why the United States and England are among the top 3 countries in terms of the number of publications. Another factor linked to this finding is the possibility to make connections between different research groups within the scientific community [51].

Clinical manifestations and obstetric and perinatal outcomes have been the main concern in this field, which have been addressed in 18 of the 20 most cited articles on COVID-19 and pregnancy. Most of these studies state that there are no differences in the symptomatology compared with that of nonpregnant patients. The article with the largest number of patients, written by Yan et al [36], reviewed the cases of 116 pregnant women and concluded that there is no evidence of increased risk of maternal death, spontaneous abortion, or preterm birth. Three single-center reviews with a small number of patients diagnosed with mild SARS-CoV-2 pneumonia (31 patients) came to the same conclusion, as none of them reported maternal deaths, intensive care unit admissions, nor poor perinatal outcomes [26,30,52]. In contrast, Zaigham et al [33] presented a systematic review of 108 patients, including 3 maternal intensive care unit admissions, 1 neonatal death, and 1 intrauterine death. Among these 20 most cited articles, the study by Hantoushzadeh et al [42] described the poorest maternal outcomes with 7 maternal deaths in a group of 9 pregnant women with severe SARS-CoV-2 pneumonia. It should be noted that most of the patients included in these publications were in the third trimester of pregnancy, and that no control groups were studied. In addition, some of the articles included cases of COVID-19 diagnosed by clinical criteria, without molecular (polymerase chain reaction) testing.

The imaging test used for diagnosis in the studies mentioned above was consistently chest CT. Two of the most cited articles presented in the second group identified after applying the clustering function addressed a radiation-free exam as a new alternative that could be particularly beneficial to pregnant patients. These publications were written by Moro et al [53] and Buonsenso et al [54], and propose using lung ultrasound examinations to recognize pathological patterns, some of which are especially suggestive of COVID-19 infection.

At the end of 2020, there was an upward trend in the numbers of studies that evaluated the effect of the COVID-19 pandemic on the mental health of women during pregnancy and the perinatal period. Studies conducted in Qatar [55], Iran [56], and the United States [57], and a meta-analysis by Hessami et al [58] provide evidence that the COVID-19 pandemic significantly increases the risk of anxiety among women during these periods. They concluded that these findings can be used to inform public health interventions, among which, consideration should be given to routine mental health screening of vulnerable groups and support measures for susceptible populations.

Regarding birth, some colleges of obstetricians such as the Royal College of Obstetricians and Gynaecologists in the United Kingdom initially developed guidance in March 2020 and affirmed that the delivery mode should be determined primarily by obstetric indication. They also recommended against routine separation of affected mothers and their babies [35]. In the most cited publication of this topic group, Della Gatta et al [46] stated that most pregnant patients with COVID-19 gave birth preterm by cesarean delivery, some of them on an elective basis. In most cases, the indication for cesarean delivery was not clearly specified, and it is certainly possible that the decision was influenced by the understandable anxiety toward the potential consequences of a new viral infection. It should be considered that this study was published in April 2020, when the available literature around the obstetric implications of COVID-19 was still very limited. Nevertheless, the fact that this elective intervention contributed to the favorable neonatal outcomes observed seemed unlikely even then. In this respect, on a review of the mode of delivery between December 2019 and April 2020, Debrabandere et al [59] also concluded that COVID-19 status alone became a common indication for cesarean delivery early in the pandemic, based on an attempt of obstetricians to serve their patients in the safest way possible given the climate of constantly evolving guidelines. As the literature expanded with no evidence for the intrauterine vertical transmission of COVID-19 from infected pregnant mothers to their fetuses [26,60], studies suggesting that vaginal delivery was associated with a low risk of intrapartum SARS-CoV-2 transmission to the newborn were also published [61]. A review article published in June 2020 concluded that neither vaginal delivery nor cesarean section conferred additional risks, and there was minimal risk of vertical transmission to the neonate from either mode of delivery [62]. In conclusion, as some clinical guidelines originally recommended, currently, the delivery mode should be decided based on contemplating the obstetric conditions, considering a cesarean delivery because of COVID-19 only if the mother has severe illness.

The precocity and efficacy of the vaccines developed against COVID-19 has been the most significant advance against the pandemic. Data from vaccinated pregnant people and small prospective cohort studies have not shown harmful effects, and have demonstrated a maternal immune response and transfer of maternal antibodies across the placenta and into breastmilk to confer passive immunity against SARS-CoV-2 in newborns after maternal vaccination with mRNA vaccines [63-65]. Based on these increasingly reassuring data regarding the safety and efficacy of COVID-19 vaccines during pregnancy, as well as data that pregnancy itself is associated with an increased risk of severe infection, currently, all pregnant women are recommended to undergo COVID-19 vaccination [66].

The development of vaccines has not prevented the constant search for therapeutic medicines, both among existing drugs with different indications and in the development of new drugs. Several antiviral agents are being used and evaluated for the treatment of COVID-19. Remdesivir, molnupiravir, and a combination of PF-07321332 (nirmatrelvir) and ritonavir (marketed under the name Paxlovid) are three antivirals with different mechanisms of action that have demonstrated efficacy



in clinical trials in terms of different markers of disease progression [67]. Remdesivir has been used without reported fetal toxicity in some pregnant people with Ebola and Marburg virus disease [68], and is being used to treat pregnant patients with severe COVID-19 [69], although almost all randomized trials of the drug have excluded pregnant and breastfeeding people. To date, dexamethasone is the only proven and recommended experimental treatment for pregnant patients with COVID-19 who are mechanically ventilated or who require supplemental oxygen. Although hydroxychloroquine and lopinavir/ritonavir may be used during pregnancy and lactation within the context of clinical trials, data from nonpregnant populations have not shown a benefit [10]. In any case, for most of these drugs, studies on efficacy, safety, and tolerance in pregnant women are limited.

The number of citation network studies has been increasing, as this is a very accessible and intuitive method of analysis, which provides a global overview of the different fields of study within a specific topic. The COVID-19 pandemic context has led to an abundance of publications quickly since the beginning of the outbreak. From late 2020 through 2021, thousands of scientific papers have appeared on COVID-19. In early 2020, studies about the scientific literature on COVID-19 and bibliometric analyses were published to summarize the research hotspots and compile a review to provide a reference for researchers. From disease inception to March 1, 2020, the first corresponding authors of the publications were from 20 different countries and the papers were published in 80 different journals. Lou et al [14] performed a search in PubMed using the keyword “COVID-19,” and identified and analyzed the data, including title, corresponding author, language, publication time, publication type, and research focus. Their results showed that China provided a large number of research data for various research fields during the outbreak of COVID-19, and most of the findings played an important role in preventing and controlling the epidemic around the world, which is expected since the pandemic began in China, as mentioned above. A bibliometric analysis of publications in five high-impact journals indexed to the SCI-EXPANDED database was also published [15]. By June, *The Lancet* was the journal with the highest number of contributions, and China, the United States, and the United Kingdom were the most represented countries [15,16]. Consistently, these countries were also identified to have the highest number of publications on COVID-19 and pregnancy in our analysis. In a textual analysis of 5780 publications extracted from the Web of Science, Medline, and Scopus databases, the most common topics found were guidelines for emergency care and surgery, viral pathogenesis, and global responses in the COVID-19 pandemic [16]. In Italy, a systematic review and bibliometric analysis of the scientific literature on the early phase of COVID-19 was performed, but with limited international impact [17]. Most articles focused on the hospital and clinical management of COVID-19.

Furthermore, citation networks were used to investigate the strategic themes, thematic evolution structure, and trends of coronavirus during the first 8 months of COVID-19 in the Web of Science database in 2020 [18]. The thematic evolution

structure showed that the themes were evolving over time. The results of the strategic diagram highlighted “chloroquine,” “anxiety,” “pregnancy,” and “acute respiratory syndrome,” among others, as the clusters with the highest number of associated citations. Citation network analysis has also been used on the subject of pediatrics, identifying publication trends and topic dissemination, and showing the relevance of publishing authors, institutions, and countries [19]. The studies were published in 969 different journals, headed by *The Lancet*, and the authors were from 114 different countries with the most productive countries being the United States, China, and Italy. Pediatric research about COVID-19 has mainly focused on the clinical features, public health issues, and psychological impact of the disease. This is one of the few publications that has performed a bibliometrics analysis on COVID-19 and a specific health care area. Most recently, the interdisciplinary status of coronavirus-related fields was investigated via COVID-19. To this end, bibliometric indicators of interdisciplinarity were calculated and a cooccurrence analysis method was applied [20]. The disciplinary diversity of COVID-19-related papers published from January to December 2020 showed an upward trend. This reflects that COVID-19 has had a major impact not only on health but also on economics, politics, and the environment. Therefore, coronavirus-related issues are more complicated and difficult to adequately address by relying on a single field.

Moreover, CitNetExplorer software allows for the analysis of all existing studies on a particular topic, enabling much more in-depth studies to be performed. This might change the way in which research is performed in the different fields of study.

## Conclusions

This study offers a specific and objective analysis of the main articles published on COVID-19 and SARS-CoV-2 during pregnancy. In addition, it was possible to visualize, analyze, and explore the most cited articles and citation networks existing to date using the Web of Science and CitNetExplorer databases.

In light of above, we can conclude that articles that make up the bibliographic reference for knowledge about COVID-19 and pregnancy at this point lack some qualities such as unification of diagnostic criteria, a high number of patients, and comparisons with control groups. Furthermore, the possibility of using specific alternatives for pregnancy, such as lung ultrasound for diagnosis, is not widely described.

Consequently, COVID-19 is a relevant field for researchers, with the number of publications continuously on the rise. Owing to the accumulation of scientific knowledge, we have been able to understand the clinical features during pregnancy and the effect on perinatal outcomes. Recent studies have also provided data regarding the safety and efficacy of COVID-19 vaccines during pregnancy. With respect to drugs for treatment of the disease, studies on efficacy, safety, and tolerance in pregnant women are limited. These results could form the basis for further research and guide decision-making in COVID-19 research and treatments. Future bibliometric and scientometric studies on COVID-19 should provide updated information to analyze other relevant indicators in this field.

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## Conflicts of Interest

None declared.

Multimedia Appendix 1

Additional data.

[DOCX File , 898 KB - [pediatrics\\_v5i1e29189\\_app1.docx](#) ]

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## Abbreviations

**CitNetExplorer:** Citation Network Explorer

**CORD-19:** COVID-19 Open Research Dataset

**CT:** computed tomography

**MERS:** Middle Eastern respiratory syndrome

**SARS:** severe acute respiratory syndrome

**SCI-EXPANDED:** Web of Science Core Collection's Science Citation Index Expanded database

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Original Paper

# Using a Patient Portal to Increase Enrollment in a Newborn Screening Research Study: Observational Study

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## Abstract

**Background:** Many research studies fail to enroll enough research participants. Patient-facing electronic health record applications, known as patient portals, may be used to send research invitations to eligible patients.

**Objective:** The first aim was to determine if receipt of a patient portal research recruitment invitation was associated with enrollment in a large ongoing study of newborns (Early Check). The second aim was to determine if there were differences in opening the patient portal research recruitment invitation and study enrollment by race and ethnicity, age, or rural/urban home address.

**Methods:** We used a computable phenotype and queried the health care system's clinical data warehouse to identify women whose newborns would likely be eligible. Research recruitment invitations were sent through the women's patient portals. We conducted logistic regressions to test whether women enrolled their newborns after receipt of a patient portal invitation and whether there were differences by race and ethnicity, age, and rural/urban home address.

**Results:** Research recruitment invitations were sent to 4510 women not yet enrolled through their patient portals between November 22, 2019, through March 5, 2020. Among women who received a patient portal invitation, 3.6% (161/4510) enrolled their newborns within 27 days. The odds of enrolling among women who opened the invitation was nearly 9 times the odds of enrolling among women who did not open their invitation (SE 3.24, OR 8.86, 95% CI 4.33-18.13;  $P < .001$ ). On average, it took 3.92 days for women to enroll their newborn in the study, with 64% (97/161) enrolling their newborn within 1 day of opening the invitation. There were disparities by race and urbanicity in enrollment in the study after receipt of a patient portal research invitation but not by age. Black women were less likely to enroll their newborns than White women (SE 0.09, OR 0.29, 95% CI 0.16-0.55;  $P < .001$ ), and women in urban zip codes were more likely to enroll their newborns than women in rural zip codes (SE 0.97, OR 3.03, 95% CI 1.62-5.67;  $P = .001$ ). Black women (SE 0.05, OR 0.67, 95% CI 0.57-0.78;  $P < .001$ ) and Hispanic women (SE 0.07, OR 0.73, 95% CI 0.60-0.89;  $P = .002$ ) were less likely to open the research invitation compared to White women.

**Conclusions:** Patient portals are an effective way to recruit participants for research studies, but there are substantial racial and ethnic disparities and disparities by urban/rural status in the use of patient portals, the opening of a patient portal invitation, and enrollment in the study.

**Trial Registration:** ClinicalTrials.gov NCT03655223; <https://clinicaltrials.gov/ct2/show/NCT03655223>

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**KEYWORDS**

electronic health records; patient portals; patient selection; research subject recruitment; race factors; racial disparities

## Introduction

### Advent of Patient Portals and Their Use in Research Recruitment

Failure to recruit a sufficient number of participants is a common barrier to the successful and timely completion of research studies [1]. Insufficient accrual of participants may require additional resources to achieve target enrollment, and failure to meet enrollment goals may result in underpowered studies [2,3].

Electronic patient portals are web-based applications owned and administered by health care institutions that allow patients to access their electronic health records (EHRs). In the past two decades, a growing number of patients have used this technology to manage their health care and communicate with their providers [4-6]. Estimates of patient portal use vary by study, subpopulation, and measured outcome, but reports range from 25.8% to 84.1%, and longitudinal analyses indicate that utilization rates are growing [7-16]. In a national US sample, Turner et al [17] found that 24.9% of participants reported using at least one patient portal tool in 2017, compared to only 12.6% in 2011. As adoption becomes widely accepted, researchers have recognized the opportunity to use EHR data to identify eligible research cohorts and send recruitment invitations to potential participants via the patient portal [18,19]. Direct messaging through patient portals enables a study to efficiently contact eligible patients and facilitates low-touch, low-cost outreach to large numbers of patients, an approach that is particularly advantageous for studies with large target sample sizes. In addition, once a system of electronic recruitment is established, the process of identification, prescreening, and outreach can be automated and repeated.

Studies using patient portal research invitations for recruitment report a wide range of study enrollment rates, with 1.8% to 24.7% of those who received an invitation consenting to participate [20-27]. A summary of 14 studies that sent research recruitment invitations through the patient portal at a single medical center found that condition-specific studies had higher response and enrollment rates compared to general health studies [23]. The ADAPTABLE (Aspirin Dosing: A Patient-Centric Trial Assessing Benefits and Long Term Effectiveness) study, a pragmatic trial with a recruitment target of 15,000 participants, reported enrollment rates from four different modes of outreach: patient portal, email, mailed letter, and in-person communication with the research coordinator. Although in-person recruitment had the highest enrollment rates of all the modes, patient portal, and email outreach yielded the most overall study enrollment because they allowed the study team to approach many more potential participants than did the other modes [24]. A recent study comparing in-person, email, and patient portal recruitment of adults from primary care and bariatric clinics also found that electronic forms of outreach resulted in the most overall study participants in spite of lower recruitment efficiency compared to in-person recruitment [27].

Despite the advantages of using patient portals to recruit for research, they remain primarily clinical tools, and using them to send research invitations may run the risk of decreasing patients' trust in the health care system or utilization of the

platform for clinical purposes. However, there is some evidence that patients find recruitment through patient portals acceptable. Plante et al [25] reported only 2 complaints and 1 request to unsubscribe from future messages in a study that sent 6896 invitations, and Gleason et al [28] noted that most patients reported research recruitment to be an acceptable use of patient portals in a satisfaction survey from a study that sent 1303 invitations. Patients who find patient portal recruitment to be unacceptable, however, may not open a message, send a complaint, or complete a satisfaction survey. Thus an in-depth understanding of factors influencing acceptability of patient portal recruitment remains to be determined.

Demographic disparities between patient portal users and nonusers present a major barrier to the recruitment of a representative study sample. Studies have shown that patient portal nonusers are more likely to be racial/ethnic minorities, older, male, low socioeconomic status, low health literacy, and live in a rural area [8,23,29-31]. Patient portal recruitment may, however, decrease study population disparities that result from certain demographic groups being approached for research participation less frequently in clinic settings [32,33]. There is some evidence that clinicians as gatekeepers may contribute to the under-representation of certain populations, particularly among patients with minority backgrounds [33]. Mass electronic invitations may be a universal recruitment outreach approach reflective of demographic variation. Some studies have recommended that patient portal recruitment be one part of a comprehensive outreach approach, including approaches that specifically target traditionally under-represented groups [34].

### Early Check: A Research Study Piloting the use of a Patient Portal to Recruit Pregnant Women

In this article, we describe our use of invitations sent through the Epic EHR and patient portal (MyChart) within UNC Health (UNCH). At UNCH, the patient portal is branded *my UNC Chart*. We used *my UNC Chart* to recruit for Early Check, a research study offering screening to all newborns in the state of North Carolina for a panel of genetic conditions. With a target recruitment rate of over 10,000 newborns per year, an online consent process that does not require contact with a research coordinator, and broad eligibility criteria, Early Check is a study for which recruitment messaging through patient portals is a good fit. Additionally, the target populations for recruitment outreach are pregnant women and mothers of newborns; this group is relatively younger and female, both groups which have been shown to be more likely to open a patient portal account and use patient portals to manage their health [15]. Two recent studies reported a rate of patient portal utilization between 34% and 72% of pregnant patients [21,35]. One study recruited pregnant women to a research study through a patient portal and found 34% of pregnant patients used their patient portal, and when invited to their study, 11% consented and completed their questionnaire [21].

Since Early Check began recruitment in October 2018, the primary outreach method has been personalized direct mail letters and emails on letterhead from the North Carolina Department of Health and Human Services, a study partner, sent postnatally to all women with a listed mailing or email

address in the North Carolina newborn screening records. A social media outreach campaign was piloted from March to September 2019. We resumed social media advertising on Facebook and Instagram on April 1, 2020. An evaluation of the direct mail outreach impact on study enrollment showed that approximately 4% of all women who were sent a recruitment letter enrolled their newborn in the study, and the enrollment rate among women who also received a recruitment email was approximately 5% [36]. An analysis of the social media campaign from March 2019 to September 2019 showed that paid ads on social media resulted in 3.5 additional daily enrollments in the study for each day ads were run [37]. To further increase outreach to eligible participants, we used *my UNC Chart* to send recruitment invitations to pregnant women whose newborns would be eligible for Early Check.

## Objective

In this article, we describe the use of a patient portal to recruit research participants for Early Check and report on characteristics of mothers who received and opened a research recruitment message and enrolled their newborns in the study. We addressed two research questions:

1. Is receipt of a research invitation through *my UNC Chart* patient portal associated with enrollment in the Early Check research study within 27 days after receipt of the invitation?
2. Is there a difference in opening a research invitation or enrollment in Early Check by a mother's race/ethnicity, age, or rural/urban home address location?

To address these questions, we examined data on 4510 UNCH patients who were invited to participate in Early Check through *my UNC Chart* between November 22, 2019, and March 5, 2020.

## Methods

### Early Check Research Study

A collaboration between RTI International, the University of North Carolina at Chapel Hill, Wake Forest School of Medicine, Duke University, and the North Carolina State Laboratory of Public Health, Early Check is a large research study offering screening for a panel of conditions to all newborns in the state of North Carolina [38]. The panel includes fragile X syndrome (October 2018-current), spinal muscular atrophy (October 2018-March 2021), and Duchenne and related muscular dystrophies (November 2020-current). Newborns are eligible if they have a newborn screening in North Carolina and live in North Carolina or South Carolina. Newborns may be enrolled in the study by their mother or legally authorized representative in the event the mother is unavailable, between the start of the mother's second trimester and when the newborn is one month old. During the phase of the study described herein, permission for the newborn to participate was completed entirely online without direct engagement with a research recruiter [39]. The Office of Human Research Ethics at the University of North Carolina at Chapel Hill serves as the central Institutional Review Board for Early Check (#18-0009), and they approved these activities.

### Recruitment Using my UNC Chart Invitations

The process of identifying women within UNCH to be sent an invitation to participate in Early Check via *my UNC Chart* began with a computable phenotype, a data query that "use[s] EHR data exclusively to describe clinical characteristics, events, and service patterns for a specific patient population [40]." UNCH's enterprise data warehouse, the Carolina Data Warehouse for Health (CDWH), was queried using the computable phenotype to identify invitation recipients. UNCH's appointment discharge paperwork provides patients with a unique ID that can be used to activate their *my UNC Chart* account. Women were invited if they had ever activated their *my UNC Chart* account, regardless of how recently they had logged into the account. The primary criteria in the computable phenotype were: a) having an active pregnancy "episode of care," and b) being in the second or third trimester of pregnancy (ie, 13-42 weeks' gestation).

In Epic@UNC, a pregnancy Episode of Care groups all prenatal encounters and diagnoses for a pregnancy. A pregnancy Episode of Care can be generated at any time during the pregnancy, although ideally, it is generated at the time a pregnancy is first confirmed or at the time a pregnant woman transfers her care from another health care system. Pregnancy Episodes of Care are designed to automatically resolve after delivery, specifically after any of the following: a) 48 weeks with no linked encounter; b) 364 days after the episode creation date; c) 84 days after the estimated delivery date in the patient's medical record. An Episode of Care may also be manually resolved after the baby is born. Pregnancy Episodes of Care are not designed to resolve automatically when a woman loses her pregnancy; the Episode of Care must be manually resolved (eg, closed out) in the case of pregnancy loss.

Since a cohort based on active pregnancy Episodes of Care may unintentionally include some women who have lost their pregnancy, women were excluded from receiving an invitation if their health record showed any of a series of International Classification of Diseases 10th revision or current procedural terminology codes associated with elective or spontaneous abortion within 10 months of the date that the CDWH was queried. Women were also excluded if they had indicated in their communication preferences that UNCH was not permitted to contact them through *my UNC Chart*. Women were only sent one invitation, so they were also excluded from the cohort if they had already been sent an invitation for the study during the same pregnancy Episode of Care. The computable phenotype with inclusionary and exclusionary codes and a figure showing the text of the research invitation can be found in the [Multimedia Appendices 1 and 2](#).

### Data

We consolidated data from four sources: (1) UNCH patient records with *my UNC Chart* invitation data; (2) ZIP code-level rural-urban commuting area (RUCA) approximation codes, from which we derived dichotomous urbanicity status; (3) newborn screening records gathered from the North Carolina State Laboratory of Public Health, to which Early Check mailing list data have been appended; and (4) enrollment information collected through the Early Check permission portal. After



cleaning and standardizing the data, we iteratively matched records from *my UNC Chart* to the newborn screening and Early Check permission portal datasets using several combinations of data fields appearing in two or more sources, including phone number, email address, name, date of birth, and street address (including ZIP codes). We visually inspected the combined data set after each pass to find and update mismatched records or duplicates. The final data set used in the analysis contained one record per patient with variables derived from all four sources.

The main analyses presented in this report focus on all 4510 women living in North Carolina or South Carolina who had not yet enrolled in Early Check and were sent invitations via *my UNC Chart* from November 22, 2019, through March 5, 2020. To standardize results from batches of invitations sent on different dates, we set a 27-day window for recruitment and enrollment outcomes starting from the date participants were sent a *my UNC Chart* invitation. We selected a 27-day window to avoid any overlap with a social media ad campaign for Early Check that began April 1, 2020. We also compiled aggregate data for women with patient records in the UNCH system who did not have an active *my UNC Chart* account but would have otherwise met the eligibility criteria for an invitation. We used this aggregate data to estimate the proportion of Early Check-eligible UNCH patients who were reachable through *my UNC Chart* and to examine whether there are differences by age, race and ethnicity, or urbanicity between women who received an invitation and those who did not.

## Measures

### *Early Check Enrollment*

We converted enrollment dates into a dichotomous variable indicating whether women granted permission for their babies to participate in Early Check within 27 days of being sent a *my UNC Chart* invitation, enrolled (1) or not enrolled (0). Among women who enrolled a child in the study within the 27-day timeframe, we also calculated the number of days it took them to enroll.

### *Opened my UNC Chart Invitation*

Using the earliest date that women logged into their account to view the invitation, we derived a dichotomous variable recording whether women opened the invitation within 27 days of when it was sent, yes (1) or no (0). We also calculated the number of days it took women to open the invitation.

### *Contact Via Direct Mail and Email*

Using variables recording the dates that postnatal Early Check outreach materials were sent, we created a set of dichotomous variables indicating whether each woman was sent a postnatal recruitment letter or email up to 27 days of being sent a *my UNC Chart* invitation (for each type of mailing, yes [1] or no [0]).

### *Age*

We converted women's date of birth to age in years, anchoring it to the date when we sent the recipient a *my UNC Chart* invitation (ie, invitation date-date of birth/365.25). We then transformed this into a 5-level categorical variable: Under 20, 20 to 24, 25 to 29, 30 to 34, and  $\geq 35$  years.

### *Race and Ethnicity*

We used race and ethnicity data from the UNCH patient records and recoded these into a single variable that aligns with the race and ethnicity categories used in resident live birth reports published by the North Carolina Department of Health and Human Services: non-Hispanic White alone, non-Hispanic Black alone, Hispanic, and non-Hispanic any other race or unknown [41].

### *Urbanicity*

To measure urbanicity, we constructed a variable based on RUCA codes associated with the patient residential ZIP codes recorded in the *my UNC Chart* data. RUCA codes were developed by the US Department of Agriculture to classify Census tracts by population density, proximity to large urban centers, and daily commuting flows [42]. For this analysis, we used ZIP code RUCA approximation codes developed by the University of Washington and recoded these into a two-level urbanicity measure developed for the National Cancer Institute's Surveillance, Epidemiology, and End Results database [43,44]. Under this coding scheme, we collapsed RUCA codes associated with each ZIP code of residence into two categories indicating whether the location was urban area commuting focused (ie, urban) or not (ie, rural). ZIP codes with 1 of 10 RUCA codes (ie, 1.0, 1.1, 2.0, 2.1, 3.0, 4.1, 5.1, 7.1, 8.1, or 10.1) were classified as urban (1) and all other codes were classified as rural (0).

## Statistical Analysis

We conducted logistic regressions to test for differences in whether women enrolled their newborns in the study or opened the *my UNC Chart* invitation by outreach methods, urbanicity, race and ethnicity, and age. The model estimating enrollment included whether women opened the invitation as a predictor variable; all other regressors were the same in both models. Cases with missing values on one or more regressors were excluded by listwise deletion in the logistic regression models. In addition to reporting model estimates, we also present the predicted probabilities for significant categorical variables, which represent the rates of enrollment and invitation-opening within levels of those variables while controlling for other regressors in the models. To examine potential differences by urbanicity, race and ethnicity, and age between women who were sent invitations through *my UNC Chart* and patients in the UNCH system who were otherwise eligible but did not have an active *my UNC Chart* account, we conducted  $\chi^2$  tests of independence. We followed up significant  $\chi^2$  tests involving independent variables with more than 2 categories using two-sample z tests for the difference of proportions. For these pairwise comparisons, we used a Bonferroni-adjusted alpha level of .0085. We conducted all analyses using Stata Statistical Software (version 16.0; StataCorp).

## Results

### Sample Characteristics

In total, 12,036 patients within the UNCH system fit the computable phenotype that would have made them eligible to

receive an invitation from November 22, 2019, through March 5, 2020, but only 4510 out of 12,036 (37.5%) had an active *my UNC Chart* patient portal account. We compared the demographic characteristics of women to whom we sent a *my UNC Chart* invitation to those who did not receive an invitation because they did not have an active account. We found no significant differences by age ( $\chi^2 [4, N=12,036]=3.51; P=.48$ ) or urbanicity ( $\chi^2 [2, N=12,036]=0.37; P=.54$ ), but we did find differences by race/ethnicity ( $\chi^2 [3, N = 12,036] = 180.99; P<.001$ , Cramér's  $V = 0.12$ ). A greater percentage of non-Hispanic White patients (2527/5852, 43.2%) had an active *my UNC Chart* account compared to non-Hispanic Black patients (932/2738, 34.0%,  $z=8.05; P<.001$ ), Hispanic patients (531/1,916, 27.7%,  $z=12.03; P<.001$ ), or non-Hispanic patients of any other race (520/1530, 34.0%,  $z=6.50; P<.001$ ). Hispanic patients were significantly less likely to have an active *my UNC Chart* account than patients in any of the other three race/ethnicity groups. The full contingency table comparing whether women had an active *my UNC Chart* account by race and ethnicity is shown in [Table 1](#).

Characteristics of North Carolina or South Carolina residents who were sent an invitation to participate in Early Check from November 22, 2019, through March 5, 2020, are presented in [Table 2](#). The sample excludes 18 patients who had already enrolled their newborns in Early Check before their *my UNC Chart* invitation was sent. Invitations were sent in five batches, with approximately half of the recipients (2466/4510, 54.7%) included in the first mailing on November 22, 2019. Two-thirds of all recipients (3054/4510, 67.7%) logged into their *my UNC Chart* accounts and opened the invitation within 27 days of when it was sent. Among women who opened the invitation, it took them 2.45 days (SD 4.83) on average to do so; however, the distribution is positively skewed, with 68.6% (2094/4510) opening it within 24 hours. Relatively few women (357/4510, 7.9%) were sent a postnatal recruitment letter or a personalized email (24/4510, 0.5%) within 27 days of being sent the *my UNC Chart* invitation. This observation is not unexpected, given that the computable phenotype was designed to target women with an active pregnancy as early as the 13th week of gestation.

**Table 1.** Cross-tabulation of having an active *my UNC Chart* account by race and ethnicity (N=12,036).<sup>a</sup>

Active <i>my UNC Chart</i> account	Race/ethnicity, n(%)				
	White, n	Black	Hispanic	Other	Total
Yes	2527 (43.2)	932 (34.0 <sup>b</sup> )	531 (27.7 <sup>c</sup> )	520 (34.0 <sup>b</sup> )	4510 (37.5)
No	3325 (56.8)	1806 (66.0)	1385 (72.3)	1010 (66.0)	7526 (62.5)
Total	5852 (100.0)	2738 (100.0)	1916 (100.0)	1530 (100.0)	12,036 (100.0)

<sup>a</sup> $\chi^2(3, N=12036)=180.99; P<.001$ , Cramér's  $V= 0.12$

<sup>b, c</sup>Percentages among participants with an active *my UNC Chart* account across race/ethnicity columns are significantly different at a Bonferroni-adjusted  $P<.009$



**Table 2.** Characteristics of women who were sent a *my UNC Chart* invitation (N=4510).<sup>a</sup>

Characteristic	Values, n (%) <sup>b</sup>
<b>Enrolled in Early Check within 27 days of <i>my UNC Chart</i> invitation<sup>c</sup></b>	
Yes	161 (3.6)
No	4349 (96.4)
<b>Opened <i>my UNC Chart</i> invitation within 27 days</b>	
Yes	3054 (67.7)
No	1456 (32.3)
<b>Postnatal outreach methods sent within 27 days of <i>my UNC Chart</i> invitation</b>	
<b>Recruitment letter</b>	
Sent letter	357 (7.9)
No letter	4153 (92.1)
<b>Personalized email</b>	
Sent email	24 (0.5)
No email	4486 (99.5)
<b>Date invitation sent</b>	
November 22, 2019	2466 (54.7)
January 7, 2020	931 (20.6)
January 29, 2020	423 (9.4)
February 12, 2020	272 (6.0)
March 5, 2020	418 (9.3)
<b>Age (years)</b>	
Under 20	169 (3.7)
20-24	791 (17.5)
25-29	1224 (27.1)
30-34	1386 (30.7)
≥35	940 (20.8)
<b>Race/ethnicity</b>	
White	2527 (56.0)
Black	932 (20.7)
Hispanic	531 (11.8)
Other or unknown	520 (11.5)
<b>Urbanicity</b>	
Urban	3615 (80.2)
Rural	892 (19.8)
Unknown	3 (0.1)

<sup>a</sup>Analysis excludes 18 patients who were sent a *my UNC Chart* invitation after enrolling in Early Check.

<sup>b</sup>Percentages may not sum to 100 due to rounding.

<sup>c</sup>For this analysis, we set a 27-day enrollment window from the date the *my UNC Chart* invitations were sent to normalize results from batches of invitations sent on different dates.

### Early Check Enrollment

In all, 3.6% (161/4510) of women who received a *my UNC Chart* invitation enrolled their newborns in the study within 27 days. Excluding 8 women who enrolled their newborns in Early

Check without opening the invitation, women took on average 3.92 days (SD 6.50) to enroll. Similar to the distribution for the time it took to open the invitation, the enrollment timing distribution was positively skewed, with 63.4% (97/4510) enrolling within 1 day of opening the invitation.

Our first research question examined whether and to what extent women who opened a research invitation sent to them through *my UNC Chart* were more likely to enroll in Early Check within 27 days of receiving the invitation. The overall logistic regression model predicting enrollment was significant ( $\chi^2 [11, N=4507]=134.90; P<.001, R^2_{McFadden}=.10$ ). As shown in [Table 3](#), the odds of enrolling among women who opened the invitation was nearly 9 times the odds of enrolling among women who did not open and who therefore did not view their invitation (SE 3.24, OR 8.86, 95% CI 4.33-18.13;  $P<.001$ ). Expressed in terms of predicted probabilities holding everything else in the model constant, 4.88% of women who opened the invitation (SE 0.38, 95% CI 4.13%-5.63%) enrolled their newborns in Early Check within 27 days of when it was sent compared to only 0.58% of women who did not open the invitation within that time frame (SE 0.02, 95% CI 0.18%-0.99%) and most likely became aware of the study through another outreach method. Being sent a postnatal recruitment letter ( $P=.57$ ) or a personalized email invitation ( $P=.53$ ) did not have a significant additional impact on enrollment within the 27-day period.

Our second research question asked, in part, whether there are differences in enrollment by race/ethnicity, age, or urbanicity. Although we observed no significant differences in enrollment rates across age groups, race/ethnicity and urbanicity were both related to enrollment. The odds of enrolling for Black women who were sent a *my UNC Chart* invitation was 0.29 times the odds of White women (SE 0.09, OR 0.29, 95% CI 0.16-0.55;  $P<.001$ ). Expressed in terms of predicted probabilities, whereas 4.49% of White women (SE 0.40, 95% CI 3.72%-5.27%) enrolled their newborns in Early Check within 27 days of when their invitations were sent, only 1.38% of Black women enrolled their newborns (SE 0.41, 95% CI 0.57%-2.19%). We found no other differences in enrollment by other race/ethnicity groups. Additionally, women with a home address in urban zip codes were more likely to enroll than women from rural zip codes (SE 0.97, OR 3.03, 95% CI 1.62-5.67;  $P=.001$ ). Controlling for the other variables in the model and expressed in terms of predicted probabilities, 4.04% of urban women (SE 0.32, 95% CI 3.41%-4.67%) enrolled their newborns in Early Check compared to 1.40% of rural women (SE 0.42, 95% CI 0.57%-2.22%).

**Table 3.** Logistic regression analysis predicting Early Check enrollment ( $N=4507$ ).

Predictor	OR	SE	<i>P</i> values	95% CI <sup>a</sup>
<b>Opened invitation within 27 days of when it was sent</b>				
Reference = no	1.0	— <sup>b</sup>	—	—
Yes	8.86	3.24	<.001	4.33-18.13
<b>Postnatal recruitment letter</b>				
Reference = not sent a recruitment letter	1.0	—	—	—
Sent a recruitment letter	1.20	0.37	.565	0.65-2.20
<b>Postnatal personalized email invitation</b>				
Reference = not sent an email invitation	1.0	—	—	—
Sent an email invitation	1.98	2.16	.531	0.23-16.82
<b>Race/ethnicity</b>				
Reference = White	1.0	—	—	—
Black	0.29	0.09	<.001	0.16-0.55
Hispanic	0.63	0.20	.135	0.34-1.16
Other	0.62	0.16	.068	0.36-1.04
<b>Urbanicity<sup>c</sup></b>				
Reference = rural	1.0	—	—	—
Urban	3.03	0.97	.001	1.62-5.67
<b>Age (years)</b>				
Reference = under 20	1.0	—	—	—
20-24	0.97	0.75	.969	0.21-4.43
25-29	1.87	1.38	.396	0.44-7.92
30-34	1.92	1.41	.376	0.45-8.07
≥35	2.58	1.90	.198	0.61-10.90
Constant	0.00	0.00	<.001	0.00-0.01

<sup>a</sup>The analysis excluded 3 women for whom geolocation data were insufficient to compute urbanicity.

<sup>b</sup>The reference levels are fixed parameters, not estimates, so no measures of precision were calculated.

<sup>c</sup>'Urbanicity' is a variable indicating whether women live in an urban or rural area based on residential ZIP code (see measures section).

### Opened my UNC Chart Invitation

Our second research question also considers associations of race/ethnicity, age, and urbanicity on whether women opened the research invitation sent to them through *my UNC Chart*. As shown in [Table 4](#), the logistic regression model that predicts opening the invitation was significant ( $\chi^2[10, N=4507]=62.38$ ;  $P<.001$ ,  $R^2_{McFadden}=.01$ ). Women who were sent a postnatal recruitment letter by mail within 27 days of a *my UNC Chart* invitation were significantly less likely to open the invitation (SE 0.09, OR 0.76, 95% CI 0.60-0.96;  $P=.02$ ). Holding everything else constant and expressed in terms of predicted probabilities, 62.1% of women who were sent a postnatal recruitment letter opened their *my UNC Chart* invitations (SE 2.6, 95% CI 56.9%-67.2%) versus 68.2% of women who were not sent a recruitment letter (SE 0.7, 95% CI 66.8%-69.6%). Whether women were sent a postnatal personalized email within the 27-day timeframe was not significantly associated with

opening the *my UNC Chart* invitation ( $P=.19$ ), nor was urbanicity ( $P=.75$ ). However, race/ethnicity and age were both significantly related to opening the invitation. Black women were significantly less likely than White women to open the invitation (SE 0.05, OR 0.67, 95% CI 0.57-0.78;  $P<.001$ ), with 61.4% of Black women (SE 1.6, 95% CI 58.3%-64.5%) opening the invitation compared to 70.4% of White women (SE 0.9, 95% CI 68.6%-72.2%). Hispanic women were also less likely to open the invitation than were White women (SE 0.07, OR 0.73, 95% CI 0.60-0.89;  $P=.002$ ), with an estimated 63.4% of Hispanic women opening their invitations. Lastly, opening the *my UNC Chart* invitation differed significantly by age. Compared to women under 20 years of age, women aged 25 to 29 years (SE 0.26, OR 1.51, 95% CI 1.08-2.10;  $P=.02$ ), 30 to 34 years (SE 0.28, OR 1.67, 95% CI 1.20-2.33;  $P=.003$ ), or 35 years or more (SE 0.25, OR 1.44, 95% CI 1.03-2.03;  $P=.35$ ) were significantly more likely to open the invitation. The predicted probabilities of opening the *my UNC Chart* invitation by age are shown in [Table 5](#).

**Table 4.** Logistic regression analysis predicting whether the *my UNC Chart* invitation was opened ( $N=4507$ ).

Predictor	OR	SE	P values	95% CI
<b>Postnatal recruitment letter</b>				
Reference = not sent a recruitment letter	1.0	— <sup>a</sup>	—	—
Sent a recruitment letter	0.76	0.09	.022	0.60-0.96
<b>Postnatal personalized email invitation</b>				
Reference = not sent an email invitation	1.0	—	—	—
Sent an email invitation	0.57	0.24	.185	0.24-1.31
<b>Race/ethnicity</b>				
Reference = White	1.0	—	—	—
Black	0.67	0.05	< .001	0.57-0.78
Hispanic	0.73	0.07	.002	0.60-0.89
Other	0.99	0.11	.928	0.80-1.22
<b>Urbanicity<sup>b</sup></b>				
Reference = rural	1.0	—	—	—
Urban	0.97	0.08	.747	0.83-1.14
<b>Age, years</b>				
Reference = under 20	1.0	—	—	—
20-24	1.26	0.22	.178	0.90-1.78
25-29	1.51	0.26	.015	1.08-2.10
30-34	1.67	0.28	.003	1.20-2.33
≥35	1.44	0.25	.035	1.03-2.03
<b>Constant</b>	1.70	0.29	.002	1.22-2.38

<sup>a</sup>The reference levels are fixed parameters, not estimates, so no measures of precision were calculated.

<sup>b</sup>The analysis excluded 3 women for whom geolocation data were insufficient to compute urbanicity.

**Table 5.** Predicted probability of opening a *my UNC Chart* invitation by age ( $N= 4507$ ).

Predictor	% <sup>a</sup>	SE	95% CI
<b>Age, years</b>			
Under 20	58.9	3.8	51.5-66.3
20-24	64.4	1.7	61.0-67.7
25-29	68.3	1.3	65.7-70.9
30-34	70.4	1.2	68.0-72.8
≥35	67.3	1.5	64.3-70.4

<sup>a</sup>Predicted probability expressed as a percentage controlling for covariates included in the logistic regression model.

## Discussion

### Principal Findings

We examined the utility of sending research invitations to pregnant women through a patient portal and whether opening an invitation was associated with enrollment in the study. We found an association between opening a patient portal research invitation and enrollment in the study but found disparities by race/ethnicity in having a *my UNC Chart* patient portal, opening the invitation, and enrolling in the study.

The use of EHR data to identify and contact eligible participants through their patient portal proved to be successful. The findings show that the *my UNC Chart* patient portal within UNCH could be used to send recruitment invitations to over 4500 pregnant women whose newborns would be eligible for Early Check over a period of approximately 15 weeks. These results demonstrate the efficiency of using patient portals to send recruitment invitations to large numbers of potential research participants, compared to the time and effort it would require to contact thousands of participants through other methods like phone or in-person recruitment. As such, patient portals are especially

valuable for studies seeking to approach and enroll very large numbers of participants.

Despite contacting thousands of eligible women, those we contacted accounted for a minority (4510/12,036, 37.5%) of patients at UNCH who met the computable phenotype during the time period of this study; a majority of eligible women did not have active *my UNC Chart* accounts and thus could not receive a recruitment message. However, for a study like Early Check with broad eligibility criteria and for which patients will become newly eligible over time as women become pregnant, *my UNC Chart* still proved an efficient method to contact thousands of eligible women.

Overall, patient portal research invitations sent through *my UNC Chart* were associated with enrollment in the Early Check study among women who opened those invitations. We found that a majority of women who received a *my UNC Chart* research invitation opened it, and of those who opened it, 4.88%, expressed in predicted probability, enrolled their newborn. In comparison, a previous analysis of the other primary recruitment method for Early Check, postnatal letters and emails to new mothers showed an overall statewide enrollment rate of 4% [36]. For those women who were sent a postnatal letter in addition to the recruitment invitation through *my UNC Chart*, the receipt of the postnatal letter did not increase the odds of enrollment. We did not independently compare *my UNC Chart* recruitment with direct letters and emails.

The findings demonstrated disparities in the use of patient portals, opening of research invitations, and enrollment in the study by race/ethnicity. There were also disparities in enrollment by urban/rural home address and in opening research invitations by age. Black women and Hispanic women were less likely to open an Early Check recruitment invitation sent through *my UNC Chart* and were less likely to enroll in the study after opening the invitation compared to non-Hispanic White women. We also found disparities by race and ethnicity among women we had hoped to reach using *my UNC Chart* invitations because they did not have an active *my UNC Chart* account. Members of traditionally underrepresented racial and ethnic minority groups were less likely than non-Hispanic White women in our target audience to have an active *my UNC Chart* account. Hispanic women were least likely to be *my UNC Chart* users, a finding that may be partially due to the availability of *my UNC Chart* in English only.

In our analysis of *my UNC Chart* by age and rural/urban home address, we found that there was no difference by age or urbanicity in those who had an active *my UNC Chart* account. Age was not significantly associated with opening the message or enrolling in the study except for women less than 20 years of age who were less likely to open the invitation. We found that women from urban areas were significantly more likely to enroll their newborns in the study compared to women from rural areas. It is not clear why urban women were more likely to enroll their newborns in the study although proximity to academic medical institutions and research familiarity may play a role.

## Comparison With Prior Work

Our enrollment rate among women who received Early Check *my UNC Chart* patient portal research recruitment invitations was similar to other studies using patient portals for recruitment, including the ADAPTABLE study performed in the same health system using a similar messaging protocol (4.4%) and a review of 13 studies recruiting through the patient portal of a single health system (2.9%-3.4%) [20,23,24]. Some studies have reported higher enrollment rates using patient portals ranging from 7% to 38% [22,28,32,34]. Bower et al [21], a study that also recruited pregnant women through patient portals, had a higher enrollment rate (11%) compared to the enrollment rate we report here (161/4510, 3.6%). The reasons for the differing enrollment rates across these studies are unclear but may be partially due to the target study population, demographics of patient portal users at an institution, type of study, demand on participants, formatting of the message, and the timing of the invitation in relation to a scheduled medical appointment. More research is needed on the factors associated with successful recruitment through patient portals and on the acceptability of using patient portals to recruit for research, to identify those studies for which a patient portal recruitment approach is likely to be most productive and acceptable.

The findings of racial and ethnic disparities in the users of *my UNC Chart*, opening of the recruitment invitation, and enrollment in the study are consistent with the findings across other studies examining the use of patient portals for recruitment and the use of patient portals for clinical care [8,23,29,32,34]. It is important to recognize that patient portal recruitment approaches have limited reach and may compound the problem of underrepresentation in health research. Identifying barriers to patient portal use for clinical care and intervening with specific subgroups to address those barriers may improve the reach of patient portals and their utility in recruiting a diverse research sample [17]. In the meantime, research administrators should use patient portals as part of a broader recruitment strategy and not the sole recruitment method.

## Limitations

The study examined patient portal research invitations sent to pregnant women, and findings may have limited generalizability to other types of patients. Findings may also have limited generalizability to organizations that use a patient portal other than Epic MyChart. It is also a limitation of the study that we did not directly compare the effectiveness of recruitment to Early Check through *my UNC Chart* research invitations to recruitment through postnatal letters and emails. We were unable to conclude whether one of these recruitment approaches was superior in enrolling newborns in the Early Check study or whether one approach would have resulted in a more representative sample.

## Conclusions

Patient portals are an effective way to recruit participants for research studies and are especially useful for studies with large target sample sizes. There remain substantial racial and ethnic disparities in the use of patient portals, the response to receipt of an invitation, and enrollment in the study.



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## Authors' Contributions

LG, RP, SA, AL, AG, MD, EP, and DB conceptualized the study. EP, SA, AL, RP, LG, and DB contributed to the methodology, while AL and MD provided the software. RP performed the formal analysis, and MD, AL, RP, and SA completed the data curation. LG, RP, and SA drafted the original manuscript. LG, RP, SA, AL, AG, MD, EP, and DB reviewed and edited the manuscript. LG, SA, and AL administered the project, and DB acquired the necessary funding.

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## Conflicts of Interest

DBB reports current external funding to RTI from Janssen Pharmaceuticals and The John Merck Fund and prior external funding to RTI from Orchard Therapeutics, Travere, BioMarin, and Sarepta Pharmaceuticals. RTI also received donated reagents and equipment from Asuragen.

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LMG reports receiving grants from Janssen Pharmaceuticals, the John Merck Fund, Sarepta Therapeutics, Muscular Dystrophy Association, and donated reagents and equipment from Asuragen, outside the submitted work.

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## Multimedia Appendix 1

Computable Phenotype for Carolina Data Warehouse for Health Query (CDWH).

[PDF File (Adobe PDF File), 103 KB - [pediatrics\\_v5i1e30941\\_app1.pdf](#) ]

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## Multimedia Appendix 2

Text of the Early Check *my* UNC *Chart* Research Invitation.

[PDF File (Adobe PDF File), 100 KB - [pediatrics\\_v5i1e30941\\_app2.pdf](#) ]

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## Abbreviations

- CDWH:** Carolina Data Warehouse for Health
- EHR:** electronic health record
- NCATS:** National Center for Advancing Translational Sciences
- RUCA:** rural-urban commuting area
- UNCH:** UNC Health

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Original Paper

# Listening to Stakeholders Involved in Speech-Language Therapy for Children With Communication Disorders: Content Analysis of Apple App Store Reviews

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## Abstract

**Background:** With the plethora of mobile apps available on the Apple App Store, more speech-language pathologists (SLPs) have adopted apps for speech-language therapy services, especially for pediatric clients. App Store reviews are publicly available data sources that can not only create avenues for communication between technology developers and consumers but also enable stakeholders such as parents and clinicians to share their opinions and view opinions about the app content and quality based on user experiences.

**Objective:** This study examines the Apple App Store reviews from multiple key stakeholders (eg, parents, educators, and SLPs) to identify and understand user needs and challenges of using speech-language therapy apps (including augmentative and alternative communication [AAC] apps) for pediatric clients who receive speech-language therapy services.

**Methods:** We selected 16 apps from a prior interview study with SLPs that covered multiple American Speech-Language-Hearing Association Big Nine competencies, including articulation, receptive and expressive language, fluency, voice, social communication, and communication modalities. Using an automatic Python (Python Software Foundation) crawler developed by our research team and a Really Simple Syndication feed generator provided by Apple, we extracted a total of 721 app reviews from 2009 to 2020. Using qualitative coding to identify emerging themes, we conducted a content analysis of 57.9% (418/721) reviews and synthesized user feedback related to app features and content, usability issues, recommendations for improvement, and multiple influential factors related to app design and use.

**Results:** Our analyses revealed that key stakeholders such as family members, educators, and individuals with communication disorders have used App Store reviews as a platform to share their experiences with AAC and speech-language apps. User reviews for AAC apps were primarily written by parents who indicated that AAC apps consistently exhibited more usability issues owing to violations of design guidelines in areas of aesthetics, user errors, controls, and customization. Reviews for speech-language apps were primarily written by SLPs and educators who requested and recommended specific app features (eg, customization of visuals, recorded feedback within the app, and culturally diverse character roles) based on their experiences working with a diverse group of pediatric clients with a variety of communication disorders.

**Conclusions:** To our knowledge, this is the first study to compile and analyze publicly available App Store reviews to identify areas for improvement within mobile apps for pediatric speech-language therapy apps from children with communication disorders and different stakeholders (eg, clinicians, parents, and educators). The findings contribute to the understanding of apps for children with communication disorders regarding content and features, app usability and accessibility issues, and influential factors that impact both AAC apps and speech-language apps for children with communication disorders who need speech therapy.



**KEYWORDS**

eHealth; mobile health; mHealth; mobile app; communication disorders; speech therapy; language therapy; children; mobile phone

## Introduction

### Background

In recent decades, the Apple App Store has experienced a drastic increase in the number of mobile apps across multiple genres (eg, education, games, and health and fitness) for children. Many of these apps are designed for children with communication disorders; many are also used by their speech-language pathologists (SLPs) during assessments and interventions [1-3]. Different genres of mobile apps may be used for assistive, educational, and recreational purposes within the context of speech-language therapy depending on the communication abilities of children with communication disorders. For example, children with complex communication needs benefit from using augmentative and alternative communication (AAC) apps installed on mobile tablets (eg, iPad [Apple Inc]). Such devices enable AAC users to communicate with others via prestored symbols, pictures, and texts as an alternative communication modality [4,5]. In addition, educational speech therapy apps, including game apps that contain speech sound stimuli or language-based activities, have been implemented during therapy to target specific intervention domains [2,6,7].

The design and implementation of mobile apps for use by children with communication disorders is a research area that draws attention from both clinical researchers and human-computer interaction researchers. In recent years, human-computer interaction scholars have designed apps for children with autism, cleft palate, speech sound disorders, cochlear implants, and other communication disorders [8-12]. Given the variety of needs among children with communication disorders, developers and designers may encounter difficulties obtaining verbal or written user feedback on app content and features while creating and revising these apps; consequently, they must rely on reports from key stakeholders that surround the circle of care of children with communication disorders [13,14]. Some stakeholders included within the circle of care of children with communication disorders are SLPs; parents; teachers; and, sometimes, the children with communication disorders themselves. Involving all stakeholders in the initial design process would be costly, time-consuming, and unwieldy, and there are multiple obstacles to conducting empirical user studies examining the app use experience of children with communication disorders directly [15-17].

App Store reviews offer an opportunity to investigate app user experience from a multi-stakeholder perspective, which has heretofore been unexamined. App Store reviews are publicly available data sources from customers, serving as a communication avenue for app users to express their needs and challenges with the apps they purchased and downloaded. App Store reviews not only influence decisions by other users regarding app purchases but also bring awareness to developers about critical issues related to app design and development,

including but not limited to criticism of current app features and functions and ideas for new app features.

### Relevant Work

Previous user review studies have examined thousands of app reviews from different genres of apps on the Apple App Store [18-20] and the Google Play Store [18,21-23]. Popular apps can receive a large volume of reviews daily. However, analyzing these linguistic data and categorizing reviews in large amounts may be difficult, specifically when dealing with varying quality of reviews and with mixed sentiments within a single review [18]. Researchers have used manual coding as well as automated data mining techniques (eg, natural language processing for topic, semantic, and sentiment analysis) to analyze linguistic data on a large scale, categorize various user intent, and organize user feedback for feature extraction [21,22,24,25]. Studies that analyze popular game, social, communication, and productivity apps (eg, Angry Birds [Rovio Entertainment], Facebook [Meta Platforms], Pinterest, WhatsApp [Meta Platforms], and Dropbox) have suggested that user reviews offer valuable feedback for information giving, information seeking, feature requests, and problem discovery, along with rich contextual descriptions of feature requests and ideas for improvements [18,20,22]. Fu et al [21] further found that even user complaints can be useful, as the number of complaints were highest following a release, with top complaints primarily related to content attractiveness, app stability, and cost. Khalid et al [20] found similar trends, with more than half of the complaints addressing functional errors, feature requests, and instances of the app crashing.

Although previous research on app reviews has focused on non-health-related apps, research is lacking regarding user reviews for apps targeting individuals with disabilities or apps related to health-related interventions. One area of research that is growing is regarding the efficacy of mental health apps. For example, researchers have begun to investigate the potential positive impact of mental health apps, particularly in increasing access to mental health interventions. Although prior studies on user reviews for general popular apps can be useful to guide review analysis for health-related apps [19-22,26], research on apps in health intervention highlights the additional importance of user engagement, especially among consumers who have specific health needs or disabilities [27,28]. Torous et al [29] and Stawarz et al [23] examined the effectiveness and user engagement of cognitive behavioral therapy apps and found that in addition to poor usability and failure to meet user needs, users also have low engagement and rising uncertainties about the effectiveness of mental health apps [29]. These studies have identified the need for further exploration of how App Store reviews might increase designer and developer knowledge of user issues, enabling evidence-based design practices that could increase the user-reported efficacy of health-intervention apps.

Despite the vast number of commercial mobile apps available for children, there have been very few published studies related to user-reported satisfaction regarding the efficacy of speech-language therapy apps for children. A recent study [30] examined the content and quality of mobile apps for speech-language therapy in adults with communication disorders; however, to our knowledge, no published studies have examined publicly available user reviews to understand the user experience with speech-language apps of children with communication disorders. Investigating the review content for pediatric speech-language apps not only allows adult stakeholders to share the user challenges of children with communication disorders with app designers but also enables researchers to understand the communication needs of both children and adults. Children with communication disorders typically depend on their caregivers, educators, and therapists to make decisions regarding app recommendations; however, owing to the lack of up-to-date research regarding systematic guidelines for app selection and evaluation, clinical decision-making can be difficult for the adult stakeholders of children with communication disorders [31]. Parents often make purchase decisions based on usability reviews and ratings from the App Store, and even clinicians have to rely on word of mouth, marketing offers, or cost to make decisions when purchasing apps for use during therapy [1].

Investigating user reviews across different genres of mobile apps can inform design practitioners about specific usability issues that may impede the interaction of children with communication disorders with the apps, and helps clinicians learn about app content and features to make clinical recommendations that best serve their clients' needs. Previous studies have reported that app users often use the same linguistic patterns to communicate a problem but that linguistic patterns may vary more when making feature requests. This variance makes automatic analysis difficult to successfully identify and categorize user perspectives on feature requests [18,22]. This study uses automatic review extraction and manual review screening and analysis to examine user reviews from a selected set of mobile apps for pediatric speech therapy from the Apple App Store. By identifying app feature requests and critical usability issues, as well as multiple influential factors (eg, financial, sociocultural, ethical, and political) affecting user experiences, this study seeks to inform designers and developers who aim to create child-centered and clinically informed speech-language apps for children with communication disorders.

## Methods

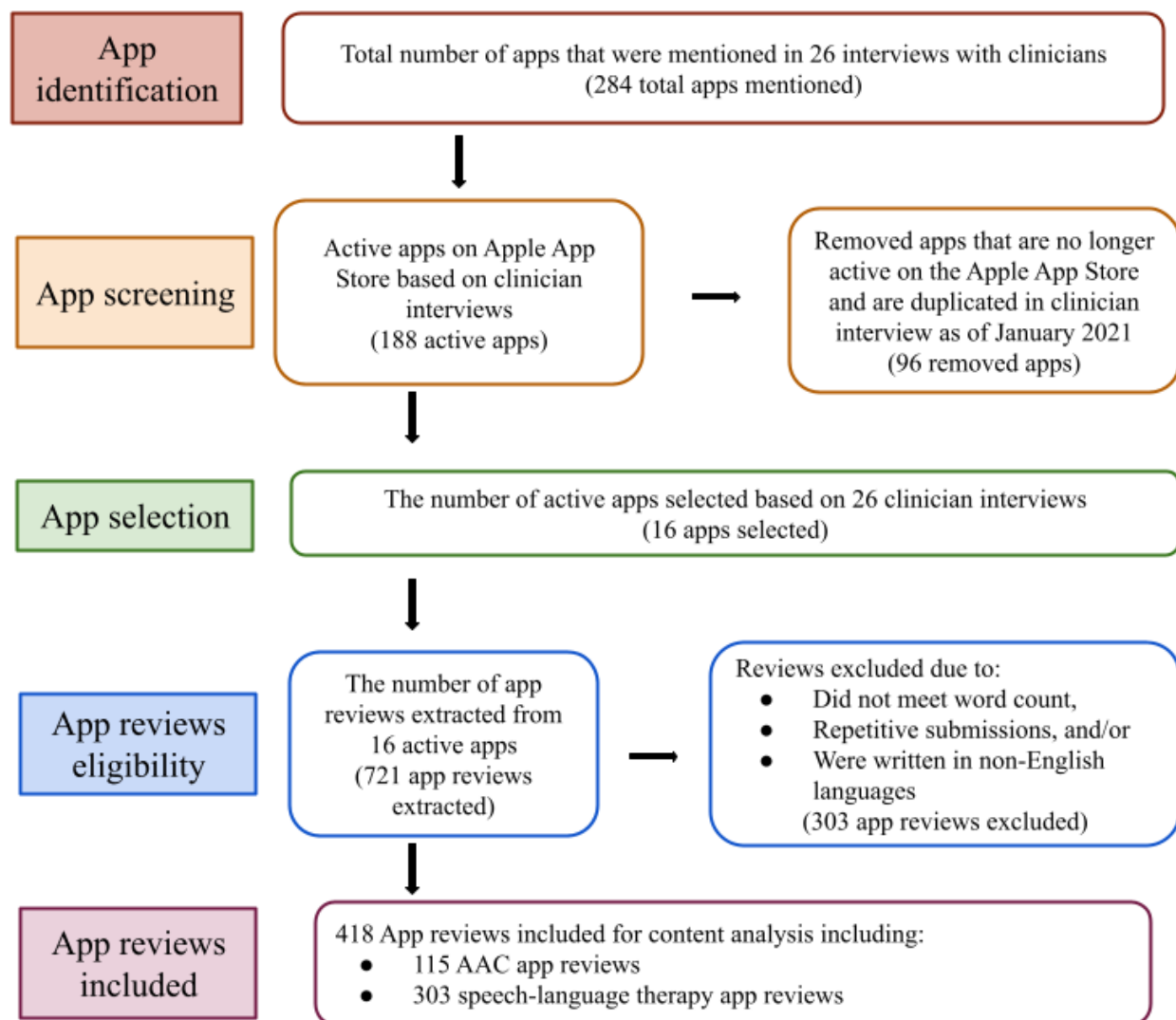
### App Selection and Screening

This study builds on a prior qualitative interview study with 26 SLPs who reported a total of 284 mobile apps they use with

children during speech and language therapy [15,16]. These participating SLPs ranged across multiple settings such as schools, private practices, hospitals, and home health services from various states in the United States ([Multimedia Appendix 1](#)). Using apps collected from the SLPs' interviews enabled us to examine technological tools that clinicians reported using rather than querying app searches through researcher-designed keywords on the Apple App Store. We used multiple verification and categorization steps for app selection and screening, as indicated in [Figure 1](#). First, we verified whether the 284 apps mentioned by SLPs were inactive or active on the Apple App Store. Inactive apps were apps that were no longer available on the Apple App Store, whereas active apps were apps available for consumers to download and use as of January 2021. We identified and excluded 33.8% (96/284) apps that were no longer active and classified the remaining 66.2% (188/284) active apps into four categories as follows: (1) AAC apps, (2) speech-language apps, (3) game apps that do not contain therapy content, and (4) utility apps. These four categories are consistent with prior research on app reviews for individuals with visual impairments, as Torres-Carazo et al [27] have reported that these individuals use games and utility apps in addition to various kinds of assistive technology apps. A previous study [1] suggested that in their university clinic, AAC apps (eg, Proloquo2Go) were the apps most frequently checked out by speech-language pathology clinicians. This study stated that student clinicians also preferred speech-language apps with content-specific visual feedback and apps that allowed them to target a variety of speech and language therapy goals [1]; therefore, researchers must consider both AAC apps and speech-language apps, as both genres of apps are designed for speech-language intervention and are frequently used by SLPs when working with children with communication disorders.

Next, to further categorize these apps into specific speech and language therapy domains, we followed the Big Nine intervention domains from the American Speech-Language-Hearing Association [32]. The Big Nine domains include articulation, fluency, voice and resonance, receptive and expressive language, hearing, swallowing, cognitive aspects of communication, social aspects of communication, and communication modalities [32]. The final 5.6% (16/284) of selected apps had the most user reviews and covered multiple American Speech-Language-Hearing Association Big Nine domains in the areas of articulation, receptive and expressive language, social aspects of communication language, and communication modalities. These 16 chosen apps include 7 (44%) AAC apps ([Multimedia Appendix 2](#)) and 9 (56%) speech-language therapy apps ([Multimedia Appendix 3](#)).

**Figure 1.** A flowchart for app selection, app review extraction, and content analysis. AAC: augmentative and alternative communication.



### App Review Extraction

To ensure that the 16 selected apps had adequate app reviews, we organized these apps from the most to the least number of web-based app reviews available for content analysis. We used a Really Simple Syndication feed generator provided by Apple and an automatic Python crawler developed by our research team, which enabled app reviews and other related information, such as review date, reviewer name, review title, and content, to be extracted and exported to the comma-separated values file format for the iOS apps selected in this study. We extracted a total of 721 app reviews from all 16 apps, with review dates ranging from 2009 to 2020.

After app review extraction, we first manually reviewed and excluded 42.2% (304/721) of the app reviews, including 8.3% (60/721) AAC app reviews and 33.8% (244/721) speech therapy app reviews. These reviews were excluded because they were too short, repetitive, written in languages other than English, or not applicable for pediatric speech therapy. We then conducted a content analysis of a total of 418 reviews, including 115 (27.5%) AAC reviews and 303 (72.5%) speech therapy app reviews, all with at least 20 words per review to ensure adequate

content was included in each review (Figure 1). For the app *Articulation Station* and *Word Vault Essential*, only reviews from the free versions were included because of an insufficient number of reviews for the pro version compared with the free version (Multimedia Appendices 2 and 3). This is consistent with a prior research [19], which discovered that more reviews were written for free apps than for paid apps; as a result, apps in the games category, which are typically free, tend to receive the highest number of reviews compared with other app categories where apps more frequently must be purchased.

### Qualitative Coding of App Reviews

This study used manual coding for app reviews; for manual coding to be effective, it is vital to have a coding system that provides clear definitions and examples when determining what should be classified under each code. Although discrepancies can occur during manual analysis, a coding guide is one way to help limit the number of times reviews will need to be looked at by multiple individuals. The research team consisted of one licensed SLP, YD, one graduate clinician, AT, and three remaining authors, SC, JV, and YL, who were licensed SLP assistants. The qualitative coding process involves several steps.

First, we used a subset of apps, including 19% (3/26) AAC apps (*Proloquo2Go*, *GoTalk NOW*, and *Language Acquisition Motor Planning Words for Life* [LAMP WFL]) and 19% (3/26) speech-language apps (*Articulation Station*, *Language Empires*, and *Between the Lines Level 1 HD*), the SLP and the graduate clinician generated initial codes using a deductive coding scheme from a prior interview study [16,33] and literature in universal design guidelines [33,34] and educational app evaluation heuristics [35]. After the initial codes were developed, the 3 SLP assistants coded the remaining reviews of the other apps and used the constant comparison method [36-38] to merge codes into broader categories and developed a codebook (Multimedia Appendix 4). Disagreements with content analysis were resolved using the negotiated agreement approach [39]. Individual codes in the codebook covered several areas including client characteristics (eg, age, type of disability, level of ability, and length of app use), clinician characteristics (eg, clinical setting, clinician location, clinician specialty, and length of app use), additional stakeholders (technical vs nontechnical personnel), clinical practice (eg, intervention area and domain, therapy goals and activities, workplace productivity, evidence-based practice, and research), app characteristics (eg, genre, content, use technique, and data management), device issues (eg, hardware vs software), usability issues (with a focus on control, error, aesthetics, customization, and accessibility), and recommendations (eg, app referral, suggestions for improvement, and feature requests). In addition, each app review was labeled when the review content specified the identity of an individual reviewer (eg, an SLP or a parent). In the next section, we discuss specific findings related to app content and features, usability and accessibility issues, and recommendations for future improvement mentioned by the users based on 2 genres of AAC and speech-language apps. Finally, we concluded by discussing multiple influential factors (eg, financial, sociocultural, ethical, and moral) that affect the implementation and use of both AAC apps and speech-language apps.

## Results

### App Characteristics: Content and Features, Usability, and Recommendations for AAC Apps

#### AAC App Content and Features

In this study, app reviews were coded based on information related to the app genre, app use technique, app content, and data management. For AAC apps, reviews were written by a range of critical stakeholders for children with communication disorders, including parents, SLPs, and AAC specialists, as well as AAC app users themselves. Identification of stakeholders was determined by the AAC reviews' content (eg, pronouns mentioned, explicitly self-identified role, or unique characteristics). A total of 112 stakeholders were identified in the AAC reviews. The number of app reviewers were classified into six specific categories. Of the 112 stakeholders, the top 3 stakeholder groups who reviewed AAC apps included 51 (45.5%) parents, 24 (21.4%) AAC users, and 18 (16.1%) SLPs. In contrast, of the 112 stakeholders, only 1 (0.9%) educator, 2 (1.8%) AAC specialists, and 16 (14.3%) unknown stakeholders

left app reviews. App reviewers were marked as unknown when there was insufficient information to identify which stakeholder group they were a part of.

Users of 56% (9/16) of AAC apps cover a wide age range, from toddlers to school-aged children and young adults. Users' characteristics include various different types of physical and communication-related disabilities (eg, autism, language delay, Down syndrome, cognitive impairments, and mutism). When reviewing the 9 AAC apps, app reviewers compared design features and app characteristics across AAC apps (eg, *Proloquo2Go*, *Speak For Yourself*, and *TouchChat HD*). For instance, reviewers praised the app *Proloquo2Go* for its popularity in educational settings across elementary, junior, and high schools. A parent of a 6-year-old nonverbal autistic son praised the *Proloquo2Go* app, saying that it brings "the power of communication and made it accessible to some of the most vulnerable people in society." Specifically, reviewers stated that AAC apps such as *Proloquo2Go* provide users the opportunity to use a list of core vocabulary words or high-frequency words (eg, want and more) in an "easy to add or rearrange" layout. Similarly, 10 reviews reported positive features, such as easy customization and personalization in the app LAMP WFL. Some individuals use the LAMP WFL app as a primary source of communication, whereas others use it to supplement other modes of primary communication modalities, such as sign languages. Unlike *Proloquo2Go*, LAMP WFL has a fixed display with static core words to support the user's motor planning. This facilitates an evidence-based approach for AAC intervention, which was reported to be beneficial by parents. One parent specifically stated the following:

*I like that the buttons on the original page can't be changed/moved around like in other apps. It helps the child memorize the placement of the buttons, so less frustration.*

#### AAC App Usability Issues

Despite these positive reviews, user complaints were also reported, including usability issues such as missing content (eg, lack of fringe vocabulary or low frequency words) or unsatisfying content in relation to the high cost of AAC apps. App reviewers also noted difficulties accessing AAC apps across different types of devices owing to a lack of compatibility. Consequently, we categorized these hardware issues under the Level 2 code device, which primarily looks at AAC app issues related to hardware and software. An example of how this affects AAC users is that if they need to transition to a new device (eg, after breaking their current device), previously programmed app content may be lost or abandoned. To address this concern, apps such as *CoughDrop* and *GoTalk NOW* offer cloud-based storage systems to connect to Wi-Fi automatically. During the COVID-19 pandemic, many clinicians who have used these speech-language therapy apps with their clients in settings such as schools and private practice clinics have transitioned into providing therapy services on the web. One SLP who specializes in AAC and assistive technology used *CoughDrop* via teletherapy and stated the following:

*Through telepractice ST services, I work with students across state lines and this app allows me the ability*



*to create and synchronize boards from the comfort of my home to students in other states. This past year after collecting data in the reports sent by the app, two of the districts I contracted with purchased life-time apps for three students on trial. So what makes it a Guru AAC App? It is cloud based, user friendly, one can use the picture library within the app, or use your own cam pictures or web pictures, not to mention the great 1:1 communication from its developers any time I have reached out to them.*

Enabling cloud-based data management solutions for AAC apps reduces the burden of transferring AAC data for both users and their therapists, which is especially beneficial during teletherapy.

AAC app reviews highlighted usability issues primarily in critical areas of user errors, controls, aesthetics, customization, and accessibility (Table 1). A total of 69 AAC reviews were coded for usability issues. The most common user errors for AAC apps were related to issues such as navigation and controls (eg, scrolling), selection (eg, icons), and delays during app use (eg, importing photos). These errors led to increased user frustration that impacted the ability of children with communication disorders to engage in functional communication. Analysis of 56% (9/16) of AAC app reviews related to user errors highlighted the importance of improving vocabulary and message selection and increasing efficient navigation and control to offer timely communication experiences for users with disabilities. Some recommendations in the reviews included allowing users to choose photos and edit icons to add vocabulary. Other challenges related to user control were reported to affect users' ability to personalize and customize AAC apps. Some complaints and recommendations included updates that changed button placement that were previously learned, inability to increase low volume in noisy environments, fast pace of programmed speech rate, and lack

of personalization and inclusion of user-specific voice output for aesthetic purposes. App reviews for *Speak For Yourself* and *TouchChat HD* emphasized the lack of diversity in options from the voice bank that failed to make users feel represented via their own voices when using AAC systems. For example, one review left on *TouchChat HD* requested voices that could represent children rather than adults, and another reviewer for *Proloquo2Go* mentioned the following:

*More subtle adjustment of pitch is required - I don't want to sound like a mickey mouse at the level above normal! The acapella female voices do need to improve.*

These reviews reflected user needs for controlling and using high-quality synthesized speech to represent voice profiles for users across different age groups and genders.

In addition to AAC app users, other stakeholders have also experienced app malfunction when using the app, which interfered with their clinical practices while trying to gather accurate data. Clinicians have reported varying user challenges, such as the inability to control language and images that were considered inappropriate for certain individuals. App reviews also revealed differences in perspectives between SLPs and parents. For instance, the app *LAMP WFL* has 15 reviews from parents reporting dissatisfaction, such as AAC item images that they consider inappropriate for their children; clinicians and special education teachers reported more dissatisfaction regarding therapy target areas that could be addressed via this app and recommended more social content to be included. In addition, caregivers specifically emphasized the critical need to have the support of a knowledgeable clinician to successfully program the AAC system onto its designated device. A user who downloaded *CoughDrop* felt that programming this particular AAC app can be challenging "unless you have a therapist that's well versed in making changes."



**Table 1.** User reviews on usability issues and recommendations for augmentative and alternative communication (AAC) apps.

AAC app name	App usability		App recommendations	
	Characteristic	Review	Characteristic	Review
CoughDrop	Compatibility	“Half of the time the changes I make on either the computer or iPad do not stay changed. With it only doing a few features it should be a lot easier to navigate.”	Programing	“Keep looking unless you have a therapist that’s well versed in making changes I wouldn’t bother with this.”
TouchChat HD	User errors	“The only problem is that when I edit a button in one screen my changes affect absolutely unrelated button in another screen, which is obviously a bug.”	Compatibility	“In the very least, if you purchased the \$300 iPad app, they should offer a credit for the same iPhone app.”
Speak for yourself	Visual aesthetics	“Too many buttons. They don’t make sense (e.g., ‘little’/mouse picture goes to page with about a hundred flowers???? What is that about!!!!!!).”	Aesthetics	“If I could change three things, it would be the voices, the rigidity, and the grammar.”
Tobii Dynavox compass connect	Efficiency	“It’s been an hour since the app finished downloading and I STILL haven’t been able to get started on it.” “I downloaded it on my new iPad and when I try to open it, the wheel just spins and then it closes down.”	Data storage	“Not [recommend] takes up [too] much storage takes forever to install.”
LAMP WFL <sup>a</sup>	Customization	“However, the main drawback is that for a 12-year-old, the app’s vocabulary is severely lacking. There are not enough words. (For example the words blueberry and coyote are not in the vocabulary along with other words.)”	Volume	“My son loves this app but the volume is kinda low. Today I put it on maximum volume but could barely hear him while driving. It’s fine if your at home with no noise otherwise it’s difficult to hear. Please fix.”
Proloquo2Go	Navigation and control	“The sensitivity on this app is extremely annoying. Just scrolling will cause a button to be pushed at random. It’s quite annoying when you’re trying to use this and random buttons are getting pushed not by you intentionally.”	User errors	“My one problem is that it’s too easy for her to get into edit mode and start deleting/editing or adding nonsense buttons. Could you please add a password option to get into edit mode?”
GoTalk NOW	Programing	“Go Talk Now is an easily programmable communication app for sure. Updating buttons is quick and there are video guides to show how-to’s of creating books, even a free lite version to trial it.”	Data storage	“On my wish list for GTN is an easier way to backup communication books of more than 5 pages at a time for an iPad 2.”

<sup>a</sup>LAMP WFL: Language Acquisition Motor Planning Words for Life.

## App Characteristics: Content and Features, Usability, and Recommendations for Speech-Language Apps

### Overview

In contrast to AAC apps, a total of 188 App Store reviews for speech-language apps were written by 51 (27.1%) SLPs, 39 (20.7%) educators, 32 (17%) parents, 5 (2.7%) other professionals, and 61 (32.4%) unknown stakeholders. This distribution of stakeholders is likely because, in addition to parents who actively seek apps to help their children, SLPs are the primary users of these apps. In the reviews for speech-language apps, clinicians not only recommended app content and features that addressed their clients’ needs but also provided app critiques so that the app designers and developers could improve apps to align with clinical practice guidelines for speech and language intervention. In the following section, we describe reviewer feedback related to content and features and usability issues in areas of user errors, aesthetics design, and desirable control and customization.

### Articulation Apps

Articulation apps were reported to be used by children from ages 2 to 6 years, including individuals who, according to the reviews, have autism, speech delays, articulation disorders, and apraxia. The desirable content and features of these articulation apps focused on four key components: (1) include a variety of articulation targets speech sounds and corresponding letters, along with a plethora of target words; (2) offer consistent verbal models and opportunities for high volumes of repetition; (3) enable the selection of speech sound targets based on the ability level of a client (eg, sounds in isolation, in all word positions, and at the sentence level); and (4) allow clients to progress at multiple linguistic hierarchy levels by following the development of phoneme acquisition and evidence-based practice guidelines. For example, clinicians especially enjoyed the function of recording voice production and data tracking in the app Articulation Station, as it offers direct feedback for children with communication disorders to improve perception of their own speech production. One SLP stated in the review that “the students love the record function and it is useful for

them to hear back their own productions.” Clinicians also commented that having the data collection and tracking functions help them save time and allow them to compare data across multiple sessions to measure overall therapy progress. In addition, reviewers commented that picture-card apps such as *Word Vault Essential* are convenient and portable for use with various clients for multiple therapy goals beyond articulation and phonology, as some of the word lists can be used to target language and pragmatic intervention. In addition to SLPs, educators (eg, teachers and reading specialists) and parents also left reviews for these speech therapy apps, and parents especially praised that these articulation apps could be incorporated multiple times daily outside speech therapy sessions at school and, therefore, become a supplement to help complete speech therapy exercises at home.

In terms of usability, there were 11 reviews that praised the aesthetic design of apps, such as the *Lively Letters-Phonics* app and stated that the app content was stored in a “neat, organized fashion” and that the in-app activities were “visually appealing, clear, and fun;” 2 recent reviews from July 2020 specifically mentioned that the app *Lively Letters-Phonics* was “a huge help during remote learning with the ability to use the lively letters on screen” in the pandemic context it was “so easy to use with Zoom meetings. The students were engaged and the activities helped to keep the lesson moving.” A total of 21 reviewers, mostly SLP clinicians, raised concerns regarding the app *Speech Blubs: Language Therapy* and its poor animation, incorrect pronunciations, inconsistent and low volume of sounds, and unnatural quality in voice recordings when computer-generated artificial speech is used instead of human voice recordings. One SLP raised a specific concern about the *Speech Blubs: Language Therapy* app by questioning the evidence-based design within the app, as well as the validity of parent reviews:

*I am a speech-language pathologist. I was quite interested in this app to use in sessions and for parents to use at home. After looking through it, I wouldn't recommend it and am surprised other therapists do recommend it. First off, it really does not follow developmental speech milestones. It seems random to me and is not consistent with anything I do with children who are diagnosed with delays of expressive language, receptive language, apraxia, autism etc. Furthermore, from most of the reviews I read, it seems most parents are using this for their toddlers to develop language and first words. This app does not follow the typical developmental milestones of speech. It should start with early developing sounds to the early developing consonant-vowel combinations mixed with age appropriate play and functional communication words. I am sure that initially, children will say a few new words or sounds just from the novelty of the app (which occurs in speech therapy as well). However, I would like to hear from these parents after a month or so to see if progress continues or if they see some initial progress, wrote a positive review, then progress plateaus and they just cancel the subscription and forget about it. Because here's the thing, I feel like*

*the majority of what I do with young children who aren't talking, is teaching parents how to play with their children with real toys, teaching how to securely attach (bond) with your child through play (no screens!), and how to elicit language during play. Children already get too much screen time and need to be interacting with and playing with real people and real toys. We need to be following developmental milestones with real play and interactions to build language and attachment together because communication is purely social so it needs to be done socially- not on their own with an app. This app will lead to mimicry but likely not lead to functional communication. This is my professional opinion. It appears other therapists find some merit in it (were they compensated for their reviews?) but I do not see how this could lead to functional communication and do not feel it should be called a speech therapy app.*

Reviewers also complained about the app *Word Vault Essential* and reported incidents of erased data, frequent errors, too many advertisements, and incomplete content information, all of which affected user experiences for both clients and clinicians. Across all articulation apps, reviewers identified four usability issues and recommended the following user control and customization features: (1) enable selection of speech sound targets based on the client's ability level (eg, sounds in isolation, in all word positions, and at the sentence level); (2) allow pause and resume content to meet the clients' own pace; (3) hide certain visual stimuli (eg, junk food, rifles, and mythological characters) from younger children; and (4) integrate the use of games and reward systems to increase client engagement. These issues related to control, error, and customization were present in 21 reviews.

### **Receptive, Expressive, and Social Language Apps**

Receptive, expressive, and social language apps were reported to be used by different age groups of users, including students in kindergarten, elementary, middle, and high school with autism, Asperger, and communication disorders spanning varying domains (eg, articulation, fluency, language, and social communication). For example, 1 SLP reported using the app *ChatterPix Kids* with students who have cochlear implants or hearing aids to encourage oral communication, although this app is not specifically designed for children with hearing impairments. Another SLP wrote a review for *ConversationBuilder* stating the following about the app:

*A wonderful tool to use with my ASD students...what an amazing tool it is for facilitating other speech needs in a more spontaneous and naturalistic way: especially for my students with fluency issues...Also amazing for carryover of articulation and other expressive language needs.*

Reviews of these language apps came from multiple adult stakeholders such as SLPs, educators, and parents, and they commented that apps such as *Language Empires*, *ConversationBuilder*, and *ChatterPix Kids* were easy to use by professional educators and clinicians as well as by caregivers (eg, parents). As versatile as articulation apps, these language apps can be used with clients with mixed language ability levels

via individual or group therapy in schools, clinics, and at home. Specifically, these apps were used to target various language goals (eg, vocabulary development, semantic relationship, sentence production, story retell, conversation expansion, and turn-taking), as well as social pragmatic skills (eg, listening to intonations, inferencing figurative speech, reading body language in social scenarios, and sequencing social stories). Reviewers also shared that apps such as *ChatterPix Kids* are customizable with individualized pictures and voices, allowing endless possibilities for creative play (eg, making a skit with multiple people and making videos to express feelings) in addition to promoting communication via listening and speaking.

Language app reviewers described the following desirable content and features: (1) ability to integrate web-based data collection; (2) ability to record and replay answers for users to identify correct and incorrect responses; (3) ability to allow users to choose the level of difficulty in clinical practice; (4) ability to allow users to import and upload their own photos and videos to differentiate between fiction and nonfiction concepts; (5) ability to allow users to save and email conversations generated through app use to reinforce skill use from home to school; (6) ability to provide more concrete differentiations for answer choices; and (7) ability to use reward systems (eg, trophies) as motivators to attend to and complete tasks. In reviews for the *Social Detective* app, one reviewer commented that the app “follows the concepts in from the book and asks the user to make a smart guess using their social tool boxes about different social behaviors and interactions” suggesting this app has been used in conjunction with a physical companion workbook based on the Social Thinking curriculum to reinforce student learning. However, owing to limited content, 4 reviews consisted of requests for more up-to-date content in the *Social Detective* app’s video modules and specifically highlighted the need to diversify characters with more people of color in video modules to take on various character roles (eg, engaging in expected and unexpected behaviors). In addition

to such features, users also requested automated reading features, despite the fact that many of these apps were designed to be used by children with adult assistance. In a review of the *ConversationBuilder* app, one English-as-a-second-language teacher in the elementary school commented the following:

*One thing that would improve this app is if the language choices were read aloud by the iPad so that non-readers could access the app independent of a peer or adult who can do the reading.*

Another parent also commented that she hopes that her 4-year-old daughter would be able to:

*Touch the screen and hear the sentences. I am fine reading to my daughter but would like her to try reading on her own and getting hints if she needs them.*

In terms of usability issues across 3 language apps (*Between the Lines*, *Level 1 HD*, and *ChatterPix Kids*), user errors were commonly seen with reports of the inability to save, email, and print the data of incidents of accidental removal or deletion of the data by the app. Clinicians suggested the following control and customization features across all the language apps: (1) customize controls to turn on or off background scenes to minimize visually distracting illustrations; (2) adjust sound effects for correct versus incorrect responses; (3) allow adequate response time for users; and (4) remove inappropriate slang and random reinforcers. It is worth mentioning that the adult stakeholder group had mixed reviews for the app *ChatterPix Kids*. Although one reviewer (identity unknown) stated that the app is “a perfect way to let the kids create fun stories in a safe and child friendly environment,” another teacher warned parents that the app is not appropriate for children as user-generated video contents can easily contain profanity. Although not directly impacting usability, these mixed reviews highlighted additional user needs around content moderation and monitoring in these speech-language apps (Table 2).

**Table 2.** Feature requests and recommendation from speech-language app reviews.

Intervention domain	Feature requests and recommendation	Sample quotes from reviewers
Articulation apps (Articulation Station, Lively Letters-Phonics, Speech Blubs: Language Therapy; and Word Vault Essential)	<ul style="list-style-type: none"> <li>• Add letters and a plethora of target words</li> <li>• Offer consistent verbal models and a high-volume repetition</li> <li>• Allow voice recordings for self-monitoring of own production</li> <li>• Able to collect, track, and compare data</li> <li>• Follow developmental milestones and evidence-based practice (eg, multiple linguistic hierarchy levels, and phonological processes)</li> </ul>	<ul style="list-style-type: none"> <li>• Articulation Station: "It's easy to use, has a plethora of target words to choose from, includes multiple linguistic hierarchy levels for students to practice their targeted sound at, and it even has a record and play back button for students to work on self monitoring and correcting."</li> <li>• Lively Letters-Phonics: "I'm a mom of two. One stronger reader and one weaker. They both LOVE this app! With letter sound stories, music, games and an opportunity to practice reading and spelling words...I will NEVER go back to flash cards again!"</li> <li>• Speech Blubs: Language Therapy: "This app does not follow the typical developmental milestones of speech. It should start with early developing sounds to the early developing consonant-vowel combinations mixed with age appropriate play and functional communication words."</li> <li>• Word Vault Essential: "Would have been nice to know the app would erase all my students' data the day I decided not to continue the subscription. Trying to write IEPs and all profiles are gone."</li> </ul>
Receptive, expressive, and social language apps (Language Empires, Conversation Builder, ChatterPix Kids, Social Detective, Between the Lines Level 1 HD)	<ul style="list-style-type: none"> <li>• Integrate web-based data collection</li> <li>• Ability to record and replay client answers</li> <li>• Allow users to import individualized photos and voices</li> <li>• Add reward systems (eg, trophies) as motivators</li> <li>• Improve video and audio quality</li> <li>• Reduce aversive sound effects</li> <li>• Customize controls (eg, enable on or off) based on individual clients' needs</li> </ul>	<ul style="list-style-type: none"> <li>• Language Empires: "I use this app with my high school students. Before my students check their answers I have them explain their reasons for their choices. My students especially enjoy the vocabulary, why, inference and predicting sections. The data collection is perfect for IEP goal updates."</li> <li>• ConversationBuilder: "The different levels are helpful. Some students need the multiple choices of level one. Other students are ready for open-ended conversation turns. It is so interesting to compare the responses of my students with ASD to students who do not have difficulty with conversation."</li> <li>• ChatterPix Kids: "It helps my class because we are doing writing on animals and we are using the app to share...reports on our animals. It is also fun to play with friends on the app. But, one thing I'd change though would be to have more time to say what you want to say."</li> <li>• Social Detective: "The only criticism is that the sound effect for correct responses is aversive to some kids I know. They stopped playing the app because of the sound."</li> <li>• Between the Lines Level 1 HD: "One minor complaint I have is found within game mode. The child has no control over the aiming of the item used to throw and whilst this may remove frustration for some children, it causes great frustration for others. I would recommend a control feature to allow an "on or off" for this area based on the individual needs of the child."</li> </ul>

## Influential Factors for AAC and Speech-Language Apps

User feedback on both AAC and speech-language apps highlighted multiple influential factors shaping the perceptions and attitudes toward the apps. These factors include financial factors (eg, cost and pricing models), sociocultural factors (eg, multilingual capability and inclusive design in-app content), and ethical factors (eg, related to inclusive design). All AAC app users complained about the cost of the apps, except for the AAC app *CoughDrop*. In contrast to other AAC apps, which use a one-time app purchase of several hundred dollars, *CoughDrop* implemented a subscription-based model of US \$6/month, which offered an alternative pricing model for AAC apps. This pricing model may have reduced the initial purchase cost burden for the users. AAC app users commented that, compared with other genres and categories of apps on the Apple App Store, the App Store lacks diversity on multiple devices despite the high cost. Users for some AAC apps (eg, *Speak For Yourself*, *LAMP WFL*, and *Tobii Dynavox Compass Connect*)

have commented that these apps are priced too high given their limited customization or personalization capabilities (eg, *Speak for Yourself*). Other critiques include the argument that some apps demand too much time and storage to install (eg, *Tobii Dynavox Compass Connect*). With the change to a new Apple App Store design, more campaigns for specific apps have been featured, including apps for accessibility and health purposes. These likely made discounts more visible compared with before. For example, 1 user of *LAMP WFL* shared that "Last year iTunes offered this app half off on Autism Awareness Day." App reviews for speech and language apps have relatively fewer complaints related to cost, which is likely owing to the different types of pricing models available. In contrast to AAC apps, which can cost nearly US \$300, the most expensive speech-language app is less than US \$50 for a one-time purchase. In addition, many apps offered free and pro versions. *Speech Blubs: Language Therapy* was the only app that used a US \$9.99/month subscription-based model after a 7-day free trial. However, some users complained that their monthly subscription was charged for the whole year, whereas others



commented that they were unable to afford the price during the COVID-19 pandemic. App users also reported mixed sentiment and contrasting perceptions regarding pricing for different speech-language apps (eg, *Word Vault Essential*, *Lively Letters-Phonics*). User perception of pricing is closely related to the amount and quality of app content, as users of apps such as *Social Detective* and *Articulation Station* both expressed their desire to have more content (eg, sound stimuli and video modules) for better replay ability and repeated use.

In addition to these financial factors, some user comments addressed factors related to cultural–linguistic diversity and ethical design for children. For example, reviewers for *Articulation Station* commented that the apps designed for younger learners should use age-appropriate words and eliminate certain images (eg, rifles and guns) to minimize exposure to violent content. One *LAMP WFL* user commented that “the Spanish vocabulary is a wonderful addition,” whereas another user of *Proloquo2Go* complained that:

*Given the developers are from the Netherlands, I am surprised there is no Dutch language voice - only American, British and Indian English voices are available at present (although I would like to see more children's voices available in all these versions).*

One reviewer for the speech-language app *Social Detective* stated that:

*I work with primarily African-American students, so I find it troubling that the only person of color featured in the initial segment (16 video clips) of the app is an African-American tween male engaged in arguably the most overt “unexpected” behavior of all the children featured in the video clips within that segment. Perhaps I’m being too sensitive, but it strikes me as a subtle perpetuation of racial stereotypes.*

Although such a report was only found in 1 review, it highlights the importance of inclusive design in app content for users from diverse cultural and ethnic backgrounds.

## Discussion

### Principal Findings

This study is one of the first to examine publicly available user reviews of speech-language therapy apps for children with communication disorders in the Apple App Store. Based on the analysis of a total of 418 reviews extracted across 16 apps written between 2009 and 2020, this study explored app content and features, as well as usability challenges related to both AAC apps and speech-language apps. Investigating user reviews regarding speech-language therapy apps informs app designers and developers who are interested in creating mobile apps for children with communication disorders that meet specific user needs and challenges. It also helps connect designers and developers with clinical recommendations based on SLPs’ evaluation of app qualities while working with children with communication disorders from a wide range of age groups and abilities. User reviews differ across the two genres of apps, with AAC apps being reported to have more issues with usability and speech therapy apps having more requests for additional

app features to enhance clinical practice. Analysis of different stakeholder perspectives using AAC app reviews indicated that AAC apps gave users the ability to increase their communicative output. App reviewers praised AAC apps for giving their children a voice and the ability to interact with others, but also expressed that they would like to see improvements in app usability and accessibility. AAC app designers and developers should acknowledge features related to usability (eg, navigation and control) and appeal (eg, layout) and should focus on creating ease of learning, as well as programing and customization with compatibility across multiple hardware devices and systems (eg, mobile to desktop).

Reviews for speech-language apps also pointed to positive app content and features, as well as issues in usability for both children with communication disorders and their stakeholders. Primary complaints for speech-language apps were reported in areas of usability (eg, navigation and control and software and hardware compatibility) and appeal (eg, visual and audio features). Features such as child-friendly content and customization are highly preferred. Reviewers praised speech-language apps that followed evidence-based design practice guidelines and developmental milestones (eg, *Lively Letters-Phonics*), as well as apps that were available as supplementary companions to nondigital therapy materials (eg, *Social Detective*). Speech-language apps have dynamic visual features that make the apps engaging and entertaining for children to participate in speech therapy activities. As a result, these apps offered children pleasant experiences while completing speech activities at home as a carryover practice. In contrast, some apps (eg, *Speech Blubs: Language Therapy* and *Word Vault Essential*) were criticized owing to a lack of evidence-based design considerations in the app content. Therefore, it is highly recommended that speech-language app designers and developers consider collaborating with SLPs to implement developmentally appropriate app design practices [40] that are used during therapy sessions to align app features with evidence-based design.

The findings from this study contribute new insights regarding user experiences with different AAC apps and speech-language apps across multiple stakeholders (eg, parents, special education teachers, and clinicians). App Store reviews from different stakeholders further reinforced findings from prior ethnographic research that children with communication disorders interact with various assistive, educational, and even game apps as “a larger ecology of speech tools, including interactive games and apps” [13]. As many children with communication disorders are unable to communicate their needs directly owing to communication disorders, these reviews offer insight from and highlight the importance of adult stakeholders from the circle of care of children with communication disorders. These stakeholders not only share the use of apps, but also benefit from these apps as they support therapy intervention and home exercises outside the conventional therapy environments. Many recommendations in app reviews were specifically provided by parents and SLPs who thoughtfully explained their children and clients’ individualized needs across a range of communication areas. For parents, speech-language apps offer direct understanding regarding the therapy activities that their children



can participate in to improve in different areas of communication (eg, articulation, language, and social pragmatics). Specific app features, such as data collection and visualization of progress across time frames (eg, day-to-day and month-to-month), provide parents with structured support to reinforce traditional therapy practices. Similarly, clinicians find value in tracking data within and across sessions, especially when working with clients who have different articulation and language goals. For SLPs, digitized speech-language apps also offer a greater portability across different settings compared with traditional paper-based therapy materials. As many apps can help increase engagement with therapy in children with communication disorders, clinicians are motivated to use speech apps as a dynamic way of teaching and targeting various goals. In addition, school-based SLPs have limited time with their clients and, therefore, often group clients with different types of disorders and levels of ability together. Apps that have the ability to collect data from clients (eg, *Language Empires*, *Between the Lines Level 1 HD*, and *Articulation Station*) and send data via emails for parents to view help bridge the home-school disconnect between different members of a child's care circle. For app designers and developers, it is critical to evaluate these multi-stakeholder considerations in the app design and development process to support functional therapy activities across home, educational, and medical settings [41]. These user insights can be beneficial for app designers and developers to develop additional content and features that support clients who receive speech therapy better.

This study also compared multiple influential factors related to both AAC and speech-language apps. It was reported that many individuals who rely on AAC apps to communicate experience financial burdens when purchasing and maintaining the ongoing use of AAC apps, as nearly all AAC apps had user reviews related to the financial factors of app purchase and use. Speech-language therapy apps are typically offered as free or as paid pro versions, with only the *Speech Blubs: Language Therapy* not offering a free version (after a 7-day trial) and operating on a subscription-based pricing model. On the basis of these different pricing models across all apps, app designers and developers may need to attend to other marketing decisions across different revenue models, such as offering one-time purchases (eg, *Proloquo2Go* and *TouchChat HD*), subscription-based models (eg, *CoughDrop* and *Speech Blubs: Language Therapy*), or free versus paid versions. In addition, app reviews also revealed issues with a lack of representation of cultural and linguistic diversity in app content and the need for more consideration of inclusive design, an area that warrants additional research in the mHealth literature in general. Specifically, reviewers indicated that app content did not represent characters or linguistic variations from a variety of cultural and ethnic groups; as a result, individuals with linguistic variations and from minority groups can be marginalized by being unrepresented. It is important to note that only very few prior mHealth literature have considered the impact that cultural background can have on app user experiences. The latest research by Guzman et al [26] attempted to investigate cultural differences by looking for correlations between certain cultural backgrounds and various features of App Store reviews. Researchers have reported that sentiment, content, rating, and

length differ at the country level and that these reviews follow specific cultural patterns. App designers and developers need to be sensitive to variations in cultural and linguistic patterns to design accessible and inclusive AAC and speech-language apps for children with communication disorders.

### Limitations

This study has several limitations that could be addressed in future research. First, although many apps have both iOS and Android versions, we only reviewed iOS apps owing to the high adoption of mobile devices (eg, the iPad) in the field of speech-language pathology. Second, as the goal of the study is to capture user insights from all app reviews over the period of the app's history, the app analysis focused primarily on review content and did not specifically track or categorize app content and features mentioned in the review over different app versions. Third, we did not conduct any analysis with the star rating of each review, which may offer additional quantitative evaluation for app reviews. Fourth, many app reviewer identities remained unknown, as the reviewers did not disclose personal information (eg, whether they are an SLP or a parent) in their review. Therefore, we were unable to infer the backgrounds of all the people who wrote the reviews. Fifth, for speech-language apps, we only reviewed free versions to obtain more reviews; however, given that free versions are limited in the content offering compared with pro versions, this may contribute to the large distribution of reviews that include complaints about financial barriers and lack of comprehensive content. Sixth, this study only included clinician-recommended apps and likely neglected apps that are primarily used by caregivers and parents, who are also important stakeholders in their children's speech and language development. Finally, despite our prior research indicating that clinicians use apps with their clients, clinicians' app use does not necessarily indicate that these apps are empirically supported by research.

### Conclusions

Even with the vast number of iOS mobile apps for children with special needs, few research studies have investigated user insights regarding speech-language therapy apps designed for children with communication disorders. Owing to their communication disorders, the user experiences of children with communication disorders can be difficult to obtain and collect directly; however, analyses of App Store reviews from different stakeholders around the circle of care of children with communication disorders offers valuable information to researchers about specific app features that can support the communication development of children with communication disorders; the analyses also highlights usability issues that can be improved to reduce the frustration of children with communication disorders while using mobile apps. To our knowledge, this is the first study to analyze publicly available App Store reviews from different stakeholders (eg, SLPs, parents, and special educators) to examine pediatric speech-language therapy apps for children with communication disorders. These findings contribute to the understanding of desirable app content and features as well as the usability and accessibility issues with both AAC apps and speech-language apps. App reviews also revealed influential factors that highlight

ongoing financial, sociocultural, and ethical and moral considerations for app design and development for children with communication disorders who need speech therapy. This study took place during the COVID-19 global pandemic, which resulted in lockdowns in many schools and clinics, preventing face-to-face therapy and resulted in more children with communication disorders learning from home with their caregivers. As many providers have transitioned to the use of remote learning and teletherapy, App Store reviews revealed

that many of these speech therapy apps have supported different stakeholders, such as SLPs and parents, during remote learning and teletherapy. Future research should seek to develop in-depth analysis from these App Store reviews and evaluate individual app content and features to generate design insights that can best support communication through different types of service modalities, including teletherapy, in children with communication disorders.

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## Conflicts of Interest

None declared.

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### Multimedia Appendix 1

Interviewees and mobile apps they use.

[[XLSX File \(Microsoft Excel File\), 300 KB - pediatrics\\_v5i1e28661\\_app1.xlsx](#) ]

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### Multimedia Appendix 2

A list of 7 augmentative and alternative communication apps.

[[DOCX File , 501 KB - pediatrics\\_v5i1e28661\\_app2.docx](#) ]

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### Multimedia Appendix 3

A list of 9 speech-language therapy apps.

[[DOCX File , 495 KB - pediatrics\\_v5i1e28661\\_app3.docx](#) ]

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### Multimedia Appendix 4

Codebook for app store review.

[[DOCX File , 22 KB - pediatrics\\_v5i1e28661\\_app4.docx](#) ]

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## Abbreviations

**AAC:** augmentative and alternative communication

**LAMP WFL:** Language Acquisition Motor Planning Words for Life

**SLP:** speech-language pathologist

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Original Paper

# Using Wearable Cameras to Categorize the Type and Context of Screen-Based Behaviors Among Adolescents: Observational Study

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## Abstract

**Background:** Automated wearable cameras present a new opportunity to accurately assess human behavior. However, this technology is seldom used in the study of adolescent's screen exposure, and the field is reliant on poor-quality self-report data.

**Objective:** This study aimed to examine adolescents' screen exposure by categorizing the type and context of behaviors using automated wearable cameras.

**Methods:** Adolescents (mean age 15.4 years, SD 1.6 years; n=10) wore a camera for 3 school evenings and 1 weekend day. The camera captured an image every 10 seconds. Fieldwork was completed between February and March 2020, and data were analyzed in August 2020. Images were date and time stamped, and coded for screen type, content, and context.

**Results:** Data representing 71,396 images were analyzed. Overall, 74.0% (52,842/71,396) of images contained screens and 16.8% (11,976/71,396) of images contained multiple screens. Most screen exposures involved television sets (25,950/71,396, 36.3%), smartphones (20,851/71,396, 29.2%), and laptop computers (15,309/71,396, 21.4%). The context of screen use differed by device type, although most screen exposures occurred at home (62,455/64,856, 96.3%) and with solitary engagement (54,430/64,856, 83.9%). The immediate after-school period saw high laptop computer use (4785/15,950, 30.0%), while smartphone use (2059/5320, 38.7%) peaked during prebedtime hours. Weekend screen exposure was high, with smartphone use (1070/1927, 55.5%) peaking in the early morning period and fluctuating throughout the day.

**Conclusions:** There was evidence for high screen use during the after-school and weekend period, mostly through solitary engagement, and within the home environment. The findings may inform the basis of larger studies aimed at examining screen exposure in free-living conditions.

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**KEYWORDS**

adolescent; screen time; smartphone; television

## Introduction

Electronic screens, such as those of smartphones, tablets, and televisions, are ubiquitous in modern society [1]. Systematic reviews and meta-analyses have shown that higher levels of adolescent screen use are associated with detrimental health outcomes, such as increased adiposity [2,3] and depression [4,5], as well as low academic achievement [6]. Others argue that the health effect of screen use is complex [7], and for well-being, it may be negligible [8] or, in some cases, beneficial [9]. To better understand the impact on adolescent outcomes, it is important to use robust methods of measuring screen use [10]. However, the current evidence is limited by several methodological factors.

First, the vast majority of screen use evidence has relied on self-reported data [11]. There is widespread consensus that such reporting of sedentary behavior lacks measurement precision due to recall difficulties and is prone to numerous biases (eg, social desirability) [12]. In addition, traditional self-reported measures of screen use, such as questionnaires and time use diaries, focus primarily on televisions, computers, and video games, and have largely ignored smartphones and tablets, which make up an increasingly large proportion of adolescent discretionary screen use [13,14]. Furthermore, there have been recent increases in newer digital media use among adolescents, such as social networking and online communication [15], which might be replacing television viewing [16]. Therefore, measurement needs to adapt to the modern reality of screen use and be flexible to allow for the incorporation of new technologies as they emerge [1].

Second, there is the issue of *multiscreening*, the simultaneous use of multiple screens, which may have implications for the measurement of screen use. At present, most questionnaires assess each screen use behavior independently and then sum these individual behaviors to calculate *total* screen time. Therefore, this may preclude accurate estimates of an individual's overall screen exposure if they are using multiple screens concurrently [17]. Given that self-reported and other-reported data indicate that adolescents may be more likely to use multiple screens than any other age group [18,19], it is important to gather information about the patterns of use in this population. This includes examining the task combinations that underpin these patterns, in addition to which media types are typically used for the primary activity or the secondary activity.

Third, most studies have used aggregated *total* screen use measures or have grouped them into broad categories (eg, television and computer). Such methodology fails to investigate the different types of content that may moderate the effects of screen exposure on children's health, social, and developmental outcomes [20]. When these aspects have been measured, the context of these behaviors is often overlooked, specifically, "when," "where," and "with whom" adolescents are using screens. Using aggregates of behavior masks the context specificity of each behavior and thus precludes accurate conclusions about specific behaviors occurring at specific time points and in specific contexts [21]. Such contextual information might be used when designing interventions to inform new

policies specifically designed to influence adolescents' screen use.

Fourth, despite the importance of temporal patterning to better understand the physical activity levels of young people [22], studies that have investigated this aspect of screen use are limited. When temporal patterning is measured, the evidence tends to rely on self-report, such as time use diaries [21,23]. While these allow for the recording of behaviors as well as locations throughout the day [24], the recording of activities relies on the judgement and memory of participants, depending on the time completed. Moreover, time use diaries can also be burdensome for participants, possibly causing involuntary changes in activity behavior throughout the day [23]. It is necessary to identify and corroborate the trends in the temporal, social, and environmental contexts of adolescents' screen-based behaviors using less obtrusive low-burden device-based measures.

Automated wearable cameras present an emerging opportunity to more accurately assess adolescents' exposures to screens, including the social and environmental contexts in which they occur [25]. Such cameras have the advantage of monitoring behaviors through a first-person perspective in free-living conditions [26,27]. Human behavior research has increasingly employed this technology, as the devices become smaller, more affordable, and capable of capturing more data [28-32]. For example, wearable cameras have been used to investigate children's physical activity [33], diet [34], exposure to blue space [35], food and alcohol marketing [36,37], green space, transport, and smoking [38]. Moreover, wearable cameras have been applied to examine adult's sedentary behaviors [32]. However, few studies on adolescent's sedentary behaviors have used this technology, with the field being mainly reliant on poor quality self-reported data.

Smith et al recently demonstrated wearable cameras to be a feasible and acceptable method of measuring evening screen exposure among New Zealand adolescents [39]. This study collected 41,734 images across 39 evenings, showing that almost half of the images contained screens, most commonly those of smartphones, while 5% contained multiple screens. However, data were derived largely from nonschool days, owing to examination during study breaks or holidays, and thus, the findings may not reflect adolescents' typical screen use. For instance, available evidence suggests that adolescents spend over 70% of their after-school time sitting [40], with a large proportion spent using screens [41,42].

To address current gaps in evidence, this study aimed to use automated wearable cameras to examine adolescents' screen exposure during the evenings and weekends of a typical school term. In particular, we aimed to describe (1) the frequency and the types of devices being used; (2) the content being viewed; (3) the social and environmental context in which such behaviors occur; and (4) the temporal patterning of screen-based behaviors. We also aimed to describe differences in screen time between weekdays and weekend days.

## Methods

### Ethics Approval

Ethical approval was obtained from the University of Southern Queensland Human Research Ethics Committee (H19REA248). In line with international guidelines [43], this study adhered to strict procedures for using wearable cameras in human research. Data were collected between February and March 2020 (before any effects of COVID-19 restrictions) and analyzed in August 2020. Written informed parental and adolescent consents were obtained before data collection.

### Sampling and Recruitment

Ten participants (aged 13-17 years) were recruited from a secondary school in Queensland, Australia. All students in grades 8 to 11 (age 13-17 years; N=100) attended a face-to-face information session in which they were invited to take part in a research study. At the end of the session, the principal investigator (GT) answered questions and provided research packs to adolescents interested in participating (n=17). Written parental and adolescent consents were obtained for 10 adolescents (response rate 59%).

### Measures

#### *Sociodemographic Questionnaire*

Before data collection commenced, parents were asked to complete a brief questionnaire concerning demographic characteristics, including the highest education level, household income, and employment status.

#### *Automated Wearable Cameras*

Participants were asked to wear an automated camera (Brinno TLC120) on 4 randomly allocated days (using an online random number generator), including 3 school weekday evenings (all waking hours after returning home from school) and 1 weekend day (all waking hours). The automated camera was programmed to take a picture every 10 seconds. The camera had a weight of 101 g, had a size of 60×60×35 mm, captured a 112° field of view, and did not record audio or video. The battery had a capacity of 6 days when using the 10-second interval. Images

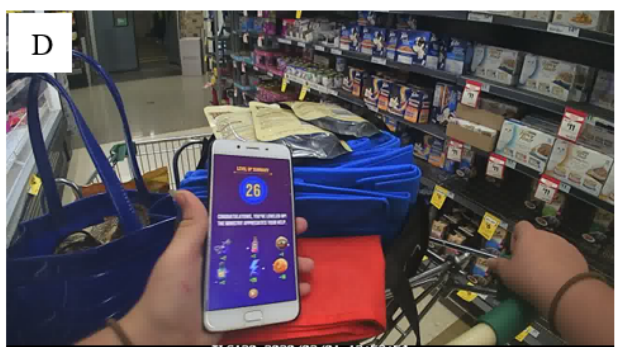
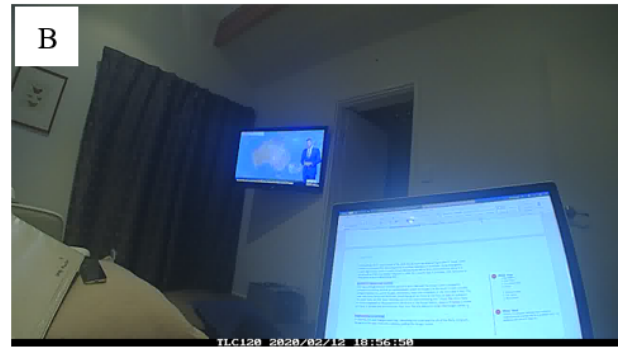
were date- and time-stamped. Participants were instructed to wear the camera on an adjustable chest-mounted harness. An information session, facilitated by the first author, provided instructions on how to turn the camera on/off, how to wear the harness, and how to charge the camera, if necessary. Information sheets were also provided to participants that offered examples of when participants should remove or turn the camera off (eg, going to the bathroom or getting undressed). Lastly, a statement of research was handed to participants to help explain the study to third parties (eg, public, friends, and family), if required.

The camera automatically processed images into time-lapse videos (.avi), which were then manually converted into single images (.jpg) using the open-source software FFmpeg (version 4.3). Participants and parents were offered an opportunity to review and delete images before the first author viewed them. To protect participant privacy, the remaining images were securely stored using a password-protected storage server only accessible to the image coders.

### Image Coding

Examples of images and coding are presented in [Figure 1](#). Image coding was completed between April and July 2020. Images for each participant were manually coded by the first author in a spreadsheet, based on a pre-established codebook for wearable camera research on children's screen use. The coding protocol was structured into different annotation groups ([Multimedia Appendix 1](#)). For each annotation group, the coder identified all the images and categorized only the screen components specific to that group. Images with multiple screens were coded for multiscreening, detailing the primary, secondary, or background activity. Images with inactive or absent screens were also coded, in addition to blurry or blocked images because of the position of the camera. Obscured images (such as those where the camera was facing the ceiling) in the middle of image sequences containing screens were coded based on the nonobscured preceding and subsequent images. A subset of images (10%) was repeat coded by a second researcher, and interrater reliability was tested using the Krippendorff ( $\alpha$ ) statistic to determine consistency between coders for all coding categories. Interrater reliability was interpreted using the guidelines of Krippendorff [44].

**Figure 1.** Sample of images and coding of screen-based behaviors. (A) Primary screen: television; content: game > action; content classification: recreational; secondary screen: smartphone; content: TV programs > action animation; content classification: recreational; location: home > living room. (B) Primary screen: laptop computer; content: creative > productivity software; content classification: educational; background screen: television; content: TV programs > action; content classification: recreational; location: home > bedroom. (C) Primary screen: smartphone; content: social media > Instagram; content classification: social; location: transport > public transport; other behavior: food > beverage. (D) Primary screen: smartphone; content: game > simulation; content classification: recreational; location: public > food retail.



## Data Analyses

IBM SPSS Statistics version 21.0 was used for descriptive analyses. Daily camera wear time was calculated as the total number of minutes the camera was turned on. Captured time (minutes) was the number of images divided by 6 (assuming each image represented 10 seconds). The frequency and percentage of images were calculated for each screen-based device for each annotation group (eg, location and social interaction). Descriptive data are provided to describe the frequency and types of devices being used, the content being viewed, and the social and environmental context in which such behaviors occur. To analyze the temporal patterning and to compare screen-based behaviors between the different evening segments, equal time segments of 3 hours were utilized. For each time period, the frequency of each screen-based behavior was computed, and the percentage of behaviors occurring at that time period has been reported. Temporal data were analyzed and reported separately for weekdays and weekend days because they have different structures and are likely to lead to different behavioral choices. Differences between weekday and weekend screen use were analyzed using the chi-squared test, and expressed as a percentage of images (standardized by weekday and weekend wear times). Based on previously established definitions [45], weekday after-school time segments were

defined as follows: “after school to 18:00,” “18:00 to 21:00,” and “21:00 to sleep” (eg, when the camera was removed prior to bedtime).

## Results

### Interrater Reliability

The average reliability between the 2 coders across all categories was acceptable ( $\alpha=.81$ ) [44]. With regard to agreement, the  $\alpha$  values were .89 for device attention, .86 for device type, .77 for content type, .88 for content classification, .60 for physical setting, .85 for social setting, .84 for social interaction, .72 for co-existing behaviors, and .88 for the uncodable category.

### Sample Characteristics

The characteristics of the participants are presented in Table 1. Five girls and five boys participated, with an average age of 15.4 years (SD 1.6 years). The main language spoken at home was English (9/10, 90%), with an average of 4 persons living in the household. Participants' parents who responded were mainly mothers (8/10, 80%), married (9/10, 90%), and earning a total annual household income >AUD 78,000 (9/10, 90%; 1 AUD = 0.73 USD), and had completed a university or tertiary qualification (8/10, 80%).



**Table 1.** Characteristics of the sample.

Variable	Value (N=10)
Gender (% female)	50
Parent gender (% female)	80
Age (years), mean (SD)	15.4 (1.6)
Number of people in the household, mean (SD)	4.0 (1.1)
<b>Main language, n (%)</b>	
English	9 (90)
Other	1 (10)
<b>Total annual household income (AUD<sup>a</sup>), n (%)</b>	
>78,000	9 (90)
31,200-41,599	1 (10)
<b>Parents' highest level of education, n (%)</b>	
University or tertiary qualification	8 (80)
High school	1 (10)
Year 12 or equivalent	1 (10)
<b>Parental marital status, n (%)</b>	
Married	9 (90)
Separated/divorced	1 (10)

<sup>a</sup>1 AUD = 0.73 USD.

## Overview of Images

A total of 71,396 images, derived from 30 school weekday evenings and 10 weekend days, were coded and included in the analysis. This represented just under 200 hours of total camera wear time. [Multimedia Appendix 2](#) shows the mean and median (IQR) numbers of images collected, camera wear time, captured time, and screen time per day for weekdays and weekend days. The camera wear time averaged 230.5 minutes on a weekday evening and 508.1 minutes on a weekend day. The camera captured, on average, 1365 images per weekday evening and 3045 images per weekend day, equating to 227.5 minutes and 504.2 minutes of captured time, respectively. Of this, 167.7 minutes were spent, on average, using screens on a weekday evening, and 371.3 minutes were spent on a weekend day. The results showed that there was no significant difference between weekday and weekend screen use (72.7% vs 73.1%,  $P=.23$ ).

## Device and Content Type

[Table 2](#) shows the frequency and percentage of different screens and activities in the entire image set (N=71,396). In total, 52,842 (74.0%) images contained screens. The most common screens were televisions (25,950/71,396, 36.3%), smartphones (20,851/71,396, 29.2%), and laptop computers (15,309/71,396, 21.4%), while fewer images contained tablets (2720/71,396, 3.8%), desktop computers (20/71,396, <1%), and wearable smartwatches (1/71,396, <1%).

The most common activities, as determined by the proportion of images recorded by the wearable camera, differed according to the screen domain. For instance, our data showed that conventional television sets were popular among adolescents, although this comprised mostly playing *action* games (ie, including fighting, shooter, or platform games) via gaming consoles (14,032/25,950, 54.1%), rather than watching traditional *action* television programs (ie, programs with real people or animals), which accounted for less than half of all television occurrences (11,803/25,950, 45.5%). Given this information, the results for “television set” occurrences were described by (1) television set: *television viewing* and (2) television set: *action gaming*. For smartphones, watching television programs through online streaming sites, such as Netflix and YouTube (10,432/20,851, 50.0%), social networking (5642/20,851, 27.1%), and communicating (1618/20,851, 7.8%) constituted the main content types, compared to creative content, such as *productivity software* (eg, Word, Excel, and PowerPoint), which made up 39.5% (6051/15,309) of all laptop computer occurrences. Watching television programs (4763/15,309, 31.1%) and internet use (3409/15,309, 22.3%) also made up a large proportion of content engaged on the laptop computer, while the same content accounted for 51.0% (1387/2720) and 30.3% (825/2720) across all tablet occurrences, respectively. A wearable smartwatch was captured in 1 image, showing the home screen interface. For all desktop computer images (n=20), specific content could not be determined owing to inadequate resolution.



**Table 2.** Description of devices and types of content.

Device <sup>a</sup> , broad content <sup>b</sup> , and specific content <sup>b</sup>	Value, n (%)
Any screen	52,842 (74.0)
No screen	18,554 (26.0)
Multiple screens	11,976 (16.8)
<b>Television</b>	25,950 (36.3)
<b>Television set: gaming (via console)</b>	14,032 (54.1)
Action	14,032 (54.1)
<b>Television set: television viewing</b>	11,803 (45.5)
Action	11,250 (43.4)
Action animation	464 (1.8)
Animation cartoon	89 (0.3)
Unclassifiable	115 (0.4)
<b>Smartphone</b>	20,851 (29.2)
<b>Television programs</b>	10,432 (50.0)
Action	6658 (31.9)
Animation cartoon	2794 (13.4)
Action animation	980 (9.4)
<b>Social media</b>	5642 (27.0)
Instagram	3153 (15.1)
TikTok	2046 (9.8)
Snapchat	286 (1.4)
Facebook	157 (0.8)
<b>Communication</b>	1618 (7.8)
Instant/text messaging	1182 (5.7)
Video chatting	230 (1.1)
Calling	206 (1.0)
<b>Creative</b>	675 (3.2)
Camera apps	475 (2.3)
Art apps	119 (0.6)
Productivity software	81 (0.3)
<b>General</b>	618 (3.0)
Home page, lock screen notifications	618 (3.0)
<b>Internet</b>	585 (2.8)
Browsing	320 (1.5)
Article/book/blog	265 (1.3)
<b>Gaming</b>	555 (2.7)
Simulation	405 (1.9)
Action	150 (0.7)
<b>Interactive screen media</b>	436 (2.1)
Other	411 (2.0)
Unclassifiable	25 (0.1)
Unclassifiable	290 (1.4)
<b>Laptop computer</b>	15,309 (21.4)

Device <sup>a</sup> , broad content <sup>b</sup> , and specific content <sup>b</sup>	Value, n (%)
<b>Creative</b>	6579 (43.0)
Information processing apps	6051 (39.5)
Art apps	528 (3.4)
<b>Television programs</b>	4763 (31.1)
Action	4119 (26.9)
Animation cartoon	644 (4.2)
<b>Internet</b>	3409 (22.3)
Article/book/blog	3070 (20.1)
Browsing	339 (2.2)
<b>General</b>	409 (2.7)
Home page, lock screen notifications	409 (2.7)
<b>Social media</b>	72 (0.4)
TikTok	72 (0.4)
<b>Interactive screen media</b>	44 (0.3)
Other	44 (0.3)
Unclassifiable	33 (0.2)
<b>Tablet</b>	2720 (3.8)
<b>Television programs</b>	1387 (51.0)
Action	1387 (51.0)
<b>Internet</b>	825 (30.3)
Article/book/blog	728 (26.8)
Browsing	97 (3.6)
<b>Creative</b>	420 (15.4)
Productivity software	252 (9.3)
Art apps	168 (6.2)
<b>Communication</b>	66 (2.5)
Instant/text message	66 (2.5)
<b>General</b>	13 (0.5)
Home page, lock screen notifications	13 (0.5)
<b>Interactive screen media</b>	9 (0.3)
Other	9 (0.3)
<b>Desktop computer</b>	20 (0.0)
<b>Unclassifiable</b>	20 (100.0)
Unclassifiable	20 (100.0)
<b>Wearable smartwatch</b>	1 (0.0)
<b>General</b>	1 (100.0)
Home page, lock screen notifications	1 (100.0)
<b>Unclassifiable</b>	5 (0.0)
Unclassifiable	5 (100.0)

<sup>a</sup>For the device variables, the number and percentage of images are based on the total image set (71,936 images).

<sup>b</sup>For the broad and specific content variables, the number and percentage of images are based on the respective device image set (eg, television and smartphone).

### Content Classification

As shown in [Table 3](#), *recreational* activities made up the majority (45,218/64,856, 69.7%) of all screen occurrences, compared with other content classifications, such as *educational* (10,603/64,856, 16.3%) and *social* (7450/64,856, 11.5%) activities. Concerning individual device types, all traditional

television viewing was classified as *recreational*, over half of laptop computer activities were *educational* (9361/15,309, 61.1%), and more than a third of smartphone exposure was deemed *social* (7265/20,851, 34.9%). Tablets were commonly used for *recreational* (1627/2720, 59.8%) and *educational* (1014/2720, 37.3%) purposes, although tablets comprised only 3.8% (2720/71,936) of total screen exposure.

**Table 3.** Content classification of adolescents' screen-based activities.

Device and nature of content	Value, n (%)
<b>All screens<sup>a</sup> (n=64,856)</b>	
Recreational	45,218 (69.7)
Educational	10,603 (16.3)
Social	7450 (11.5)
Other	1022 (1.6)
Unclassifiable	563 (0.9)
<b>Television set (n=25,950)</b>	
Recreational	25,788 (99.4)
Unclassifiable	115 (0.4)
Social	47 (0.2)
<b>Television set: action gaming (n=14,032)</b>	
Recreational	13,985 (99.7)
Social	47 (0.3)
<b>Television set: television viewing<sup>b</sup> (n=11,803)</b>	
Recreational	11,803 (100.0)
<b>Television set: unclassifiable (n=115)</b>	
Unclassifiable	115 (100.0)
<b>Smartphone (n=20,851)</b>	
Recreational	12,369 (59.3)
Social	7265 (34.9)
Other	615 (2.9)
Unclassifiable	374 (1.8)
Educational	228 (1.1)
<b>Laptop computer (n=15,309)</b>	
Educational	9361 (61.1)
Recreational	5434 (35.5)
Other	393 (2.6)
Social	66 (0.4)
Unclassifiable	49 (0.4)
<b>Tablet (n=2720)</b>	
Recreational	1627 (59.8)
Educational	1014 (37.3)
Social	66 (2.4)
Other	13 (0.5)
<b>Desktop computer (n=20)</b>	
Unclassifiable	20 (100.0)
<b>Wearable smartwatch (n=1)</b>	
Other	1 (100.0)
<b>Unclassifiable (n=5)</b>	
Unclassifiable	5 (100.0)

<sup>a</sup>Based on all screen-based coding interactions (including images with multiple screens).

<sup>b</sup>Comprises action, action animation, and animation cartoon programs.

### Multiscreening

As shown in [Multimedia Appendix 3](#), more than 16% (11,976/71,936, 16.7%) of images contained multiple screens, with the most prevalent combinations of screens being (1) television-smartphone (7324/11,976, 61.2%), (2) smartphone-laptop (2558/11,976, 21.4%), and laptop-television (985/11,976, 8.2%). The majority of multiscreening involved (1) televisions as the primary screen and smartphones as the background screen (5029/11,976, 42.0%) used for *gaming* and watching *television programs*, respectively; (2) smartphones as the primary screen and televisions as the background screen (2285/11,976, 19.1%) used for watching *television programs* and *gaming*, respectively; and (3) smartphones as the primary screen and laptops as the background screen (1465/11,976, 12.2%) used for *social networking* and *internet use*, respectively.

### Physical Setting

As shown in [Multimedia Appendix 4](#), nearly all screen exposures occurred in the home setting (62,455/64,856, 96.3%), such as the *living room* (37,364/64,856, 57.6%) and *bedroom* (19,473/64,856, 30.0%). Concerning individual screen domains, all action gaming (via television set) and the majority of traditional television viewing (10,793/11,803, 91.4%) occurred in the *living room*, whereas laptop computers were commonly used in the *bedroom* (8974/15,309, 58.6%). Smartphones were used in several areas, including the *living room* (8719/20,851, 41.8%) and *bedroom* (7932/20,851, 38.0%), and when in *private transport* (1564/20,851, 7.5%), while the *bedroom* (1709/2720, 62.8%) and *kitchen/dining room* (848/2720, 31.2%) served as popular locations for tablet use.

### Social Setting and Interaction

The social contexts surrounding adolescents' screen exposure are presented in [Multimedia Appendix 5](#). Most involved no in-person social interaction (54,430/64,856, 83.9%), although this differed by screen domain. In-person social interaction was greater when watching television programs, including *co-viewing* with an adult (1719/11,803, 14.6%) or child (1368/11,803, 11.6%), whereas nearly all action games were played alone (12,915/14,032, 92.0%). For smartphones, 12.8% (2668/20,851) of images involved an adult in the *background*, while fewer in-person social interactions were experienced with laptop computers, tablets, and desktop computers (with 92%-100% of all occurrences engaged in alone).

### Co-existing Behaviors

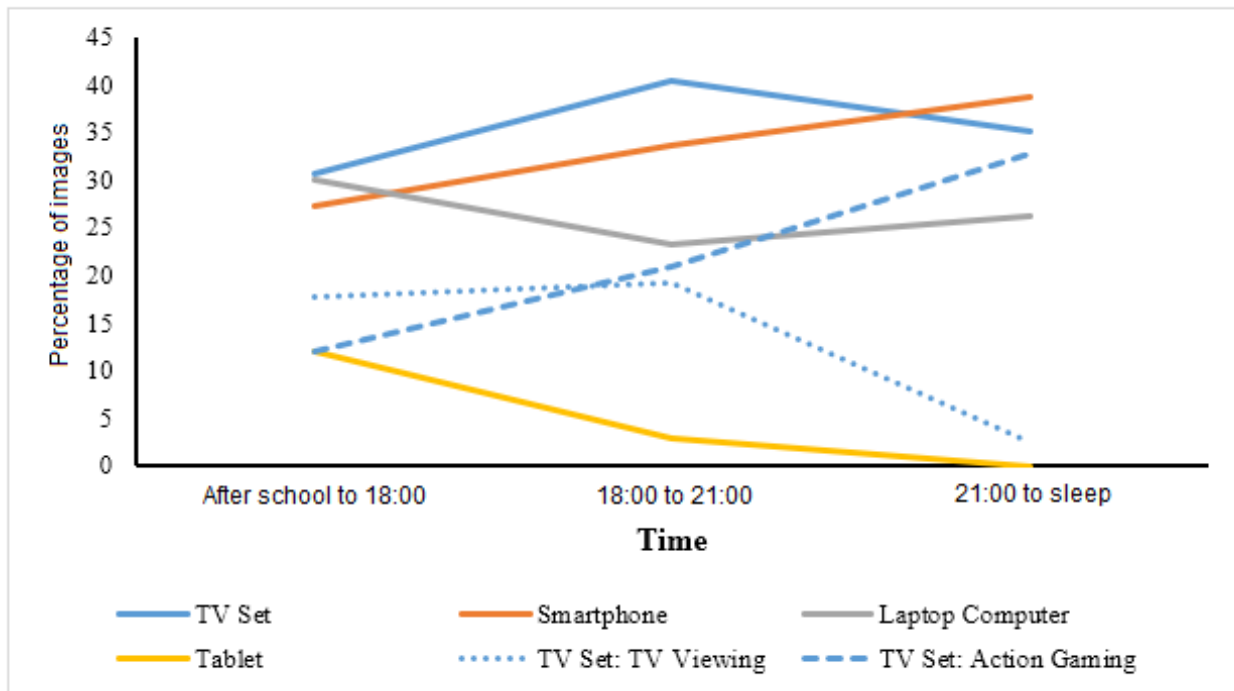
As shown in [Multimedia Appendix 6](#), the majority of screen use was in isolation (56,656/64,856, 87.4%). Some co-existing behaviors that occurred alongside screen-based behaviors included writing using a *pen and paper* (3873/64,856, 6.0%), eating a *snack* (1755/64,856, 2.7%), or eating a *meal* (1454/64,856, 2.2%), but this varied according to screen domain. Laptop (2430/15,309, 15.9%) and tablet (800/2720, 29.4%) computers were commonly used when writing with a *pen and paper*, while over 10% (1288/11803, 10.9%) of television viewing occurrences involved consuming food (eg, *snack* or *meal*).

### Temporal Patterns

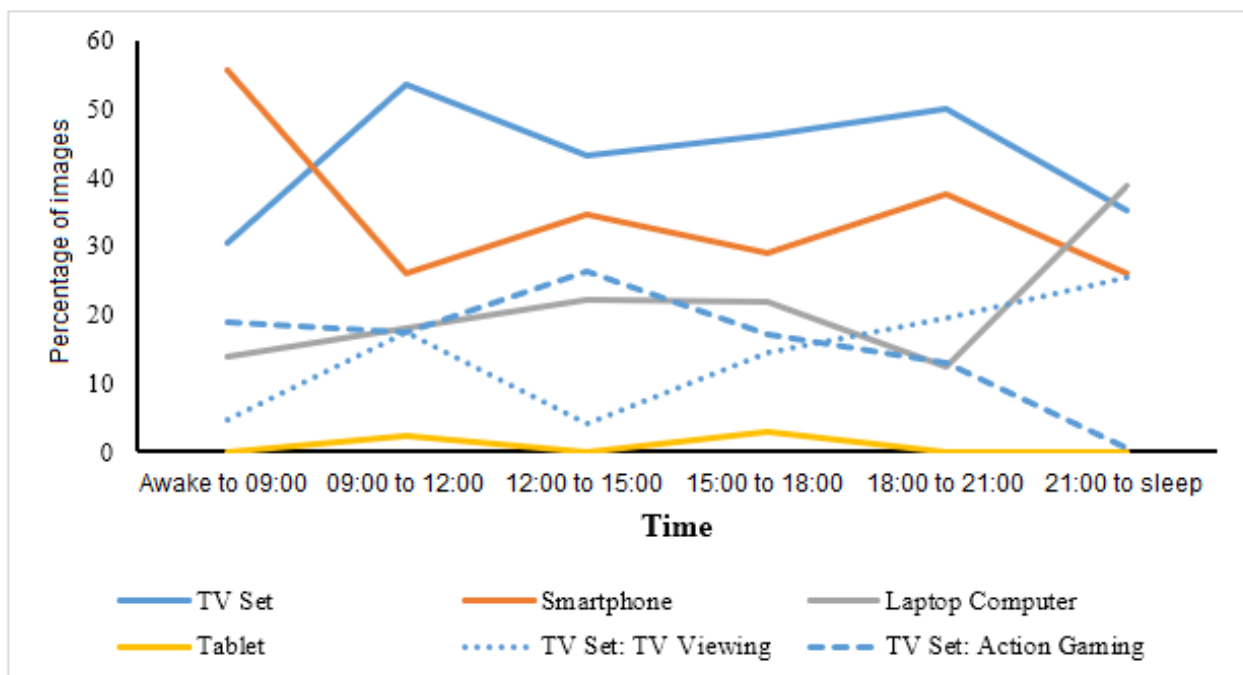
For each time period, the frequency of each screen-based behavior was computed. These data represent the percentage of behaviors occurring at that time period; thus, the results reported are necessarily descriptive. [Figures 2](#) (weekdays) and [3](#) (weekends) compare the temporal patterns of screen-based behaviors.



**Figure 2.** Occurrences of screen-based behaviors during school weekday evenings. TV: television.



**Figure 3.** Occurrences of screen-based behaviors during weekends. TV: television.



**Weekday**

Television occurrences were most common in the middle evening segment (18:00-21:00; 6593/16,359, 40.3%). This comprised mostly of playing action games (3440/16,359, 21.0%), which continued to increase into the prebedtime period ( $\geq 21:00$ ; 1738/5314, 32.7%), compared to television viewing, which was highest during the middle evening (2875/14,896, 19.3%). During the immediate after-school period ( $\leq 18:00$ ), occurrences of laptop computers (4785/15,950, 30.0%) peaked

and then consistently decreased throughout the evening. The use of smartphones increased from the early evening period (4337/15,944, 27.2%) through to the prebedtime period (2059/5320, 38.7%). Tablet computers were most common after school (1918/15,950, 12.0%), while no occurrences were captured after 21:00.

**Weekend**

Temporal patterns on the weekend were more varied than during the school weekday evening. Smartphone use peaked

(1070/1927, 55.5%) during the time period from waking to 09:00, followed by fluctuating occurrences throughout the day. Television occurrences were fairly consistent across the day, but differed by content domain, with larger occurrences of watching action programs from 18:00 (1671/8569, 19.5%) through to sleep (612/2409, 25.4%). In contrast, playing action games was common during the afternoon hours, peaking between 12:00 and 15:00 (2016/7694, 26.2%), before declining throughout the evening. Concerning laptop computer use, 38.7% (691/1785) of occurrences were captured during the prebedtime period, doubling that during the previous time period between 18:00 and 21:00 hours. Tablet computers were uncommon during the day, comprising only 2.4% (158/6583) of occurrences in the morning and 2.9% (163/5620) between 15:00 and 18:00.

## Discussion

### Summary and Interpretation of Results

This study aimed to use automated wearable cameras to describe adolescents' screen exposure. Consistent with a recent systematic scoping review [46], our data indicated that adolescents are exposed to high amounts of screen use. In particular, our data showed a greater percentage of time on smartphones, with engagement in various activities, such as watching programs, social networking, and communicating online, compared to time using television sets and engaging in conventional television viewing. This finding supports the perception that use of newer digital media is increasing, with some displacement of traditional forms of media for adolescents [16]. Indeed, reports show a decline in watching programs on conventional television sets, despite an increase in consuming television content on the internet [47]. This is likely caused by the multiple functions that smartphones offer, including the social and recreational tasks performed online [48]. Moreover, the portability of smartphones allows adolescents to use these devices ubiquitously [49]; almost anywhere in free-living conditions as reported here. Future studies need to determine effective strategies for the responsible use of contemporary screen engagement, paying attention to the use of smartphones [13]. Moreover, these findings have implications for the assessment of television viewing, a common category for screen time measurement. If television programs are watched on television sets, as well as other devices, we may be estimating behaviors incorrectly, depending on the nature of the question asked. Hence, it is possible that there may be conflating of the assessment of behaviors and devices. Better measurement that captures the types of devices used for watching television programs, in addition to the social environmental contexts of such viewing, is warranted.

This study also showed that multiscreening is evident in screen use among adolescents, supporting conclusions from a previous study [50]. Here, we revealed that multiple screens were identified in approximately 17% of images across the entire image set. This rate was more than 3 times the rate reported by Smith et al among adolescents in New Zealand [39]. An important part of understanding multiscreening is examining the combinations of tasks undertaken. Contrary to previous findings based on self-report data [19,51], our data showed that

gaming via television together with watching programs on a smartphone was the most common combination of screen exposure. Previously, it has been argued that gaming is harder to combine with another screen because it demands many cognitive capacities and behavioral responses [52]. One explanation for our findings is that although gaming was used concurrently with smartphones, the latter was predominantly used in the background and therefore was less likely to interfere with adolescents' cognitive demands of gaming. Other possible explanations are that smartphones were used to temper impatience or boredom whilst waiting for a game to load [17,48], or offered an opportunity to socialize with friends whilst watching television shows [48]. Further investigations on why adolescents engage in certain multiscreening behaviors (eg, social functions) are needed to help researchers deliver effective interventions to change screen-based behaviors, if deemed necessary. Models and theories, specific to multiscreening behaviors among adolescents, might also warrant further enquiry.

The home environment may serve as an important setting for interventions that aim to influence adolescents' screen exposure. Participants in this study spent the majority of their time at home and, as such, engaged in most of their screen time at home. Consistent with previous findings [21], the living room was strongly linked to television viewing. While expected, this finding suggests that if reductions in television viewing are sought, this location may be a target for interventions, such as through environmental restructuring involving reconfiguring seating arrangements or family rules for behaviors while in the room. In addition to the living room, the bedroom may also be an important context for screen use, particularly involving smartphones, tablets, and laptop computers, as shown in the current study. It is possible that adolescents feel they have greater privacy and have fewer interruptions from family members in this setting. This might encourage prolonged recreational use of screens in this location, often whilst sitting or lying down [48]. Indeed, reducing access to screen-based devices in the bedroom has been identified as a facilitator to reduce screen use [53], although this will not guarantee a reduction in sedentary behavior as other sedentary pursuits may be adopted as a substitute.

Corroborating recent qualitative data [41], the present study found that adolescents had very little *in-person* social interactions with others whilst using screens. Such findings support the hypothesis of time displacement for social interaction, that is, more adolescents spending time on digital media and less time on face-to-face social interaction [54]. This has led to concern over the detrimental impacts of screen use on adolescents' psychological well-being, with some finding links to depression, loneliness, and lower social connectedness [55-57], although the associations might be small and complex [8,56,58]. Others argue that digital media may instead compliment *in-person* social interaction, particularly media involving opportunities to interact online [59]. For instance, despite a lack of *in-person* social interactions observed in this study, it is highly likely that adolescents engaged in numerous online interactions whilst using screens, for example, through online communication or playing interactive video games. The

mechanisms of the putative effects of screen use on psychological well-being should be explored further to better understand the impact of lower *in-person* social interactions that might be characteristic of traditional solitary screen use, in addition to higher digital social interactions that might be typical of newer digital media. Such research may need to account for the types of devices as well as physical and social settings.

By investigating the temporal patterns of screen use, we were able to understand the typical schedule of adolescents and identify timeframes when specific screen-based behaviors compete against each other. Similar to previous self-report data [21,23], screen-based behaviors were shown to be prominent throughout the evening, starting immediately after school until the end of the day. As shown in a systematic review [42], the after-school period is linked to high screen use in adolescents. This was particularly apparent for laptop computers, which were likely used to complete educational tasks, such as homework. Despite the sedentary nature of this behavior, such tasks are generally considered to be important and valuable; thus, whether it should be reduced or replaced with other behaviors, such as physical activity, is debatable [23]. This supports the argument that sedentary behaviors should not be viewed in isolation [21].

As for television viewing, this behavior most likely occurred in the middle evening segment, corroborating previous findings using self-report [21]. However, the same behavior reduced rapidly in the prebedtime hours, comprising just 2.4% of all screen occurrences. This may be due to the changes in patterns of media consumption among young people. Here, we found that smartphones peaked in the hours before bedtime, supporting evidence that portable devices are increasingly part of the adolescent sleeping environment [60]. For instance, using data from a large population-based survey of adolescents in Norway (n=9846), Hysing et al showed that approximately 80% of boys and 90% of girls used a cell phone in the hour before going to sleep [61]. Together, these findings may cause a rise in public health concern, especially given the evidence for associations between prebedtime screen use and a number of poor sleep markers (eg, inadequate sleep quantity, poor sleep quality, and excessive daytime sleepiness) [62]. As such, smartphones may be an important target for interventions that aim to mitigate the risks associated with prebedtime screen use [63] and sleep interventions in general.

### Strengths, Limitations, and Future Research

A strength of this study was the measurement of adolescents' screen exposure, which was significantly enhanced through the use of wearable cameras. Such devices offer an improvement over existing self-report measures of lifestyle behaviors and the contexts in which they occur. A high agreement between coders was reported, similar to a previous study using wearable cameras [39]. However, these devices also have limitations. First, the 10-second epoch between image capture may have missed possible screen exposure, particularly quick and sporadic smartphone checking [49]. Future studies that compare a continuous video or 1-second epoch with longer intervals between image capture are warranted. Second, if we wish to

ascertain the function (eg, relaxation and entertainment) that different screens serve for adolescents, we are unlikely to do this through camera images. While we were able to infer the content being viewed, further qualitative work will enable a more in-depth understanding of what functions are being served by engaging in different devices and platforms. Third, there is the possibility of the Hawthorne effect, whereby participants modified their behavior in response to wearing an automated wearable camera. This may have implications for the validity of this study. Fourth, the annotation of wearable camera images was based on decisions made by the coders. This limitation may have been offset by conducting interrater reliability tests, showing an almost perfect agreement between coders [44]. The recent development of an annotation protocol for sedentary behavior in children using wearable cameras [64] shows promise, and once applied to larger samples of children, this protocol can help better understand adolescents' contemporary screen engagement. In addition to coding issues, the data processing and coding times are limiting factors and may be unsuitable for use in large-scale studies, unless an automatic recognition algorithm is developed to classify different aspects of human behavior [26].

Other limitations include a small sample size and the relatively homogenous demographic characteristics of the sample. Therefore, the results are unlikely to be generalizable to the wider adolescent population. Future research needs to consider other sociodemographic groups to confirm the key findings observed in this study. A further limitation was that due to ethical concerns raised by school principals regarding camera wearing on school grounds, we only examined screen use during the after-school period and weekends. Since screen use before and during school may yield different results and patterns, future studies are needed to examine the exposure to screen use across the day. Finally, as with other wearable camera studies, the sample size was small, and thus, the study was insufficiently powered to use temporal patterns as a means for testing differences. This should be considered in future studies with larger sample sizes.

### Conclusion

Among a small sample of adolescents, we showed high amounts of screen use, most of which occurred in the home, with little social interaction. This information might be used when designing interventions to inform new policy to influence adolescents' screen use. For example, Australian guidelines for physical activity and sedentary behavior recommend no more than two hours of recreational screen use daily for this age group [63]. Moreover, we showed that wearable cameras may provide a new approach to collect more accurate data on screen-based behaviors in free-living conditions, and with some volume. As such, we were able to both enhance traditional self-report and provide context and temporal specificity surrounding screen-based behaviors in free-living settings. Our findings may be used to inform guidelines and protocols for visual research on screen-based behaviors, and form a basis for larger-scale studies for comparisons.

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## Conflicts of Interest

None declared.

### Multimedia Appendix 1

Summary of the coding framework.

[[DOCX File , 20 KB - pediatrics\\_v5i1e28208\\_app1.docx](#) ]

### Multimedia Appendix 2

Frequency of images and camera wear time per day.

[[DOCX File , 17 KB - pediatrics\\_v5i1e28208\\_app2.docx](#) ]

### Multimedia Appendix 3

Description of multiscreening among adolescents.

[[DOCX File , 18 KB - pediatrics\\_v5i1e28208\\_app3.docx](#) ]

### Multimedia Appendix 4

Physical setting of adolescents' screen-based activities.

[[DOCX File , 18 KB - pediatrics\\_v5i1e28208\\_app4.docx](#) ]

### Multimedia Appendix 5

Social setting and interaction of adolescents' screen-based activities.

[[DOCX File , 17 KB - pediatrics\\_v5i1e28208\\_app5.docx](#) ]

### Multimedia Appendix 6

Co-existing behaviors of adolescents' screen-based activities.

[[DOCX File , 23 KB - pediatrics\\_v5i1e28208\\_app6.docx](#) ]

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Original Paper

# An Objective System for Quantitative Assessment of Television Viewing Among Children (Family Level Assessment of Screen Use in the Home-Television): System Development Study

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## Abstract

**Background:** Television viewing among children is associated with developmental and health outcomes, yet measurement techniques for television viewing are prone to errors, biases, or both.

**Objective:** This study aims to develop a system to objectively and passively measure children's television viewing time.

**Methods:** The Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) system includes three sequential algorithms applied to video data collected in front of a television screen: face detection, face verification, and gaze estimation. A total of 21 families of diverse race and ethnicity were enrolled in 1 of 4 design studies to train the algorithms and provide proof of concept testing for the integrated FLASH-TV system. Video data were collected from each family in a laboratory mimicking a living room or in the child's home. Staff coded the video data for the target child as the gold standard. The accuracy, sensitivity, specificity, positive predictive value, and negative predictive value were calculated for each algorithm, as compared with the gold standard. Prevalence and biased adjusted  $\kappa$  scores and an intraclass correlation using a generalized linear mixed model compared FLASH-TV's estimation of television viewing duration to the gold standard.

**Results:** FLASH-TV demonstrated high sensitivity for detecting faces (95.5%-97.9%) and performed well on face verification when the child's gaze was on the television. Each of the metrics for estimating the child's gaze on the screen was moderate to good (range: 55.1% negative predictive value to 91.2% specificity). When combining the 3 sequential steps, FLASH-TV estimation of the child's screen viewing was overall good, with an intraclass correlation for an overall time watching television of 0.725 across conditions.

**Conclusions:** FLASH-TV offers a critical step forward in improving the assessment of children's television viewing.

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**KEYWORDS**

television; screen media; digital media; measurement; child; gaze; machine learning; mobile phone

## Introduction

### Television Viewing and Other Screen Use Among Youth

The American Academy of Pediatrics Council on Communications and Media has reported that children spend more time using screen media (television, movies, smartphones, tablets, computers, etc) than time in school [1]. Data from the Kaiser Family Foundation for the United States found children aged 8-18 years spend about 7.5 hours using screen media on a typical day, with some of the screen exposure involving multitasking several screens [2]. Nationally representative data of US children in 2020 found that children aged 5 to 8 years use an average of 3 hours and 5 minutes of screen media daily [3]. The types of screens children use have changed over the last decade [3,4]. Web-based videos, subscription streaming services, and television account for 73% of screen media use by children aged <8 years [3]. Similarly, in 2015, 62% of youths aged 9-12 years reported they watched television every day and television viewing remained one of the media activities enjoyed the most by tweens [5]. Television viewing therefore remains an important component of children's overall screen use, which has been linked to detrimental cognitive development [6], worse child psychosocial outcomes [7], lower school achievement [7], child obesity [7,8], cardiometabolic risk [7], and decreased fitness [8]. Thus, higher levels of screen media use is a public health concern [9].

### Measuring Television Viewing Among Youth

Unfortunately, current methods to assess children's television viewing and other screen media use remain inadequate, making it unclear how accurate television and screen media exposure estimates are. Tools are needed to objectively measure children's use of screens across screen media platforms to ultimately inform a composite measure of *screen use*. New tools to track people's screen use on mobile devices rely on background apps that record smartphone use [10,11] or obtain intermittent automatic screenshots of the mobile device to record how it is being used over a specific period [12]. Although both are important contributions to improve the assessment of children's screen media use, they do not account for exposure to larger screens, such as televisions, computers, and stationary video game consoles. The risk of obesity differs based on the type of screen media used by a child [13,14], highlighting the importance of measuring all forms of screen media exposure. Although children's screen media use is rapidly evolving with the use of many different devices and multiple web-based platforms for viewing content [15], television viewing is still a prominent behavior among youth [1,3,5,16].

The current gold standard to measure children's screen use is direct or video-recorded observations that allow coding of the time a child spends watching a television screen [17-19]. Although accurate, this is too expensive and intrusive for most research studies, especially in-home settings. Most previous

studies have relied on subjective recall by youth or their parents to assess television viewing and screen use [2,4,11,17]. This subjective assessment is prone to many sources of bias and errors, resulting in low accuracy estimates [18]. The most common method, self-reported or parent proxy-reported surveys of television viewing behaviors [17,19], has rarely been compared with a gold standard. Those that have, did not perform well. Anderson et al [18] compared parent-reported television diaries and general estimates of television viewing to the gold standard in a child's home over the same period. Parent completed television diaries correlated moderately well with coded video observations ( $r_{91}=0.67-0.86$ ;  $P<.001$ ). However, the correlation between parent estimates and coded video observations was significantly weaker ( $r_{92}=0.27$ ;  $P<.01$ ) [18]. Furthermore, there was significant sample selection bias of families willing to participate in the study involving a high participant burden (television diaries), biased toward White, middle-class, and 2-parent households.

Objective automatic or passive methods for measuring children's television viewing and use of other large stationary screens (computers and videogame systems) are needed to better assess children's typical screen viewing and use behaviors. In the future, objective assessment of television viewing could be added to output from assessment tools of other screen platforms, such as mobile devices [11], for a composite measure of screen use among children. We are therefore developing an objective and automatic system to measure television viewing to allow a more comprehensive and accurate assessment of children's television viewing to inform the assessment of screen media exposure. This paper describes the design and development of the resulting assessment tool, Family Level Assessment of Screen Use in the Home-Television (FLASH-TV), and the data acquired by the FLASH-TV system.

## Methods

### Ethics Approval

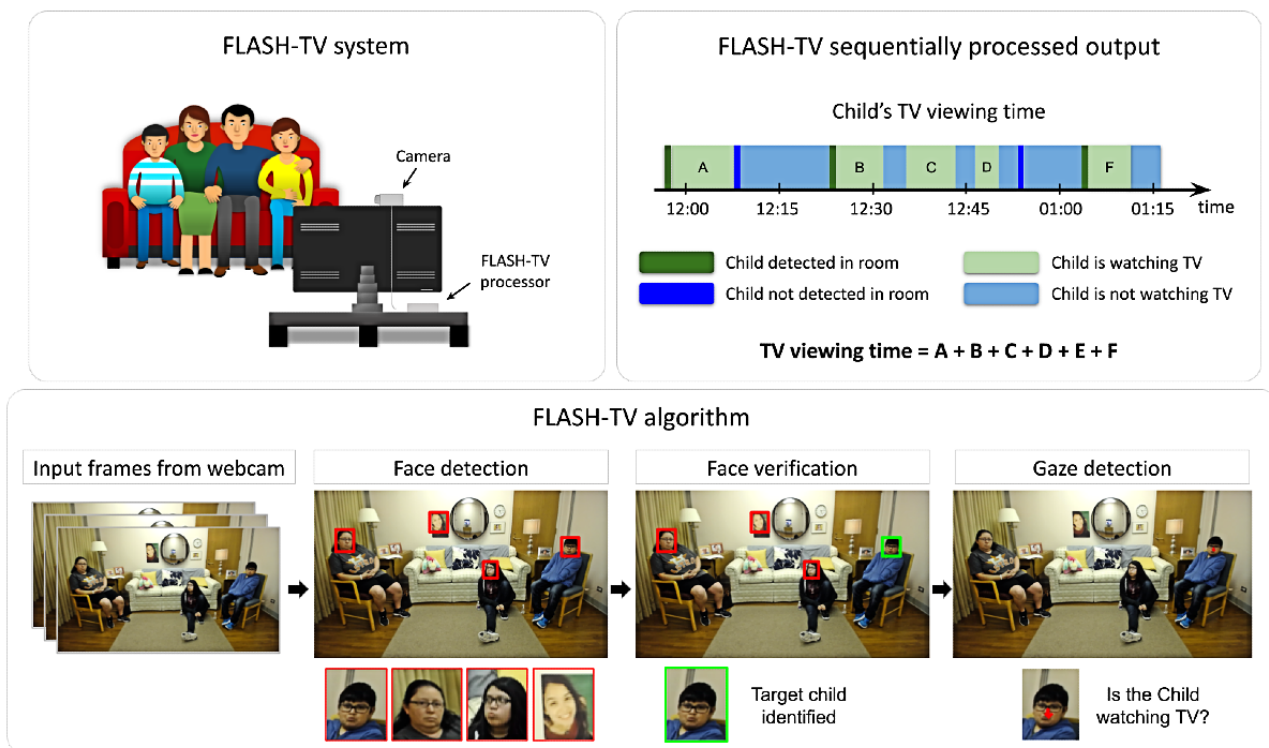
The Institutional Review Board at Baylor College of Medicine reviewed and approved the study protocol (H-40556).

### Overview of FLASH-TV Development

The overall goal of FLASH-TV is to estimate the total time a target child views a television or other large screen. To achieve this, FLASH-TV consists of a video camera (Logitech c930e 1080p) placed directly on or near the television, with the camera facing the viewers. The video camera records high-resolution images (approximately 1 megapixel or greater) at a rate of 15-30 frames/s. Computer vision and machine learning algorithms analyze each frame of the recorded video. Video analysis follows three stages: (1) *face detection*—to detect any faces present in every frame of the video, (2) *face verification*—to isolate and localize the presence of the target child in any frame, and (3) *gaze estimation*—to determine whether the target child is looking at the television (Figure 1).



**Figure 1.** The integrated Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) system. The FLASH-TV system takes as input video frames and processes it through a sequence of 3 steps: (1) Face detection, (2) Face verification, and (3) Gaze estimation to create a log containing a child’s television viewing time.



**Data Collection Using the FLASH-TV System**

Four small, iterative design tests were conducted to obtain video data to develop, train, and test the 3 steps required for a robust FLASH-TV. Three of the design tests were conducted in an observation laboratory at Baylor College of Medicine, which was set up as a living room. One of the design tests was conducted at the family’s home to test the system under natural circumstances. A parent and 2 siblings (one who was identified as the target child) were invited to participate in the task-based protocols. Inclusion criteria for each parent–sibling triad were: parent or legal guardian of children; target child aged 6-11 years and sibling aged 6-14 years; family fluent in English; and parents willing to allow their children to watch age-appropriate television or movies and play age-appropriate digital games. Exclusion criteria were: parent or child with developmental, medical, mental, or physical diagnosis that would prevent him or her from following the protocol. The research protocol was reviewed and approved by the institutional review board at Baylor College of Medicine with institutional review board reciprocity by Rice University via an established authorized agreement. All methods were performed in accordance with the Declaration of Helsinki and according to the federal and institutional guidelines. Informed written consent was provided by the parents of each triad for participation in the study and assent provided by all the children who participated. Participants in all design studies were offered an opt-in on the consent form to have their images used in reports and presentations that describe the development of FLASH-TV. All parents and children depicted in this document opted-in and additionally provided consent for their images to be used in publications by reviewing and signing the Baylor College of Medicine, media

release form. Of the 22 participating families, one triad’s video data from design test 2 was corrupt. Here, we present the data from the remaining 21 triads.

Each design test protocol lasted approximately 90 minutes and contained minor variations. Each protocol required participants to watch television, engage with a mobile tablet, or play with physical toys while being video recorded by the observation room cameras as well as the prototype FLASH-TV system. Participants were asked to change their positions in the room (eg, from the couch to the floor) while performing each task for a few minutes at a time. For certain protocol segments, participants were asked to leave the room for a short period to ensure that FLASH-TV would detect their absence and return. The lighting of the room was varied for some tasks during several of the design tests to assess the robustness of FLASH-TV under bright, dim, and dark conditions. Each protocol included a 20- to 30-minute free-play portion to capture naturalistic viewing of a television screen by children when toys and a mobile device were also available. The room set up varied for each family, including different locations of the television and chairs in room and different room decorations. Design test 3 differed from design tests 1 and 2 as it included 2 separate, approximately 30-minute visits, 1 week apart from the observation laboratory so that the face verification could be assessed with participants across days. Design test 4 was conducted at the family’s home using a slightly modified protocol. An example of task-based protocols is provided in [Multimedia Appendix 1](#).

FLASH-TV consisted of a high-definition, wide-angle video camera (Logitech 1080p webcam running at 15-30 frames/s) placed on top of the stationary screen (large computer monitor



in the laboratory observation room or a television at the family's home). The FLASH-TV video data from each of the design tests were reviewed and coded by trained behavioral research staff to determine whether the child was watching television. The research staff coded video data (available at the frame level) was considered the *gold standard* for training and testing the FLASH-TV machine learning algorithms. The target child was identified in each video frame, and then coded with one of four codes for the target child: watching screen, not watching screen, out of frame, or cannot tell using duration coding (one code was applied to the video data and remained until the child's behavior changed). Eight research staff were trained and certified to correctly label gaze or no gaze  $\geq 90\%$  of the time. Overall, 10% of each family's video data were double coded by 2 independent staff to determine interrater reliability ( $\kappa=0.88$  with an SD 0.23 for laboratory observations;  $\kappa=0.83$  with an SD 0.25 for in-home observations).

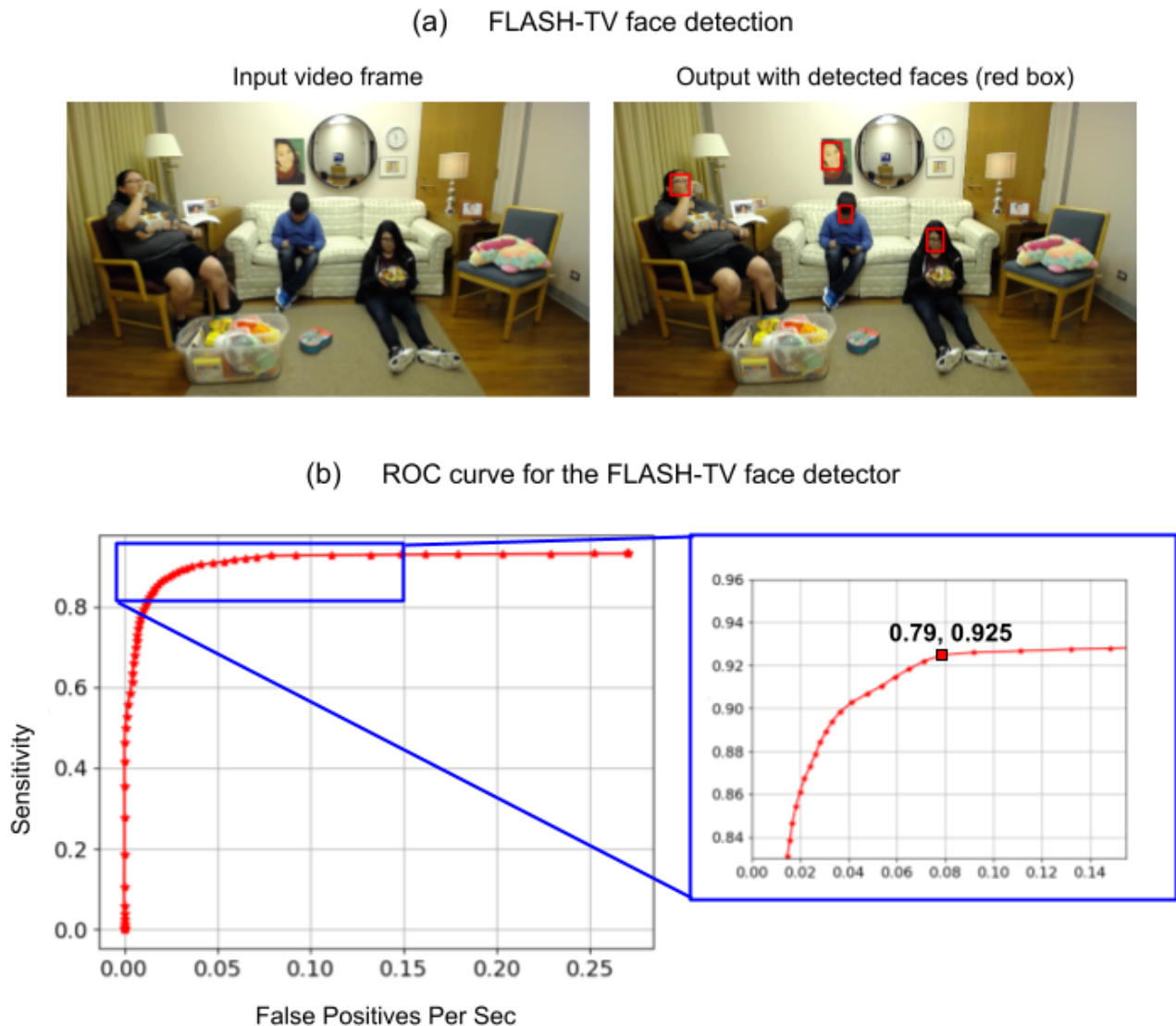
### Face Detection

YOLOv2 [20], a state-of-the-art convolutional neural network (CNN) originally proposed for object detection, was modified to develop the face detection component of FLASH-TV, using a publicly available code base [21]. The modification was based on a transfer learning paradigm in which previously learned model information from the YOLOv2 system was refined and adapted to the FLASH-TV context. YOLOv2 CNN was

originally trained to detect common objects (eg, cars, humans, traffic lights, and animals), but was adapted for the FLASH-TV face detector to extract the parents', siblings', and target children's faces from design test videos. We retained the first 16 layers of the original YOLOv2 model, whereas all the YOLOv2 layers after layer 16 were replaced with our own convolution and detection layers. The entire network was returned using large-scale public facial data sets [22-24] to refine the FLASH-TV face detector. The FLASH-TV face detector returned *bounding boxes* with the 2D spatial coordinates around all detected faces in each video frame, as shown in the second box from the left in Figure 1.

A receiver operating curve analysis was performed on 10,000 test frames from design test triads 1, 2, and 3, stratified according to the task and lighting conditions to identify the threshold for the face detector. At the selected operating point, the false positive rate per second was 0.79, and the sensitivity was 92.5%. The goal was to set the face detector threshold in a range to avoid missing faces (false negatives) in exchange for accepting higher false positives. A false positive rate of 0.79 per second could be tolerated because most of these false positives would be screened out during the next stage of processing (the face verification step; Figure 2). In practice, about 96% of the false positives were screened out by face verification, achieving an effective false positive rate of 0.03 false positive face detections per second.

**Figure 2.** Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) face detection. (a) FLASH-TV face detector takes an input frame and detects faces in the image, shown in red boxes (b) Receiver operating curve (ROC) for the face detector. The region indicated in the blue box in the ROC is enhanced in an inset to show the selection of the operating point. At the operating point, we have 0.79 false positives per second and a sensitivity of 92.5% to optimize false negatives.



### Face Verification

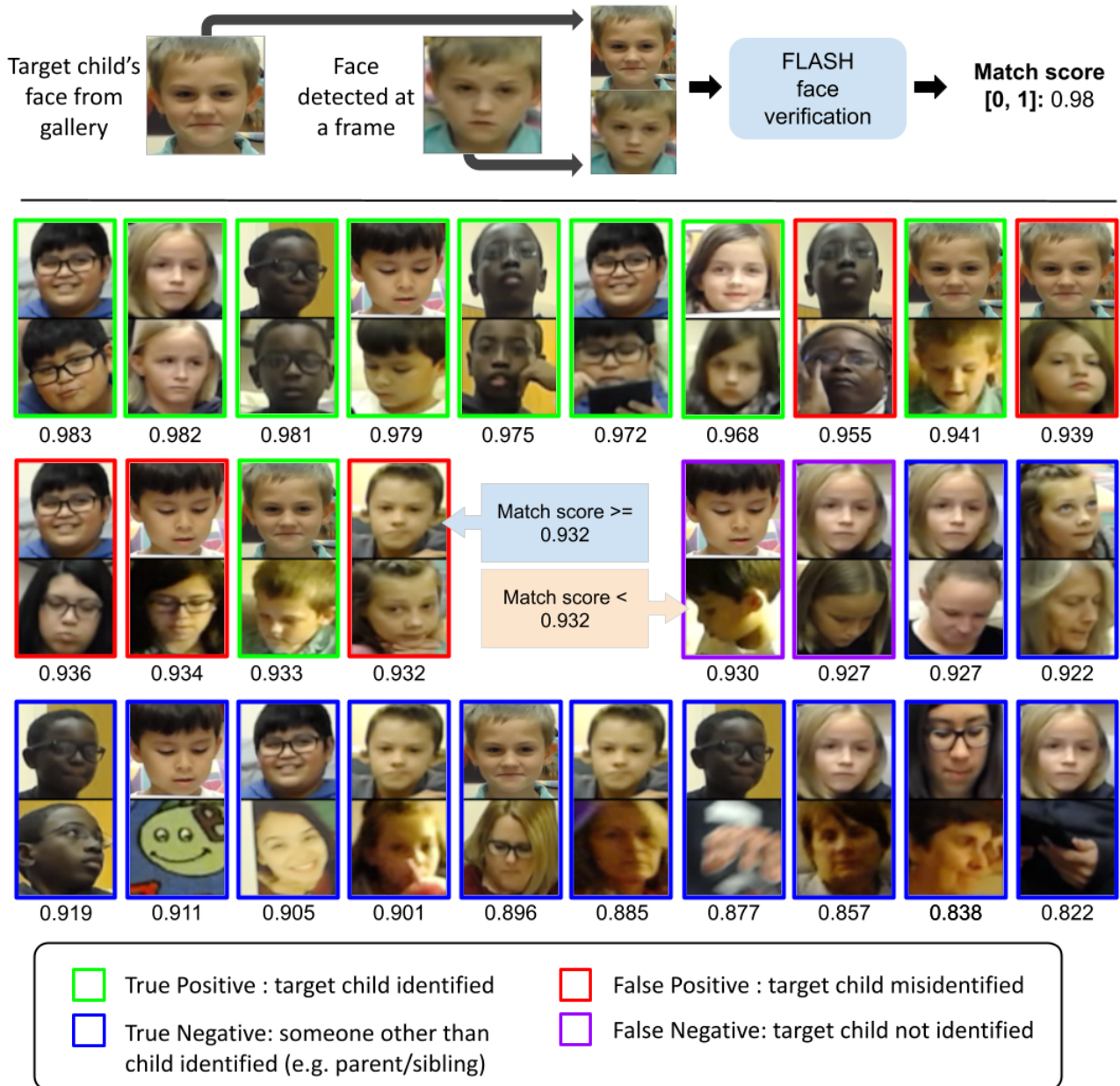
The goal of FLASH-TV face verification was to determine whether any of the detected faces corresponded to the target child. DeepFace [25], a state-of-the-art method for face verification, was used to learn the face-specific features for face verification using deep neural networks with residual connections. A publicly available implementation of this approach from FaceNet [26,27] was trained for face verification on a publicly available data set, VGGFace2 [28], consisting of 3.3 million faces of 9000 identities. The resulting algorithm was tested on the Labeled Faces in the Wild test set [29] consisting of 5749 celebrities that were divided into 6000 face pairs, and DeepFace accuracy on this data set was 99.6%.

To compute the similarity between the face in the bounding box (output of face detector) to the gallery of images of the target child, the correlation among their FaceNet features was measured. For design tests 1 and 2, approximately 33,000 randomly selected test frames were used, and for design test 3,

approximately 4000 randomly selected test frames were used. As seen in Figure 3, the match score is closer to 1 when comparing the faces of the target child to another image of the target child. A match score threshold of 0.93 (identified by receiver operating curve analysis) was used in our implementation of FLASH-TV as it provided a reasonable trade-off between false positives and false negatives.

Preliminary analysis of face verification performance indicated that the low-light level with the resultant noisy image was the principal cause of face verification errors. Therefore, we refined the face verification model by retraining the system on a large data set of synthetic low-light, high-noise videos (where noise was added to existing video data to simulate low-light conditions). Further, we exploited the continuity of face identity across successive video frames by automatically tracking and smoothing identity evolution across frames. FLASH-TV face verification resulted in 93% accuracy in identifying the target child (see *Results* section for details).

**Figure 3.** Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) face verification. Demonstration of the FLASH-TV face verification approach. All faces identified in the face detection step are compared with a series of images of the target child’s face obtained at the start of the study protocol. The FLASH-TV algorithm assigns a similarity score of each face identified to an image of the target’s child’s face. At a match score threshold of 0.932, we optimize our true positives and true negatives compared with staff coding of faces among a random sample of 6000 pairs of faces with half pairs being similar faces. Face pairs with match scores above the threshold are considered as similar faces and below that as dissimilar faces. We show example face pairs with match scores in the range (0.991-0.822). Actual false positives and miss detection rates were much lower but we show several examples of each here simply for illustrative purposes.



**Gaze Detection**

The goal of FLASH-TV gaze detection was to determine whether the target child was looking directly at the television (from which we inferred attention to the television). This was done by first detecting the target child’s eyes and then estimating their gaze direction (in relation to the location of the television). Prior gaze detection systems focused on estimating gaze direction from high-resolution images of eyes recorded on mobile phones, tablets, or laptops, where the distances were less than a meter [30-34]. Unfortunately, the FLASH-TV gaze detector had to work with the small facial image sizes (typically <50x50 pixels) captured in the bounding boxes from the video

data as the subjects were farther away (2-4 m), and the camera had to cover a large field of view. Consequently, existing trained models for gaze estimation could not be directly used within the FLASH-TV context.

We adapted the Gaze360 approach of Kellnhofer et al [35] for FLASH-TV gaze estimation using a publicly available code base [36]. Gaze360 [35] provided a direction vector specifying the direction in which the person was looking (Figure 4). For FLASH-TV gaze detection, a dichotomous output, whether the child’s gaze was or was not on the television was desired. To obtain this dichotomous output from the gaze direction, angular limits were set on the direction of the vector, which should be



identified as gaze, and outside, which should be no-gaze. These angular vector limits depended on where the face was in the frame and the relative position of the television (eg, notice the gaze directions for different locations in the video frame shown in Figure 4). To address this, the video frame was divided into multiple regions, for which we identified the angular limits for each. To account for the location of the television in the room,

we labeled each FLASH-TV data set with relative position information between the FLASH-TV camera and the television. For example, of the 16 triads for design tests 1, 2, and 3, we have 10 triads with television in the center and 5 with television in the left. One family's data were obtained from a unique position (below television) and could not be used in gaze estimation training or testing.

**Figure 4.** Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) gaze estimation. All images identified as the target child by the FLASH-TV face verification step in a bounding box are processed for the direction of the child's gaze based on Gaze360 algorithms [35]. This illustrates the resulting gaze vector (red arrow) that are classified as true positives (gaze) or true negatives (no gaze) by the system. Note, the angle of the gaze vector that is considered a true positive (gaze) will depend on the location of the television in the foreground. The approximate television location is indicated by a green box at the bottom of each image.



We used the leave-one-out strategy to evaluate the Gaze360 on FLASH-TV data. For each design test, we removed one of the family triads as test data and used the remaining families' video data to train the algorithm. This was repeated for each triad in the design tests. The training data were used to obtain the angular limits for the gaze vector, which were then applied to the test data, resulting in a dichotomous gaze or no-gaze output. This binary output was compared with the gold standard human coding of the video data. Our FLASH-TV gaze detector achieved an accuracy of 87% (see the *Results* section for details).

At the end of each data collection session, the parents were asked about their perceptions of FLASH-TV using a structured interview guide. The brief interviews were audio-recorded,

transcribed, and coded for themes by 2 trained staff members using NVivo (version 11, QSR International; 2015).

### Statistical Analysis

A summary of the algorithms used by FLASH-TV for face detection, face verification, and gaze estimation can be found in [Table 1](#). For each individual step of video data processing, FLASH-TV output was compared with the gold standard (staff-coded video data), and the accuracy, sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV), false positives per second, and processing time were calculated within each family and then averaged across families ([Table 2](#)).

**Table 1.** Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) algorithms.

FLASH-TV methods	Algorithm used	FPS <sup>a</sup> processing
Face detection	Modified YoLo [20]	20
Face verification	FaceNet [26,27]	12
Gaze estimation	Gaze360 [35,36]	30

<sup>a</sup>FPS: frames per second.

**Table 2.** Outcome metrics assessed.

Outcome metric	Formula	Interpretation in reference to gaze
Accuracy	$\frac{TP^a + TN^b}{TP + TN + FP^c + FN^d}$	Overall how often does FLASH-TV <sup>c</sup> make a correct prediction for gaze
Sensitivity	$\frac{TP}{TP + FN}$	High sensitivity indicates that when the child is watching television, FLASH-TV reports it as "Gaze" (few false negatives)
Specificity	$\frac{TN}{TN + FP}$	High specificity indicates that frames in which child is not watching television, FLASH-TV reports it as "no gaze" (few false positives)
PPV <sup>f</sup>	$\frac{TP}{TP + FP}$	High PPV indicates FLASH-TV "gaze" output corresponds to the child actually watching television
NPV <sup>g</sup>	$\frac{TN}{TN + FN}$	High NPV indicates FLASH-TV "no gaze" output corresponds to the child actually NOT watching television
FPR <sup>h</sup>	$\frac{FP}{FP + TN}$	High FPR corresponds to incorrectly identifying the child is watching television, when the child is actually NOT watching television

<sup>a</sup>TP: true positive (ie, FLASH-TV gaze agrees with the gold standard).

<sup>b</sup>TN: true negative (ie, FLASH-TV no gaze agrees with the gold standard).

<sup>c</sup>FP: false positive (ie, FLASH-TV gaze does not agree with the gold standard).

<sup>d</sup>FN: false negative (ie, FLASH-TV no gaze does not agree with the gold standard).

<sup>e</sup>FLASH-TV: Family Level Assessment of Screen Use in the Home-Television.

<sup>f</sup>PPV: positive predictive value.

<sup>g</sup>NPV: negative predictive value.

<sup>h</sup>FPR: false positive rate.

For face detection and face verification, the results were presented for the overall video data and stratified on whether the child's gaze was on the television or not, as identified during the gold standard staff-coded video data. Stratifying by child gaze allows FLASH-TV to be evaluated in the context in which FLASH-TV needs to perform well, when the child is actually watching television, to estimate the target child's screen viewing or use time. The robustness or reliability of the face verification to identify the target child across different days was assessed in design test 3, when the parent-sibling triad returned to the observation laboratory for a second data collection session about 1 week after the initial data collection. As the 2 visits were

conducted on the same family, the average difference between visits in the outcome metrics (sensitivity, specificity, accuracy, PPV, NPV, and false positive rate) was calculated and tested using the nonparametric Wilcoxon signed-rank test.

To further assess the face verification across different days, exploratory generalized linear modeling was conducted to determine the difference in the outcome metrics (sensitivity, specificity, accuracy, PPV, NPV, and false-positive rate) by visit. A compound symmetry correlation structure was assigned to account for the nesting of repeated measurements within each family per visit (because of multiple frames per visit). A Poisson



distribution was specified for all metrics except PPV, where a binomial was specified to fit the data. The effects of visit and family were tested as the main effects. The estimated difference in the response probabilities (least square means) of the outcome was obtained.

The goal of FLASH-TV was to estimate the target child's television viewing time. The target child's total television viewing time was estimated by sequentially running the 3 steps of FLASH-TV and summing the duration of time the child's gaze was on the screen (given in minutes:seconds format). To assess the target child's television viewing time estimated by the FLASH-TV system compared with the gold standard, the agreement between the number of frames identified as television viewing (after sequentially running each step) by the FLASH-TV was compared with staff codes using the prevalence and bias-adjusted  $\kappa$ . Moreover, reliability was assessed by means of the intraclass correlation coefficient (ICC) using a generalized linear mixed model accounting for the binary outcome (television viewed or not viewed). A random frame nested within the family effect was specified to reflect the ordering of the frames within family. Correlations of  $\leq 0.35$  were defined as weak, 0.36 to 0.67 as moderate,  $\geq 0.68$  as high, and  $\geq 0.9$  as very high [37]. The ICC was also used to determine the

reliability of the target child's total television viewing time estimated by the FLASH-TV system compared with the gold standard using a generalized linear mixed model specifying a lognormal distribution for the continuous outcome and random frame nested within the family. Data from the in-home data collection were used to independently test each algorithm step and then the sequential assessment of each step for the overall estimation of television viewing time for the child. Analyses were conducted using SAS (version 9.4, SAS Institute, Inc). Significance was determined using a two-sided  $\alpha$  value of .05. Face recognition and verification algorithms can introduce potential race bias if the algorithm accuracy varies according to the race of the child [38]. Therefore, we report television viewing time estimates from FLASH-TV and the gold standard stratified by child race, but the small sample size precludes statistical comparisons.

## Results

### Overview

The demographics of the 21 parent-child triads (Table 3) indicate a racially and ethnically diverse sample of families took part in the design tests.

**Table 3.** Demographics.

	Overall	Design test 1	Design test 2	Design test 3 (2 visits)	Design test 4 (in-home)
Parent-sibling triads (n)	21	5	6	5	5
<b>Children, n (%)</b>	42 (100)	10 (100)	12 (100)	10 (100)	10 (100)
Age (years), mean (SD)	10.2 (2.1)	10.1 (2.5)	9.9 (2.1)	10.5 (1.9)	10.5 (2.0)
Sex (female), n (%)	25 (57)	6 (60)	5 (42)	7 (70)	7 (70)
<b>Race and ethnicity, n (%)</b>					
Non-Hispanic White	16 (38)	4 (40)	4 (33)	2 (20)	6 (60)
Hispanic White	8 (19)	2 (20)	0 (0)	4 (40)	2 (20)
Non-Hispanic Black	10 (24)	2 (20)	6 (50)	2 (20)	0 (0)
Hispanic Black	2 (5)	0 (0)	0 (0)	2 (20)	0 (0)
Asian	2 (5)	0 (0)	2 (17)	0 (0)	0 (0)
Other (mixed or Hispanic Other)	4 (10)	2 (20)	0 (0)	0 (0)	2 (20)
<b>Parent, n (%)</b>	21 (100)	5 (100)	6 (100)	5 (100)	5 (100)
Age (years), mean (SD)	43.9 (8.7)	42.6 (6.9)	46 (9.4)	43.8 (8.6)	42.8 (6.7)
Sex (female), n (%)	19 (91)	5 (100)	6 (100)	5 (100)	3 (60)
<b>Race and ethnicity, n (%)</b>					
Non-Hispanic White	9 (43)	3 (60)	2 (33)	1 (20)	3 (60)
Hispanic White	4 (19)	1 (20)	0 (0)	2 (40)	1 (20)
Non-Hispanic Black	5 (24)	1 (20)	3 (50)	1 (20)	0 (0)
Hispanic Black	1 (5)	0 (0)	0 (0)	1 (20)	0 (0)
Asian	1 (5)	0 (0)	1 (17)	0 (0)	0 (0)
Other (mixed or Hispanic Other)	1 (5)	0 (0)	0 (0)	0 (0)	1 (20)
<b>Education, n (%)</b>					
High school	2 (10)	0 (0)	0 (0)	1 (20)	1 (20)
Some college	6 (29)	2 (40)	1 (17)	2 (40)	1 (20)
College	9 (43)	3 (60)	3 (50)	1 (20)	2 (40)
Graduate school	4 (19)	0 (0)	2 (33)	1 (20)	1 (20)

## Face Detection

Table 4 reports the outcomes for FLASH-TV face detection algorithm alone. The FLASH-TV face detector achieved a mean conditional (ie, when the child's gaze was on the television) sensitivity of 95.5% (SD 4.79%) with 0.43 (SD 0.51) false positives per second for design tests 1 and 2 on approximately 33,000 test frames. For design test 3, the conditional sensitivity was 96.4% (SD 3.61%) with 0.2 (SD 0.06) false positives per second on approximately 4000 randomly selected test frames. The face detector was also tested with the in-home data from design test 4, which provided 7.5 hours of video data from 5 parent-sibling triads. The face detector's conditional sensitivity was 97.9% (SD 0.02%) with 0.3 (SD 0.15) false positives per

second on approximately randomly selected 20,000 test frames, supporting a high accuracy in real-life scenarios and providing greater confidence that the face detector is functioning at an appropriate accuracy to be used in the three-step process of estimating a child's screen use on larger screens. Our current FLASH-TV face detector is running at 20 frames per second. Exploratory qualitative review of the false positives (regions that are not human face) identified by the FLASH-TV face detector included patterns in cushions and surroundings, cartoon faces, and animal faces (Figure 5). Examples of false negatives (human faces that are not detected) identified by FLASH-TV face detector (lacking a red bounding box) included instances when the faces were not oriented upright (eg, reclining on sofa), were partially occluded, or were in low-light settings.

**Table 4.** Family Level Assessment of Screen Use in the Home-Television face detection<sup>a</sup>.

	Sensitivity (%; range)	Positive predictive value (%; range)
<b>Design tests 1 and 2 (n=11 triads)</b>		
Overall (target child, sibling, and parent)	91.9 (83.2-96.7)	86.6 (67.4-93.9)
With gaze on television (target child)	95.5 (78.8-96.9)	74.9 (53.6-93.0)
Without gaze on television (target child)	87.7 (78.8-96.9)	55.1 (26.8-73.0)
<b>Design test 3—two visits combined (n=5 triads)</b>		
Overall (target child, sibling, and parent)	96.2 (93.4-98.7)	83.5 (72.3-89.8)
With gaze on television (target child)	96.4 (87.5-100.0)	61.9 (38.4-73.4)
Without gaze on television (target child)	89.8 (73.0-96.4)	48.1 (37.6-64.0)
<b>Design test 4—in-home observation (n=5 triads)</b>		
Overall (target child, sibling, and parent)	92.0 (83.9-99.5)	70.1 (54.5-86.6)
With gaze on television (target child)	97.9 (94.7-99.9)	52.5 (30.8-75.4)
Without gaze on television (target child)	86.1 (65.2-97.5)	42.1 (30.7-71.7)

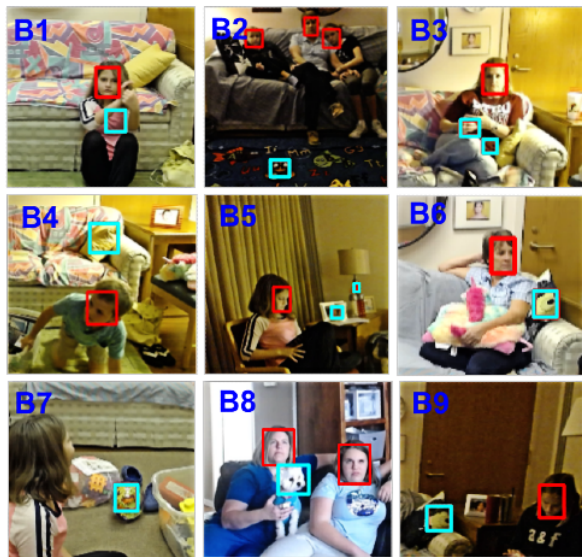
<sup>a</sup>True negatives are not meaningful to assess for face detection because they represent everything in the video that is not detected as a face. Therefore, accuracy, specificity, and negative predictive values (that depend on true negatives) were not calculated for face detection.

**Figure 5.** Face detection results. (a) Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) face detector captures the faces (indicated in red boxes) across tasks and lighting conditions. (b) Examples of false positives (regions that are not human face) identified by FLASH-TV face detector. Notice the patterns identified as faces (B1, B3, B4, B6, B7, and B9); also the cartoon face detected (B2) and the animal face detected (B8). (c) Examples of false negatives (human faces that are not detected) by FLASH-TV face detector (lacking a red bounding box). The face detector has difficulty in detecting faces, when the faces are not orientated upright (C3, C4, and C7), when the face is partially occluded (C5, C6, and C8), and when the lighting is dark (C2 and C9).

(a) Face detection results (faces detected in red bounding box)



(b) False positives (in cyan bounding box) from the face detector



(c) False negatives (pointed by blue arrow) from the face detector



**Face Verification**

Table 5 reports the outcomes for FLASH-TV face verification algorithm alone. For design tests 1 and 2, our face verification method achieved a mean conditional (ie, when the child’s gaze was on the television) sensitivity of 93.1% (SD 7.03%) for identifying the target child on approximately randomly selected 33,000 test frames. For design test 3, a conditional sensitivity

of 96.1% (SD 3.77%) was achieved on randomly selected approximately 4000 test frames. Similarly, on our in-home data set from design test 4, the sensitivity was 91.3% (SD 15.71%) for identifying the target child. The current speed of face verification is 12 frames per second. Examples of false positives and false negatives for face verification for the target child can be found in Figure 6. Exploratory qualitative review of the errors revealed these happened when the target child’s face was



partially occluded when they were not watching television and when the lighting in the room was dim, similar to face detection. Note that not identifying the target child's face when there is no-gaze will not affect our final television watching time.

Using the Wilcoxon signed-rank test to test the mean difference across visits 1 and 2 in design study 3, small differences in mean sensitivity ( $-0.05$ , SD 0.46), accuracy ( $-0.01$ , SD 0.18), and NPV ( $-0.01$ , SD 0.15) were identified, with mean values being lower in visit 2 than in visit 1. These differences were identified overall, and were no longer significant for times when the child's gaze was on television for all outcomes except NPV. The

generalized linear models showed that the outcome metrics (sensitivity, specificity, accuracy, PPV, NPV, and false positive rate) did not differ by visit. Mean differences in response probabilities for visit 2 relative to visit 1 for the sensitivity was 0.99 ( $P=.86$ ), specificity 0.99 ( $P=.37$ ), accuracy 0.99 ( $P=.93$ ), PPV 0.87 ( $P=.48$ ), NPV 1.0 ( $P=.87$ ), and the false-positive rate 1.07 ( $P=.27$ ). Mean differences did not change remarkably after stratifying by gaze status (not shown). However, large differences between family pairs ( $>20\%$ ) were observed only for PPV, specifically 23.32% (95% CI 16.71%-32.29%) and 44.41% (95% CI 32.77%-60.18%). These differences persisted only when the child was viewing television.

**Table 5.** Family Level Assessment of Screen Use in the Home-Television face verification of target child.

	Accuracy (%; range) <sup>a</sup>	Sensitivity (%; range) <sup>a</sup>	Specificity (%; range) <sup>a</sup>	Positive predictive value (%; range) <sup>a</sup>	Negative predictive value (%; range) <sup>a</sup>
<b>Design tests 1 and 2 (n=11 triads<sup>a</sup>)</b>					
Overall	92.8 (83.6-96.8)	78.0 (59.2-92.3)	97.2 (88.6-99.6)	89.0 (65.0-98.8)	93.8 (88.9-97.7)
With gaze on television	97.8 (94.6-99.6)	93.1 (77.1-98.9)	99.4 (96.9-100)	98.2 (90.5-100)	97.7 (93.4-99.6)
Without gaze on television	91.2 (87.7-96.5)	71.9 (51.9-92.0)	96.6 (84.9-99.4)	85.9 (54.8-98.8)	92.4 (87.1-97.4)
<b>Design test 3—two visits combined (n=5 triads)</b>					
Overall	94.5 (85.5-99.0)	83.7 (42.2-97.2)	97.3 (90.3-99.6)	89.7 (64.2-98.9)	95.84 (87.3-99.1)
With gaze on television	96.1 (83.5-99.6)	96.1 (85.9-98.6)	96.2 (82.8-100)	89.5 (53.7-100)	98.08 (95.9-99.5)
Without gaze on television	92.9 (84.7-98.7)	73.9 (24.6-98.2)	97.7 (90.2-100)	90.1 (65.5-100)	93.80 (84.6-99.4)
<b>Design test 4—in-home observation (n=5 triads)</b>					
Overall	94.3 (82.6-99.1)	86.9 (66.3-98.7)	99.1 (98.5-99.75)	97.7 (93.9-99.5)	92.7 (73.8-99.4)
With gaze on television	95.7 (81.3-99.9)	91.3 (63.4-99.9)	99.8 (99.5-100)	99.7 (99.3-100)	93.6 (72.6-99.5)
Without gaze on television	91.2 (83.3-96.1)	79.7 (42.0-97.0)	96.8 (94.8-98.8)	92.3 (81.0-98.7)	89.9 (79.7-98.6)

<sup>a</sup>Data analyzed at the frame (ie, bounding box). Given the small sample sizes in each design test, the mean and range (minimum–maximum) are reported.



**Figure 6.** Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) face verification results. This figure shows the frames from different participants where the FLASH-TV face verification identifies the target child in the frame. True positives indicate when the child is identified correctly. False positives indicate when a parent or sibling is mistaken as the target child and false negatives indicate when the target child is not identified correctly. Most of the errors occur when the target child’s face is partially occluded when they are not watching television and when the lighting in the room is dim. Note that if the target child’s face is not identified when there is no-gaze, it will not affect our television viewing time.



**Gaze Detection**

Table 6 reports the output for the gaze estimation algorithm alone. For gaze detection with television position in center (10 families), the mean accuracy was 87.2% (SD 7.38%) and mean sensitivity and specificity of 81% (SD 25.3%) and 86.8% (SD 7.14%), respectively (Table 5). For television position to the

left of the room (5 families), the mean accuracy was 87% (SD 6.05%) and mean sensitivity and specificity of 76.2% (SD 20.9%) and 90.8% (SD 2.94), respectively. The current speed at which our gaze detection processes the frames is 30 frames per second. Figure 7 illustrates the most common errors for gaze estimation.

**Table 6.** Gaze detection of target child.

Television position	Accuracy (%; range)	Sensitivity (%; range)	Specificity (%; range)	Positive predicative value (%; range)	Negative predictive value (%; range)	False positives rate (%; range)
Center of wall (n=10) <sup>a</sup>	88.0 (74.1-93.1)	73.2 (27.8-95.3)	91.2 (75.8-96.9)	82.1 (68.1-93.7)	87.8 (75.3-98.1)	8.82 (3.1-24.3)
Left corner of room (n=5) <sup>a,b</sup>	87.1 (76.8-91.8)	76.2 (54.0-96.1)	90.8 (87.3-94.4)	74.2 (65.5-86.2)	91.5 (76.5-98.7)	9.2 (5.62-12.7)
In-home television position varied (n=5) <sup>c</sup>	75.6 (54.9-93.7)	73.4 (45.2-95.4)	82.7 (71.2-91.1)	90.8 (73.4-97.3)	55.1 (30.7-80.6)	17.3 (8.9-28.8)

<sup>a</sup>Design tests 1 to 3 (in observation laboratory data collection).

<sup>b</sup>One family’s data from design tests 1 to 3 were obtained from a unique position (below television) and could not be used in gaze estimation training or testing.

<sup>c</sup>Design test 4 (in-home data collection).

**Figure 7.** Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) gaze estimation errors. This illustrates examples of errors from the FLASH-TV gaze estimator. The top two rows show false negatives resulting from FLASH-TV identifying no gaze on television, but staff coded gaze (gold standard). Qualitative assessment identified common reasons for false positives included low-light conditions (second row), the child’s face orientation not orientated upright (first row leftmost). Bottom two rows show false positives when FLASH-TV identified gaze, but the staff coded no gaze (gold standard). Qualitative assessment identified common reasons for false negatives included that gaze estimator has difficulty when children pay attention to something close to the television but not on the television (third row) and low-resolution (fourth row middle). The television location is indicated by a green box at the bottom of each image.



**Overall Television Viewing Time Estimation**

When implementing the 3 steps sequentially to estimate the target child’s television viewing time, the ICC was 0.725 when comparing the child’s estimated television viewing time per the FLASH three-step algorithm to the gold standard for total time, coded by staff (Table 7). The prevalence and bias-adjusted κ statistic was 0.728 (95% CI 0.727-0.729; P<.001) and the ICC comparing the number of frames identified as television viewing

by the FLASH-TV with the human labelers was 0.401. The breakdown of correlations under different conditions is shown in Table 7. Figure 8 shows the comparison of television viewing time between FLASH-TV and the gold standard across 20 triads from our design tests.

A comparison of the television viewing time estimated by FLASH and the gold standard by race and ethnicity found that FLASH-TV underestimated television viewing time in all groups (Table 8).



**Table 7.** Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) estimation of target child's television viewing time during a 90-minute observation period.

Television position	FLASH-TV estimated television viewing time (minutes; range)	Gold standard television viewing time (minutes; range)	Television viewing frame by frame, $\kappa^a$ (95% CI)	ICC <sup>b</sup> of total television viewing time	ICC of television viewing frame by frame
Overall	17.47 (4.7-44.0)	21.72 (8.93-43.0)	0.728 (0.727-0.729) <sup>c</sup>	0.725	0.401
Center of wall (n=10) <sup>d</sup>	17.08 (4.7-44.0)	20.2 (12.2-43.0)	0.787 (0.786-0.788) <sup>c</sup>	0.717	0.428
Left corner of room (n=5) <sup>d,e</sup>	12.26 (5.5-23.3)	13.24 (8.93-22.5)	0.791 (0.789-0.793) <sup>c</sup>	0.762	0.392
In home, television position varied (n=5) <sup>f</sup>	23.5 (9.9-37.4)	33.3 (23.3-42.7)	0.499 (0.497-0.502) <sup>c</sup>	0.354	0.293

<sup>a</sup>Prevalence and bias-adjusted  $\kappa$  statistic.

<sup>b</sup>ICC: intraclass correlation.

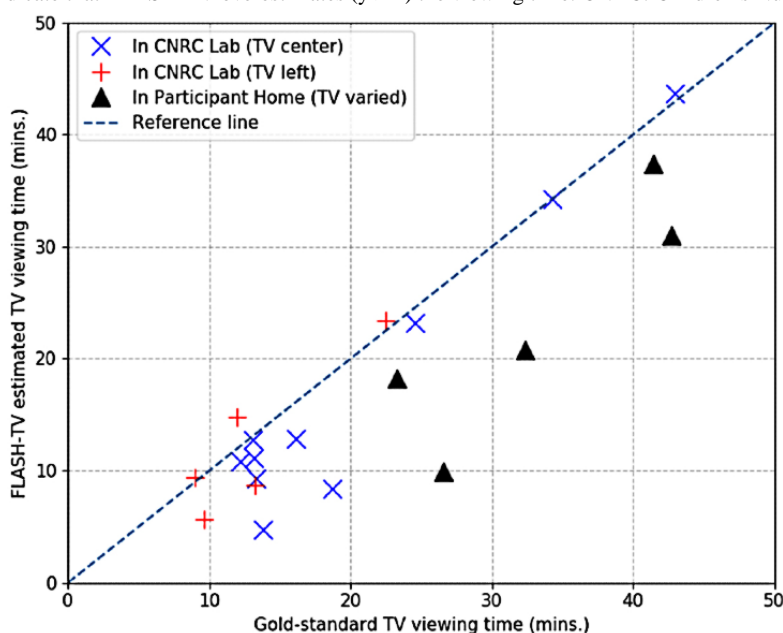
<sup>c</sup> $P < .001$ .

<sup>d</sup>Design tests 1 to 3 (in observation laboratory data collection).

<sup>e</sup>One family's data from design tests 1 to 3 were obtained from a unique position (below television) and could not be used in gaze estimation training or testing.

<sup>f</sup>Design test 4 (in-home data collection).

**Figure 8.** Scatter plot of gold standard television viewing time versus Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) prediction. This plot compares gold standard television viewing time with FLASH-TV prediction for the 20 triads from our design tests. The television position for each data point is indicated in the legend. Most of our data points lie along the reference diagonal line ( $y = x$ ) indicating the agreement between FLASH-TV and gold standard. The points below the diagonal indicate FLASH-TV underestimates ( $y < x$ ) the television viewing time, whereas the points above the diagonal indicate that FLASH-TV overestimates ( $y > x$ ) the viewing time. CNRC: Children's Nutrition Research Center.



**Table 8.** Exploration of race bias of Family Level Assessment of Screen Use in the Home-Television (FLASH-TV) television viewing estimates.

Child race and ethnicity	FLASH-TV estimated television viewing time (minutes), mean (SD)	Gold standard television viewing time (minutes), mean (SD)
Black <sup>a</sup> (n=5)	7.62 (2.41)	13.26 (3.45)
Hispanic <sup>b</sup> (n=5)	25.17 (10.46)	27.93 (9.95)
Non-Hispanic White (n=8)	20.0 (12.38)	25.16 (13.43)
Other <sup>c</sup> (n=2)	12.06 (3.85)	12.63 (0.92)

<sup>a</sup>Black includes African American and Hispanic Black

<sup>b</sup>Hispanic includes Hispanic-White and Hispanic-unknown

<sup>c</sup>Other includes Asian and Hispanic-Filipino.

## Participants' Thoughts About FLASH-TV

Most parents felt comfortable with or neutral toward having FLASH-TV in their home, especially as it would be helpful for them to see how much screen time their children obtained. Some participants were concerned with privacy: whether the camera would be recording all the time and who will have access to their data. Suggestions for improvement included having the ability to turn off the device at will, limiting to only video or audio data, and getting a breakdown about how their data are stored and processed.

## Discussion

### Principal Findings

FLASH-TV is being developed as an automated, objective assessment for measuring children's screen use on stationary screens (eg, televisions, gaming systems, and computers) in the home, using deep-learning computer vision algorithms to process video data obtained from in front of a stationary screen. The FLASH-TV system estimates the time a child spends watching a specific screen by processing video data in three sequential steps for (1) face detection, (2) face verification of the target child, and (3) gaze detection of the target child. The findings from our study suggest that with further refinement, the FLASH-TV system can be a useful assessment tool for children's viewing of large stationary screens. Output from FLASH-TV could be used in combination with other new assessment tools of other screen media use [11] to develop a composite of children's screen media use across platforms.

### FLASH-TV Performance of Algorithms

The current version of FLASH-TV demonstrated high sensitivity for detecting faces when the child's gaze was on the television (95.5%-97.9%) and poor-to-moderate PPV (52.5%-74.9%; Table 4). In developing the FLASH system, a low PPV was accepted for face detection to maximize the sensitivity (true positive rate) and keep false negatives low. This allows the FLASH-TV system to have a larger pool of images for the second step, face verification, which filters out all segments from step 1 that are not the target child, resulting in fewer false negatives from incorrect detection of the target child.

FLASH-TV demonstrated high (all >90%) accuracy, sensitivity, specificity, NPV, and PPV (Table 5) for correctly identifying the target child's face under the condition that the child's gaze

was on the television, even when tested in the child's home. The small differences in outcome metrics identified for face verification across visits by the same child were only present when the child was not watching television, except for the NPV. A significant difference in NPV between the 2 visits may indicate that FLASH-TV has some difficulty in identifying true negatives across days for a child. However, in this small sample, there were no differences in the outcome metrics by visit with the generalized linear models, which accounted for the correlation of data within a family. However, differences were found between families only for PPV. Qualitative assessment of the video data for face verification, where FLASH-TV performed the worst, suggests that the primary sources of error were when the child's face was partially occluded or in dim lighting. Training the FLASH-TV face verification further in simulated darkened images of the child may help alleviate this moving forward.

The accuracy, specificity, and NPV were relatively high (>85%) for FLASH-TV when the gaze assessment was in the observation laboratory, compared with the home (>75%). However, the sensitivity was only moderate (73.2%-76.2%) and similar for each condition. PPV was higher and NPV was lower for in-home assessments. Data collected in the home, a free-living situation, are likely to contain more variability that will need to be addressed. In addition, qualitative assessment of gaze estimation suggests that the primary sources of error were low light, low resolution, and the child's head orientation not being upright. Training the FLASH-TV gaze estimator on more varied data from different room configurations, different-sized televisions, and different locations of the television in the room should help address this moving forward. Simulating the current data with different head configurations and lighting conditions can provide additional training data to further refine the gaze estimator.

### FLASH-TV Estimation of Television Viewing

When combining the 3 sequential CNN visual-processing steps, FLASH-TV estimation of the child's television viewing time was overall good (ICC for overall time watched television of 0.725 across conditions). However, a moderate ICC (0.401) was obtained when comparing the FLASH-TV system output for television viewing with the staff codes at the frame level. This suggests that sources of variability other than FLASH-TV or staff contribute to the estimation of a child's television viewing time at the frame level, such as family unit, television position, or lighting during data collection. Therefore,

FLASH-TV should not be used to assess gaze at extremely refined time increments defined at the frame level (1/30th of a second). In fact, researchers are unlikely to analyze children's television viewing data at the second or minute level, reducing the impact of these unexplained sources of variability at the frame level. The next steps in refining the FLASH-TV output will include assessing whether smoothing the data into longer time epochs (eg, 5 s, 15 s, or 30 s) will smooth the variability caused by errors at the frame level to help improve the robustness of FLASH-TV in estimating children's television viewing.

Qualitative analyses of the video data for the families where FLASH-TV performed the worst in estimating the child's television watching time found that differences in the child's viewing position were the most common challenge. Similar to other approaches using video images to measure children's screen use [39], accuracy was impaired when children were reclining or laying on a couch or chair causing part or most of their face to be obscured. In these instances, the FLASH-TV often would not correctly identify the target child or their gaze, causing underestimation of television viewing. Training the FLASH-TV algorithms on larger data sets with the child reclining or laying down may help this.

Despite its current limitations, FLASH-TV is a significant improvement over current self- or parent-report methods that estimate how much time children spend watching television using gross categories. The ICC for the child's total television viewing time for FLASH-TV was high (0.725), slightly better than that previously reported for television diaries ( $r=0.67$ ), and much better than general estimates by parents ( $r=0.27$ ) [18], which are commonly used in research [17]. Given how the data are collected within a family, our ICC estimates take into account nesting within the family unit, making them pragmatic and beneficial for powering future family-based studies. FLASH-TV also substantially decreases participant burden, which was noted to generate selection bias when using television diaries [18]. Other tools, such as TV Allowance, have been proposed as an objective assessment of television viewing among children [40]. The TV Allowance was developed for parents to limit their child's access to television screens and required the child or parent to enter the child-specific code each time the child watches television. This may cause misclassification errors if the child is not watching the entire time the television is turned on or watches under another family member's code. The TV Allowance only had a moderate correlation with parental estimates of television viewing in 4- to 7-year-old children [40] and preschool children [41]. In both studies, no comparison was made to the gold standard for direct or video-recorded observations. To our knowledge, the TV Allowance is no longer available for purchase. Forward-facing, wearable cameras automated to record images at frequent time intervals have also been investigated to estimate children's screen use [39]. Such cameras appear to effectively capture images of screens (televisions, laptops, and smartphones) to which the child is exposed when the child is upright. However, similar to FLASH-TV, these cameras had problems when the child was laying down (capturing ceiling images instead). In addition, exposure to a screen does not mean that the child is

attending to the programming. Furthermore, such cameras are dependent on the child wearing the camera, and wear time declines every evening over a 3-day study period from 78% to 51% of the evening time [39]. Placing the camera on the television instead, like FLASH-TV, places less burden on the child to complete the television watching assessment.

### Race Bias

Machine learning algorithms for face recognition and verification have come under scrutiny for not being as accurate across races, termed race bias [38]. Previous work has demonstrated that the source of race bias is related to both data-driven factors (eg, the representativeness of training data sets, the representativeness of the study population, and image conditions) and scenario-modeling factors (eg, thresholds used for face verification) [38]. Exploratory analyses of FLASH-TV suggest FLASH-TV underestimation of television viewing in all groups, but this may be greater among Black and non-Hispanic White children. However, the small sample size and variability in television viewing time between groups make statistical comparisons difficult at this stage. The design studies intentionally included a diverse sample of children to provide diverse training data to minimize the data-driven causes of race bias with FLASH-TV. Further refinement of FLASH-TV is needed, with continued attention to prevent the possibility of a race bias. If race bias occurs with larger sample sizes, approaches to mitigate race bias will be explored such as race-specific thresholds for face verification [38].

### Privacy Concerns

Assessments based on the collected images of a child's varied surroundings raise concerns about privacy. Scientists using forward-facing wearable cameras have developed frameworks to manage the ethical considerations for capturing vast amounts of image data in various contexts [42,43]. The single location and context of the image data collected by FLASH-TV is different from that of wearable cameras. However, privacy issues remain. Some parents who participated in the design studies raised concerns about privacy issues with FLASH-TV. Once developed and deployed as a tool for measuring children's television watching, the goal is to have FLASH-TV preserve privacy by only storing the processed output of the FLASH-TV machine learning algorithms and not storing the video data. This should address most of the parents' concerns, but illustrating this to families before data collection may be important. However, until FLASH-TV has undergone further refinements and enhancements, studies require the video data to be stored to allow a gold standard for training the machine learning algorithms and to compare the FLASH-TV output. Such validation studies are critical to ensure the resulting system accurately captures a child's television viewing behaviors and times [17] to allow for higher quality assessment in exposure studies and to assess the effect of television viewing reduction interventions.

### Limitations

To date, FLASH-TV has only been assessed during relatively short periods in task-based protocols to simulate scenarios of children's typical screen use behaviors. Future studies will need



to assess how robust FLASH-TV is in estimating a child's screen use across multiple days. Most of the design tests conducted during the development of FLASH-TV were conducted in an observational laboratory. The location of the television in the room varied slightly across families, in addition to the participants' location during each protocol. However, gaze estimation depends on the gaze vectors of the child. Therefore, the algorithms need to be trained on additional video data to capture a child's gaze on a television screen in different positions in the room, resulting in different potential gaze vectors for the child. The sample of participants who took part in the design tests to help develop FLASH-TV were of varied race and ethnic backgrounds. FLASH-TV may not perform equally well for face detection and face verification across all families. Future analyses in larger, diverse data sets should evaluate whether child race, ethnicity, age, and similarity to sibling affect FLASH-TV time estimates for television viewing to ensure FLASH-TV works well across all groups of children.

Finally, FLASH-TV does not assess content watched, or whether the child was active or sedentary while watching television or playing videogames. Future research should investigate the integration of FLASH-TV output with other data sources, such as accelerometer data, to better characterize the activity levels of children as they engage with screens.

## Conclusions

We have designed, developed, and performed initial design tests of FLASH-TV, the first-of-its-kind, quantitative, objective, automatic measurement tool for children's television viewing. FLASH-TV offers a critical step forward in the assessment of children's television viewing. Objective assessment of television viewing from FLASH-TV could be added to output from assessment tools of other screen platforms, for a composite measure of screen use among children to better inform research on the impact of screen use on children's health and developmental outcomes.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Sample task-based protocol for design test 1.

[\[DOCX File, 14 KB - pediatrics\\_v5i1e33569\\_app1.docx\]](#)

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## Abbreviations

**CNN:** convolutional neural network

**FLASH-TV:** Family Level Assessment of Screen Use in the Home-Television

**ICC:** intraclass correlation coefficient

**NPV:** negative predictive value

**PPV:** positive predictive value

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Original Paper

# Usability Testing of a Patient-Centered Mobile Health App for Supporting and Guiding the Pediatric Emergency Department Patient Journey: Mixed Methods Study

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## Abstract

**Background:** Patient experience in emergency departments (EDs) remains often suboptimal and can be a source of stress, particularly in pediatric settings. In an attempt to support patients and their families before, during, and after their visit to a pediatric ED, a mobile health (mHealth) app was developed by a multidisciplinary team based on patient-centered care principles.

**Objective:** This study aims to evaluate the usability (effectiveness, efficiency, and satisfaction) of a new mHealth app, *InfoKids*, by potential end users through usability testing.

**Methods:** The app was assessed through an in-laboratory, video-recorded evaluation in which participants had to execute 9 goal-oriented tasks, ranging from account creation to the reception of a diagnostic sheet at the end of the emergency care episode. Effectiveness was measured based on the task completion rate, efficiency on time on task, and user satisfaction according to answers to the System Usability Scale questionnaire. *Think-aloud* usability sessions were also transcribed and analyzed. Usability problems were rated for their severity and categorized according to ergonomic criteria.

**Results:** A total of 17 parents participated in the study. The overall completion rate was 97.4% (149/153). Overall, they reported good effectiveness, with the task successfully completed in 88.2% (135/153) of cases (95% CI 83%-93%). Each task, with the exception of the first, created difficulties for some participants but did not prevent their completion by most participants. Users reported an overall good to excellent perceived usability of the app. However, ergonomic evaluation identified 14 usability problems occurring 81 times. Among these, 50% (7/14) were serious as their severity was rated as either *major* or *catastrophic* and indicated areas of improvements for the app. Following the suggested usability improvements by participants, mitigation measures were listed to further improve the app and avoid barriers to its adoption.

**Conclusions:** Usability of the *InfoKids* app was evaluated as good to excellent by users. Areas of improvement were identified, and mitigation measures were proposed to inform its development toward a universal app for all ED patients visiting a digitalized institution. Its contribution could also be useful in paving the way for further research on mobile apps aimed at supporting and accompanying patients in their care episodes, as research in this area is scarce.

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**KEYWORDS**

usability; user-centered design; information systems; mobile apps; emergency service; hospital; pediatrics; mobile phone



## Introduction

### Background

An emergency department (ED) visit is often the first point of contact for patients with a health care institution and thus a showcase of its efficiency. Providing patients with a positive experience should take high priority [1] and is one of the fundamental determinants of health care quality [2]. In a recent meta-synthesis, a study by Graham et al [1] conceptualized a model to understand the most commonly identified drivers of the ED patient experience. These included interpersonal and informational communication, patients' expectations and empowerment, recognition of emotional needs, actual and perceived waiting times, competent care, and physical and environmental needs [1]. A similar conceptual framework was also developed by Sonis et al [3,4]. The same drivers have been observed in other studies focusing on identifying the determinants of patient and family experience in the pediatric EDs [5-11]. This highlights the essential nature of these drivers and the attention that should be paid to them when implementing an intervention to improve the adult or pediatric ED patient experience and ED efficiency. Several recent reviews have demonstrated a strong correlation between a positive ED patient experience and a range of benefits at the individual and institutional levels. These include increased therapeutic compliance [12]; improved health clinical outcomes [1,13,14]; outpatient [15], inpatient [16], and staff satisfaction [12]; reduced complaints and medicolegal risks [17]; institutional profitability and reputation in the community [12,18,19]; and other health care system goals [13].

Unfortunately, the hectic, unpredictable, crowded, demanding, and time-pressured environment of the ED may adversely affect patient experience [13]. In particular, there is strong pressure from public and institutional leaders to alleviate overcrowding and long waiting times experienced in the ED [20]. Overcrowding because of nonurgent visits negatively impacts the quality of care and patient safety (prolonged waiting times, delays in diagnosis and treatment, delays in treating seriously ill patients, and medication errors). It also affects the costs of care and patient experience. For hospitals, crowding results in loss of revenue because of patients leaving the ED without being seen, diversion of EDs secondary to patient dissatisfaction, and shifting of the market share to competitors [21]. Moreover, overcrowding exposes ED staff to stressful and unpredictable work-related events, resulting in decreased productivity and increased turnover [22,23].

The body of literature assessing conventional intervention strategies aimed at improving these specific ED issues is highly heterogeneous [24-34]. Proposed interventions vary widely and often require major structural or organizational changes that are not necessarily easily scalable to all hospitals. Importantly, a few address the aforementioned drivers of the ED experience in a scoping and integrative manner along the entire patient journey. Successfully addressing these dimensions requires enlisting patients and families as allies in designing, implementing, and evaluating care systems through patient-centered care approaches [35]. One solution to the

serious challenges facing the ED today may be found in information technologies, which have the potential to both reduce institutional burdens and improve patients' experience [36]. Supported by the rapid spread of mobile devices in the community and their innovative features (eg, versatile connectivity, on-board computing and communication capabilities, privacy, and small size), mobile apps may provide such a solution within the easy reach of end users. However, to date, there is a lack of studies on the potential use of mobile apps to individually support the entire emergency care journey. On the basis of this finding and guided by the principles of patient- and family-centered care [5,35], we developed InfoKids [37], an integrated eHealth solution composed of 3 modules connecting patients, caregivers, and administrative clerks through a web and mobile app, with the aim of supporting the entire emergency care process, thus facilitating caregiving and administrative work and streamlining the arrival of patients in the ED [38]. This system is freely available at Geneva University Hospitals, Geneva, Switzerland, for pediatric patients. It is expected to be soon redesigned to cover the entire population seeking ED care (ie, adult, geriatric, and gynecologic) in a service area of more than 1 million individuals. Before scaling up this app to such a large population, an essential step in determining the potential for the success of this patient-centered eHealth intervention was to assess its capacity to meet end users' needs and improve health care at our institution before clinical effectiveness testing [39-42].

### Objective

This study aims to evaluate the usability of the InfoKids mobile app to support the entire patient's ED journey through quantitative and qualitative usability metrics in a laboratory setting. We then aim to identify potential problems related to its use and formulate mitigation measures to inform both the development of its upcoming version as a universal app for all ED outpatient consultations in our hospitals and future mobile app development in this medical field by other research groups.

## Methods

### Study Design

The usability of the app was assessed through a scenario-based, summative evaluation of human-computer interactions using a mixed methods approach [43]. Multitask quantitative and qualitative usability metrics were used and are described in detail in subsequent sections.

### Definition of Usability

Usability is defined as "the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" [44]. Usability of a mobile app can be measured by the completeness and successfulness whereby users solve specified tasks centered around the main features of the app. Conversely, systems with poor usability can lead to low goal achievement efficiency or technology not being used [45].

## Participants and Setting

The study was conducted in a medical informatics usability laboratory room at Geneva University Hospitals to standardize the intervention and technically facilitate measurements. The evaluation framework was a user-task-system interaction, deliberately omitting the user's real environments [43]. Tasks were performed on an LG G5 mobile phone with a 5.3-inch screen size at a resolution of 2560×1440 pixels and an Android operating system V7. According to recommendations on the minimum sample size required to conduct a summative evaluation, at least 15 participants were planned to be recruited [46]. Participants were recruited through advertisements posted on Facebook groups and displayed at the Geneva University Medical Center. Participation was open to adults with children of pediatric age (0-16 years). Exclusion criteria were non-French-speaking persons and those who had previously used the app.

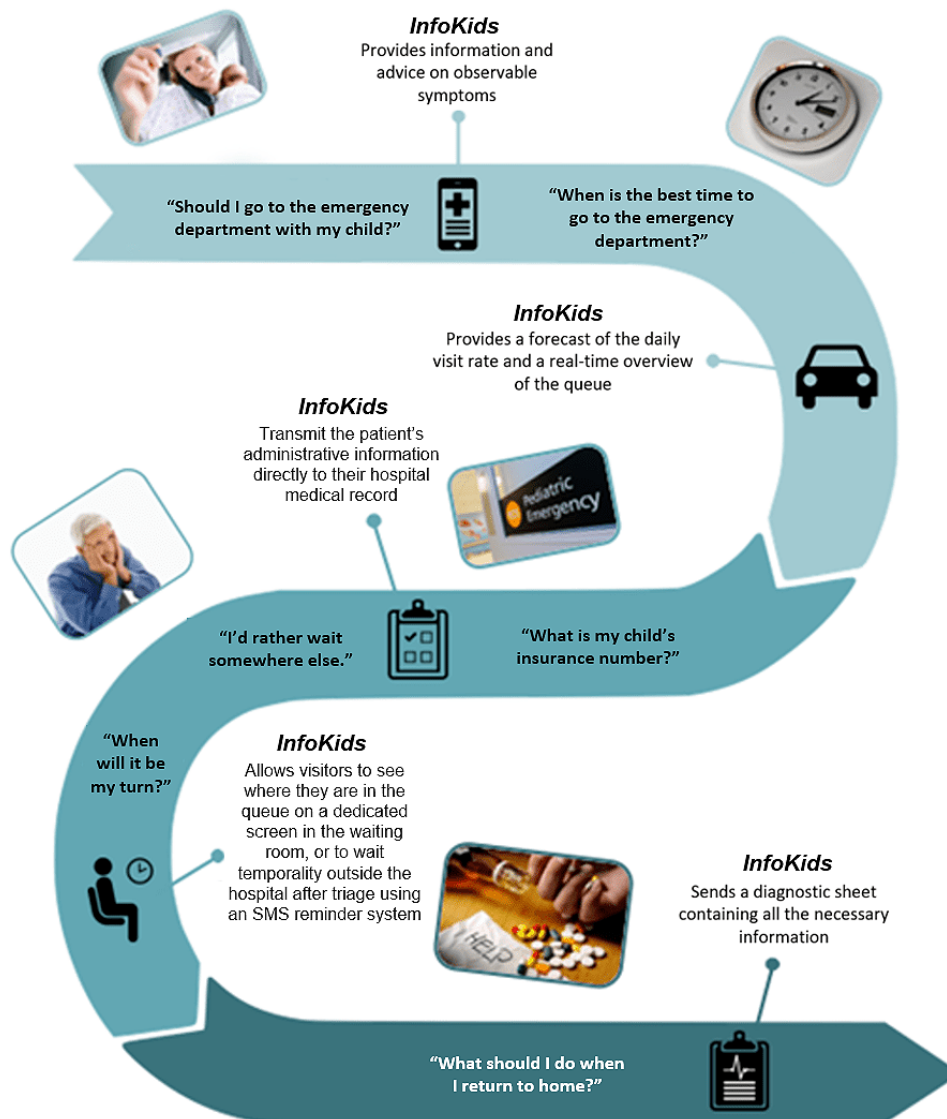
## InfoKids Mobile App

### Overview

The app was developed by a multidisciplinary team using a user-centered design approach to support each dimension of patient-centered care [37], which is an important approach to consider when developing a mobile health (mHealth) tool for patients. It is primarily defined by considering the needs and

values of each patient and helping them to be more actively engaged with shared decision-making about their care [35,47]. Such patient involvement is a key element in high-quality health care [48].

A needs analysis guided by the Picker Institute's patient-centered care dimensions was conducted among patients and their relatives to identify the specific requirements for the app [49]. System specifications were also identified to translate them into functionalities based on the collected needs of pediatric emergency physicians and nurses and observations of the workflow of caregivers and administrative clerks (Figure 1) [37]. Observations were performed to map out a generic patient journey [37,50]. Improvements were identified from this upstream work and incorporated into the app. In the previous stages of the app's development, heuristic evaluations were performed by 3 ergonomics experts following the guidelines given by Nielsen and Mack [51] to identify any problems and correct them before proceeding with usability testing. In its current version, the InfoKids mobile app is designed to support parents throughout their entire journey in the pediatric ED; that is, from the onset of the first symptoms to their return home. The interface was designed using hedonic elements to make it more enjoyable and aiming to increase its acceptance. The app is available to the local community through free downloads from the Apple App and Google Play stores.

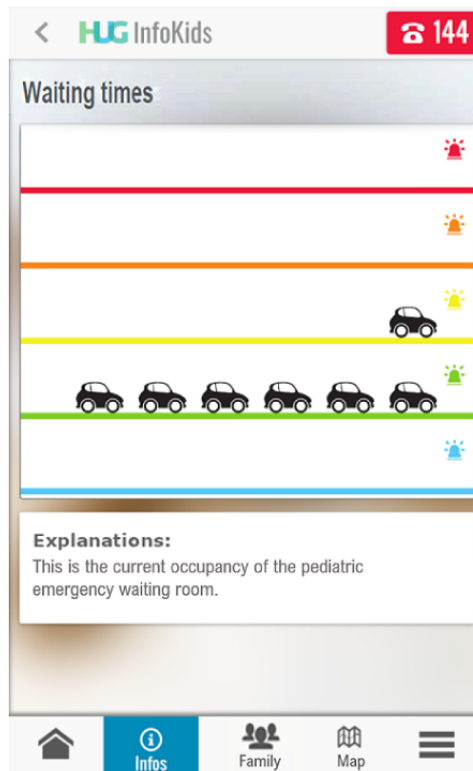
**Figure 1.** The *InfoKids* app process.

### Preconsultation Stage

The app guides parents through a hierarchical organization of symptoms with medical advice on actions to take; that is, manage the symptom at home, need to visit a private practitioner, or require an ED visit. Classification of symptom terminology was established through a card-sorting study [52]. First, this allows parents to make better decisions on how to deal with symptoms and decide whether to consult. Second, the app contains educational videos aimed at responding to the most common questions that parents may have when visiting the ED. Third, it emotionally supports patients by avoiding unrealistic expectations through the display of ED waiting room occupancy in real time. Occupancy is represented by a metaphoric display of a road where patients are represented as cars queuing (Figure 2). According to the Canadian Triage and Acuity Scale [53], 5

levels of emergency are represented by 5 lanes, as displayed on the screen. Each patient is represented by a car in the sequential order of arrival from right to left for each lane, left being the most recent arrivals. Patients with the highest level of urgency are represented by an ambulance rather than a car. Notably, the same view is displayed on a large television screen hanging on the wall of the ED waiting room. The app also provides a graphic forecast of daily occupancy based on statistics from the 5 previous days. This allows a better distribution of visits throughout the day by offering patients the possibility to consult during the least busy periods (Figure 3) and better perceive expected wait times before being seen by a physician. The app also provides guidance on the hospital location through GPS features and informs the hospital in real time of the patient's upcoming arrival.

**Figure 2.** Screenshot of the *InfoKids* mobile app displaying the emergency department occupancy in the waiting room in real time. The Canadian Triage and Acuity Scale categorizes patients by both injury and physiological findings and ranks them by severity from 1 (highest, red) to 5 (blue). By clicking the 144 icon, the user is connected directly to the national emergency call center. HUG: Hôpitaux Universitaires de Genève.



**Figure 3.** Screenshot of the *InfoKids* mobile app displaying forecasts of daily occupancy based on the statistics of the previous 5 days. The vertical graduation from green (bottom) to red (top) indicates the expected daily occupancy rate from low to high. HUG: Hôpitaux Universitaires de Genève.





### Per-Consultation Stage

When parents decide to consult, they can inform the ED of their arrival by a simple click. By doing so, administrative entries recorded in advance within the app are automatically and securely communicated to the hospital. This aims to empower the patient as warrantor of the quality of the administrative data stored in the clinical information system and to reduce the risk of patient misidentification [54]. It also aims to improve the efficacy of ED organizations by shifting the paradigm from an impromptu influx of patients arriving *at the door* to an anticipated occupation, allowing a more efficient management of medical resources. In addition, after triage and when appropriate, patients with nonurgent conditions are offered the possibility to leave the ED temporarily without losing their position in the waiting queue and then called by semiautomated phone messages as soon as a physician is available. These

features enable the hospital to act upstream for the regulation of patient flow and overcrowding by a more judicious allocation of health care resources, such as a more rational repartition of caregivers and consultation rooms.

### Postconsultation Stage

At the time of discharge, the app automatically sends an informative sheet based on the patient's diagnosis, thus assuring a personalized follow-up. Each sheet offers clear explanations regarding the current condition or trauma, appropriate treatment, prerequisites for a return to the community, and symptoms that require medical attention. The quality and safety of the information provided rely on the core information library supplied by pediatric emergency physicians and endorsed by Geneva University Hospitals. All these features (Table 1) are explained in an in-app tutorial composed of pop-ups and videos.

**Table 1.** Summary of InfoKids functionalities per stage of consultation.

Stage	Functionality	Goal	User actions
Preconsultation	Creation of a user profile	Share securely patient information with the hospital.	Enter parent and child legal information (identity, postal address, insurance, etc) and health records.
Preconsultation	Tutorial	Inform how to use the app and how a consultation at the ED <sup>a</sup> takes place.	Browse the tutorial.
Preconsultation	Real-time visualization of ED waiting room occupancy	Assist in making decisions about the most appropriate time to consult at the ED.	Visualize occupancy and forecasts.
Preconsultation	Symptoms decision tree classifier	Help with the decision to consult and improve the patient experience.	Identify the symptoms and obtain advice on how to manage them.
Preconsultation	Guidance	Find the ED location (GPS).	Follow the GPS.
Per-consultation	ED already informed upon patient arrival	Anticipate the patient's arrival.	Confirm departure.
Per-consultation	Symptoms, chronic illnesses, allergies, and usual treatments entered by the parent into the app are automatically communicated to the ED	Empower patient as warrantor of the quality of the administrative data stored in the clinical information system; reduce patient misidentification.	Enter the child's administrative and personal data in the app beforehand; automated sending of this information at the time of announcement of departure to the ED by a simple click.
Per-consultation	Temporarily leave the ED while waiting for a scheduled consultation	Reduce the waiting time and improve the patient experience.	Accept the legal discharge document, allowing to temporarily leave the ED.
Postconsultation	Personalized diagnostic sheet	Improve therapeutic adherence and the patient experience.	Provide access to diagnostic and therapeutic follow-up.

<sup>a</sup>ED: emergency department.

### Procedure

Participants were invited by emails to individual sessions. The study procedure was explained to the participants upon arrival at the evaluation laboratory. Written informed consent was obtained from all the participants. After completing a baseline questionnaire on demographics and user experience with smartphones, the participants were asked to imagine themselves in a situation where they had heard about the InfoKids app and to follow a scripted and timed standardized scenario. The scenario was developed to sequentially guide the user toward the completion of 9 goal-oriented tasks covering the main functionalities of the app (Textbox 1; Multimedia Appendix 1). The sequence of tasks reflected the sequence of actions that parents seeking medical advice for their sick child with worrying

symptoms at home would have to perform. For reasons related to the study design and use of the app, the possibility of patients being able to temporarily leave the ED while waiting for a scheduled consultation was not evaluated but will be the subject of further research. For greater realism, the dates and times were adapted to the time of the experiment. No training on the app was offered before the evaluation began to avoid preparation bias. The participants were not given any assistance to complete the tasks. Study investigators only intervened to encourage participants to keep talking during the intervention, thus avoiding bias of results and minimizing any disruption of participants' thoughts. The participants were informed that their interaction with the app and their verbal exchanges would be video recorded.

**Textbox 1.** Goal-oriented test tasks.**Goal-oriented test tasks**

- Task 1: open the app, enter your personal data as requested, and accept the terms of use.
- Task 2: create a profile for your child and close the app ([Multimedia Appendices 2 and 3](#)).
- Task 3: imagine that 2 days later, your child has cough and you are seeking medical advice. Open the app and look for advice ([Multimedia Appendix 4](#)). Read the tips on what you can do at home to manage the situation on your own. Also read the tips on when you should go to the pediatrician in the next 24 hours. Close the app.
- Task 4a: 1 week later, you plan to go to the pediatric emergency room because of the worsening of your child's cough and health condition. You are wondering about the current emergency room occupancy and want to see how busy the waiting room is ([Figure 2](#)). The date is (date of examination), current time is (time of examination). Are there many people in the emergency department (ED)? Can you describe what the cars represent on the screen? Can you describe what the different lines represent?
- Task 4b: Does occupancy in the ED over the last few days allow you to predict whether the wait on that day will be long? Can you describe what the graph represents ([Figure 3](#))?
- Task 5: you decide to go to the ED with your child. Inform the ED of your arrival and return to the home page ([Multimedia Appendix 5](#)).
- Task 6a: you are seeking information on the location of the ED. Go to the tutorial to find information on how to use the mapping tool (GPS).
- Task 6b: after viewing the tutorial, indicate the location of the ED building on the map and return to the home page ([Multimedia Appendix 6](#)).
- Task 7: you went to the emergency room and came home. You receive a notification on your app regarding the diagnosis made in the ED and read it. What is the physician's diagnosis? What home care information is necessary?

To understand participants' thoughts, the concurrent *think-aloud* method was applied by asking them to verbalize during task completion [55]. Upon completion of the scenario, the moderator had a debriefing with each participant following a semistructured grid interview, with the aim of assessing overall experience with the tool and usability improvements and perform a retrospective *think-aloud* method to analyze difficulties encountered and understand their causes [56]. Finally, to assess user satisfaction, the participants were asked to complete the System Usability Scale (SUS) questionnaire [57,58].

**Scenario**

A pediatric emergency physician (JNS) wrote a credible and standardized scenario based on these tasks, which was then screened and approved by two ergonomists (JR and AR) at the evaluation laboratory. In the scenario, the participant decides to install the app in the eventuality that an ED visit might be necessary. Shortly after, the participant (ie, the parent) needs to use the app for the first time following the onset of cough in their child. A week later, when the cough and the child's health had deteriorated, the parent had to use the app again to be guided and supported to go to the ED with the child.

**Usability Analysis****Quantitative Evaluation**

The participant's task performance was measured by the following metrics:

1. *Effectiveness* is defined as the accuracy and completeness in which users achieve the specified goals [44]. Effectiveness is calculated in three different ways:
  - *Task completion rate (TCR) per participant*, that is, the percentage of tasks successfully completed, whether with ease or difficulty [59]. This is calculated using the following equation:
 
$$\text{TCR per participant} = (\text{number of tasks completed successfully} / \text{total number of tasks undertaken}) \times 100 \text{ (1)}$$
 When a task cannot be started and evaluated (ie, because of a problem with the Wi-Fi connection), it is coded as *nonavailable*.
  - *Distribution of task success by task* is defined as the proportion of participants completing a task according to three possible levels of achievement: (1) the task is considered *completed with ease* when the user has successfully completed the task without any errors or difficulties; (2) *completed with difficulty* when the task was completed, but with difficulties that could have been solved by the participant; and (3) *failed to complete* when the task is left incomplete or abandoned or the participant gave incorrect answers. When a task cannot be started and evaluated (ie, because of a problem with the Wi-Fi connection), it is coded as *nonavailable*.
2. *Efficiency* is defined as the level of resource use required for users to achieve specified goals in relation to accuracy and completeness [44]. This is calculated in three different ways:
  - *Time on task* is defined as the average amount of time (in seconds) taken to complete a given task from the moment the participant finished reading the instructions

until the task was completed (whether with ease or with difficulty) or abandoned.

- *Time-based efficiency (TBE)* is defined as the time spent by users in absolute value to ensure the accurate and complete achievement of tasks using the 2 equations described in a study by Ben Ramadan et al [59].
  - *Overall relative efficiency (ORE)* is defined as the ratio of the time spent by effective users to ensure accurate and complete achievement of tasks to the total time taken by all users (ie, including the time spent by ineffective users) using the 2 equations described in a study by Ben Ramadan et al [59].
3. *Satisfaction* measured by administering the SUS questionnaire designed by Brooke [57,58], a highly robust and versatile tool to measure participants' subjective assessment of usability [60]. SUS is a 10-item questionnaire (Multimedia Appendix 7), with 5 response options for respondents for each item, based on their level of agreement from 1 (*strongly disagree*) to 5 (*strongly agree*). Following the Brooke scoring system [57,58], for odd-numbered statements 1, 3, 5, 7, and 9 (positively worded items), the score contribution is equal to the scale position minus 1 (eg, *strongly agree* 5–1=4). For even-numbered statements 2, 4, 6, 8, and 10 (negatively worded items), the score contribution is equal to 5 minus the scale position (eg, *strongly agree* 5–5=0). Each score contribution falls within the range of 0 to 4. The participants' scores for each item are then summed and multiplied by 2.5 to convert the original scores from 0 to 40 to 0 to 100. Although the scores range from 0 to 100, these are not percentages of usability and should be considered only in terms of their percentile ranking. To obtain an SUS score of 100, the respondent must answer 5 to all odd questions and 1 to all even questions. It is generally considered that a score is good starting from 75 and fair between 50 and 75. A score below 50 reveals strong disagreement in terms of satisfaction [60]. As the participants were French speaking, the French translation of the questionnaire was used [61]. As age could be a potential confounder correlated with usability scores [60], we also analyzed SUS scores according to two age categories ( $\leq 40$  years and  $>40$  years).

### Qualitative Evaluation

Qualitative data from the concurrent, retrospective *think-aloud* and debriefing were used to assess the overall experience with the tool, identify usability problems, understand the cause of difficulties, and identify usability improvements. Usability problems encountered by the participants during the tasks were rated using the Nielsen severity scale [62] and categorized using the ergonomic criteria of Bastien and Scapin [63]. The Nielsen scale ranges from 0 to 4, with higher scores positively correlated with greater problems (0=no usability problem; 1=cosmetic problem that does not need to be addressed unless extra time is available on the project; 2=minor usability problem: fixing this should be given low priority; 3=major usability problem: important to fix and should be given high priority; and 4=usability catastrophe: imperative to fix this before releasing the product). The Nielsen criteria [51] used to rate the severity of usability problems are (1) the frequency of occurrence of a

problem (common or rare?), (2) its impact on the user's experience (easy or difficult for users to overcome?), and (3) its persistence (a unique problem on first use or will it persist to bother users?). As some studies have shown that severity ratings are subjective and can vary significantly from one assessor to another [64], they were conducted independently by 2 ergonomists. In case of disagreement, the ratings were averaged [65]. However, to avoid disagreement, both ergonomists agreed to classify usability problems that led to failure as a *usability catastrophe*. The Bastien and Scapin [63] method consists of a list of 18 ergonomic criteria that are generally used to identify and understand the most well-known interface problems. The categorization of usability problems following these criteria was performed independently by both ergonomists. In case of disagreement, the evaluators discussed together to reach a consensus.

### Data Collection

Participants' task performance was video-recorded and audio-recorded to retrospectively analyze the usability of the app. Video and audio captures were acquired with an Elmo L-12iD camera document placed above the phone. Morae software (TechSmith Corporation) was used to analyze the video and audio recordings of participants' interactions with the app. Subsequently, the recordings and usability metrics were transcribed onto Microsoft Excel spreadsheets. The SUS paper questionnaires were collected immediately after the intervention and subsequently transcribed onto Microsoft Excel spreadsheets. Two researchers (JR and VGR) analyzed the success rates of each task and their duration independently of each other. In case of disagreement, both researchers discussed together to reach a consensus. All data collected were anonymized.

### Data Analysis

Descriptive statistics were used to summarize continuous measures at a significance level of .05. Frequency counts were used for summarizing categorical measures. Age categories and SUS mean scores were compared to make comparisons between user characteristics and satisfaction. Data were analyzed, and graph figures were created with GraphPad Prism 9 and Microsoft Excel.

### Ethics Approval and Consent to Participate

The study was submitted to the Regional Research Ethics Committee (Req-2021-00505), which waived the need for further evaluation by issuing a *no objection* statement, as such projects did not fall within the scope of the Swiss federal law on human research [66]. Only data from a fictitious patient were used in this study. Written informed consent was obtained from all participants before the intervention. No participants' medical information was used. Participants were not identifiable on video and audio recordings. Participants' data and results obtained through the intervention were deidentified and assigned an individual identifying code that did not contain identifying information. Data were secured by protected access passwords at Geneva University Hospitals on secured hard disks. This study was conducted in accordance with the Declaration of Helsinki [50] and principles of Good Clinical Practice [51].

## Results

Between June and September 2017, a total of 17 participants participated in the study. Baseline demographic characteristics are shown in [Table 2](#).

### Participant Characteristics

**Table 2.** Demographic characteristics of study participants (N=17).

Characteristics	Values, n (%)
<b>Gender</b>	
Woman	15 (88)
Man	2 (12)
<b>Age categories (years)</b>	
21-30	3 (18)
31-40	4 (24)
41-50	8 (47)
51-60	2 (12)
<b>Number of children</b>	
1	9 (53)
2	5 (29)
3	2 (12)
4	1 (6)
<b>Parents with a child aged (years)</b>	
0-3	6 (35)
3-6	7 (41)
6-9	7 (41)
9-12	1 (6)
12-15	3 (18)
<b>Already visited Geneva pediatric ED<sup>a</sup></b>	
Yes	12 (71)
No	5 (29)
<b>Type of phone</b>	
iOS	7 (41)
Android	9 (53)
Windows phone	1 (6)
<b>Possession of a smartphone</b>	
<1 year	0
From 1 to 2 years	0
More than 2 years	17 (100)
<b>Frequency of mobile apps use</b>	
Often (daily)	17 (100)
Regularly (several times per week)	0
Sometimes (once to several times per month)	0
Rarely (once to several times per year)	0
Never	0

<sup>a</sup>ED: emergency department.



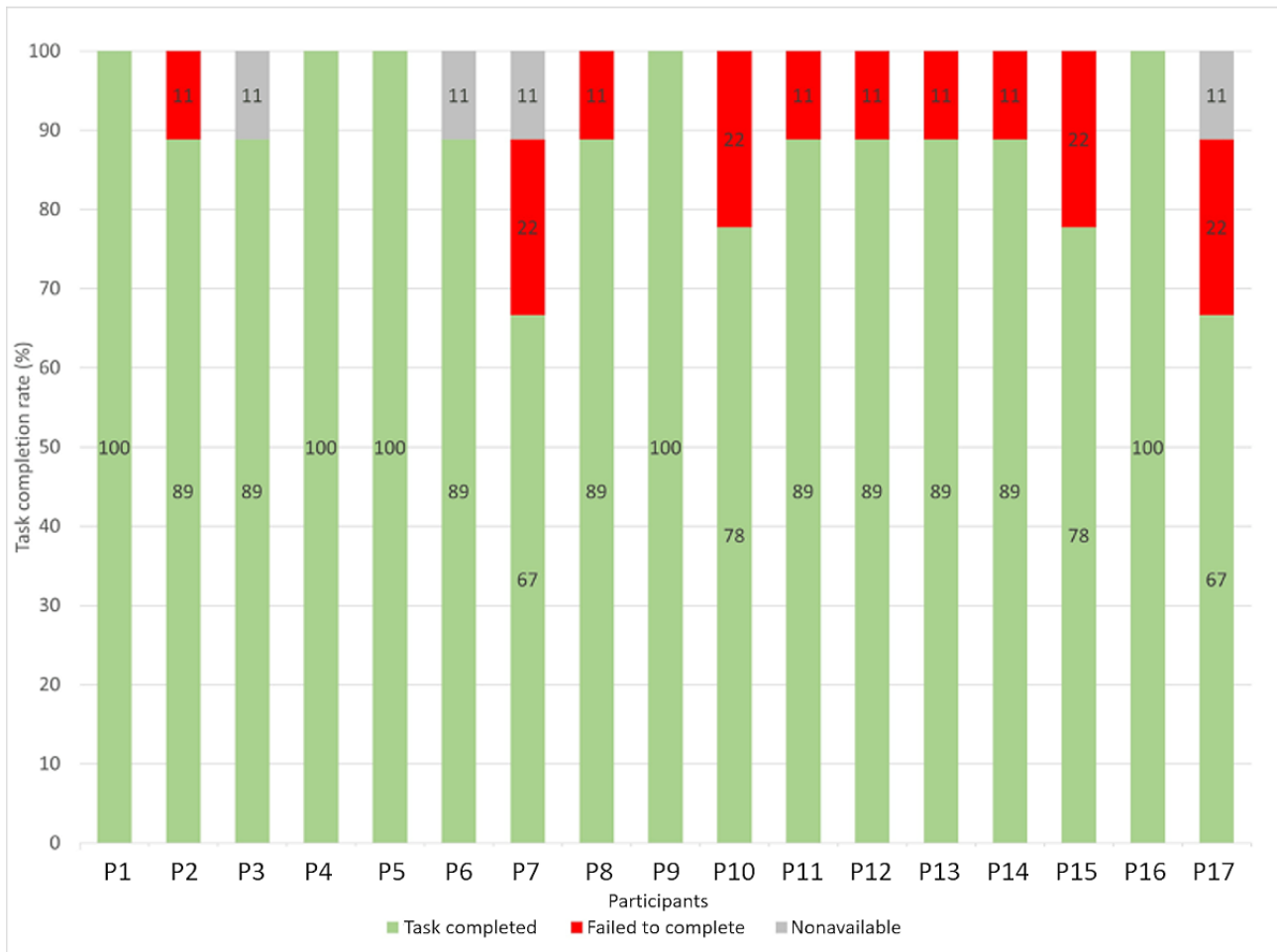
**Quantitative Evaluation**

**Effectiveness Per Participant**

The overall completion rate (tasks completed and failed) was 88.2% (135/153). A total of 4 participants did not perform some tasks, 2 (50%) participants ignored task 6a, 1 (25%) participant experienced a problem with the Wi-Fi connection in task 6b, and 1 (25%) participant experienced a software bug in task 7.

The mean overall success rate, defined as the percentage of tasks that participants completed successfully (whether with ease or difficulty), was 88.2% (135/153; SD 10.63%; 95% CI 83%-93%). An analysis of almost 1200 usability tasks showed that the minimum accepted average TCR was 78% [67]. In this study, the TCR per participant ranged from 67% to 100% (Figure 4).

**Figure 4.** Task completion rate per participant for the 9 assigned tasks. *Task completed* represents the percentage of tasks successfully completed by a participant, whether with ease or difficulty. *Failed to complete* defines the percentage of tasks that participants failed to complete. *Nonavailable* represents the percentage of missing data when a task could not be started and evaluated.



**Effectiveness Per Task**

Of the 9 assigned tasks, 4 (44%) were achieved 100% by all participants (Figure 5); 2 (22%; tasks 4b and 7) reached a TCR per task of 94%; 1 (11%; task 6a) reached a TCR of 82%; and 2 (22%) scored below 78%: task 6b with a value of 71% and

task 4a with a value of 53%. Of note, all tasks with a value of less than 100% were related to either browsing through the pages of the app or understanding the information displayed. Figure 5 shows that task 4a appeared to be most complicated. Tasks 4b, 6a, and 6b also seemed problematic for some participants.

**Figure 5.** Task completion rate per task (N=17 participants). *Task completed* represents the percentage of participants who successfully completed the task, whether with ease or difficulty. *Failed to complete* defines the percentage of participants who failed to complete the task. *Nonavailable* represents the percentage of missing data when a task could not be started and evaluated.

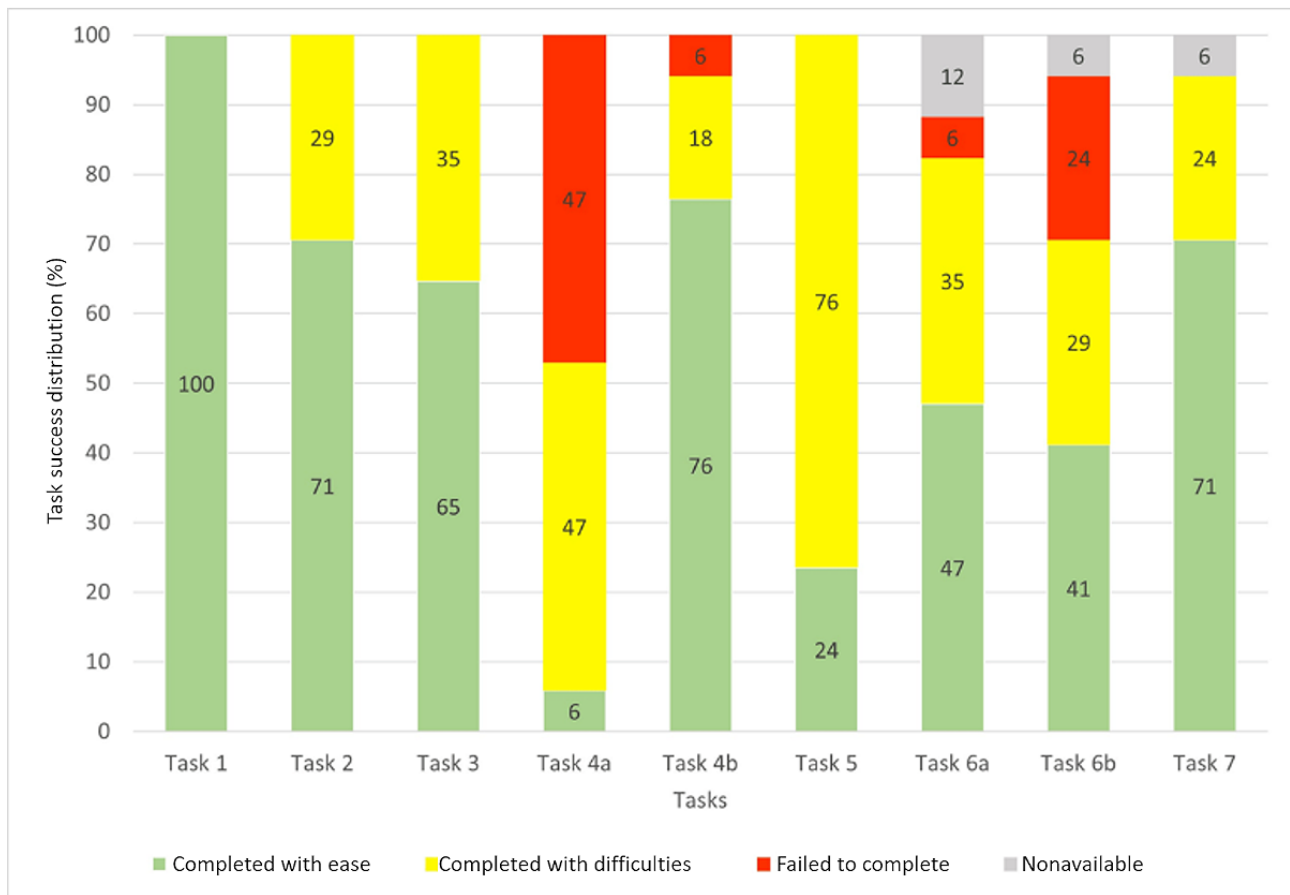


**Task Success Distribution Per Task**

The observed task success distribution is shown in Figure 6. Task 1 was completed with ease by all the participants (17/17, 100%), followed by task 4b (13/17, 76%). Tasks 2 and 7 were completed with ease by 71% (12/17) of the participants. Task 3 was completed with ease by 65% (11/17) of the participants,

but tasks 6a, 6b, 5, and 4a were completed with ease by only 47% (8/17), 41% (7/17), 24% (4/17), and 6% (1/17) of the participants, respectively. Apart from task 1, all tasks led to difficulties with a *completed with difficulties* rate ranging from 18% to 76%. Participants encountered failures during four tasks (4a, 4b, 6a, and 6b), with a *failed to complete* rate ranging from 6% to 47%.

**Figure 6.** Task success distribution per task (N=17 participants). *Completed with ease* represents the percentage of participants who completed the task with ease. *Completed with difficulty* represents the percentage of participants who completed the task with difficulties. *Failed to complete* defines the percentage of participants who failed to complete the task. *Nonavailable* represents the percentage of missing data when a task could not be started and evaluated.



**Efficiency: Time on Task**

The mean overall time on task for all tasks was 101.26 (SD 44.07) seconds. Tasks 1, 2, and 4a had a higher time on task than the other tasks (Table 3). These findings showed that the

most complicated task (ie, task 4a) was the third most time-consuming task, although it did not require much action compared with tasks 1 and 2, which were the longest and required several pieces of data to be entered into the app, thus explaining their duration.

**Table 3.** Time on task per study task.

Task	Time on task (seconds), mean (SD)
Task 1: Create a parental account	142.58 (38.96)
Task 2: Create a child profile	182.56 (58.64)
Task 3: Find the <i>symptoms</i> page	96.86 (46.36)
Task 4a: Find and understand the <i>waiting times</i> page	138.61 (71.4)
Task 4b: Find and understand the <i>forecast</i> page	55.93 (34.27)
Task 5: Inform of the departure to ED <sup>a</sup>	80.08 (58.98)
Task 6a: Find the <i>tutorial</i> page	59.93 (27.06)
Task 6b: Find the <i>map</i> page	62.34 (47.16)
Task 7: Find the <i>diagnostic</i> sheet	92.46 (52.84)

<sup>a</sup>ED: emergency department.

Multimedia Appendices 8 and 9 show the TBE and ORE for every single performed task, respectively. Multimedia Appendix

8 shows that tasks 1, 2, and 4a had the shortest TBE. Therefore, creating the parental account and the child’s profile was not the

most efficient task. Task 4a showed the lowest efficiency, with the shortest TBE (0.0065 tasks per second) and lowest ORE (50.2%).

**Satisfaction: SUS Questionnaire**

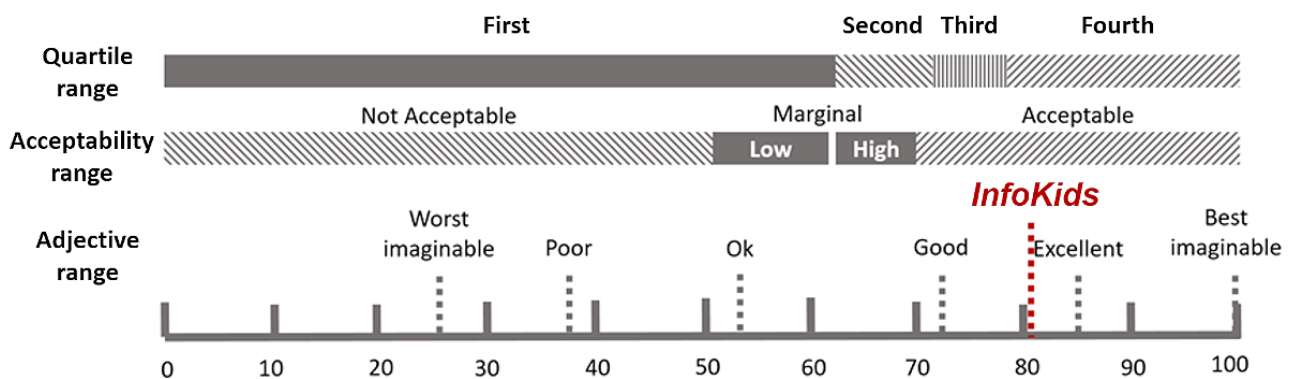
The mean overall SUS score was 80.88 (SD 8.57; Table 4). This shows that the usability of the InfoKids app was perceived as

good to excellent [68] (Figure 7). The detailed scores indicate that of the 17 participants, 4 (24%) assessed the app as fair, 5 (29%) as good, and 8 (47%) as excellent. Mean SUS scores were similar when analyzed by two age categories, ≤40 years (mean 82.14, SD 9.94 years) and >40 years (mean 80, SD 8.42 years; Mann–Whitney *U* test=29.5; *P*=.60).

**Table 4.** System Usability Scale (SUS) questionnaire results.

	Question 1	Question 2	Question 3	Question 4	Question 5	Question 6	Question 7	Question 8	Question 9	Question 10	SUS score (sum×2.5; maximum 100)
P1	3	3	3	4	4	4	4	4	4	4	92.5
P2	3	3	4	4	3	4	3	4	4	3	87.5
P3	3	2	2	4	3	3	3	2	3	3	70
P4	4	3	3	4	3	3	4	4	3	4	87.5
P5	3	3	3	4	3	2	3	4	3	2	75
P6	3	3	3	4	3	2	3	4	3	4	80
P7	3	1	2	4	3	3	3	4	3	4	75
P8	4	3	3	4	4	4	3	4	4	3	90
P9	3	3	4	4	3	3	4	4	4	3	87.5
P10	4	0	4	0	3	1	4	4	3	3	65
P11	4	3	3	4	3	4	3	4	4	4	90
P12	3	3	3	2	3	3	4	4	4	3	80
P13	4	3	3	3	4	3	4	4	4	4	90
P14	4	3	3	2	3	3	3	4	3	3	77.5
P15	4	3	3	4	4	4	4	4	4	1	87.5
P16	3	3	3	3	3	3	3	2	2	3	70
P17	2	3	3	3	3	3	3	2	3	3	70
Values, mean (SD)	3.35 (0.59)	2.65 (0.84)	3.06 (0.54)	3.35 (1.08)	3.24 (0.42)	3.06 (0.8)	3.41 (0.49)	3.65 (0.76)	3.41 (0.6)	3.18 (0.78)	80.88 (8.57)
Values, median (IQR)	3 (3-4)	3 (3-3)	3 (3-3)	4 (3-4)	3 (3-3)	3 (3-4)	3 (3-4)	4 (4-4)	3 (3-4)	3 (3-4)	80 (75-87.5)

**Figure 7.** Overview of the modified System Usability Scale rating table with inserted value ranges [68].





## Qualitative Evaluation

### Usability Problems

The *think-aloud* method identified 14 usability problems with a total of 81 occurrences. Table 5 describes the frequency of

usability problems per task and the frequency of each usability problem that led to task completion with difficulties or failures. A total of 9 usability problems led to difficulties to complete a task only, and 5 led to difficulties to complete a task and failures.

**Table 5.** Frequency of 14 usability problems, difficulties, and failure.

Tasks and usability problems	Frequency of the usability problem (n=81), n (%)	Frequency with which it led to task completion with difficulty (n=62), n (%)	Frequency with which it led to failure to complete the task (n=19), n (%)
<b>Task 1: create a parental account</b>			
None	0 (0)	0 (0)	0 (0)
<b>Task 2: create a child profile</b>			
Participants expected to access the child's profile by clicking directly on the card	1 (1)	1 (2)	0 (0)
Participants wondered if information had been properly saved	4 (5)	4 (6)	0 (0)
<b>Task 3: find the symptoms page</b>			
Participants did not directly find the symptoms' list	5 (6)	5 (8)	0 (0)
Participant did not directly find the cough symptom	1 (1)	1 (2)	0 (0)
<b>Task 4a: find and understand the waiting times page</b>			
Participants did not directly find the waiting times page	13 (16)	8 (13)	5 (26)
Participants faced difficulties to understand the meaning of the cars and the different colored lines	10 (12)	2 (3)	8 (42)
<b>Task 4b: find and understand the forecast page</b>			
Participants had difficulties in finding the page.	4 (5)	3 (5)	1 (5)
<b>Task 5: inform of the departure to the ED<sup>a</sup></b>			
Participants had difficulties in finding this feature.	7 (9)	7 (11)	0 (0)
Participants did not understand that they had to select the child.	13 (16)	13 (21)	0 (0)
<b>Task 6a: find the map tutorial page</b>			
Participants expected to access the map tutorial directly in the map page.	6 (7)	5 (8)	1 (5)
Participants had difficulties in finding the map tutorial because of a pop-up hiding the button.	2 (2)	2 (3)	0 (0)
<b>Task 6b: find the location of the ED</b>			
Participants did not understand the meaning of the "H" icon indicating the location of the ED on the map.	9 (11)	5 (8)	4 (21)
<b>Task 7: find the diagnostic sheet</b>			
Participants did not directly find the page.	4 (5)	4 (6)	0 (0)
Participants had difficulties in finding the section to access the diagnostic sheet.	2 (2)	2 (3)	0 (0)

<sup>a</sup>ED: emergency department.

Identified usability problems were rated by their severity scores. Of the 81 occurrences of usability problems, 2 (2%) were rated with a severity score of 1 (cosmetic), 22 (27%) were rated 2 (minor), 17 (21%) were rated 2.5 (between minor and major), 11 (14%) were rated 3 (major), and 29 (36%) were rated 4 (catastrophic; Table 6; Multimedia Appendix 10 [62,63]). None of the participants experienced major or catastrophic usability problems when completing tasks 1, 3, and 7 but tasks 2, 4a, 4b,

5, 6a, and 6b were the most problematic. When analyzing the time on task, the longest time taken to complete task 2 seemed to be related to the time required to access and fill this page compared with other tasks, although the completion rate was optimal and usability problems were reported as minor. The third longest time taken to complete task 4a appeared to be related to the many usability problems graded as catastrophic.

**Table 6.** Severity scores, identification of usability problems, frequency, percentage, and related task.<sup>a</sup>

Usability problems	Value (n=81), n (%)	Related task
<b>Severity score 1</b>	2 (2)	N/A <sup>b</sup>
Access the child's profile	1 (1)	2
Find the cough symptom	1 (1)	3
<b>Severity score 2</b>	22 (27)	N/A
Select the child	13 (16)	5
Message hiding the button to access the map tutorial	2 (2)	6a
Find the symptom page	5 (6)	3
Find the diagnostic sheet: Select the history section	2 (2)	7
<b>Severity score 2.5</b>	17 (21)	N/A
Find the waiting times page	13 (16)	4a
Find the diagnostic sheet: Reach the information page	4 (5)	7
<b>Severity score 3</b>	11 (14)	N/A
Record the information entered	4 (5)	2
Find the page to inform about departure to the ED <sup>c</sup>	7 (9)	5
<b>Severity score 4</b>	29 (36)	N/A
Find the forecast page	4 (5)	4b
Find the location of the ED	9 (11)	6b
Understand the waiting times page	10 (12)	4a
Find the map tutorial	6 (7)	6a

<sup>a</sup>Severity score: 1=cosmetic, 2=minor, 3=major, and 4=catastrophic.

<sup>b</sup>N/A: not applicable.

<sup>c</sup>ED: emergency department.

Most problems identified (34/81, 42%) were related to the significance of codes' criteria, whereas 35% (28/81) problems were related to compatibility criteria, 21% (17/81) to the guidance criterion, and 2% (2/81) to explicit control (Table 7).

**Table 7.** Ergonomic criteria associated with identified usability problems with its number of occurrence and frequency.

Ergonomic criteria	Usability problems	Number of occurrence and percentage of the usability problem, n (%)
<b>Guidance</b>		17 (21)
Guidance—prompting	Select the child	13 (16)
Guidance—immediate feedback	Recording of information entered	4 (5)
<b>Explicit control</b>		2 (2)
User control	Message hiding the button to access the <i>map tutorial</i>	2 (2)
<b>Significance of codes</b>		34 (42)
	Find the <i>symptom</i> page	5 (6)
	Find the <i>cough</i> symptom	1 (1)
	Find the <i>waiting times</i> page	13 (16)
	Find the <i>forecast</i> page	4 (5)
	Find the location of the ED <sup>a</sup>	9 (11)
	Find the <i>diagnostic</i> sheet: select the <i>history</i> section	2 (2)
<b>Compatibility</b>		28 (35)
	Access the child's profile	1 (1)
	Understand the <i>waiting times</i> page	10 (12)
	Find the page to inform about departure to the ED	7 (9)
	Find the <i>map tutorial</i>	6 (7)
	Find the <i>diagnostic</i> sheet: reach the information page	4 (5)

<sup>a</sup>ED: emergency department.

### Debriefing Interviews

All participants (17/17, 100%) reported positive feedback regarding their overall experience with the app. More specifically, when asking them about the strengths of the app by an open question, 71% (12/17) of participants emphasized the usefulness of the proposed features, such as the information on waiting times, advice according to symptoms, the diagnostic sheet, and the ability to inform the ED of their arrival. Moreover, 65% (11/17) noted the ease of use because of the quickly accessible menu and its intuitiveness.

Regarding app improvements and mitigation measures, 35% (6/17) of participants expressed several needs: (1) an improved ED geolocation on the map; (2) rewording the *history* section to *diagnostic history* to find the sheet more easily; (3) improved explanation of the meaning of the 5 colored emergency lanes; and (4) placement of the *I am coming to the ED* button on the home page to facilitate its access. Participants also expressed their wish to have new features such as information about the laboratory results and treatment plan in the *diagnostic* sheet (3/17, 18%), ability to exchange with the ED directly through the app with a *chat* option (1/17, 6%), and the ability to share the *diagnostic* sheet with another family member (1/17, 6%).

## Discussion

### Principal Findings

In this study, we report an overall good-to-excellent perceived usability of a patient-centered mHealth app aimed at covering the entire emergency care process by supporting patients before, during, and after an ED visit. Given the high percentage of patient-centered assigned tasks that participants successfully completed, we observed a good overall rate of understanding of how the app worked. Participants found most of the features useful, particularly the recommendations provided according to their child's symptoms, access to information related to waiting times and the diagnosis made in the ED, and ability to inform the ED upon their arrival. However, the ergonomic evaluation identified 81 occurrences of 14 usability problems, of which 50% (7/14) were serious, as their severity ratings were either major or catastrophic. These results indicated areas for app improvements. From participants' and ergonomists' suggested usability improvements, mitigation measures were listed to further improve the app and avoid barriers to its adoption (Table 8).

**Table 8.** Identified usability problems and mitigation measures.

App's features and identified usability problems	Mitigation measures
<b>Editable list of children</b>	
The edit button on the child's profile was not obvious enough	The whole patient's profile card should be made clickable.
<b>Child's profile page</b>	
Uncertainty as to whether the entries for chronic illnesses and regular medications are saved in the app	Entries for chronic conditions and regular medications should be visible on the patient's profile page.
<b>Browsing through the pages or menus</b>	
Difficulty in locating the ED <sup>a</sup> departure announcement button	The <i>I am coming to the ED</i> button should also be placed on the home page.
Difficulty in locating the <i>diagnostic</i> sheet	The <i>history</i> page should be changed to <i>diagnostic history</i> .
Difficulty in locating the <i>map tutorial</i>	The <i>map tutorial</i> should be placed directly in the <i>map</i> page. The tutorial could start automatically when the map is used for the first time, as is the case in many apps.
Difficulty in locating the <i>waiting times</i> page, the <i>forecast</i> page, and the <i>symptom</i> page	The tree-testing and card-sorting techniques should be used to improve the information architecture and the nomenclature. A search bar should also be added.
<b>Symptoms' decision tree</b>	
Difficulty in browsing through the symptom's decision tree	A search bar and more redundancy should be added.
<b>Real-time display of the ED waiting room</b>	
The meaning of "occupancy" in the waiting room was not clear for nonacquainted users	The busy screen should be redesigned using a more explicit graphic representation and adding a caption. Representing patients by avatars and not by cars could be more intuitive for the user.
<b>Geolocation and guidance to the ED</b>	
Geolocation markers were not explicit enough on the <i>map</i> page	Knowing that icons are images and that images can be polysemic, their understanding can vary from one person to another. To reduce this effect, a locator pin with a textual indication could be used. In addition, it could be enlarged and bounced to attract the user's attention.
<b>ED departure feature <i>I am coming to the ED</i></b>	
No prompt to indicate to the user that they must select the child to be announced on departure to the ED	A selection checkbox should be set up so that users understand that they need to select a child.
It should be easily possible to hide the pop-up message confirming the patient's departure to the ED	The chevron must be enlarged to make it more visible.

<sup>a</sup>ED: emergency department.

Apps' attrition has emerged as an area of particular concern in recent literature on new technological innovations [69,70]. Even when apps are evidence based, this does not guarantee that they will be used consistently over time. Similar to other health information technologies, the benefits of apps can only be achieved if end users intend to adopt them [71]. Poor usability and a lack of user-centered design have been described as 2 drivers for low adoption rates of mobile apps [45]. Although usability has been identified as a key component of good practice in the development of digital apps [72], only a small fraction of medical apps publish their usability evaluation results, despite their growing number [42]. The main concerns of these apps are health conditions or diseases such as mental health [45,73], cancer [74,75], nutrition [76], diabetes [77,78], chronic disease self-management [79,80], and child health [81-86], among others [42].

However, there is no app that addresses more broadly patients' accompaniment throughout their entire ED care journey (ie,

before, during, and after their visits), as well as providing personalized health information and support to manage illness or trauma. We found only 2 studies describing the usability evaluation of prototype app versions providing a personalized treatment schedule and an indoor navigation service for outpatients [87,88]. Moreover, both apps seem to be limited to this sole in-hospital purpose, without patient-centered information regarding their disease, and restricted to Android operating software systems. A study by Westphal et al [89] described a very promising web-based system for providing real-time information to ED patients regarding the procedures that they may encounter during their journey. However, similar to the previous 2 studies, this system focused only on the patient's journey within the hospital and did not address the patient's experience over the entire course of care.

The InfoKids app aims to bridge these gaps. Importantly, it is intended for wider use within our institution. Through the current iterative processes of development and evaluation, it is

intended to soon become a more universal tool to connect the whole population seeking ED care (ie, adults, geriatric, and gynecologic) in a service area of more than 1 million people. In this sense, this study contributes to this iterative development process. Given its interconnection with the hospital's computerized system, this app has the potential to ensure better coordination, continuity, and transition of care, thus improving both the patient experience and hospital efficiency.

### Strengths

This study had several strengths. To our knowledge, this was the first report of findings of the usability evaluation of an app supporting the longitudinal patient care transition from home up to ED discharge. Second, the mixed methods approach used in combination with different types of usability methods was another strength already identified by studies recognizing the utility of using qualitative and quantitative approaches for app usability testing [72,90]. Third, the 9 goal-oriented tasks assessed were centered around the main features of the app. The fact that users can perform a set of tasks centered around these features that are representative of those that users would normally use in clinical care was identified as a good way to determine the usability of the app and its features and workflow [91]. Fourth, this study added to the literature that recommends more usability studies focused on patient-centered apps [72,91-97]. It also contributed to the effort to publish usability studies based on academic development and patient-centered care, rather than a purely commercial development approach [42].

### Limitations

Our study had some limitations. First, we used an artificial laboratory environment, which has a low degree of fidelity. As a result, the generalizability and transferability of the results may be limited in real-life settings. Furthermore, the results obtained were based on an assessment of usability with participants who were naïve to its use. Therefore, it can be assumed that in-depth use of the app beforehand could have improved the perception of its usability among people who had used it before and avoided certain problems of comprehension and navigation. Interestingly, the use of a tutorial that was supposed to correct these problems seems to have been a source of difficulties for users in itself, if only to find it in the app. Therefore, it might be judicious in future versions to replace it with an interface offering contextual help on each page, rather than a long tutorial to memorize or search for. These assumptions should be addressed in future studies. Another limitation is that the small sample of 17 users might not have been sufficiently large to reveal all usability issues. However, it was assumed that 5 users are already a sufficient sample to reveal 85% of usability problems, whereas 15 users were sufficient to uncover almost 97% of problems [98]. In contrast, the fact that only one scenario was proposed to users in an arbitrary order set by the investigators raises concerns about the applicability of the results to any other clinical situations or

navigational pattern in the app. This scenario was chosen to test most of the functions of the app according to a logical workflow model that parents wishing to consult with their child in the emergency room would follow. However, it cannot be excluded that other scenarios could have generated other navigation schemes and usability problems or facilitation. For example, if task 4a (evaluated as the most complicated task) had not been interposed between the choice of symptoms (task 3) and the announcement of departure to the ED (task 5) in this scenario, it is possible that no navigational problems would have occurred. It might be interesting in a future study to test the usability of the app based only on several standardized scenarios without predefined tasks. Instead, tasks and navigation would be left to users' discretion, as in real life. Finally, as the InfoKids app is intended to be used in case of emergency (or at least perceived as such by parents), the quiet and nonstressful laboratory environment used in the study may appear to be a limitation. Guidelines for conducting usability testing recommend establishing a calm and relaxed atmosphere in which users can work without feeling stressed [99-101], although stress in usability testing has rarely been studied so far. One of the few existing studies by Janneck and Dogan [99] compared a usability test performed in a laboratory under calm and relaxed conditions with a test situation in which several stressors (time pressure, noise, and social pressure) were applied. They observed that participants under stressful conditions demonstrated poorer performance in the execution and accuracy of tasks and rated the usability and user experience of the software much more negatively. However, it should be noted that although various situations tend to elicit different patterns of stress responses, there are also individual differences in perceived and behavioral stress responses to the same situation [102]. Indeed, future research assessing the impact of stressors on the usability of InfoKids would provide valuable input for future development in the adult setting.

### Conclusions

The usability of mHealth apps is an important factor for their adoption and use. This study addresses a gap in the literature by reporting findings from a usability evaluation relevant to a patient-centered mobile app designed to support the entire emergency care process by assisting patients before, during, and after an ED visit. Our results show that the usability of the current version of InfoKids is rated as good to excellent by users. However, areas for app improvement are identified and mitigation measures are proposed. These usability problems will be addressed in updated releases of InfoKids and will be used to inform the development of its next version as a universal app for all patients seeking ED care. The next step would be to determine whether this mobile app benefits ED patient experience and ED efficiency in a real-life patient environment and clinical conditions. Given the paucity of research in this area, we conclude that our findings could also be useful in paving the way for further research on mobile apps aimed at supporting and accompanying patients in their care episodes.



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## Conflicts of Interest

FE has business interests in a company that may be affected by the research reported in the enclosed paper. FE has fully disclosed those interests and has in place an approved plan for managing any potential conflicts arising from that involvement.

### Multimedia Appendix 1

Description of the expected handling tasks of the app and criteria for the determination of completion for each task.

[[DOCX File , 14 KB - pediatrics\\_v5i1e25540\\_app1.docx](#) ]

### Multimedia Appendix 2

Screenshot of the *family* page. On the *family* page, each child is represented by a card containing their photo, the child's first name, and an *edit* button located at the bottom right of the card. To access the child's profile and edit the data, it is necessary to click this button. As many children as necessary can be added.

[[PNG File , 443 KB - pediatrics\\_v5i1e25540\\_app2.png](#) ]

### Multimedia Appendix 3

Screenshot of the child's profile page. The *chronic illnesses* button must be clicked to view the child's chronic illnesses.

[[PNG File , 143 KB - pediatrics\\_v5i1e25540\\_app3.png](#) ]

### Multimedia Appendix 4

Screenshot of the *symptom* page.

[[PNG File , 260 KB - pediatrics\\_v5i1e25540\\_app4.png](#) ]

### Multimedia Appendix 5

Screenshot of the child selection page.

[[PNG File , 108 KB - pediatrics\\_v5i1e25540\\_app5.png](#) ]

### Multimedia Appendix 6

Screenshot of the *H* icon indicating the localization of the emergency department on the map.

[[PNG File , 1043 KB - pediatrics\\_v5i1e25540\\_app6.png](#) ]

### Multimedia Appendix 7

The 10-item System Usability Scale questionnaire.

[[DOCX File , 12 KB - pediatrics\\_v5i1e25540\\_app7.docx](#) ]

### Multimedia Appendix 8

Time-based efficiency per task (N=17 participants).

[[PNG File , 6 KB - pediatrics\\_v5i1e25540\\_app8.png](#) ]

### Multimedia Appendix 9

Overall relative efficiency per task (N=17 participants).

[[PNG File , 7 KB - pediatrics\\_v5i1e25540\\_app9.png](#) ]

### Multimedia Appendix 10

Details regarding the usability problems identified.

[[DOCX File , 19 KB - pediatrics\\_v5i1e25540\\_app10.docx](#) ]

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## Abbreviations

- ED:** emergency department
- ORE:** overall relative efficiency
- SUS:** System Usability Scale
- TBE:** time-based efficiency
- TCR:** task completion rate

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Original Paper

# Health Care Professional and Caregiver Attitudes Toward and Usage of Medical Podcasting: Questionnaire Study

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## Abstract

**Background:** Podcasts are used increasingly in medicine. There is growing research into the role of podcasts in medical education, but the use of podcasting as a tool for pediatric parent/caregiver health education is largely unexplored. As parents/caregivers seek medical information online, an understanding of parental preferences is needed.

**Objective:** We sought to explore health care professional and parent/caregiver awareness and views on podcasting as a health education tool.

**Methods:** This survey study was conducted and distributed via in-person collection from parents/caregivers ( $\geq 18$  years old) in the waiting room of an academic pediatric primary care clinic, targeted social media promotion, and professional listservs for health care professionals in pediatrics. Statistical analysis included chi-square tests of independence between categorical variables.

**Results:** In total, 125 health care professionals and 126 caregivers completed the survey. Of those surveyed, 81% (101/125) of health care professionals and 55% (69/126) of parents/caregivers listened to podcasts ( $P < .001$ ). Health care professionals and parents/caregivers listed the same top 3 quality indicators for medical podcasts. Podcast listeners were more likely to have higher incomes and use professional websites for information. The survey elicited a variety of reasons for podcast nonengagement.

**Conclusions:** Health care professionals appear to be more engaged in medical education podcasts than parents/caregivers. However, similar factors were valued when evaluating the quality of a pediatric podcast: accuracy, transparency, and credibility. Professional websites may be one avenue to increase podcast uptake. More needs to be done to explore the use of podcasts and digital media for medical information.

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**KEYWORDS**

podcasts; social media; caregiver; parent; parenting; education; pediatrics; podcasting; patient education

## Introduction

Since 2006, podcasts have been growing in popularity and influence [1]. Within the medical profession, podcasting is also on the rise. An increasing number of research studies have been conducted on designing podcast content, ensuring the quality of that content, and using audio learning in continuing medical education [2-7]. Although the fields of emergency medicine and critical care appear to have the highest engagement in this medium, there are a number of notable pediatric podcasts that

have a growing listenership (PediaCast, Primary Care Perspectives, Peds RAP, Pediatrics On Call) [8-11].

Podcasting as a medium for delivery of medical and health information has many advantages for both parents and health care professionals. Many pediatric podcasts are produced by professionals who elevate evidence-based messaging during a time where antiscience messaging is a widespread problem. Podcasts provide health information in a medium that is easily accessed in times of need, such as overnight when health care providers are not immediately available and parents are looking

for digital health information. This is facilitated by podcast archives, which can serve as educational repositories that can be accessed over time [3]. Podcasts also afford real-time and up-to-date learning, so health care professionals can efficiently stay abreast of recent guidelines and field advancements [3,12].

Ongoing assessments of podcasts as a tool for medical education have highlighted their growing popularity—likely due in part to their accessibility and free content—and support continued promotion and content creation in this arena [3,8,13]. However, a review of podcasting and medical education from 2017 showed that no papers were published on the impact of podcasting on patients [2]. This is likely because much of the focus in the literature revolves around continuing medical education for physicians and student learners, and not on parental/caregiver engagement or experience with this medium [14].

In a world that is increasingly digitally connected, our goal was to survey both pediatric health care professionals and parents/caregivers on their views of podcasting as a form of medical education, to explore which podcasts pediatric health care professionals are engaging with for their own education and may be recommending to patients, and to identify how podcasts compare to other digital media in meeting the educational needs of pediatric health care professionals and parents/caregivers.

## Methods

A cross-sectional prospective survey study to collect data on podcasting as a tool for medical education for both health care professionals and parents/caregivers was performed. Survey design and analysis were modeled after the CHERRIES (Checklist for Reporting Results of Internet E-Surveys) format [15]. The target population included both pediatricians at Children's Hospital of Philadelphia (CHOP) and parents/caregivers bringing their children to a CHOP outpatient pediatrics practice in South Philadelphia (CHOP Primary Care, South Philadelphia). The survey was created in REDCap and survey completion was through the REDCap website for all participants. The survey was disseminated to physicians through an American Academy of Pediatrics and internal CHOP listserv. The study was reviewed by a CHOP Institutional Review Board and granted an exemption due to the anonymous collection of data.

The survey was created and developed by the investigators to answer how podcasting is used for pediatric medical education for health care professionals and parents/caregivers. Based on existing consensus quality indicators, we designed our questions around the 3 themes of credibility (eg, “The information presented by the podcast is accurate”), content (eg, “The content is relevant particularly for my practice/patients”), and design

(eg, “The content is conversational/entertaining”) [16]. The complete survey is provided in [Multimedia Appendix 1](#).

The survey was distributed as an open survey without password protection, as no identifying data points were collected on participants. Contact with pediatric health care professionals was made online and the survey was distributed over listservs. Contact with parents/caregivers was made in person by visiting the CHOP Primary Care, South Philadelphia practice. For the recruitment of both health care professionals and parents/caregivers, notice of the survey was also posted on Facebook and Instagram via accounts held by the authors of the study. No incentives were offered for study completion except the ability to add to current scientific literature. The survey was distributed from May 2019 through August 2019. The entire electronic survey consisted of 4 screens without the ability to review entries once they were made. All items on the survey had to be completed for the survey to be submitted.

Descriptive statistics, such as means, medians, and counts/percentages were used to describe the population. Differences between subgroups of the populations (health care providers versus parents/caregivers and podcast listeners versus nonlisteners) were examined using chi-square tests of independence to test for association between categorical variables. A  $P$  value of  $>.05$  was considered significant. All statistical analyses were done using R (version 3.6.1; R Foundation for Statistical Computing).

## Results

The survey was completed by 251 participants ([Table 1](#)). Of the survey respondents, 125 were health care professionals and 126 were parents/caregivers. The median ages of the respondents were 30-39 years for health care professionals, and 30-39 years for parents/caregivers. Notably, parents/caregivers were significantly more likely to be under the age of 30 ( $P=.02$ ). There were no significant differences in gender and self-identified race between the two groups. Health care respondents were more likely to have higher educational attainment and incomes ( $P<.001$  for both), with the median annual income being  $\geq$ US \$200,000 for health care professionals and US \$125,000 for parents/caregivers. Of the health care professionals, pediatricians made up the largest group of respondents (95/125, 76%). No health care professionals surveyed used Facebook, Instagram, or YouTube for learning, whereas a larger contingency of parents/caregivers used Facebook (1/126, 1%), Instagram (10/126, 8%), or YouTube (9/126, 7%) for medical information. In addition, 2.4% (3/125) of health care professionals and 0.8% (1/126) of parents/caregivers used Twitter as a source of medical information.

**Table 1.** Demographics.

Characteristic	Podcast listeners (N=170), n (%)	Podcast nonlisteners (N=81), n (%)
<b>Age cohort (years)</b>		
18-20	3 (1.8)	2 (2.5)
21-29	26 (15.3)	12 (14.8)
30-39	90 (52.9)	33 (40.7)
40-49	33 (19.4)	22 (27.2)
50-59	15 (8.8)	8 (9.9)
≥60	3 (1.8)	4 (4.9)
Male sex	28 (16.5)	18 (22.2)
<b>Race</b>		
White	144 (84.7)	57 (70.4)
Black	6 (3.5)	8 (9.9)
Asian	17 (10)	12 (14.8)
Other	3 (1.8)	4 (4.9)
Hispanic or Latino	13 (7.7)	8 (9.9)
<b>Annual income (US \$)</b>		
0-9999	2 (1.2)	6 (7.4)
10,000-24,999	3 (1.8)	4 (4.9)
25,000-49,999	4 (2.4)	6 (7.4)
50,000-74,999	11 (6.5)	13 (16.1)
75,000-99,999	9 (5.3)	4 (4.9)
100,000-124,999	18 (10.6)	5 (6.2)
125,000-149,999	14 (8.2)	3 (3.7)
150,000-174,999	15 (8.8)	5 (6.2)
175,000-199,999	17 (10)	6 (7.4)
≥200,000	68 (40)	19 (23.5)
Decline to answer	9 (5.3)	10 (12.4)
<b>Marital status</b>		
Single	25 (14.7)	20 (24.7)
Married	141 (82.9)	56 (69.1)
Widowed	0 (0)	0 (0)
Divorced	3 (1.8)	1 (1.2)
Separated	0 (0)	4 (4.9)
Other	1 (0.6)	0 (0)
<b>Education</b>		
Less than high school	1 (0.6)	3 (3.7)
High school degree/equivalent	4 (2.4)	10 (12.4)
Some college	6 (3.5)	8 (9.9)
Associate	2 (1.2)	9 (11.1)
Bachelor	25 (14.7)	8 (9.9)
Graduate	132 (77.7)	43 (53.1)
<b>Role</b>		
Health care provider	101 (59.4)	24 (29.6)

Characteristic	Podcast listeners (N=170), n (%)	Podcast nonlisteners (N=81), n (%)
Parent/caregiver	69 (40.6)	57 (70.4)

Although over half of respondents in both groups listened to podcasts, far more health care professionals engaged in the medium (101/125, 81%) than parents/caregivers (69/126, 55%;  $P<.001$ ). Of the parents/caregivers who listened to podcasts, more than half (58/69, 84%) had a bachelor's degree or higher and most of the respondents were White (47/69, 68%). Approximately 5% (6/126) of parents/caregivers had never heard of a podcast. As a whole, podcast listeners were more

likely to have higher incomes ( $P=.001$ ). Those who used podcasts were more likely to use professional websites as additional sources of information, whereas those who did not favored YouTube ( $P<.001$ ). Both health care professionals and parents/caregivers agreed on the top 3 desired qualities of a podcast: accuracy of the information presented, a distinction made on the podcast between fact and opinion, and podcast host qualifications (Textbox 1).

**Textbox 1.** Podcast qualities valued by listeners, ranked by percentage of respondent 5/5 (“always”) ratings.

Physicians	
1.	Accuracy of information (107/125, 85.6%)
2.	Authors are qualified (98/125, 78.4%)
3.	Fact vs opinion is clear (86/125, 68.8%)
4.	Professionalism (65/125, 52%)
5.	Relevancy to patients (64/125, 51.2%)
Caregivers	
1.	Accuracy of information (77/126, 61.1%)
2.	Authors are qualified (69/126, 54.8%)
3.	Fact vs opinion is clear (65/126, 51.6%)
4.	Content is entertaining (47/126, 37.3%)
5.	Professionalism/relevancy (39/126, 31%)

The most commonly listed reason for not listening to podcasts was a lack of time (19/125, 15.2% of providers and 36/126, 28.6% of parents/caregivers); however, a majority of respondents who did not listen to podcasts cited other reasons, including finding them too slow, being overwhelmed by the options, lacking a routine for them, and not finding them entertaining. Even though most health care professionals listened to podcasts themselves, only 21/125 (17%) recommended podcasts to their patients as a form of education.

## Discussion

In a survey completed by 251 health care professionals and patients' parents/caregivers, there were significant differences in the pattern of podcast use between the two groups. Although a majority of each group surveyed listened to podcasts, health care professionals were significantly more likely to use podcasts as an educational medium. Given the extensive amount of research and quality improvement that has gone into the medical podcasting sphere, this is perhaps not a surprising finding [4,16].

Both educational status and income level were higher in those who listened to podcasts. Lower income in the parent/caregiver group compared to the health care professional group resulting in fewer resources may explain the disparity seen in podcast use between the two groups of individuals. Smartphones have been shown to be the most popular device for listening to podcasts: 65% of podcast consumers listen to podcasts on mobile

devices, compared to 25% on computers or laptops, and 10% on smart speakers [1]. In low-income households with incomes below US \$30,000 a year, 29% do not own a cell phone and 44% do not have broadband internet services, and therefore have limited access to podcasts [17].

Podcast listeners, whether health care providers or parents/caregivers, tended to agree on the 3 top qualities they look for in medical podcasts, identified in this study as the following: accuracy of the information presented, a distinction made on the podcast between fact and opinion, and podcast host qualifications. This was a surprising finding, given previous literature suggesting health care educators seemed to require less stringent qualifications for podcasts as compared to other media, with coherence, citations, and expertise required for blogs but not for podcasts [4]. Accessibility across multiple platforms, identified as a major criterion for a quality podcast in that study, was not one of the top 3 qualities identified in our study. We hypothesize this could relate to advancements in smartphone and streaming technology in the past few years making podcasts more accessible overall.

Our study shows a high rate of listenership among surveyed health care providers (101/125, 81%), which is consistent with numbers from other recent studies showing podcast listenership rates among internal medicine and emergency medicine residents of 59% and 89%, respectively [18,19]. Medical podcasts represent an accessible and flexible means of continuing medical



education (CME) for health care professionals who have completed formal training, as well as for trainees who seek supplementation to more traditional avenues of medical education. Many currently available pediatric podcasts offer CME credits for their audience, such as Peds RAP [20], and cover seasonal and salient topics of interest, such as diagnosing and treating “long COVID” in children (Pediatrics on Call Episode 64 [21]). There are also examples of national societies as well as residents/fellows creating podcasts with specialty-specific content (eg, “Bowel Sounds: The Pediatric GI Podcast” [22]), showcasing the ability of the medium to serve diverse medical education needs [23,24]. For trainees who attend required didactics as live lectures or case discussions, often 30-60 minutes in length and during the workday, a podcast covering the same material that can be archived and listened to on a flexible timetable is an invaluable self-directed learning resource that gives listeners the discretion to engage when they so desire. Further studies on the efficacy of podcasting as a medical education tool should be explored.

Interestingly, in our study, while a large majority of health care professionals listen to educational podcasts, only 17% (21/125) of them recommend podcasts as a resource to patients or parents/caregivers. Although this study did not specifically address the reasons why they did not refer parents/caregivers to these podcasts, this may be due to the types of podcasts being consumed and the motivations behind their use. An iTunes search of pediatric podcasts at the time of writing uncovered 25 podcasts, only 5 of which included parents/caregivers in their targeted audience. Instead, the majority of podcasts aim to be “edutainment,” or medically educational entertainment, for physicians [24]. Pediatricians in remote hospitals have previously reported that podcasts help them stay connected to colleagues in their field and up to date with recent practice patterns [25]. More recently, a subset of medical podcasts has targeted early-stage trainees with the goal of increasing exposure to different areas of interest within pediatrics (eg, Charting Pediatrics [26]). The style and content of these pediatric podcasts cater more to health care professionals and trainees than to patients and parents/caregivers, which likely factors into why so few providers surveyed indicated they would recommend medical podcasts to patients and their families. Health care professionals may not want to direct their patients toward resources that use medical jargon or present health care information that is difficult for a family to interpret in the context of their individual situations. Health care professionals value the physician-patient relationship and may wish to preserve direct communication of medical advice between the provider and patient/guardian. Finally, the electronic medical record has been designed to facilitate the inclusion of more traditional paper printouts for patient education, a more historic form of guidance and a tested resource. Given the time-pressured environment of outpatient medicine and the lack of a centralized medical podcast repository, describing and facilitating access to podcasts would place an additional cognitive load on the health care professional, making it less likely that such an action would be taken. Further qualitative research may elucidate the reasoning behind provider hesitancy to recommend podcasts to patient families. This information would guide podcast creators

on how to broaden their audience to include patients and parent/caregivers in addition to health care professionals.

The vast majority of health care professionals and parents/caregivers did not use social media platforms as a source of medical information, despite their known popularity in the personal lives of both groups. Of note, the listed social media platforms (Facebook, Instagram, Twitter, YouTube) lack the quality indicators our study’s participants cited as most important when they seek educational podcasts, such as accuracy, transparency, and a qualified host. This is an interesting contrast to prior surveys that have identified a high percentage of health professionals who use social media for education [27]. Differences may be due to the demographic surveyed (eg, attending physicians versus graduate medical trainees) or survey wording that precluded the consideration of subconscious consumption of information on social media.

Our study is subject to the many limitations inherent to an online survey. There was no way to ensure the survey was only filled out once per respondent. Recruitment through social media may make the data regarding other sources of information difficult to interpret (eg, a patient responding to the survey through Facebook evidently uses Facebook for information). The survey was internally created and not a previously validated survey. A popular pediatric podcast is hosted by one of the authors, so an internally distributed survey may skew the physician population toward higher listenership. In addition, because the survey was distributed in one clinic within a hospital network in one city, the results have narrow generalizability, although the demographics of the listeners surveyed were typical of national podcast listeners [1]. Of note, the sampled parents/caregivers were mostly White, though the clinic where they were surveyed serves a primarily non-White demographic (26% White). This highlights potential biases in the administration of the survey, such as selection bias, language barriers (the survey was only offered in English), nonresponse bias, or the use of a White surveyor. Next steps may attempt to address this by reaching a more representative sample of the communities served. Other future work might include examining the motivations of physician versus parent/caregiver in listening to podcasts, qualitative studies on effective presentation of podcast information to parent/caregivers to promote message uptake, and optimizing dissemination of podcasts as an education tool at different points of contact with the health care system (primary care versus the emergency room versus the hospital setting).

In summary, although many health care professionals and parents/caregivers alike use podcasts as a source of information, there is unrealized potential for more engagement with this medium that health care professionals can help to facilitate. With the evolving world of data overload, targeted efforts at improving use of podcasts in patients and parents/caregivers may offer this population a source of updated, accurate medical information. Furthermore, awareness of trustworthy messaging is urgently needed in the setting of rising antivaccine and antisience sentiment. There are data supporting the sustainability of podcasts over time, suggesting that a medical professional’s recommendation of podcast use, if accepted, may lead to lasting use and ongoing education for parents/caregivers

[28,29]. This may be particularly salient during the COVID-19 pandemic and the increasing use of telemedicine and other virtual ways of delivering health care and medical information, particularly in remote areas, where reliable medical information is not as easy or as convenient to access. Given that both health care providers and parents/caregivers primarily used professional websites to obtain medical information, podcasters should

consider partnering with professional websites among other creative solutions to increase uptake of the medium. Educational podcasts that can offer accurate, transparent, and credible medical information to health care providers, patients, and their families are likely to continue to grow as an enduring form of medical education.

### Authors' Contributions

JP and KKL conceptualized and designed the study, drafted the initial manuscript, and reviewed and edited the manuscript. CL, MSZ, and ERW performed the literature search and reviewed and edited the manuscript. MH organized and analyzed the data, generated figures, and drafted sections of the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

### Conflicts of Interest

None declared.

### Multimedia Appendix 1

Sample of survey administered to participants.

[[DOCX File, 19 KB - pediatrics\\_v5i1e29857\\_app1.docx](#)]

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## Abbreviations

**CHERRIES:** Checklist for Reporting Results of Internet E-Surveys

**CHOP:** Children's Hospital of Philadelphia

**CME:** continuing medical education

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Original Paper

# Pediatric Tele–Home Care Compared to Usual Care: Cost-Minimization Analysis

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## Abstract

**Background:** Although home hospitalization has been a well-known and widespread practice for some time in the adult population, it has not been the same case in the pediatric setting. Simultaneously, telemedicine tools are a facilitator of the change in the health care model, which is increasingly focused on home care. In a pioneering way in Spain, the in-home hospitalization program of the Hospital Sant Joan de Déu in Barcelona allows the child to be in their home environment at the time they are being monitored and clinically followed by the professionals. Besides being the preferred option for families, previous experience suggests that pediatric home hospitalization reduces costs, primarily thanks to savings on the structural cost of the stay.

**Objective:** The aim of this study is to compare the average cost of a discharge by tele–home care with the usual care and to analyze the main drivers of the differential costs of both care models.

**Methods:** A cost-minimization analysis is conducted under a hospital's perspective, based on observational data, and estimated retrospectively. A historical control group of similar patients in terms of clinical casuistry to children hospitalized at home was used for comparison.

**Results:** A 24-hour stay at the hospital costs US \$574.19, while the in-home hospitalization costs US \$301.71 per day, representing a saving of almost half (48%) of the cost compared to usual care. The main saving drivers were the personnel costs (US \$102.83/US \$284.53, 35.5% of the total), intermediate noncare costs (US \$6.09/US \$284.53, 33.17%), and structural costs (US \$55.16/US \$284.53, 19.04%). Home hospitalization involves a total stay 27.61% longer, but at almost half the daily cost, and thus represents a saving of US \$176.70 (9.01%) per 24-hour stay.

**Conclusions:** The cost analysis conducted under a hospital perspective shows that pediatric tele–home care is 9% cheaper compared to regular hospital care. These results motivate the most widespread implementation of the service from the point of view of economic efficiency, adding to previous experiences that suggest that it is also preferable from the perspective of user satisfaction.

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**KEYWORDS**

cost analysis; pediatric tele–home care; home care service; health economics; telehealth; economic evaluation; telemedicine; pediatrics



## Introduction

Although home hospitalization in adult hospitals is widespread and well known, and has been well studied from an economic perspective [1-3], it is not the same case in the pediatric environment, with a few exceptions [4,5]. Home is a child's natural environment. The European Association for Children in Hospital Charter establishes that a child should only be admitted to the hospital if absolutely necessary and must be discharged as soon as possible [6]. At the same time, currently available telemedicine tools allow real-time monitoring of a patient's clinical status and regular follow-up with families [7]. In this sense, technology is a facilitator of the change in the care model, and it is increasingly oriented toward home care [8,9].

The Sant Joan de Déu Hospital in Barcelona is a third-level university hospital located in Catalonia, Spain, specializing in the fields of pediatrics, gynecology, and obstetrics. It is a privately owned hospital that operates as part of the public health system. It sees approximately 26,000 discharges annually, with around 250,000 outpatient consultations; 15,000 surgical interventions; and 120,000 emergencies. This health center plays a double role in the Catalan health system: on the one hand it is the reference hospital for the population of the nearest geographical area; on the other, it is a high-complexity reference center at a Catalan, Spanish, and international level. Consequently, the population treated in the hospital presents pathologies of both low and high complexity. The program "SJD a Casa" (SJD At Home) of the Sant Joan de Déu Hospital, a pioneering initiative in Spain, was born in response to this need, and it allows the child to be monitored in their home environment while being followed clinically by the hospital professionals. It is an alternative for stable patients who require hospital treatment but not its infrastructure. Home hospitalization empowers the patient and their families, who can get involved in the direct care of the child, increasing their comfort and promoting family-centered care. Prior studies show that home hospitalization is safe [10] and that clinical effectiveness is not significantly different to conventional hospitalization, even for pediatric patients [11]. Furthermore, prior reporting states that experiences are positive [12-19]. After the success of the pilot program, with families preferring home hospitalization in 94% (61/65) of cases [20], "SJD a Casa" started operating in an ordinary way on November 1, 2019.

In a situation where the capacity to expand hospital beds is limited by the lack of space, especially in an urban context, this model of care frees up space by increasing the capacity to care for highly complex patients [21]. Previous experience suggests that pediatric home hospitalization reduces costs, relative to usual care, especially because of the effect of savings on the structural cost of the stay, which more than offsets the costs of possible readmission [22]. In addition, in a pandemic state, minimizing contact with users may be especially appropriate to prevent outpatient infections [23]. In this context, the aim of this study is to perform a cost-minimization analysis from a hospital perspective.

## Methods

### Study Design

A cost-minimization analysis was performed based on an observational study, including both direct and indirect costs. The analysis followed the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) [24,25]. The study spans from November 1, 2019, to June 30, 2020; it assesses the time horizon from admission to discharge, and it has been conducted under a hospital perspective. No discount rate was used. Unidentified clinical and sociodemographic data from the patients was extracted from the hospital administrative database, while the economic analysis relies on observational data (hospital's accounting department) and was estimated retrospectively. The study was carried out in accordance with the Helsinki Declaration [26]. Data was analyzed using a Google Drive Spreadsheet.

### The SJD Home Intervention

The intervention and characteristics of the families who used the service has been documented in previous studies [20]. When the care team, whether from the hospitalization ward, outpatient department, or emergency department, detects a potential case of hospitalization at home, it contacts the referent of this program, which evaluates it according to the inclusion criteria (30 minutes of isochronous, clinical stability, voluntary consent, and adequate living conditions in the home). The family is then informed about the home care service, and if they agree to participate, they are asked to give informed consent. Finally, the nurse of the team trains the family to be able to carry out the necessary care and delivers a kit. The program is thought to have a maximum of 12 patients; therefore, 15 kits are available. This kit contains the four devices for remote telemonitoring (thermometer, pulse oximeter, blood pressure monitor, and scale) and a tablet that uses Bluetooth with specific software that records device information and allows video calls. The service includes two types of health care: face-to-face, with a daily visit from a pediatrician or nurse, and 24-hour continuous care with real-time telemonitoring by nurses (between 8 AM to 10 PM) and by the emergency department staff (between 10 PM to 8 AM).

### Participants

From November 1, 2019, to June 30, 2020, a total of 357 patients received the pediatric tele-home care service. Among these episodes, only those who were first admitted to the hospital and subsequently were admitted to home hospitalization were selected. We detected three types of patients. First, some were admitted to the tele-home care program to end their treatment; these patients were fairly stable and had shorter stays. Second, some patients had pathologies that required a longer stay. Third, some patients had an underlying pathology. With the aim of having a more precise control group, we only included the first group of patients. The principal pathologies seen at home are acute respiratory diseases (bronchospasm, bronchiolitis, pneumonia), infections in need of intravenous treatment (eg, urinary infections, sepsis, skin and soft tissue infections, and otorrinolaringologic infections), nephrotic syndromes, and wounds in need of nurses' healing. The main procedures done



at home are oxygen therapy, nebulizations, and intravenous treatments (antibiotics and serum therapy). Although the main referral service is general pediatrics, other departments that also refer patients to the tele-home care program are surgery, nephrology, or oncology among others. The resulting study population included 181 patients.

A historical control group of patients with the same clinical casuistry and diagnostics to the children hospitalized at home were used for comparison. A review was made for diagnoses of comparable patients maintaining the same criteria of principal diagnostic, principal procedure, and service origin (pediatrics). All patients of the usual care that were used as a comparison group met all the inclusion criteria to be admitted to the program, except the 30 minutes of isochronous (children living further cannot be included in the treatment group for logistic reasons).

### Outcome Measures

Although in the usual care model personnel expenses include wages of pediatricians, nurses, residents, and nursing assistants, the tele-home care program is operated only by pediatricians and nurses. With respect to operating expenses, pharmacy, fungibles, and various purchase costs are included. Expenses per patient consist of the costs of the medicines given to patients. Laboratory, anatomy, diagnostic imaging, and blood bank costs are covered in the intermediate care costs. Intermediate noncare costs include the costs of admissions, stretcher bearers, cleaning of the spaces and clothing, menus offered to the hospital's patients, and other intermediate expenses. Of these, the only ones attributable to the tele-home care program are laboratory,

admissions, and blood bank costs. Some expenses are specific to the tele-home care program, such as the cost of the transportation, the renting of the tablet, and other purchases. Lastly, there are some structural expenses, such as the costs of supplies, amortizations of the computer system, and other expenses. Only the last two are included as tele-home care costs. The quantification of costs is done by the hospital's own accounting department using administrative data. All costs are with prices for the year 2020. The study does not take into account any other amortization costs, as they are considered nonsignificant.

## Results

A total of 181 patients with ages between 0 and 21 (average 3.95, SD 5.00, median 2) years used the program. A total of 91 (50.3%) were female. The most frequent diagnoses were related to a respiratory disease (86/181, 47.5%), infection (51/181, 28.2%), and other less common pathologies. On average, patients spent 1.94 (SD 1.25) days at the hospital before being transferred to their homes, where they stayed for 2.82 (SD 1.25, min 1.10, max 8.38) days. This means that, in total, the mean of the whole hospitalization (conventional hospitalization plus home hospitalization) was 4.76 days. In comparison, the average total hospitalization of the control group was 3.73 (SD 2.47) days.

Table 1 shows the total average expenditure for a hospital and in-home hospitalization of a 24-hour stay, the difference between both to estimate the savings, and the percentage that each type of cost represented in the total amount of savings.

**Table 1.** Costs per day, according to type of hospitalization, by size of saving.

Type of cost	Usual care (US \$)	Tele-home care (US \$)	Variation (US \$)	Total variation (%) <sup>a</sup>	Total savings (%)
Staff	261.51	158.67	102.83	33.52	35.50
Noncare intermediates	118.08	21.99	96.09	31.32	33.17
Structural	140.80	85.63	55.16	17.98	19.04
Intermediates	27.29	7.37	19.91	6.49	6.88
Operating	26.50	10.85	15.65	5.10	5.40
Tele-home care	N/A <sup>b</sup>	17.17	-17.17	5.60	N/A
Total	574.19	301.71	272.48	100.00	100.00

<sup>a</sup>In absolute terms.

<sup>b</sup>N/A: not applicable.

A 24-hour stay at the hospital costs US \$574.19, while the in-home hospitalization costs US \$301.71 per day, representing a saving of almost half (48%) of the cost compared to usual care. The main saving drivers were the personnel costs (US \$102.83/US \$289.66, 35.5% of the total), intermediate noncare costs (US \$96.09/US \$289.66, 33.17%), and structural costs (US \$55.17/US \$289.66, 19.04%), all of them accounting for

87.72% (US \$254.09/US \$289.66) of the total savings. The cost types are detailed in Table 2, which also shows that the only incremental expense between the two interventions was the operating cost of the home hospitalization program (mainly the professional's travel costs and the devices used for telemonitoring).

**Table 2.** Costs per day, by type of hospitalization. Most important items (disaggregated).

Type of cost	Conventional care (US \$)	Tele-home care (US \$)	Difference (US \$)	Savings (%)
<b>Personal</b>				
Optional	83.92	65.76	18.16	6.66
Residents	21.45	N/A <sup>a</sup>	21.45	7.87
Nursery	116.46	92.91	23.55	8.64
Auxiliaries	39.67	N/A	39.67	14.56
Total staff	261.51	158.67	102.83	37.74
<b>Intermediation care</b>				
Admissions + secretariat	23.47	21.99	1.48	0.54
Bedding holders	16.35	N/A	16.35	6.00
Cleaning + laundry	25.57	N/A	25.57	9.38
Menu	40.01	N/A	40.01	14.69
Intermediate	12.66	N/A	12.66	4.65
Total intermediate noncare	118.08	21.99	96.09	35.27
<b>Structure</b>				
Informatics	8.41	8.41	N/A	0.00
Supplies/maintenance	53.69	N/A	53.69	19.71
Structural	77.22	77.22	N/A	0.00
Depreciation	1.47	N/A	1.47	0.54
Total structure	140.80	85.63	55.16	20.25

<sup>a</sup>N/A: not applicable.

In relation to staff costs, the results shown are lower for all types of professionals. The main savings are due to the absence of auxiliary staff (US \$39.67/US \$272.48, 14.56% of the total). As for other professionals, the costs are lower due to the lower ratio of professionals per patient. Regarding the intermediate noncare expenses, the main savings are given by the costs of food (US \$40.01/US \$272.48, 14.69%), cleaning and laundry (US \$25.57/US \$272.48, 9.38%), and bedding (US \$16.36/US

\$272.48, 6%). Finally, in terms of structure, most savings were given by supply costs (US \$53.69/US \$272.48, 19.71%).

**Table 3** summarizes the costs by discharge, weighting the daily cost of each type of stay by its average duration. Home hospitalization involves a total stay 27.61% longer but at a daily cost of almost half; it represents a saving of US \$176.70 (9.01%) per stay.

**Table 3.** Cost per discharge.

	Hospital stay (days), mean	Home stay (days), mean	Total stay (days)	Total cost (US \$)
Home	1.94	2.82	4.76	1964.76
Hospital	3.73	0	3.73	2141.75

## Discussion

### Principal Findings

This study is an economic analysis from a hospital's perspective that compares the costs of two competing treatments. On the one hand, home hospitalization allows the release of hospital beds occupied by patients who, due to their clinical situation, can stay at home. This space is especially needed in the winter because there are peaks in demand motivated by the high incidence of respiratory viruses. Thus, this intervention represents a *de facto* expansion of the hospital bed capacity. On the other hand, at times, with few patients hospitalized at home, the flexibility in human resource management and the ability

of professionals to carry out their work in other services or areas of the hospital would minimize their opportunity cost. With these conditions, home hospitalization would be an efficient option thanks to the abundance of variable costs associated with this model. This is consistent with a recent study centered in telemedicine in pediatrics that emphasizes that patients, health care professionals, and caregivers may benefit from using both telemedicine services and traditional, in-person health care services [27].

In terms of safety, some articles show that it appears that hospital at home is a safe and acceptable form of care [28]. Additionally, some studies demonstrate that clinical effectiveness of both services was not significantly different:

children presenting common pathologies that require hospital treatment but not its infrastructure could be managed at home with similar outcome measures to traditional hospital care [11]. For example, a recent systematic review that focuses on malignant and nonmalignant hematology concluded telemedicine provides similar or improved health care compared to face-to-face encounters in both pediatric and adult populations [29]. The readmission rate for home care was not significantly higher than for hospital care [20]. Additionally, in terms of satisfaction, a British study shows that 90% of parents and 63% of children stated a clear preference for home hospitalization, citing less psychosocial disruption and a perception that children recover more quickly with comfortable surroundings [11].

The facilities offered by digital health tools, combined with a gradual decline in the cost of gadgets to comparatively insignificant levels, open the door to a set of possibilities for cost-effective interventions in the field of health. The result of this work fits in with other studies that point to the positive economic impacts of telemedicine [30,31]. In the context of COVID-19, these possibilities make even more sense insofar as they can reduce travel, social contact, and consequently intrahospital infections [32]. Recent studies claim that digital approaches have played and will play substantial roles as invaluable and reliable resources to overcome restrictions and challenges imposed during the COVID-19 pandemic and to increase access to effective, accessible, and consumer-friendly care to more pediatric patients and families [33]. For example, another recent paper states that despite its limitations, the expansion of digital health care due to the COVID-19 pandemic is likely to have equitably increased access to health care for

many families, especially those living rurally and with limited financial means. It is also likely to have reduced the anxiety experienced by some children in medical settings and allowed health professionals to gain a better understanding of their patients' living circumstances [34].

This analysis has several limitations. First, this study spans from November 1, 2019, to June 30, 2020. This includes some important times for the Spanish health system due to COVID-19, and special measures had to be implemented: COVID-19 patients used the program, and although the hospital is pediatric, it accommodated adult patients. Hospital occupancy declined due to the low incident of COVID-19 and other pathologies on children in this period. Second, this analysis only includes one typology of patients: the ones who were admitted to the tele-home care program to end their treatment. It would be interesting to include the other patients in future studies. Third, provider's perspective does not include aspects that go beyond their interests, such as the possible cost of caring for the child at home by families (loss of productivity, material costs). Further research should enlarge the focus of the study and include and broaden all the potential effects of in-home hospitalization.

## Conclusion

Our analysis shows that pediatric tele-home care is 9% less expensive compared to regular hospital care while offering a quality service preferred for the children and their families, and that emptied beds for more complex cases. The use of telemedicine in the pediatric setting may serve for improving provider efficiency, lowering health system costs, and achieving greater patient satisfaction [18]. These results motivate the most widespread implementation of the pediatric tele-home care.

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## Conflicts of Interest

None declared.

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## Abbreviations

**CHEERS:** Consolidated Health Economic Evaluation Reporting Standards

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Original Paper

# Changes in Use of a Leisure Activity Mobile App for Children With Disabilities During the COVID-19 Pandemic: Retrospective Study

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## Abstract

**Background:** Participation in leisure activities is essential for child development and a human right as per the United Nations Convention on the Rights of the Child. Children with disabilities face several restrictions when participating in leisure activities as compared to same age peers without disabilities. Access to information about accessible, inclusive leisure activities is one of the barriers limiting participation, and one potential health promotion strategy is to provide access to information to increase participation. The Jooy App is a mobile app listing such activities in Canada and Australia. With the COVID-19 global pandemic and subsequent public health measures, most community-based facilities providing the activities listed on Jooy were closed. The app therefore started listing online activities offered with the expectation of continuing to provide information for families and understanding the extent to which users relied on the mobile app as a tool to identify new safe leisure opportunities.

**Objective:** This study aims to describe the engagement of the Jooy app before and during COVID-19, and to estimate the extent to which the listing of online activities was related to the engagement of the Jooy app.

**Methods:** We conducted a retrospective study comparing Jooy app use between March 2020 and February 2021 to the engagement between March 2019 and February 2020 by Jooy users. Spearman rank correlations were carried out to identify associations between the activities listed and the users' engagement from May 2020 to February 2021.

**Results:** Active engagement with the Jooy app from March 2020 to February 2021 dropped by an average of 135 engagements (64.2%) compared to engagements in 2019-2020. The largest monthly drop in engagement was observed in May 2020 by 239 engagements (88.8%). There was a strong positive correlation between the number of active users and the number of online activities listed on the app ( $r_s=0.900$ ).

**Conclusions:** The engagement with the Jooy App presented an expected decrease during the first wave of the COVID-19 pandemic. The addition of online adapted leisure activities to the app's listings during the pandemic increased app use. Access to information about inclusive activities is a barrier for children with disabilities to engage in leisure. Mobile health solutions can be responsive to contextual factors and consider the social determinants of health such as socioeconomic and public health emergency issues that can impact the participation of vulnerable populations such as children with disabilities and help eliminate barriers to participation. The provision of online leisure opportunities during the pandemic could facilitate participation in these activities during the pandemic and beyond, which is essential and beneficial for the physical and mental well-being of children with disabilities and their families.

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## KEYWORDS

COVID-19; participation; childhood disability; online leisure; app engagement; mHealth; children; parents; mobile apps; mobile health; digital health; pandemic; online leisure activities; user engagement; app usability

## Introduction

Participation of children with disabilities in leisure activities is a key determinant of their physical and mental health, and that of their families [1]. Participation in a variety of leisure activities is associated with quality of life [2]. Participation in leisure and play is also a human right as stated in the United Nations' Convention on the Rights of the Child [3], and participation in the community is a key human right as articulated in the Convention on the Rights of Persons with Disabilities [4].

Despite the benefits and importance of participation, children with disabilities face participation restrictions in comparison to their peers who do not have a disability [5,6]. Several barriers contribute to this reduced participation, one of which is limited access to information about existing activities that meet the child and families' needs [7,8]. In fact, families of children with disabilities and health care professionals indicated that information about existing resources and leisure opportunities that will include children with developmental challenges is difficult to find, requiring additional effort on the part of already overwhelmed parents. Additionally, existing activities often do not accommodate for the child's disability needs or are not aligned with the child's context (eg, are far from the house or the school) [9,10]. The Jooay App was launched in Spring 2015 to overcome this gap between families, health care providers, and community-based leisure activities. This mobile health (mHealth) solution lists inclusive and adapted leisure activities across Canada and Australia, providing free crowdsourced information about the characteristics of leisure activities offered based on geographical location.

With the COVID-19 global pandemic declared by the World Health Organization (WHO) in March 2020 [11], countries worldwide, including Canada, had to implement massive emergency public health stringency measures to protect the public with prevention protocols to limit the spread of the virus. These public health measures included self-isolation, social distancing, and stay-at-home recommendations in Canada [12]. With these measures in place, many public and private facilities were obliged to close, including most leisure activities listed on Jooay. Access to any form of leisure was made much more challenging for children with disabilities and their families, limiting essential opportunities for development and health promotion.

Lockdown restrictions following the COVID-19 pandemic had significant negative effects on the physical activity levels and mental and behavioral health of children with disabilities [13]. It was reported that these negative effects were brought on by the lack of access to facilities and activities [13]. With technology becoming essential during the COVID-19 pandemic, children need virtual opportunities to learn, live, and stay connected to maintain their physical, social, and mental well-being [14].

Before the COVID-19 pandemic, all leisure activities listed in Jooay were in-person activities requiring physical attendance. Online leisure activities began being offered as an alternative to provide some form of connection during the pandemic. In response, the Jooay App crowdsourced online activities being offered worldwide for children with disabilities on the Jooay app. As of February 2021, there were a total of 382 online activities listed.

The objective of this study was to explore the extent to which families of children with disabilities use a mobile app to access information about leisure activities for their child by understanding the changes in the pattern of use of a geolocation-based mHealth solution during the COVID-19 pandemic and to estimate the extent to which the listing of online activities was related to the users' engagement with the Jooay app. It was hypothesized that parents do use mobile apps to find activities that are appropriate for their child, and as such, the availability of online activities on the app would be positively correlated with app engagement.

## Methods

### Study Design

This study was a retrospective study that compared the Jooay app engagement between March 2020 and February 2021, for a total of 12 months, to the engagement between March 2019 and February 2020 (prepandemic). March 2020 was chosen as the beginning of the timeframe of this study because it was the month when the WHO declared COVID-19 as a global pandemic and mass closures of public facilities started happening in Canada [11,15]. The STROBE (Strengthening the Reporting of Observational Studies in Epidemiology Statement) checklist was used to guide the reporting of this study [16]. This study was approved by the Research Ethics Board of McGill University as part of a larger study.

### Population and Sample

The population of this study was users of the Jooay mobile app in Canada. Users included youth with disabilities, parents of children with disabilities, educators, and health care providers. Users of the app provide consent to have their deidentified data analytics used for research purposes upon registration with the app. Data on Jooay app engagement was collected each month within the time frame previously listed.

### Jooay App

Jooay is a free mobile and web-based app that helps children with disabilities and their families locate leisure opportunities that are inclusive and accessible, are in the communities where they live, suit their needs and abilities, match their preferences, and can help them develop and participate in society [17]. Jooay is also a social platform to help parents, rehabilitation professionals, educators, and communities connect, exchange, and learn from each other's experiences. Currently, as of February 28, 2021, Jooay lists 3250 activities across all 10

Canadian provinces and 1 territory (Yukon), with 3124 total users. As of March 2021, Jooy is also available in Australia. This study reports on app use in Canada only.

### Measures: Variables

Two variables were investigated for this study. The first variable was the number of online leisure activities available on the Jooy app; this is a discrete variable (ie, count). The addition of online leisure activities started in May 2020, 2 months after the declaration of a pandemic in March 2020 and continued to be updated and expanded until February 2021. The second variable was app engagement over the determined periods of time. App engagement was determined by the number of unique users that activated a session on the Jooy app in the specified month [18].

### Data Analysis

Descriptive statistics were performed using Excel software (Microsoft Corporation). App engagement was compared in the 12-month period of the COVID-19 pandemic (March 2020 to February 2021) to the engagement in the corresponding months before the pandemic (March 2019 to February 2020). Spearman

rank correlation analysis was conducted using SPSS 27 (IBM Corp) between the number of online activities available to users and the app engagement from May 2020 to February 2021, as previously defined, to estimate the relationship between the two variables.

## Results

### User Characteristics

As of February 28, 2020, there were 3124 registered users of the Jooy app. Of those who have reported their sex (n=936), 627 (67%) were female and 309 (33%) were male. Participants' characteristics are described in Table 1. Users were asked to select the category that best represented who they were (eg, parent, health professional, or educator) and the classification of disability that best described the individuals they were seeking activities for (could select more than one). The majority of participants were parents of children with disabilities, and their children had a range of disabilities, predominantly autism spectrum disorder or physical disabilities, though 37.7% (n=1400) of participants did not select one specific disability type.

**Table 1.** User characteristics.

Characteristics	Users, n (%)
<b>User types (n=3124)</b>	
Parents	1260 (40.3)
Health care professionals	656 (21.0)
Other	267 (8.5)
Community organizations	251 (8.0)
Educators	222 (7.1)
Individuals	167 (5.3)
Not disclosed <sup>a</sup>	301 (9.6)
<b>Disability<sup>b</sup> (n=3714)</b>	
Autism spectrum disorder	660 (17.8)
Physical	651 (17.5)
Intellectual	524 (14.1)
Behavioral	234 (6.3)
Visual	141 (3.8)
Auditory	104 (2.8)
Not disclosed <sup>a</sup>	1400 (37.7)

<sup>a</sup>Not disclosed users are users who did not report their user type.

<sup>b</sup>A single user could report multiple disability types.

### Activity Characteristics

The Jooy app has activities across 10 different provinces, with a higher concentration of activities listed in urban centers, and the majority of activities listed in the largest provinces (Ontario

and Quebec). The types of activities are categorized as arts, sports, camps, and other on the app; the other category includes, for example, activities like life skills activities, money management, respite, and cooking. The distribution of activities listed per province can be found in Table 2.

**Table 2.** Activity characteristics (N=3250)<sup>a</sup>.

Province	Activity type, n (%)			
	Arts	Camps	Sports	Other
Ontario (n=627)	71 (11.3)	187 (29.8)	209 (33.3)	160 (25.5)
Quebec (n=530)	56 (10.5)	122 (23.0)	181 (34.2)	171 (32.3)
Alberta (n=333)	40 (12.0)	45 (13.5)	161 (48.3)	87 (26.1)
British Columbia (n=227)	9 (4.0)	25 (11.0)	130 (57.3)	63 (27.8)
Manitoba (n=124)	21 (16.9)	17 (13.7)	67 (54.0)	19 (15.3)
Saskatchewan (n=124)	8 (6.5)	33 (26.6)	31 (25.0)	52 (41.9)
Prince Edward Island (n=109)	9 (8.3)	20 (18.3)	52 (47.7)	28 (25.7)
New Brunswick (n=94)	6 (6.4)	29 (30.9)	31 (33.0)	28 (29.8)
Nova Scotia (n=84)	11 (13.1)	22 (26.2)	29 (34.5)	22 (26.2)
Newfoundland and Labrador (n=44)	5 (11.4)	1 (2.3)	32 (72.7)	6 (13.6)
Yukon (n=15)	0 (0.0)	0 (0.0)	10 (66.7)	5 (33.3)

<sup>a</sup>Of these 3250 activities, 939 were activities in Australia, activities across Canada, and activities without specified provinces.

### Jooay App Engagement

Figure 1 illustrates the app engagement pattern for the periods of March 2019 to February 2020 (prepandemic) and that of March 2020 to February 2021 (pandemic). There is a predictable trend in app engagement for the 2019-2020 period. Higher

number of app engagements were observed in April and May 2019, being the months preceding registration for summer activities; then again in September, the time for registration for Fall activities; and then finally in February, the time for registration for activities during March break in most Canadian grade schools.

**Figure 1.** The number of monthly active app engagements across the two different time periods and corresponding COVID-19 pandemic directives. WHO: World Health Organization.

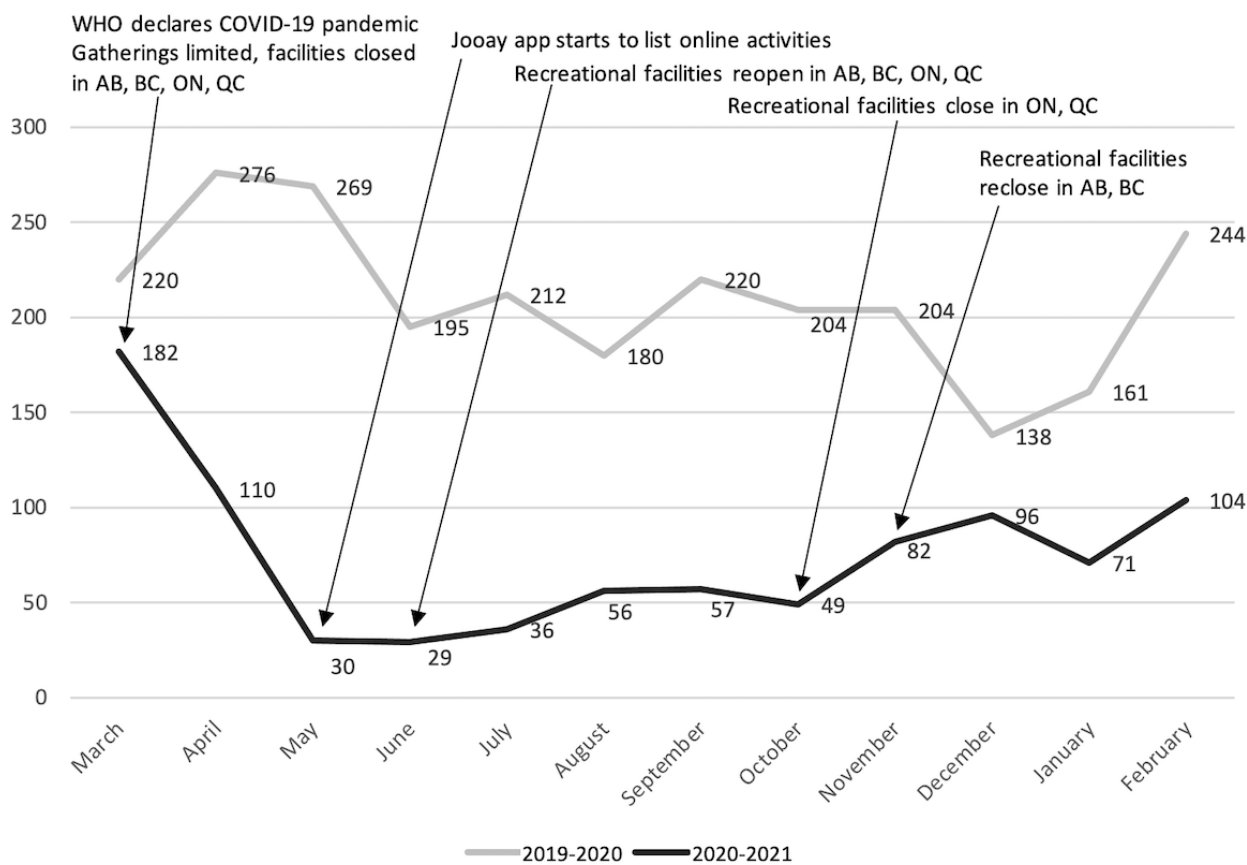
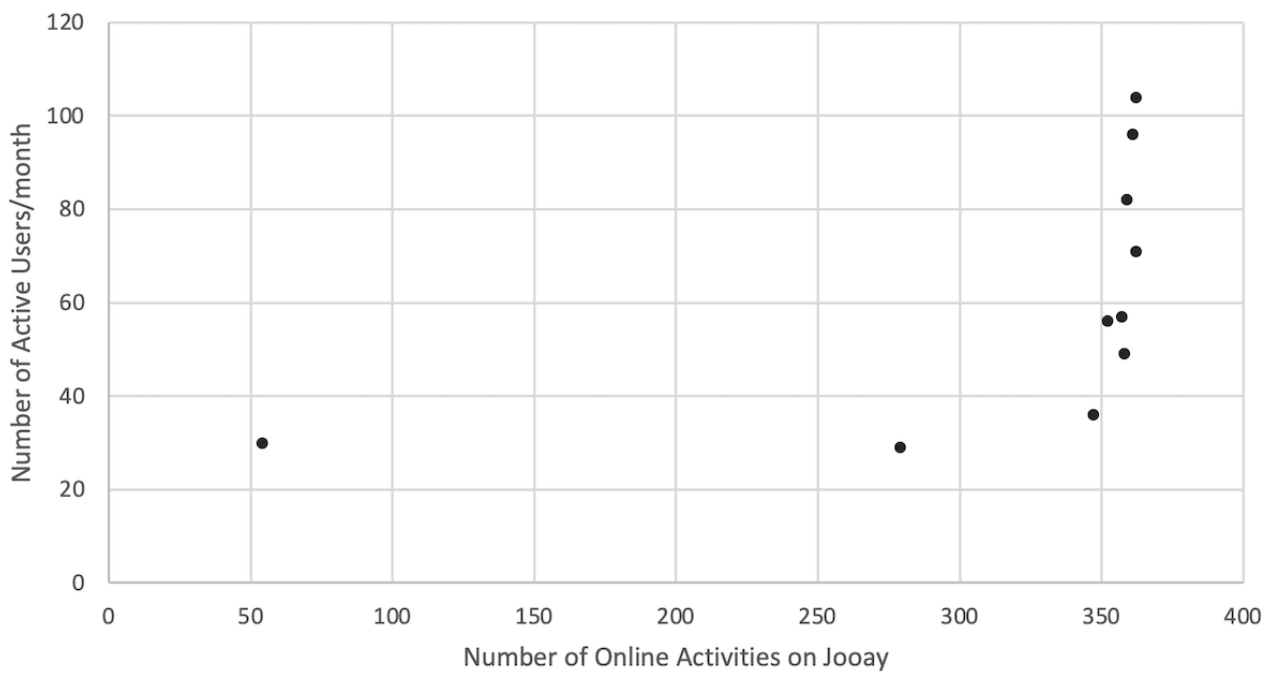


Figure 1 also presents the monthly total app engagements during the main events of the COVID-19 pandemic between March 2020 and February 2021. The active engagement of the Jooay app from the months of March 2020 to February 2021 dropped an average of 135 engagements per month (64.2%) compared to engagements by users during that same period in 2019-2020. The greatest monthly drop in engagement was observed in May 2020, with a drop of 239 monthly active users compared to that of 2019, which was a drop of 88.8%. The lowest drop in engagement was observed in March 2020, with a drop of 38 monthly active users compared to that of 2019, a 17.3% decrease.

### Availability of Online Activities

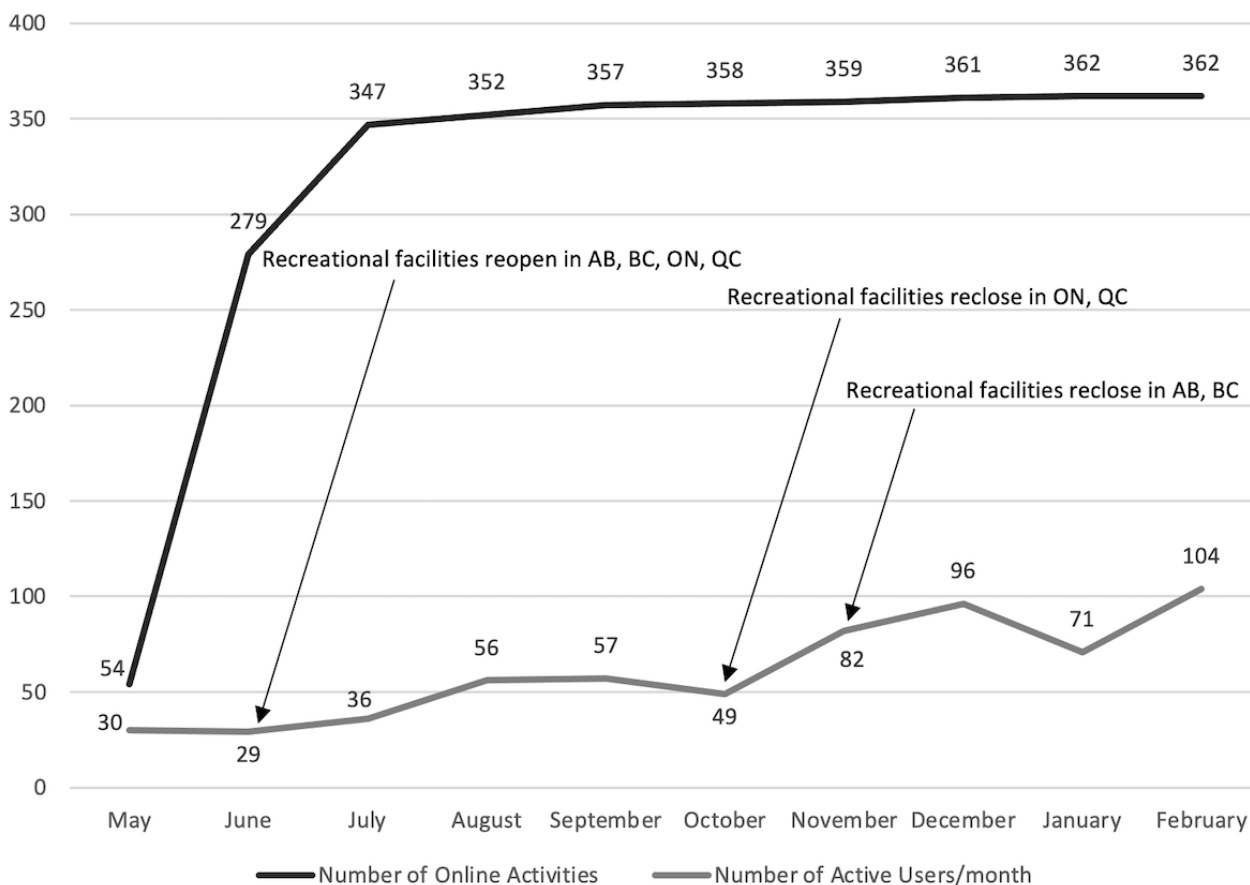
Online activities were posted on the Jooay app starting in May 2020 up until February 2021. Following the addition of online activities on the app, the number of active users gradually increased (Figure 2). There was a strong positive correlation between the number of monthly app engagements and the number of online activities listed on the app at that time ( $r_s=0.900$ ). Figure 3 presents the number of online activities available on the app and the active users.

Figure 2. Online activities on the Jooay app between May 2020 and February 2021.





**Figure 3.** The number of online activities on the Jooay app and the number of monthly active users from May 2020 to February 2021.



## Discussion

### Principal Results

This study presents the use patterns of an mHealth app targeting adapted and inclusive leisure activities for children with disabilities and describes changes that were observed during the COVID-19 pandemic and the subsequent health measures that were implemented in Canada [11]. This study shows an average drop in the monthly active engagement of the app by 135 engagements (64.2%) from the months of March 2020 to February 2021 compared to that of the same period in 2019-2020. This drop in engagement likely relates to closures and ongoing insecurity in the offering of community activities, possibly reflecting a gap in the existing opportunities for physical and leisure activities for children worldwide during this pandemic.

The global spread of COVID-19 led to unprecedented governmental measures that resulted in many restrictions in Canada. As a result, organizations providing services and activities for children with disabilities were forced to close, along with other sectors of society. Data from Statistics Canada and a WHO report on disabilities demonstrate that indeed parents of children with disabilities identified the lack of leisure opportunities, along with school closures and limited health care services as critical components for their child’s health and well-being during the pandemic [19].

On March 11, 2020, the WHO declared the COVID-19 outbreak to be a global pandemic [11]. A day before this declaration,

Canada published the recommendation for the adoption of work-from-home policies and the guidance on self-isolation [20]. This acted as a reinforcement for the provincial policies that were being rolled out and as groundwork for future provincial health policies. In Canada, although the health care system is largely determined by the Canadian Constitution, many of the roles and mandates of delivering health and social services fall under provincial jurisdiction [21]. This includes the planning and implementation of public health initiatives [21].

In the time frame of this study, the majority of activities listed on the Jooay app were found within the four largest provinces in Canada: Ontario, Quebec, British Columbia (BC), and Alberta. In all four of these provinces, recreational facilities and entertainment venues were required to close, while gatherings of more than five people in Ontario, more than 15 people in Alberta, and more than 50 people in BC were prohibited; in Quebec, gatherings of any size were prohibited, while BC recommended avoidance of gatherings of any size in March [20]. The smallest decrease in the monthly app engagement was observed in March by 38 engagements (17.3%). This may be due to engagement that was not impacted in the first half of the month and the immediacy of the implementation of the measures.

The greatest decrease in the monthly app engagement was observed in the month of May, with engagement for that month dropping by 239 engagements (88.8%) in 2020 compared to 2019. With the end of the academic year and the start of the summer season approaching, May has traditionally been the

month of high app use, during which parents and families of children with disabilities use the Jooay app to search for activities/camps that are scheduled for the summer of that year. However, with the residual fears and uncertainty of COVID-19 and the restrictions in place in May 2020, the decrease in app engagement can be understood. Closures and restrictions were maintained until June 2020; the number of people allowed in gatherings gradually increased and facilities reopened in many provinces around this time. Even with the eased measures, the engagement of the app did not change. These use patterns can shed light into important features of mobile app use as a source of information for “secondary health outcomes.” In times of crises like this, children with disabilities are likely to face greater challenges due to attitudinal, environmental, and institutional barriers [22,23]. These barriers often stem from the lack of governmental response and the persistent neglect of this vulnerable group by society [22]. In the immediate responses to the pandemic, public health measures and governmental support were not necessarily appropriately targeted to the needs of the disability community and much less to the needs of children with disabilities [24]. No specific resources nor support were provided for children with disabilities in the first year of the pandemic by the federal government, while parents and families of children with disabilities reported high concern for the well-being of their child during the pandemic [19]. Families of children with disabilities and the children themselves reported heightened levels of stress and anxiety surrounding the COVID-19 pandemic; coupled with the increased responsibility for parents to be home with the children, these families felt overwhelmed [25]. This experience of high stress and uncertainty, as well as the overwhelming demands of providing immediate care for their child at home, may explain the continued low engagement of the Jooay app in summer 2020, despite the eased restrictions. The access to online activities listed in the app as of summer 2020 may have helped families identify new safe venues for their children, but at a point of distress, a geolocation-based app may not be consulted. Previous studies found that fear linked with insufficient knowledge about the pandemic has led to a lack of understanding and incorrect decision-making by parents [26]. It could be understood that the parents just did not have the resources, support, and sufficient knowledge about the ever-evolving situation to use the app. The use of a mobile app to provide information for vulnerable groups is not largely explored and represents an untapped potential for future research.

In response to the COVID-19 pandemic and the closures of facilities following health measures, online leisure activities were listed in the Jooay app starting in May 2020. Although the overall engagement of the app decreased by an average of 64.2% in the year 2020 compared to 2019, this study shows that as more online leisure activities were made available in the Jooay app, the number of active monthly users also increased. The number of users gradually increased, possibly because users were not aware that online activities were being added to the app, and this took time to gradually disseminate. According to Statistics Canada, more than 60% of parents reported concerns with their general mental health, loneliness, and lack of opportunities to socialize for their children [19]. In addition, 50% of parents were concerned about their children’s amount

of physical activity. Therefore, the positive association between the number of online activities listed and greater Jooay app engagement can be explained in part by parent’s taking action to address these pressing concerns. A previous study found that activities listed in the app are less present in areas with lower socio and material deprivation, meaning that the number of offerings of activities is already skewed to urban centers and areas with higher population density. Closures of facilities and subsequent cancellation of in-person activities undoubtedly decreased opportunities for children to participate. Although online activities listed in the app offer an alternative to in-person activities, the lack of access to a mobile phone and to a computer and the internet poses an extra layer of inequity in the access to services, which was also exacerbated during the pandemic. Virtual platforms have become essential during the COVID-19 pandemic; it has become a solution through which children can play and interact with other peers [14]. Although the Statistics Canada report showed that approximately 70% of parents were concerned with the amount of screen time experienced by their child, technology, when accessible and available, allowed children to maintain their social, physical, emotional, intellectual, and spiritual well-being during the COVID-19 pandemic [19].

### Practical Implications

The continual offering of online leisure opportunities by service providers and organizations could help facilitate leisure participation of children with disabilities. The Jooay app will indeed continue to list online leisure opportunities. Furthermore, future health measures and policies should proactively consider the potential effects of those measures on marginalized groups such as children of the disability community by involving youth with disabilities and their families in the development and implementation of those measures and include equity and access considerations in the development of both emergency and continuous provision of services.

The combined use of mHealth solutions such as the Jooay app and other online platforms that present opportunities of essential activities such as education and leisure, provide an interesting future model to consider in the promotion of health, social inclusion, and equity. The provision of online resources for children was made an essential matter during the pandemic, accelerating the mitigation of digital access issues that persisted for many decades [27]. This study presents the reactions and habits of stakeholders in the childhood disability community, including families of children with disabilities, following a major health emergency and subsequent measures. It offers insight into how health measures and policy can affect their engagement with an online platform and how that engagement can change with the provision of online leisure opportunities. The study highlights the necessity of including marginalized groups, such as the disability community, and children and youth in the development of new solutions during emergency responses and beyond [28]. We can also understand that families do use mobile apps to find relevant information for services for their children, and therefore, this is a resource that should be further explored to decrease barriers to participation in health promotion initiatives.

## Limitations

This study presents the active engagement of Jooy, a free mobile and web-based app that helps children with disabilities and their families locate leisure opportunities that are inclusive and accessible in the communities where they live [17]. This noncommercial app has had exclusively word of mouth dissemination, and the data in the app is crowdsourced and may not be representative of leisure participation patterns both prior to and during the pandemic. The engagement does not directly translate into participation of the child with disability and does not determine if the child did indeed participate in a specific activity. However, access to information about leisure activities has been found to be a facilitator to participation [1]. The study also does not take into consideration the increase in the overall number of users over time, which may have an influence on the number of active users.

## Comparison With Prior Work

No prior work that is similar to this study has been conducted in the literature. However, the literature does show that the COVID-19 pandemic has caused an abrupt change worldwide while significantly affecting the lives of children with disabilities [29]. A recent sentiment analysis conducted by Boon-Itt and Skunkan [30] using Twitter data showed an overall negative emotion toward COVID-19, with *fear* as the most negative sentiment expressed [30]. Despite the scarce literature on the use of online/virtual environments for leisure activities for children with disabilities, the parent perspectives of pediatric telehealth during the pandemic, where therapeutic activities were provided on an online platform or by telephone, were discussed in a recent study [31]. Parents found that the greater need for management of technology and exacerbated feelings of isolation were disadvantages. However, many more advantages were reported, including emphasis on building relationships and rapport, less barriers when doing activities in the natural (home) environment, less travel, more time in the day to schedule other things, continuity of care, and decreased

stress about physical interaction during the pandemic [31]. The perceived advantages of telehealth may have also been realized with the increased engagement of the Jooy app once online activities were listed for consideration. Furthermore, a recent study by Rovetta and Bhagavathula [32] presenting the global infodemiology of COVID-19 during the pandemic showed that there is a growing number of people worldwide who are using online search engines like Google to acquire information surrounding COVID-19 and to also disseminate information related to COVID-19 using social media platforms like Instagram [32]. Online activity, engagement, and presence is something that is being observed, as the COVID-19 pandemic and its restrictions have limited the availability of other methods of communication and information transfer. Future research should study the effects of the COVID-19 pandemic on the actual participation of children with disabilities in leisure activities. This should include a focus on the benefits and challenges of online leisure activities on the participation of children with disabilities.

## Conclusion

The global COVID-19 pandemic has led to restrictions and closures in local communities, including leisure activities that are important for child health. User engagement of Jooy, a free mobile and web-based app listing adapted and inclusive leisure opportunities for children with disabilities, decreased during the pandemic. However, the subsequent listing of online activities on the app had a strong positive correlation with the gradual increase in engagement of the Jooy app once a large number of online activities appropriate for children with disabilities were added. The Jooy app has the potential to be a medium through which children with disabilities and their families can readily access information and resources related to online leisure activities in which children can participate. The provision of online leisure opportunities during the pandemic could lead to increased participation, which is essential and beneficial for the physical and mental well-being of children with disabilities and their families.

## Conflicts of Interest

KS and AM have developed the Jooy App; however, there is no monetary gain associated with the use of the App.

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## Abbreviations

**BC:** British Columbia

**mHealth:** mobile health

**STROBE:** Strengthening the Reporting of Observational Studies in Epidemiology Statement

**WHO:** World Health Organization

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Original Paper

# Evidence-Based Behavioral Strategies in Smartphone Apps for Children's Sleep: Content Analysis

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## Abstract

**Background:** Empirically supported treatments for pediatric sleep problems exist, but many families turn to other sources for help with their children's sleep, such as smartphone apps. Sleep apps are easy for families to access, but little evidence exists regarding the validity of the services and information provided in the developer descriptions of the apps.

**Objective:** The goal of this study was to examine the features and claims of developer descriptions of sleep apps for children.

**Methods:** A search of the Apple iTunes store and Google Play was conducted using the terms "kids sleep," "child sleep," and "baby sleep." Data on the type of app, price, user rating, and number of users were collected. Apps were analyzed in comparison with evidence-based behavioral strategies and were thematically coded on the basis of claims provided in developer descriptions.

**Results:** A total of 83 app descriptions were examined, of which only 2 (2.4%) offered sleep improvement strategies. The majority were sound and light apps (78%) and 19% were bedtime games or stories. Only 18 of 83 (21.6%) apps were identified as containing empirically supported behavioral sleep strategies. Despite this, many apps asserted claims that they will help children "fall asleep instantly," "cry less and sleep better," or improve child development.

**Conclusions:** A large variety of sleep apps exist for use among children, but few include evidence-based behavioral strategies according to the developer descriptions of the apps. Addressing sleep difficulties in children is important to promote physical, cognitive, and emotional development. Collaboration between sleep researchers and technology developers may be beneficial for creating evidence-supported apps to help with children's sleep in the future.

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## KEYWORDS

pediatrics; technology; smartphones; health behavior; sleep applications; children; mobile health; mHealth; smartphone applications; health applications; sleep disorders; sleep problems; developer descriptions; apps

## Introduction

Sleep problems in young children are common and associated with significant negative behavioral and physical consequences for children as well as increased sleep disruption and stress for their parents [1]. Approximately 20%-30% of infants, toddlers, and children have significant difficulties with falling asleep and night wakings, and pediatric sleep difficulties are among the most common complaints reported by parents to pediatricians

[2,3]. Empirically supported treatments for pediatric sleep problems exist, but many families face barriers in seeking appropriate care, such as difficulty accessing a provider with specialized sleep training [4,5]. In particular, pediatricians may lack knowledge about appropriate sleep interventions for children [5]. Hence, many parents may turn to other sources for help with their children's sleep, including technological strategies such as smartphone apps.

While no studies have previously examined sleep apps for children, 2 studies have examined sleep apps for adults. One study examined behavioral constructs contained within the apps to evaluate how well these apps are grounded in behavioral theory, which has a strong evidence base for sleep interventions [6]. Grigsby-Toussaint et al [6] evaluated 35 sleep apps for adults and found that only 34% incorporated evidence-based behavioral constructs. The most common behavioral constructs were realistic goal setting, time management, and self-monitoring. Authors also found a positive but nonsignificant association between higher user rating of the app and number of behavioral constructs. Another study examined empirical evidence contained within the developer descriptions of sleep apps targeted to adults from Google Play and found that only 33% of sleep apps contained empirical evidence to support claims made in the app descriptions [7]. The most common empirical evidence provided was information on how sleep is affected by drugs and alcohol (24%), food (13%), daily activities (13%), and stress (13%). User ratings were higher for the apps containing at least one source of empirical information compared to those without empirical information. However, user ratings were also higher for apps that contained a “sleep tip” function, regardless of whether these tips were based on empirical evidence. Thus, sleep apps available on the market may not be grounded in behavioral constructs or contain evidence-based

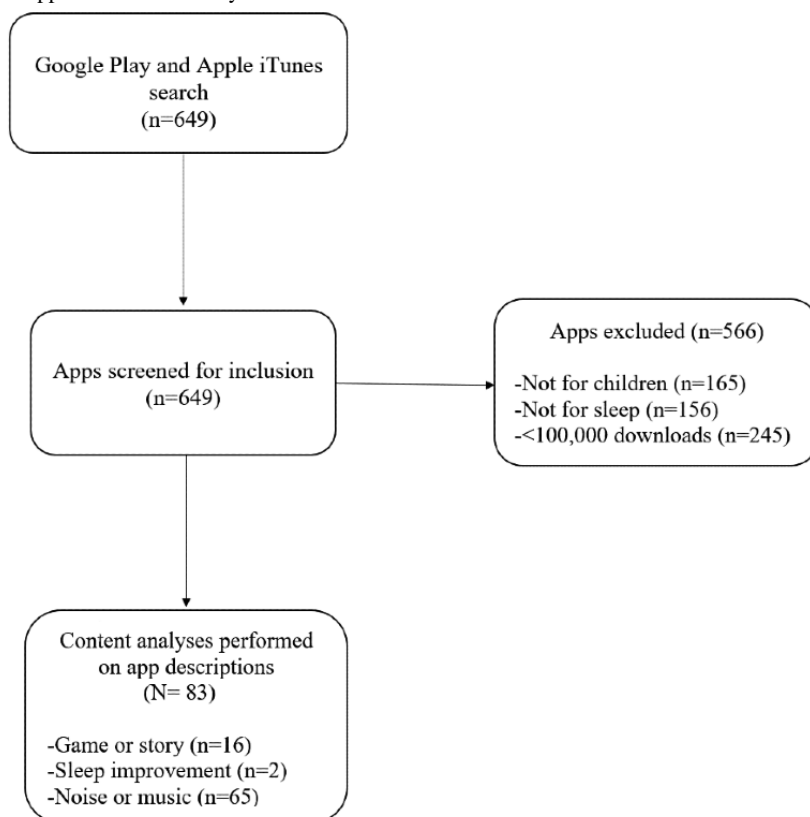
information, but this has not yet been examined for apps aimed at children.

Sleep apps are easy for families to access given today’s high rates of smart phone usage and mobile internet availability [8], but little evidence exists about the sleep apps available for children, or the validity of the services and information provided in the developer description of the apps. Because families may search for these apps independently (eg, without support of a health care professional), it is essential that the app descriptions contain accurate information. Thus, the goal of this study was to (1) examine the number and characteristics of sleep apps for children and (2) analyze the purported features and claims in the developer description of these apps. We hypothesized that a large number of sleep apps for children would exist, but that few would describe evidence-based behavioral strategies.

## Methods

An English language search of the Apple iTunes store and Google Play was conducted in December 2019, using the terms “kids sleep,” “child sleep,” and “baby sleep.” A total of 649 apps were initially identified. Apps were excluded if they were not specifically for children ( $n=165$ ) or not for sleep ( $n=156$ ). To focus analysis on apps that are actually used by parents, apps that had  $<100,000$  downloads ( $n=245$ ) were also excluded from the analysis. Figure 1 shows a flow chart of the app search.

**Figure 1.** Flow diagram for the app search in this study.



Data on the type of app, price, user rating, and number of users were collected. The developer descriptions of the apps were analyzed in terms of comparison to evidence-based behavioral strategies, using a checklist of evidence-based behavioral strategies derived from the ABC’s of SLEEPING pediatric sleep

recommendations [9]. Recommendations that received a rating of Strong or Moderate support, defined as support for the recommendation from at least 3 studies from well-designed studies without clearly contradicting findings, were included [9]. Inclusion of each strategy within the app description was

coded as 0 (not present) or 1 (present). The specific strategies included are outlined in Table 1. Additionally, descriptions were thematically coded to identify patterns in these claims [10]. Codes were generated by reading the descriptions and generating

a list of claims made by app developers. Data were coded by author IT and cross-checked by first author SLS. If there was a discrepancy in the coded data, all authors discussed and agreed upon the final data.

**Table 1.** Evidence-based behavioral strategies described in pediatric sleep apps<sup>a</sup>.

Behavioral strategies	Apps, n (%)	App name	Example description
Sufficient sleep opportunity for age	1 (1)	<ul style="list-style-type: none"> <li>Huckleberry: Baby &amp; Child Tracker<sup>b</sup></li> </ul>	“Tailored sleep schedules taking into account your child’s sleep needs”
Bedtime no later than 9 PM	0 (0)	N/A <sup>c</sup>	N/A
Consistent sleep schedule	2 (2)	<ul style="list-style-type: none"> <li>Huckleberry: Baby &amp; Child Tracker<sup>b</sup></li> <li>JOHNSON’S BEDTIME Baby Sleep</li> </ul>	“Tracks your child’s day-to-day schedule to assist with setting bed and wake times”
Bedtime routines	4 (5)	<ul style="list-style-type: none"> <li>Goodnight My Baby</li> <li>Huckleberry: Baby &amp; Child Tracker</li> <li>JOHNSON’S BEDTIME Baby Sleep<sup>b</sup></li> <li>Moshi Twilight Sleep Stories: Kids Bedtime App</li> </ul>	“Promotes a 3-step nighttime routine to help baby fall asleep and sleep through night”
Limited access to electronics during and after bedtime	0 (0)	N/A	N/A
Positivity and relaxation to help transition to sleep	16 (19)	<ul style="list-style-type: none"> <li>Baby Lullabies</li> <li>Baby Mozart Effect</li> <li>Baby Sleep</li> <li>Baby Sleep Lullabies</li> <li>Baby Sleep Lullaby Music Box</li> <li>Baby Sleep Music 2019</li> <li>Baby Sleep Sounds White Noise</li> <li>Baby Sleep: White Noise</li> <li>Baby Sleeping Music</li> <li>Baby Songs (Bipfun)</li> <li>JOHNSON’S BEDTIME</li> <li>Lullaby for Babies</li> <li>Lullaby for babies (desenvdroid)</li> <li>Moshi Twilight Sleep Stories: Kids Bedtime App<sup>b</sup></li> <li>Music Box to sleep</li> <li>Sleeptot: Baby White noise</li> </ul>	“Audio plays to calm children prior to bedtime to prepare them to fall asleep”
Independent sleep skill development	0 (0)	N/A	N/A
Emotional needs met during the day	0 (0)	N/A	N/A

<sup>a</sup>A total of 18 out of 83 (21%) sleep apps had at least one strategy.

<sup>b</sup>App from which the example description was taken.

<sup>c</sup>N/A: not applicable.

## Results

### Results Overview

A total of 83 app descriptions were examined. Only 2% (2/83) specifically claimed to offer sleep improvement strategies, while the majority (78%, 65/83) were white noise or music apps, and

19% (16/83) were bedtime games or stories. The apps were highly rated (average 4.4; range 1-5, with 5 being the most favorable rating) and most were free (65%, 54/83); the price of paid apps ranged from US \$0.99-\$239.99 (annual subscription). Table 2 contains a complete list of the characteristics of all of the apps examined.

**Table 2.** Characteristics of sleep apps for children.

App name	Price (US \$)	Rating	Users, n	Themes	Behavioral strategies
<b>Apps with sleep improvement strategies</b>					
Huckleberry: Baby & Child Tracker, Sleep Experts	119.99	4.80	>100,000	Good sleep habits	Sleep opportunity, Sleep Schedule, and routines
JOHNSON'S BEDTIME Baby Sleep	0.00	3.70	>100,000	Help fall asleep and good sleep habits	Sleep schedule, routines, and relaxation
<b>White noise or music apps</b>					
Baby Lullabies	0.00	4.50	>100,000	Stop crying	Relaxation
Baby Lullaby Songs to Sleep <sup>a</sup>	0.00	4.00	>500,000	Help falling asleep and good sleep habits	None
Baby Lyrics & Songs	2.99	4.50	>500,000	Help falling asleep	None
Baby Mozart Effect <sup>b</sup>	0.00	4.40	>100,000	Well-being and help falling asleep	Relaxation
Baby Night Light: Instant Sleep Aids & White Noises <sup>b</sup>	3.49	4.40	>1,000,000	None	None
Baby Sleep <sup>b</sup>	0.00	4.70	>500,000	Well-being and help falling asleep	Relaxation
Baby Sleep Instant <sup>b</sup>	1.00	3.80	>100,000	Stop crying	None
Baby Sleep Lullabies <sup>a</sup>	0.00	4.10	>1,000,000	Help falling asleep	Relaxation
Baby Sleep Lullaby Music Box	5.99	4.70	>500,000	Well-being	Relaxation
Baby Sleep music (leopfinpamcev) <sup>b</sup>	0.00	4.00	>100,000	Help falling asleep	None
Baby Sleep Music 2019 <sup>b</sup>	0.00	4.40	>500,000	Stop crying	Relaxation
Baby Sleep Sounds	0.00	4.80	>500,000	Help falling asleep	None
Baby Sleep Sounds- Sleep Sounds for Baby <sup>b</sup>	0.00	4.30	>100,000	None	None
Baby Sleep Sounds White Noise	0.99	4.10	>500,000	Help falling asleep	Relaxation
Baby Sleep: White Noise	3.99	4.80	>1,000,000	Stop crying	Relaxation
Baby Sleep: White Noise Lullabies for New-borns <sup>b</sup>	0.00	4.70	>1,000,000	Help falling asleep and trusted by parents	None
Baby Sleeping Music <sup>b</sup>	0.00	4.70	>100,000	Well-being and help falling asleep	Relaxation
Baby Sleeping Music (Free) <sup>b</sup>	0.00	4.10	>500,000	Help falling asleep	None
Baby Songs <sup>b</sup>	0.00	4.50	>1,000,000	Help falling asleep and good sleep habits	None
Baby Songs & Lullaby: Sounds for Bedtime & Naptime <sup>b</sup>	0.99-3.59	3.80	>100,000	None	None
Baby Songs (Bipfun)	3.59	3.80	>100,000	Well-being and help falling asleep	Relaxation
Baby Stop Crying and Sleep <sup>b</sup>	0.00	3.90	>500,000	None	None
Bedtime Music Lullaby Songs <sup>b</sup>	5.99	4.70	>100,000	None	None
Brahm's Lullaby for Babies <sup>b</sup>	0.00	4.70	>100,000	None	None
Calming music for kids to go to sleep <sup>b</sup>	0.00	4.20	>1,000,000	Well-being and help falling	None
Calms Baby with Womb Sound <sup>b</sup>	0.00	4.20	>100,000	None	None
Children Sleep Songs <sup>b</sup>	0.00	4.10	>1,000,000	None	None
Classical Music for Baby <sup>b</sup>	9.99	4.80	>100,000	None	None

App name	Price (US \$)	Rating	Users, n	Themes	Behavioral strategies
Colic Baby-Baby Sleeping Sound <sup>b</sup>	0.00	4.60	>100,000	Stop crying	None
Don't Cry My Baby (Lullaby)	0.00	4.60	>1,000,000	Stop crying, well-being, help falling asleep	None
Hair Dryer Sounds <sup>b</sup>	0.00	4.50	>100,000	Help falling asleep	None
Hatch Baby Rest	0.00 <sup>c</sup>	4.60	>100,000	None	None
iWhite Noise Baby Bedtime Sound <sup>b</sup>	0.00	4.40	>100,000	None	None
Kids Sleep Songs Free <sup>b</sup>	0.00	4.20	>1,000,000	None	None
Lullabies Relax & Sleep Baby <sup>b</sup>	3.99	4.70	>1,000,000	Help falling asleep	None
Lullabo: Lullaby for Babies <sup>b</sup>	3.99	4.80	>100,000	Help falling asleep	None
Lullaby for Babies (dream_studio) <sup>b</sup>	0.00	4.80	>1,000,000	Well-being and help falling asleep	Relaxation
Lullaby for babies (desenvdroid) <sup>b</sup>	0.00	4.80	>5,000,000	Well-being and help falling asleep	Relaxation
Lullaby for Babies (desenvmax) <sup>b</sup>	0.00	4.60	>100,000	Help falling asleep	None
Lullaby for Babies 2 <sup>b</sup>	0.00	4.80	>1,000,000	Help falling asleep	None
Lullaby for babies offline <sup>b</sup>	0.00	4.70	>100,000	Help falling asleep	None
Lullaby for Baby	7.99	4.70	>500,000	None	None
Lullaby Sleep Music for Babies <sup>b</sup>	0.00	4.60	>100,000	None	None
Lullaby Songs for Baby	9.99	4.60	>100,000	Help falling asleep	None
Lullaby Songs- Relax Music for Baby Sleep Light <sup>b</sup>	1.99	4.80	>100,000	None	None
Mozart Baby Sleep <sup>b</sup>	1.99	4.40	>100,000	Well-being	None
Music Box to sleep <sup>b</sup>	0.00	4.80	>1,000,000	Stop crying	Relaxation
Night Light	0.00	4.40	>500,000	Help falling asleep	None
Pinkfong Bedtime	9.99	4.40	>500,000	Help falling asleep	None
Sleep Baby Sleep	0.00	4.50	>100,000	Help falling asleep	None
Sleep Baby Sweet Dreams <sup>a</sup>	0.99	4.50	>100,000	Help falling asleep	None
Sleep Cute Baby Lullaby	0.99	4.50	>100,000	None	None
Sleeptot: Baby White Noise	28.99	4.50	>1,000,000	Well-being, help falling asleep, and trusted by parents	Relaxation
Sleepy Sounds	0.00	4.30	>1,000,000	Help falling asleep	None
Sound Sleeper	15.99	4.90	>100,000	Good sleep habits	None
Sound to Children Sleep	0.00	4.70	>1,000,000	Well-being, help falling asleep, and trusted by parents	None
Sounds for Baby Sleep Music <sup>b</sup>	0.00	4.70	>1,000,000	Help falling asleep	None
Sweet Dreams- Baby Songs <sup>b</sup>	0.00	3.90	>100,000	Help falling asleep	None
Sweet Lullabies ~Voice & Piano <sup>b</sup>	0.00	4.30	>100,000	None	None
White Noise & Deep Sleep Sounds- Fan & Baby Sleep <sup>b</sup>	19.99	4.50	>100,000	None	None
White Noise Baby	0.99	4.80	>1,000,000	Stop crying and well-being	None
White Noise: Baby Sleep Sounds	0.00	4.60	>100,000	Well-being	None



App name	Price (US \$)	Rating	Users, n	Themes	Behavioral strategies
White Noise Baby Sleep Sounds <sup>b</sup>	0.00	4.80	>1,000,000	Help falling asleep and trusted by parents	None
White Noise for Baby <sup>b</sup>	0.00	4.80	>100,000	Well-being	None
White Noise: Baby Sleep & Lullaby Songs Calm & Nap <sup>b</sup>	1.98	4.90	>100,000	None	None
<b>Bedtime games and story apps</b>					
Bedtime Stories for Children- Story Books to read <sup>b</sup>	1.99-19.99	4.40	>100,000	None	None
Bedtime Stories for Kids	2.49	4.30	>1,000,000	Well-being and help falling asleep	None
Bedtime Stories Goodnight: short stories	0.00	3.90	>100,000	Good sleep habits	None
Best Kids Stories: bedtime <sup>b</sup>	38.99	4.40	>1,000,000	None	None
Children's Songs Lullabies <sup>b</sup>	5.99	4.80	>100,000	None	None
Good Night Hippo	1.99	4.40	>1,000,000	None	None
Goodnight Caillou	6.99	4.10	>5,000,000	None	None
Goodnight, My Baby <sup>b</sup>	0.00	4.10	>1,000,000	Well-being and good sleep habits	Routines
Kids Bedtime Stories- Fairy Tales <sup>b</sup>	3.49	4.10	>100,000	None	None
Little Stories: Read Bedtime Story Books For Kids	13.99	4.30	>100,000	Well-being	None
Lullabies and Bedtime Stories <sup>b</sup>	0.00	3.80	>100,000	None	None
Masha and the bear: good night	5.49	3.70	>5,000,000	None	None
Moshi Twilight Sleep Stories: Kids Bedtime App	239.99	4.00	>500,000	Help falling asleep and trusted by parents	Routines and relaxation
Nighty Night- Bedtime Story	1.99	4.60	>500,000	None	None
Storybook- Bedtime Stories & Baby Sleep Massage	5.99-47.99	2.70	>100,000	None	None
Teddy Bears Bedtime Stories	3.49	4.50	>500,000	Help falling asleep	None

<sup>a</sup>Only available on the Apple App store.

<sup>b</sup>Only available on the Google Play store.

<sup>c</sup>Requires purchase of device.

## Types of Apps

### *Sleep Improvement Strategy Apps*

Sleep improvement strategies apps (n=2) are both designed for parents of young children and contain parenting advice alongside sleep logs that allow users to track their children's sleep patterns. Both of the sleep improvement apps have recommendations from sleep experts and guided steps for how to help children fall asleep. The *Huckleberry: Baby & Child Tracker, Sleep Experts* app is described as offering "an all-star team of sleep experts, personalized analysis and personalized step-by-step guidance of a traditional sleep consultant with the convenience of an app." The sleep experts reportedly include nurse practitioners, certified sleep consultants, and board-certified behavioral therapists. For a fee, users can log their children's sleep schedule and receive an analysis and recommendations. The *JOHNSON'S BEDTIME Baby Sleep* app states that it

"answers your sleep related questions, gives advice and helps track and learn your baby's sleep habits." It recommends a 3-step bedtime routine consisting of bath, massage, and quiet time, which states has been tested in infants 7 months of age and older for at least 1 week of use. While not cited in the description of the app, the *JOHNSON'S BEDTIME* app indeed has published data supporting these claims: a trial of over 400 infants (mean age 8.3 months) found that parents reported increased sleep duration and improved sleep quality after use of the app [11].

### *White Noise or Music Apps*

White noise or music apps (n=65) feature music or various sounds that are intended to be played during the night to help children sleep better. Most of the apps appear targeted for use with infants, with 45 of 83 (69%) containing the word "baby" in the app name. Two of the apps (3%) specify that they have timers to shut off the sounds after a predetermined time, while

5 apps (8%) have the ability to play sounds continuously; the remainder did not specify the duration or timing features of the sounds. In addition to playing music and sounds, the *Baby Night Light – Sleep Aid* app features sound detection such that if the app hears noises in the room, it will automatically turn on a nightlight to “soothe and put your child to sleep again when a baby wakes up.” In contrast, the *White Noise Baby* app features “looped ambient sounds and music,” allowing it to be played and maintained the entire night. These apps do not offer evidence of efficacy.

### **Bedtime Games or Story Apps**

The apps featuring games and stories (n=16) feature animals or other creatures going through a bedtime routine, becoming sleepy, and falling asleep, accompanied by music. All apps encourage parents to use the app with their toddler, preschool, or school-aged child as part of a nightly routine. For example, the *Nighty Night!* app is described as a “daily go-to-sleep ritual with cute animals, sweet lullaby music, and great narration.” Some apps indicate they should be used simultaneously while children attempt to fall asleep, such as the *Sweet Dreams: Good Night Books* app which states, “[the animals] all fall asleep and so will do [sic] your little one at the end of the app.” Only one app, *Moshi Twilight Sleep Stories: Kids Bedtime App*, utilized audio-only stories, meditations, music and sounds to help “settle and soothe kids into peaceful and restful sleep.”

### **Themes From Content Analysis**

Several themes emerged from the descriptions of the apps, including the common claim that the app has the ability to help children fall asleep quickly, improve child well-being and development, stop children from crying, help children develop good sleeping habits, and are trusted by parents.

#### **Helps Children Fall Asleep**

Many of the apps purported to be able to help children fall asleep quickly and easily (38/83, 46%). The *Sleep Baby Sweet Dreams* app stated, “the app will help you put your infant children to sleep quickly and calmly,” while the *Lullaby for Baby* app stated “children fall asleep immediately” with its use. None of the app descriptions explained the mechanisms by which the app will accomplish this nor cited evidence for this statement.

#### **Improve Well-being and Development**

Another theme was that use of the app would improve the well-being or development of children (18/83, 22%). *Mozart Baby Sleep* stated it will help babies “brain development, memory stimulation, and positive emotions.” The *Little Stories: Read Bedtime Story Books for Kids* app stated, “these stories have a positive impact on the development of your child.” Similarly, the *Baby Mozart Effect* app claimed that it “quickly helps calm your baby, reduces the stress of new life, enhances auditory and emotional awareness, induces relaxation and sleep.” However, none of these claims of supporting well-being and development were backed with evidence.

#### **Stop Crying**

One common theme was a claim that the app can stop children from crying at bedtime or at night (8/83, 9%). The *White Noise Baby* app stated that it will “help your baby relax, stop crying,

and sleep better.” Similarly, *Baby Lullabies* stated that its “natural white noise and soothing sounds helps babies cry less and sleep better.” However, none of the apps making this statement addressed evidence-based behavioral management strategies to help children learn self-soothing strategies to fall asleep independently.

### **Develop Good Sleeping Habits**

One theme of the apps was that they could help children develop positive sleeping habits and routines, often through use of games, stories, or songs (7/83, 8%). The *Goodnight, My Baby* app “let[s] your children develop a good sleeping habit when they encourage their friends to do the same.” The *Baby Songs* music app states, “with these wonderful tunes, your baby will establish a healthy bedtime routine!” Most of the apps did not provide support or describe how the app would accomplish sleep routine development. However, both the *Huckleberry: Baby & Child Tracker, Sleep Experts* app and the *JOHNSON’S BEDTIME Baby Sleep* app reported empirical support and use of behavioral strategies to improve child sleep habits. The *Huckleberry* app stated users can “access guidance from pediatric sleep experts, and daily personalized sleep plans for your child.” The *JOHNSON’S* app includes a “3-step nighttime routine, the only one that has been clinically proven to help baby fall asleep faster and sleep through the night better.”

### **Trusted by Parents**

Several apps implied that they should be used because they are endorsed by parents (5/83, 6%). The *White Noise Baby Sleep Sounds* app stated it has been “proven to be effective by generations of parents.” The *Moshi Twilight Sleep Stories: Kids Bedtime App* claims that “97% of parents surveyed agree it helps get their kids to sleep quicker, 95% say makes bedtime less stressful.” No information on survey methodology or citations were provided for these claims.

### **Behavioral Strategies**

In total, 18 (21.6%) apps were found to contain at least one evidence-based behavioral sleep strategy, most commonly relaxation (16/83, 19.3%). [Table 1](#) includes the behavioral strategies described in the apps. None of the descriptions of the apps explicitly included strategies such as bedtime no later than 9 PM, limiting access to electronics during and after bedtime, independent sleep skill development, or meeting emotional needs during the day. Three of the apps included more than one behavioral strategy: the *JOHNSON’S BEDTIME Baby Sleep* app included both bedtime routines and a consistent sleep scheduling, the *Moshi Twilight Sleep Stories: Kids Bedtime App* included relaxation and bedtime routines, while the *Huckleberry: Baby & Child Tracker, Sleep Experts* app included four strategies (relaxation, bedtime routines, consistent sleep scheduling, and sufficient sleep opportunity for age). The *JOHNSON’S BEDTIME Baby Sleep* app is the only app found to have supportive evidence from a nonrandomized real-world effectiveness trial [11].

## Discussion

### Principal Findings

Over 80 sleep apps were analyzed, which were created for the purpose of improving a child's sleep, each downloaded more than 100,000 times. Most of these are apps that purport to offer white noise or soothing music but do not actually address sleep habits specifically. Several themes emerged from the developer descriptions of the apps, including the ability to help children fall asleep quickly, improve well-being and development, stop children from crying, help develop good sleeping habits, and that the apps are trusted by parents. The majority of apps did not include evidence-based behavioral strategies for sleep in their description or claims. The apps that did include behavioral strategies mentioned the use of relaxation, consistent sleep scheduling, bedtime routines, and allowing sufficient sleep opportunity for age.

Overall, our findings show that apps targeting sleep in pediatric populations were less likely to incorporate evidence-based behavioral strategies than sleep apps targeted to adult populations (only 21.6% vs 33%-34%) [6,7]. Our findings are consistent with a lack of evidence-based support in apps for other childhood difficulties, such as apps for infant feeding [12,13]. Of note, an app may have promoted one evidence-based strategy while simultaneously being in contradiction of another; for example, many of the white noise or music apps and bedtime games or stories apps stated they could be used for relaxation at bedtime, and they appeared to be intended for use visually during the bedtime routine (in opposition to the recommendation to limit electronics during or after bedtime) [9,14]. Using an app while children are falling asleep could create a sleep onset association such that children may then not be able to fall asleep independently without utilizing electronic devices [2].

However, 3 apps contained more than one evidence-based behavioral sleep strategy. As our analysis was based solely on the app description, it is possible that the content within the app may have indicated even more of these strategies. These findings suggest that apps can be developed, which are in line with the evidence base for pediatric sleep. Unfortunately, the majority of currently available sleep apps may not be a good source of evidence-based behavioral strategies for pediatric sleep problems. Moreover, the *JOHNSON'S BEDTIME Baby Sleep* app was the only app with support from a real-world effectiveness trial [11]. Future research examining the efficacy and effectiveness of sleep apps for pediatric sleep problems is recommended.

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### Conflicts of Interest

None declared.

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### Strengths and Limitations

Sleep apps targeted at improving children's sleep have room for improvement regarding input from the scientific and clinical community. To our knowledge, this is the first review of such apps, and although a systematic approach was followed to assess each app's content, this analysis does have limitations. The current examination was for apps found with the search terms "kids sleep," "child sleep," and "baby sleep," but future analysis of apps aimed specifically at adolescents is important owing to the ubiquitous use of technology and the high risk for insufficient and delayed sleep in that age range. Our criteria excluding apps with <100,000 downloads may have resulted in missing newer apps that may possibly contain more evidence-based behavioral sleep strategies. Moreover, previous studies that examined sleep apps in adults excluded relaxing music apps, while we chose to include sound or music apps, and, in fact, they made up the majority of the apps examined. Our study did not include apps intended for general use, but we felt it was important to include sound or music apps if they indicated that they were intended to improve children's sleep and were specifically for bedtime or nighttime purposes. Finally, examination of the developer-provided app description is important since this is information parents may use to help choose which app to use for their children. However, future research is warranted to more comprehensively evaluate children's sleep apps using an empirically supported rating tool such as the Mobile App Rating Scale [8] and by downloading and user testing the specific features of each app.

### Conclusions

In summary, addressing sleep difficulties in children is important to promote physical, cognitive, and emotional development [1]. Brief behavioral interventions based on learning principles have demonstrated efficacy for children with sleep difficulties [4]. However, families face barriers in accessing evidence-based care owing to a shortage of pediatric sleep specialists and lack of training and knowledge of sleep treatments among non-sleep specialist health professionals [5]. A large variety of sleep apps aimed for use with children exist; yet, the descriptions for each app often do not include evidence-based behavioral sleep strategies. Collaboration between sleep researchers and technology developers may be beneficial for the creation of evidence-supported apps to help with children's sleep in the future. Additionally, clinicians can support families in selecting apps that align with the evidence base for pediatric sleep.

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Original Paper

# Navigating the Online World of Lifestyle Health Information: Qualitative Study With Adolescents

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## Abstract

**Background:** Adolescence is a critical life stage characterized by an interplay of biological, social, and environmental factors. Such factors influence lifestyle health-related trajectories, including dietary behaviors, physical activity levels, body weight, and sleep. Generation Z (born 1995-2015) is the most internet-dependent and technologically savvy generation in history with increasing rates of smartphone ownership across high- and low-income countries. Gaps exist in understanding what online platforms adolescents are using and barriers and facilitators of these platforms to seek lifestyle health information.

**Objective:** We evaluated adolescents' perceptions on the use of contemporary digital platforms (websites, social media platforms, smartphone apps) to seek lifestyle health information or advice.

**Methods:** Virtual focus groups were held via Zoom teleconference between July 2021 and August 2021. Eligible participants were 13 years to 18 years old, were living in Australia, and had searched for online lifestyle health information in the previous 3 months. For this study, lifestyle health information referred to key behaviors and risk factors for chronic disease, namely, diet, physical activity, weight management, and sleep. Participants were recruited through an existing database of research participants and networks of the research team. Focus groups were analyzed using the framework approach, in which data are systematically searched to recognize patterns in the data and manage, analyze, and identify themes. Focus group audio files were transcribed verbatim and independently coded by 2 researchers (RR, SSJ). Through an iterative, reflexive process, a final coding matrix was agreed on by all researchers and used to thematically analyze the data.

**Results:** We held 5 focus groups (n=32; mean age: 16.3 [SD 1.4] years; 18/32, 56% female; 13/32, 41% spoke language other than English at home). Thematic analysis revealed participants searched for information both actively (eg, on Google or YouTube) and passively (eg, scrolling social media and using existing apps preloaded to their smartphone such as Apple Health, Samsung Health, or Google Fit apps). Participants identified that the most helpful information was well-presented in terms of aesthetic appeal and layout and came from a credible and reliable source (eg, any sponsorships disclosed), and they expressed the need for the information to be relatable. Mixed views were reported for the application of lifestyle health information found online. Some participants reported behavior change, while others noted that certain advice was hard to maintain and incorporate into their lifestyle.

**Conclusions:** This study highlights the abundance and complexity of lifestyle health information online for adolescents. Adolescents in the digital age seek access to information that is appealing, credible, relevant, and actionable for lifestyle health behaviors. To appeal to needs of adolescents, future interventions for adolescents relating to lifestyle health must consider co-design



methodological approaches. Furthermore, the regulation of lifestyle health information available online warrants further investigation.

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## KEYWORDS

adolescents; chronic disease prevention; websites; social media; smartphone applications

## Introduction

Today's adolescents, defined by the World Health Organization (WHO) as aged 10 years to 19 years, make up 16% of the global population [1]. Adolescence is a critical life stage during which a complex interplay of biological, social, and environmental factors determines the trajectory of lifestyle health behaviors into adulthood [2]. Lifestyle health behaviors and risk factors that are of great importance during adolescence are diet, physical activity, weight management, mental health, and sleep hygiene, as they are predictors of adverse health outcomes in adulthood, such as obesity and cardiovascular disease [3]. Globally, most adolescents do not meet diet or physical activity guidelines [4,5], and there has been a dramatic increase in the prevalence of overweight and obesity, jumping from 4% to over 18% in the last 40 years [6]. In Australia, very few adolescents meet guidelines for diet and physical activity [7,8], and adolescents do not get enough sleep on school nights [9]. Adolescence is an opportunistic window for establishing good lifestyle health behaviors [10]. Despite this, research priorities during adolescence are often focused on reducing other high-risk behaviors such as suicides, substance use, and sexual activity, with limited attention given to research that effectively harnesses digital technologies to target prevention of chronic diseases through lifestyle risk factor management [11,12].

Adolescents are known as “digital natives” as they have been born into a ubiquitous digital environment [13], which has grown exponentially in the last 20 years. In Australia, 94% of adolescents own a mobile phone, 95% are accessing the internet daily, and they use an average of 4 different social media platforms [14]. Previous research has shown that adolescents frequently turn to online sources such as internet websites and social media for lifestyle health information [15]. A national US survey found that adolescents are primarily looking at diet and fitness information online, with more trust placed on the internet than social media [16]. Furthermore, studies have explored how adolescents search for and appraise online health information and the extent to which they trust this information [17,18]. Furthermore, there is a constant expansion in the variety of digital platforms, including the uprise of contemporary platforms such as TikTok and Discord. As such, the current evidence base exploring the use of digital platforms to obtain information on lifestyle health behaviors is outdated. Contemporary digital platforms are a highly appealing and easily accessible way for adolescents to obtain lifestyle health information, given the increasing rates of smartphone ownership and their widespread use among adolescents for the pursuit of lifestyle health information.

As the digital health space is growing, gaps exist in our understanding of what contemporary digital platforms

adolescents are using to seek this information and the barriers and facilitators of obtaining lifestyle health information on these platforms. Understanding the barriers and facilitators is crucial for governments, health organizations, researchers, and policy makers to be able to deliver appealing and effective lifestyle health promotion and support adolescents with management of chronic disease risk factors. Therefore, the aim of this study was to explore adolescent perceptions of obtaining information or advice related to lifestyle health from contemporary digital platforms.

## Methods

This study adhered to the consolidated criteria for reporting qualitative research (COREQ) guidelines for reporting qualitative research ([Multimedia Appendix 1](#)) [19]. The study protocol was approved by the University of Sydney Human Research Ethics Committee (approval number 2020/613), and participants gave informed e-consent prior to participation.

## Participants

Participants who were eligible to take part in the focus groups were aged 13 years to 18 years (inclusive). The WHO defines adolescents as 10 years to 19 years old; however, the range of 13 years to 18 years was selected to coincide with the age range of secondary education in Australia, which is a common setting for health promotion interventions by governments. Further eligibility criteria included living in Australia and having had accessed lifestyle health information online at least once in the previous 3 months. For this study, lifestyle health information referred to key behaviors and risk factors for chronic disease, namely, diet, physical activity, weight management, and sleep.

## Recruitment

Participants were recruited through an existing database from a previous cross-sectional survey (Digitalize Study) [20] and known networks to the research team. The Digitalize Study was a cross-sectional survey to find out how young people (13-18 years old) search for lifestyle health information online including which digital platforms were most used, perceived helpfulness of information on digital platforms, helpfulness for positive behavior changes, and the quality of platforms' health information. Email invitations were sent with a link to the participant information sheet. All prospective participants read the participant information sheet online, provided informed e-consent, and were directed to an online survey to indicate demographic characteristics (age, gender, postcode, and language spoken at home) and how often they searched for lifestyle health information online in the previous 3 months. A 3-month time frame was chosen so that participants had up-to-date knowledge of lifestyle health information on these digital platforms. If participants had not accessed lifestyle health

information in the previous 3 months, they were not able to complete the survey and therefore were not contacted to take part in the focus groups. All eligible participants were contacted via text message to confirm date and time of focus group and were emailed the secure teleconference link.

### Data Collection

A semistructured discussion guide was developed by the research team based on the outcomes of the Digitalize study [20] to further explore the perceptions of obtaining and using lifestyle health information online. To assess whether the focus group questions were easy to understand and acceptable, the interview guide was piloted with 2 youth advisors who currently work with the research team. The discussion guide is provided as supplementary material ([Multimedia Appendix 2](#)).

One researcher (RR) gave a brief overview of the discussion at the commencement of the focus groups. Participants were asked about where they accessed health information online (internet websites, social media platforms, and smartphone apps), why they used online sources, what type of content they found most engaging, and any potential changes to their lifestyle behaviors as a result of applying the information they obtained online. Based off their responses, the 2 platforms of most interest to the group were discussed in more detail. Questions explored how they searched for information on these online sources, what made these sources most and least appealing, and how they judged the reliability and usefulness of the information they found.

The focus groups were conducted by 2 researchers (RR, SSJ) via videoconferencing (Zoom Video Communications Inc, San Jose, CA) at a time convenient for participants. The focus groups were led by RR, and SSJ took detailed notes for each session. Each focus group took approximately 45 minutes to complete. RR has training and previous experience in conducting focus groups and semistructured interviews. Focus groups were recorded and transcribed verbatim into Microsoft Word (Version

16.54, Microsoft 365, Microsoft Corp, Redmond, WA) by RR. Recruitment of participants for focus groups ceased when thematic saturation was reached. Participants were not contacted for further focus groups or validation of transcripts. Each participant was provided with an Aus \$20 (US \$14.26) gift voucher for participation.

### Data Analysis

The framework approach was used to analyze qualitative data [21], where data are systematically searched to recognize patterns in the data and manage, analyze, and identify themes. On completion of focus groups, RR and SSJ familiarized themselves with the data and undertook thematic analysis independently. RR and SSJ developed coding labels relevant to the research question and identified emergent themes. After systematically coding all the transcripts, the research team (RR, SSJ, and SRP) discussed themes that were further developed through an iterative and reflexive process. Consensus on final themes were developed and agreed on by all researchers. Qualitative data analysis was performed using NVivo 12 (12.2.0).

## Results

### Participant Characteristics

Focus group attendance was confirmed by 37 participants; 5 participants did not attend the focus groups without providing a reason, leaving a total sample of 32. Participant characteristics are reported in [Table 1](#). Participants had a mean age of 16.3 years. From the study sample, 56% (18/32) of participants identified as female, with most participants residing in New South Wales (22/32, 69%). Two-fifths (13/32, 41%) spoke a language other than English at home. Participants varied in their frequency of accessing health information online with over one-third accessing health information online 1 to 2 times a month (12/32, 38%).

**Table 1.** Focus group participant characteristics (n=32).

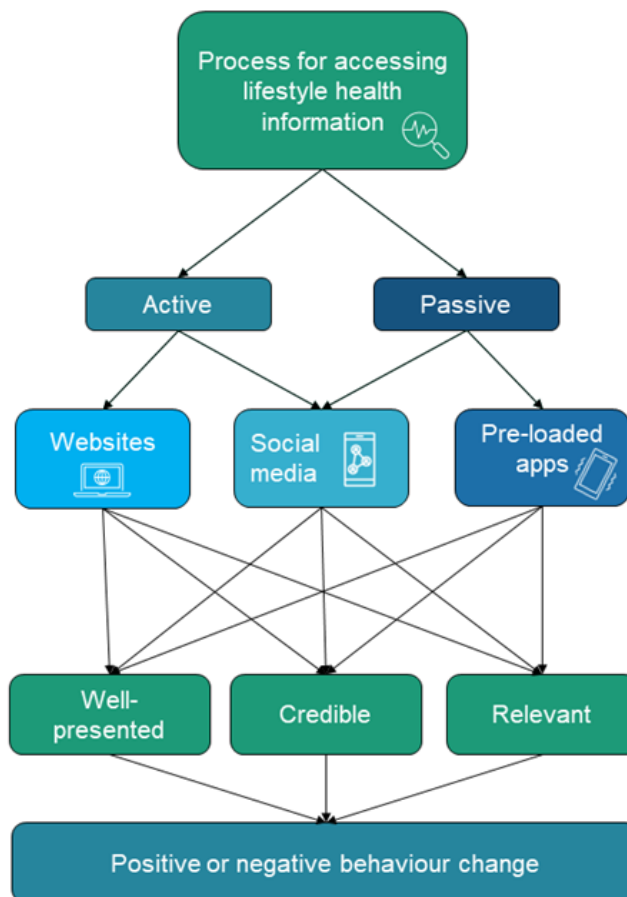
Participant characteristics	Results
<b>Age (years), n (%)</b>	
13-14	4 (13)
15-16	11 (34)
17-18	17 (53)
Age (years), mean (SD)	16.3 (1.4)
<b>Gender, n (%)</b>	
Male	13 (41)
Female	18 (56)
Prefer not to say	1 (3)
<b>Residential state in Australia, n (%)</b>	
New South Wales	22 (69)
Victoria	6 (19)
Western Australia	4 (13)
<b>Language spoken at home, n (%)</b>	
English only	19 (59)
>1 other languages spoken	13 (41)
<b>Frequency of accessing lifestyle health information online, n (%)</b>	
1-2 times a month	12 (38)
Once a week	7 (22)
A few times a week	8 (25)
Once a day	1 (3)
More than once a day	4 (13)

## Themes

### Overall Findings

Thematic analysis identified a complex interplay of 5 main themes relating to obtaining lifestyle health information across contemporary digital platforms (Figure 1). These 5 themes included the processes of accessing lifestyle health information online, the presentation of lifestyle health information online, the importance of credible and reliable information, having information relevant to adolescents, and perceived behavior changes from application of lifestyle health information found

online. These themes emerged across the 3 digital platforms that were discussed in-depth (internet websites, social media platforms, and smartphone applications). Across different digital platforms, there were distinct similarities and differences, which are explored in detail in each theme in the next sections. Despite attempting to ascertain which type of lifestyle health content (ie, diet, physical activity, weight management, or sleep) would be most engaging to adolescents, all 5 focus groups did not have a clear emerging theme, with all aspects of lifestyle health discussed. The 5 emergent themes are discussed in detail in the following sections.

**Figure 1.** Conceptualization of emergent themes related to participants obtaining lifestyle health information across contemporary digital platforms.

### Theme 1: Processes for Accessing Lifestyle Health Information Online

Adolescents identified internet websites and social media platforms as the top 2 sources for lifestyle health information online. However, they described the process for accessing information from these 2 sources differently. On digital platforms such as Google and YouTube, participants described actively searching for information of interest to them. Google searching for information was reported by most participants, who stated that they would only visit the first few websites that appeared in the search results. Websites that were commonly frequented by participants for health information were government-based websites and blogs. Some participants searched on YouTube for health information, especially relating to exercise and recipes.

*I think that I would probably go and just do a google search honestly, and then whatever would come up there is what I would do. I don't think I'd refer to a specific website. [FG2, 18M]*

*For me, it's like on Google, I usually get my information from the first like 10 or 8 websites or something, like the more backdated it is like in the second or third page, I feel like it would be less relevant to me. [FG3, 17M]*

Accessing health information on social media platforms was described differently as participants would passively receive information that appeared in their feed (from people who they

chose to follow) or by scrolling through explore pages. Participants also identified that the information that they came across on social media platforms may have been targeted to them due to algorithms used by these platforms.

*...it's not really like me actively searching up on Instagram; it's more me following like a few organizations and people like government, a few athletes, and physios and things like that. [FG4, 16F]*

*I don't search that much for things cause things I [want to] know, they usually just come to me on my feed because you know TikTok and Instagram, they are really customized... [FG5, 13F]*

Smartphone applications were also identified by some participants as being used to access lifestyle health information. Similarly, for smartphone applications, participants mostly reported using applications that were already available on their smartphone (eg, Apple Health, Samsung Health, Google Fit) rather than searching app stores for new applications. When exploring reasons behind app usage, cost was a major factor, which supports this finding of using apps that are readily available to them.

*I've [got to] say, I also use the standard health app on my phone, which is actually quite helpful cause I can track how much I exercise, how much I run, also other health-related things. [FG4, 16F]*

*As I said, my phone already came with the app, so I didn't look for it. [FG4, 17M]*

*I wouldn't spend money on an app to tell me all those things cause (sic) I can just find it on the internet. [FG4, 16F]*

### **Theme 2: Presentation of Lifestyle Health Information Online**

Participants placed a large emphasis on the importance of how lifestyle health information is presented and organized for them online to be able to easily read and to interpret the information. This included the importance of white space and the use of dot points and subheadings on websites that would make them “easy to navigate” [FG4, 17F]. They reported that, if websites were not laid out logically or in an aesthetically appealing manner, they would often look elsewhere for the same information.

*I'd say like organized well, like I don't want it to have all these clunks of information that is not actually relevant to what I'm looking for...and also like, you know, have lots of like white space on the page so it's easier to interpret and like dot points. [FG1, 14M]*

*If the layout is really bad or like the words are all really close together, it just overwhelming to look at the website so I would be way more likely to click off. [FG2, 18F]*

Another subtheme that emerged was the importance of the quality of the content. This was reported both in terms of the actual information that was being presented and the production quality of videos or posts on social media. When information was presented in a way that appeared to be high quality and aesthetically appealing, most participants reported that they found it more credible. On social media, the production of posts or videos needed to be of good quality for them to follow that person and to “dig deeper” [FG5, 13F] into the account.

*It's kind of a mix of both because if I like their content, I'll probably follow them, but if they have put like no effort into their page, it kind of like throws me off because I'm the type to like aesthetic-looking stuff. [FG5, 14F]*

*I think the information they put out is important, but I think I'm less likely to actually follow them if the production is not as good as other people. [FG5, 15M]*

### **Theme 3: Credible and Reliable Lifestyle Health Information Online**

Nearly all participants identified that they assessed whether the health information online was credible or reliable and this was achieved differently depending on the online source. For websites, participants reported looking if the information was referenced or included a bibliography. It was also recognized that participants mostly trusted government websites and well-known health organizations, but when it came to other websites, that they would “cross check” [FG1, 18F] to see whether there was a scientific backing to the information presented. By verifying this information with other sources, this demonstrates an awareness of where credible information originates.

*I think it is based off your source, but most of the government stuff is pretty good. [FG1, 17F]*

*I look for research papers, and if it's a government website or any sort of university and if it's a newsletter or something like that, then I try to check it twice with something else. [FG3, 17M]*

*I think usually when you look at information, you can just kind of judge just by the way that they're putting forward the information and also just to cross check just Google to see whether their information matches up what other people are saying majority of the time. [FG1, 18F]*

On social media platforms, participants identified multiple ways they assessed whether what they saw was credible or reliable. First, participants emphasized the importance of having a person behind the account with their credentials clearly stated. Many participants also stated that if they had a blue tick, meaning that the account was verified, this would also increase their credibility. Furthermore, the follower count of the social media account was also seen to increase reliability, with more followers making them more reliable.

*I think knowing more about the person behind it is useful because sometimes you will find information and you can tell that it is like really biased. It's information for sure, but it's what they want you to know, it's not really always true. So, if they could say like who they are and where they got the information, it would be a lot more trustworthy. [FG2, 17F]*

*Well, if I see like a tick...like that blue tick, that they're like professional, I guess, and also like if I see that they have a lot of followers, I don't know sometimes, some organizations they have [been] verified by the NSW government and things like that. [FG4, 16F]*

Nearly all participants were acutely aware of sponsorships and advertising online. On social media, influencers are often paid to promote certain products or services. For most participants, if an account was constantly promoting one product, this would be a deterrent to trusting the information that they portrayed and was seen to be “off putting” [FG2, 18F]. Participants also understood that this was a way in which these accounts generated income.

*I was just going to say that I think the content really matters and whether or not they're putting it out for the right reasons. I see, like sometimes, influencers, is that they are just kind of putting up information because they're getting paid to, you know, to advertise for those things. [FG1, 18F]*

*I think if they are constantly advocating for like I idea or like I diet or, you know, I product or something like that, kind of puts you off because it shows that it's like, it's not genuine, it doesn't show other sides, and then you're kind of being biased. [FG2, 17F]*

*If it's really pushing it and especially like Instagram and social media where it's just dedicated to that thing, to that endorsement, it's a little more off*



*putting. But you know it's how it goes, they have to do it, so if I'm good with the content that they provide otherwise, then it's OK. [FG3, 17M]*

Regarding advertising on websites, participants reported the type of advertisements were important. If the advertisement was unrelated to the website itself, then the website would be seen to be unreliable. However, having advertisements in general was seen to be acceptable, and when the information was referenced correctly, they would still consider the website to be reliable.

*Definitely the type of ads, like if I see something that I'm like no that's not right, I'll probably get off the website as soon as like I see it. [FG5, 14F]*

*Just the ads doesn't really deduct from the website for me, cause for me, it's like if they cross reference it with at least one or two sites, like the first three sites no matter how un-user friendly they are if they say the same thing, then I just take that away from it. [FG3, 17M]*

Another subtheme that was identified was that some participants assessed other people's comments on social media posts to see other opinions about whether the information that was presented was reliable. Likewise, when assessing mobile applications that they would potentially download, some participants looked at reviews on app stores to see whether other people thought the app was helpful for them.

*I do go to the comments every single video or pretty much that I'm interested in to see what other people think about it, not for information purposes but sort of to see what other people's opinion on that particular post is. [FG5, 15M]*

*I would also definitely look at the reviews and not just what the reviews say but the amount of the reviews, how many people access the app, how many people say this or that, that kind of thing. [FG4, 16F]*

#### **Theme 4: Lifestyle Health Information Relevant to Adolescents**

Most participants reported that searching for health information online was convenient. Participants reported online information as being easy to access, readily available, and regularly updated. Also, many participants reported that they accessed lifestyle health information from a variety of sources to compare the information themselves rather than seeing a health professional, which takes time and money and they may not provide the extent of information that can be found online.

*Mainly because it's very accessible and just easy to access, very like fast, just search it up, and you basically have an answer. Um, also, I guess, you can find people who are going through similar situations, like same age group just people that are, who you can relate to, and I think that's generally where you can get a lot of advice from. [FG4, 16F]*

*I think because it's always like updated, whereas if you've got like an out-of-date leaflet or something, it might not be relevant. [FG1, 18F]*

*I definitely think it's easier to look it up online because then you just get a bigger range of answers as well like if you go to a doctor, they normally just give you one straight answer. [FG2, 18F]*

When referring to social media specifically, many participants reported following accounts that were relatable. For an account to be relatable, they had to engage frequently with their followers in terms of posts or stories and have lifestyle health information and advice that would be easy to implement into their own lives. Also, it was recognized that the person behind the account was important in terms of relatability, due to a sense of familiarity. This did depend on the size of their existing following, with smaller accounts being favored as they were more likely to respond and engage with followers, whereas larger accounts were viewed as more reliable.

*I'll generally follow accounts that like I can relate to so I can kind of use their posts in my own life. [FG2, 18F]*

*You can also find people who are in the same position as you like, for example people who are the same age...and it's really easy to see if their lifestyle, like you can take something from that so that's definitely been really helpful for me. [FG4, 16F]*

*I feel like you can, you know, you can build a better relationship and get familiar with what they do on social media and if they are also influencing you in fitness, etc, you follow that. [FG3, 17M]*

*Something like lifestyle, for example, I definitely go for the people who have less followers, if it's specifically like workout videos I tend to go for the big names like Chloe Ting or those sort of ones. [FG3, 17F]*

Websites were often reported by participants as being too generalized and therefore were sometimes viewed as unrelatable and unhelpful for obtaining health information. Some participants identified that the information may not be specifically directed toward young people or in line with what they were wanting to achieve in terms of their personal goals. It was also identified that they had visited websites that provided a large variety of information but not enough detail; therefore, they were unable to make a judgement of whether that information would be relevant to them.

*I think sort of just having information that is like more relevant to you. I know that a lot of the sort of diet information that I find on the internet, it's more sort of geared towards adults. [FG3, 17F]*

*For just general health and stuff, I find the government websites pretty lackluster, like they kind of just go through the motions and give the minimum information, so like, for what I'm interested in with training, the government websites aren't that great. [FG5, 15M]*

*Sometimes, it's just like you're not there for a really wordy essay, for example, like you guys are professionals but please make it understandable for us, you know, you're not trying to show off your skills,*

*you're trying to provide information that is useful and understandable.* [FG3, 16M]

### **Theme 5: Perceived Behavior Changes Based on Online Lifestyle Health Information**

When regarding behavior change from online health information, participants reported a mixed variety of personal effectiveness. Some participants reported making changes based on information that they had seen online, including dietary changes such as restricting calories and physical activity changes including trying specific workouts that were not effective for them and subsequently viewed these behavioral changes negatively. As the behavioral changes were viewed undesirably, the changes were not sustained long term. Contrary to this, other participants reported making changes such as intermittent fasting and increasing total sleep time, which were viewed by participants as positive changes. It is important to note that, for some lifestyle changes, some of the participants viewed these positively, and others viewed them negatively, demonstrating

the complexities of lifestyle health information and how individual preference also plays an important role. Furthermore, some participants outlined desire to make changes; however, the information that they found was “too hard to integrate” [FG4, 17F] or “doesn’t last a very long time” [FG4, 16F].

*I saw something online about like how much you should be eating...a day, and I severely restricted my like caloric intake, and I noticed, like, straight away that that in it had an impact.* [FG3, 17F]

*When I found this out about intermittent fasting, it just sort of like suited me better than what the government guidelines tell you.* [FG1, 18F]

*I googled how much sleep someone of my age should be getting, and it turns out it was a lot more...than what I was getting, so I try to go to bed a bit earlier and try to wake up a bit later each day.* [FG2, 14F]

Additional quotes for all themes are listed in [Textbox 1](#).

**Textbox 1.** Quotes illustrating participants' experiences related to obtaining lifestyle health information online.

#### Theme 1. Process for accessing lifestyle health information online

- "I guess I wouldn't go to like Instagram or Facebook to look up health stuff but if it comes up on there, then I might like read it." [FG1, 17F]
- "I don't really like go on social media for like health info, but when I like scroll on Facebook and I see like news articles or like advice, I just click on the link if I'm interested, and if it's helpful, then I will just keep reading." [FG1, 18M]
- "I think that the majority of the information I find is accidental...so it's just stuff that I come across...on social media platforms. Most notably, Instagram because of the explore feature and like its content that is tailored to you." [FG3, 15F]
- "I feel like for us, like teenagers, there aren't as many people going on websites ... being regularly would more be like the accounts on Instagram." [FG5, 15M]
- "I guess for day-to-day info would be social media, but I would trace that if I actually get interested in it and go look at backup research on google or like a research facility who have done research on it." [FG3, 17M]
- "I think it's kind of a waste of money, like when you can get the exact same thing for free, and it's not like I really need it cause I'm like only 15." [FG5, 15M]
- "I use the health app as well, it kind of just tracks my sleep and steps and everything because I usually have my phone on me wherever I go." [FG5, 14F]

#### Theme 2. Presentation of lifestyle health information online

- "Some of the websites, they [are] just really convoluted and confusing, so if it's the first one that pops up but it's confusing, I will just like go to another one." [FG1, 18F]
- "I really like the pages that just kind of just sum all the points up like when they speak really, you know, sophisticated, it like, it allows you to trust what they are saying. I also like it when they sum it up at the end in just real simple English so it's straight to the point." [FG2, 16F]
- "If there's like...subheadings within the website or like the answer to it is straightforward rather than in like big paragraphs, because like I wouldn't be likely to read that and in dot points would be even easier." [FG3, 17M]
- "Yeah sorry, like headings and it being like scientific, so it is reliable but not um too scientific that we don't understand what is going on." [FG3, 18F]
- "A lot of the people who I'm like friends with, they would follow the person as well. And then like, just seeing their content, I kind of go through it, like if they're professional, you can [kind of] tell, and like they have it in their bios." [FG5, 14F]
- "The, um, production has to be eye catching for me to actually sort of dig a bit deeper into their account, but otherwise if the content is good, then I'll follow them." [FG5, 13F]
- "If they have consistently posted the same sort of content. Not necessarily about the same issue per se but like just if they have got a consistent amount of information like at least 30 posts, if it's something that I can sort of have a look through." [FG3, 15F]
- "It's definitely good if they do have a nice aesthetic side to it, but the content has to be like pretty clear and concise." [FG5, 13F]

#### Theme 3. Credible and reliable lifestyle health information online

- "Normally, if there is a verified tick or someone like known that's more trustworthy in that area, in health. So, it's like, if there is someone new with barely any followers...then it makes it less likely for you to follow that person." [FG3, 17M]
- "I just go back to the same ones if I find something useful or if it's helped me, I'll tend to go back to it because I know it's reliable and I've had a good experience with it." [FG3, 16M]
- "Usually, it's sort of based on the quality of the website because usually if it is based... and it looks nice they are sort of putting effort into it, and if it looks dodgy, then it's probably not going to be as credible." [FG3, 15F]
- "I just think the ah, the idea of having something government certified, and I think a clear distinction between advice and information." [FG4, 17M]
- "It's quite hard to sift through things that are unbiased, especially on the internet, especially with influencers as well when they are paid." [FG2, 18F]
- "I also agree with the sponsorship thing because when I found out some of the sponsorships, that's when I realized that some of this information it wasn't...like true, it was just because they were being paid to say that." [FG2, 14F]
- "Another thing that I do sometimes is before I download it, some people leave comments on App Store, which can actually end up being pretty helpful...and then if I think I don't want it anymore, I just don't download it." [FG5, 14F]

#### Theme 4. Lifestyle health information relevant to adolescents

- "I do it because a lot of the times, I feel like the health advice I'm trying to find is when a problem isn't that big of a deal, so I don't think it's worth going to someone like important." [FG2, 14F]
- "And it's also like having to see a person in real life is more daunting than actually searching up information for yourself." [FG3, 17M]

- “I would often go to an influencer even knowing that their information may not be as trustworthy just for the convenience aspect.” [FG5, 15M]
- “I say when you talk about the engaging part, social media really takes the lead there because the type of video they make is captivating and the target audience can always be found.” [FG3, 17M]
- “When it comes to diet information, I don’t really find it helpful because um, because often the diet information is only helpful for like one specific type of group and it’s like, it’s hard to find something that is directed towards me.” [FG2, 14F]
- “So, maybe if there’s a government or some other organization released like a bunch of websites that they think would be really useful and then you could check them out and like maybe get feedback from young people to see which websites they like and things like that, that would definitely help.” [FG4, 16F]

#### Theme 5. Perceived behavior changes based on online lifestyle health information

- “So, in high school, we were always told, oh you have to have 3 meals a day, and I feel like that didn’t really suit my lifestyle, but then when I found this out about intermittent fasting, it just sort of like suited me better than what the government guidelines tell you.” [FG1, 18F]
- “There is this documentary on YouTube called Dominon, and I watched probably only the first 20 minutes, and it’s made me vegan for 2 years so far. It was like, yeah it showed you like a complete other different side to the information that’s on the internet, and so yeah, it kind of did make a big change in my life.” [FG2, 17F]
- “There was this craze about like skipping for fitness, and it was like... I tried it for a bit, and I didn’t really have any results, so I stopped doing it.” [FG3, 17M]
- “I saw some different posts and things like TikTok things on Instagram of bad side effects of drinking dairy, so it was one of the factors that made me not drink dairy anymore.” [FG3, 15F]
- “With most of the things I see, it’s either too hard to integrate for myself or I already do it, so I wouldn’t say that I do anything specific that I’ve seen online.” [FG4, 17F]

## Discussion

### Principal Findings

Overall, this qualitative study provides strong insight from adolescents into the barriers and facilitators of accessing and using lifestyle health information on contemporary digital platforms. To our knowledge, this study is among the first to explore adolescents’ perceptions on their use of these contemporary digital platforms to obtain information and advice about lifestyle health. The results demonstrate that adolescents’ methods for searching for lifestyle health information differ across online platforms, with active searching for information across platforms such as Google and YouTube and passive receiving of information across other social media including Facebook, Instagram, TikTok, and Twitter. Furthermore, adolescents desired information to be well-presented, credible, and relevant to them. The findings from this study can be used to inform future research into the development of effective online lifestyle health promotion strategies and interventions for adolescents.

### Comparison With Prior Work

Previous research has shown that nearly 63% of adolescents use online information broadly to maintain a healthy lifestyle [22]. Many previous studies assessed online information as a whole, without differentiating between online platforms (eg, websites, social media). Our findings from this study appear consistent with previous research regarding the processes that adolescents use to search for health information online; however, this study elicited new findings across the different contemporary digital platforms. From an adolescent perspective, it is apparent why social media is favored over websites when it comes to lifestyle health information. Social media is a common feature in many adolescents’ everyday lives, with

mobile devices making access to social media more frequent and personalized [23]. Features available on social media platforms, such as Instagram stories and turning on notification features for favorite accounts, allow content to be highly engaging and of higher production quality. These features increased the perceived credibility of the account by adolescents and allow adolescents to curate who they follow on social media and thereby ensure that the information that they are digesting is relevant to them.

Processes used to search for lifestyle health information by adolescents included searching for information on websites and both actively and passively using social media platforms [17,22]. The passive nature of information exchange on social media is potentially increasing due to the increasing amount of targeted advertising across different social media platforms. In 2021, social media advertising was projected to reach Aus \$199 million (US \$21.7 million), which is a growth of 4.9% [24]. Users now have less control over the information content within their social media feeds [25]. A study by Hausmann et al [15] suggested only 25% of adolescents agreed that social media could help them obtain useful health information, despite almost ubiquitous use of social media among adolescents. In this study, participants identified several barriers to ascertain whether information on social media was useful. Such barriers included the use of sponsorships and advertising by companies and influencers on social media and the targeted nature of information due to algorithms employed on these platforms. eHealth literacy is the ability to seek, find, evaluate and appraise, integrate, and apply information to solve a health problem in an electronic environment [26]. eHealth literacy was not assessed as part of this study; however, adolescents demonstrated awareness of broad social media advertising and sponsorship strategies. Evaluations of eHealth literacy in the



context of contemporary digital platforms warrant further investigation.

Co-design is widely used in the development of eHealth interventions to increase their acceptability and effectiveness among adolescent populations, as they are particularly hard to engage [27,28]. This same methodology can be applied to the development of online health information to increase its appeal in terms of organization of information and relevance to adolescents. A previous systematic review of Australian websites found that very few websites were written specifically for adolescents and none were found to be excellent quality, interactive, and written in plain English [29]. This finding was also demonstrated in our study, with adolescents reporting that information found on websites was often too hard to understand, too difficult to navigate, or not relevant to them. To ensure that information is presented in a format that adolescents understand and is relevant to them, co-design of online health information with adolescents could be utilized to increase its acceptability and effectiveness in management of chronic disease risk factors.

The digital space is highly unregulated, and this challenges the credibility of online health information. Due to the rise in user-generated content on digital platforms and popularity of using social media to access lifestyle health information, it is becoming increasingly difficult to regulate digital content, with authors often unidentifiable [30]. As explored in this study, participants reported a preference for “a face behind the account” and being clearly able to see their qualifications in the biography section of their profile to increase credibility and trust in the account. Furthermore, adolescents are acutely aware of advertising and sponsorships within content across social media platforms. The WHO has recognized the influence of food marketing as detrimental to children in many countries. Although regulations have been put in place surrounding advertising to children in Australia (aged 0-14 years) [31], regulations around the world rarely address adolescents [32]. This is despite an increase of more than US \$400 million spend on advertising between 2012 and 2019 by the fast food industry targeting children and adolescents [33]. Social media platforms are commercial companies with advertising as their sole generation of income [34]. Currently, there are minimal laws surrounding advertising on social media in Australia, particularly sponsored posts [35]. For example, advertising of weight loss products in Australia must be truthful, accurate, and not mislead consumers [36], but this does not apply to sponsorships. It is important to note that adolescents currently have access to what they perceive as both helpful and harmful lifestyle health information online. Through the addition of regulation and legislation around these areas, there is the capability to make information more useful and credible and potentially lead to behavior change that is helpful for the prevention of chronic

disease while also causing minimal harm. Therefore, the regulation of advertising toward adolescents is a challenging space, and further research is required to explore the influence of advertising on contemporary digital platforms toward lifestyle health behaviors of adolescents.

### Strengths and Limitations

This qualitative study has several strengths as well as limitations. We were able to recruit a diverse sample of adolescents to take part in this study, including 41% of participants who spoke a language other than English at home and from different states throughout Australia. Also, this qualitative study is among the first to provide insights into perceived barriers and facilitators of lifestyle health information on contemporary digital platforms, allowing opinions and thoughts to be gathered from the target population. However, it should be emphasized that, as this study was advertised and took place virtually, it may limit the generalizability of the findings to adolescents with higher eHealth literacy skills. For this study, we did not capture data on the eHealth literacy skills of participants. It is possible that groups with lower eHealth literacy may also offer useful insights into their perceptions of online lifestyle health information.

### Recommendations for Development of Online Lifestyle Health Information

Considering the findings from this qualitative study and previous research, a series of recommendations has been developed regarding the development of online lifestyle health information to ensure relevancy, appeal, and engagement for adolescents:

- Employ co-design of lifestyle health information with adolescents for contemporary digital platforms.
- Conduct further research into the regulation of online lifestyle health information for adolescents.
- Consider the eHealth literacy level of adolescents in the development of online lifestyle health information for contemporary digital platforms.

### Conclusions

In summary, this study highlights the abundance and complexity of online lifestyle health information available to adolescents, which is exponentially growing across contemporary digital platforms. Adolescents in this study reported wanting access to information that was credible, appealing, and relevant to them. To develop effective online lifestyle health promotion strategies and interventions, future research should include co-design of information with adolescents and consider their eHealth literacy levels. Furthermore, the influence of advertising on contemporary digital platforms and regulations around this warrants further investigation.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Consolidated criteria for reporting qualitative research (COREQ) checklist.

[\[DOCX File, 20 KB - pediatrics\\_v5i1e35165\\_app1.docx\]](#)

## Multimedia Appendix 2

Supplementary File 2: Focus Group Discussion Guide – Digitalize Study.

[\[DOCX File, 43 KB - pediatrics\\_v5i1e35165\\_app2.docx\]](#)

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## Abbreviations

**COREQ:** consolidated criteria for reporting qualitative research

**WHO:** World Health Organization

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