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Original Paper

Implementation Effectiveness of a Parent-Directed YouTube Video ("It Doesn't Have To Hurt") on Evidence-Based Strategies to Manage Needle Pain: Descriptive Survey Study

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Abstract

Background: Despite the availability of high-quality evidence and clinical practice guidelines for the effective management of pediatric pain, this evidence is rarely used in practice for managing children's pain from needle procedures such as vaccinations. Parents are generally unaware of pain management strategies they can use with their children.

Objective: This study aimed to develop, implement, and evaluate the implementation effectiveness of a parent-directed YouTube video on evidence-based strategies to manage needle pain in children.

Methods: This was a descriptive study. Analytics were extracted from YouTube to describe video reach. A Web-based survey was used to seek parent and health care professional (HCP) feedback about the video. The 2-minute 18-second video was launched on YouTube on November 4, 2013. In the video, a 4-year-old girl tells parents what they should and should not do to help needles hurt less. The key evidence-based messages shared in the video were distraction, deep breathing, and topical anesthetic creams. A group of parents (n=163) and HCPs (n=278) completed the Web-based survey. Measures of reach included number of unique views, country where the video was viewed, sex of the viewer, and length of watch time. The Web-based survey assessed implementation outcomes of the video, such as acceptability, appropriateness, penetration, and adoption.

Results: As of November 4, 2018 (5 years after launch), the video had 237,132 unique views from 182 countries, with most viewers watching an average of 55.1% (76/138 seconds) of the video. Overall, both parents and HCPs reported strong acceptance of the video (ie, they liked the video, found it helpful, and felt more confident) and reported significant improvements in plans to use distraction, deep breathing, and topical anesthetic creams.

Conclusions: This parent-directed YouTube video was an acceptable and appropriate way to disseminate evidence about the procedure of pain management to a large number of parents.

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KEYWORDS

pain management; child; knowledge translation; social media

Introduction

Background

Despite the availability of high-quality evidence and clinical practice guidelines for effective management of pediatric pain, best available evidence is rarely used in practice for managing children's pain [1,2]. More than two-thirds of hospitalized children had no documented pain management intervention (pharmacological, psychological, or physical) for painful procedures [3]. Painful procedures are not limited to hospitalized children; even healthy children will receive up to two dozen needles before the age of 5 years [4]. Although simple, cost-effective, and evidence-based pain-relieving interventions exist for vaccination in school-aged children (eg, relaxation, distraction strategies, and topical anesthetic creams), fewer than 5% of children undergoing vaccination receive any form of pain management [4]. This is alarming as poorly managed pain is associated with a range of negative short- and long-term effects [5-8], including pain sensitization and development of needle fears and avoidance, which can contribute to vaccine hesitancy.

Existing studies of knowledge translation (KT; ie, a process that includes dissemination and application of scientific knowledge to improve health [9,10]) interventions in procedural pain management have primarily targeted health care professionals (HCPs) [11-14], yet parents can also serve as powerful and consistent pain management advocates for children [15]. A recent systematic review found that parents felt unsupported in taking an active role when their children are undergoing painful medical procedures [16]. In other health areas, interventions directed to patients have been more effective at improving outcomes than those directed to HCPs [17]. Knowledge synthesis research and clinical practice guidelines for procedural pain management in children include evidence-based recommendations that are simple for parents to implement [4,18-21]; however, most parents are unaware of these strategies [4].

Social media brings new opportunities for KT of health information to parents and an opportunity to reach a very large group of individuals. The use of social media is growing exponentially, with recent data showing that 65% of all adults now use social media (a 10-fold increase in the last decade) [22-27]. Parents are high users of social media (75% of parents use social media) [28] and are increasingly using social media for information about child health and parenting [24,28,29]. Yet, the quality of content shared about children's health on the Internet is questionable at best [30-38]. Several YouTube videos have recently been developed and evaluated as dissemination tools to address procedural pain management in neonates with good success [39,40]. There is a need to develop high-quality, evidence-based, parent-targeted KT tools to share pediatric pain management techniques to improve outcomes for parents and children.

However, developing parent-targeted KT tools for pediatric pain management is not enough. It is important to evaluate the impact of the tool. Although traditional clinical trials focus on the efficacy of interventions in reducing pain in children, implementation studies focus on outcomes associated with the intervention that determine whether an intervention actually gets used. Implementation outcomes include acceptability (ie, the intervention is satisfactory), adoption (ie, intention or action to try or use an evidence-based practice), appropriateness (ie, perceived fit of the intervention to address a particular issue or problem), feasibility (ie, the extent to which the intervention can be carried out within a particular setting), fidelity (ie, the degree to which the intervention was implemented as prescribed by the original developers), implementation cost (ie, the financial impact of the intervention), penetration (ie, integration or spread of the intervention), and sustainability (ie, the extent to which the intervention is maintained or integrated into a service setting) [41].

Objectives

The objective of this study was to develop, implement, and evaluate the implementation effectiveness of a parent-directed KT YouTube video to reach and inform parents on evidence-based strategies to manage needle pain in children. Video reach was measured using available Web-based analytics (ie, number of unique views, country where the video was viewed, sex of the viewer, and length of watch time) captured 5 years after the public launch of the video. The effectiveness of the video was assessed via several implementation outcomes (eg, acceptability, appropriateness, penetration, and adoption) among a sample of parents and HCPs who completed a Web-based survey.

Methods

"It Doesn't Have To Hurt" Video Development

A brief (2 min 18 seconds) YouTube video for parents was developed to summarize evidence-based strategies for procedural pain management in a fun and entertaining way. The video [42] is hosted on the IWK Health Centre's YouTube channel and was released on November 4, 2013. In the video, a 4-year-old girl tells parents what they should and should not do to help make needles hurt less. This video was the first in a video series to reach parents with evidence-based information about children's pain (the second video was on neonatal pain management [39]).

Before the production of the video, a storyboard and a script were developed in collaboration with a communication company based on the synthesis of existing evidence-based information that was verified by the research team, partners, and parents. Initial drafts went through several rounds of revision and refinement before finalization. Once produced, the video was disseminated using a range of Web based and social media strategies, including emails, listservs, parenting forums, magazines, news coverage (television and newspaper), discussion groups, websites, blogs, social media, and other networking sites (eg, Twitter, Facebook, and LinkedIn). To further promote the video, posters, handouts, and social media images were also created and revised, and YouTube advertising campaigns and sponsored Facebook posts were used (see Multimedia Appendix 1 [43]). The target audience for the video was primarily parents with the goal of providing evidence-based strategies to manage needle pain in children. Secondary audiences included HCPs with whom parents would be interacting during painful procedures of their children, such as doctors and nurses.

Additional funding was obtained to repromote the video in February 2015. Initially produced in English, subtitles subsequently were created and uploaded for 16 languages, including Arabic, Chinese, Danish, Dutch, Finnish, French Canadian, German, Hungarian, Icelandic, Norwegian, Persian, Polish, Portuguese, Russian, Spanish, and Swedish. Through a partnership with the Quebec Pain Research Network, a French dubbed version of the video was released in April 2017 (Ça n'a pas besoin de faire mal—Conseils pour aider les enfants à recevoir une piqûre [44]), which has over 64,000 views to date. The goal of the translations was to enhance the reach of the video not only in Canada but also around the world. Only data from the English version of the video are reported here.

Data Collection and Analysis

Reach data were collected through social media metrics available via YouTube analytics (ie, geography, view time, traffic source, watch devices, and close caption use). Although Google and its subsidiary YouTube do not publish the algorithms for generating their reports, YouTube analytics have been consistently used to report on reach statistics for videos [40]. Data were obtained from the IWK Health Centre's YouTube channel reported from the initial launch to November 4, 2018 for a 5-year period. Data were tracked annually with the 5-year data extracted and summarized in this paper (because of the changes in YouTube analytic reporting, country data are based on 4-year data).

A Web-based survey was used to collect feedback from parents and HCPs. Viewers were prompted to complete an electronic survey after watching the video available through a link in the description text on YouTube as well as through the dissemination methods mentioned above. A total of two separate surveys were created: 1 for parents and 1 for HCPs. Participants who completed the surveys were self-selected from the viewers, with no inclusion or exclusion criteria stated with survey completion implying consent. Ethics approval for the survey was obtained from the Research Ethics Board of the IWK Health Centre; the survey was left open for 2 years (from November 4, 2013, to November 1, 2015).

The approximate survey completion time was less than 10 min. Questions were developed to discover acceptability, adoption, and feasibility of the evidence-based techniques shown in the video. The same survey was used to evaluate the newborn video [39]. Aside from dichotomous yes or no questions, the other closed-ended questions were asked on a 5-point Likert scale, where 1 was *not at all* and 5 was *very much*. The survey was assessed for content validity and is available in Multimedia Appendix 2 [45]. The parent and HCP surveys differed only with respect to 1 question regarding the ages of their children and the type of HCPs, respectively. Other general demographic questions common to both surveys were the respondents' age, sex, and country. No personally identifying information were collected (eg, name and address), and no personal health information data were collected. Responses to open-ended questions were grouped using thematic analysis [46], and perceptions of use before and after watching the video were analyzed using the related samples McNemar test [47].

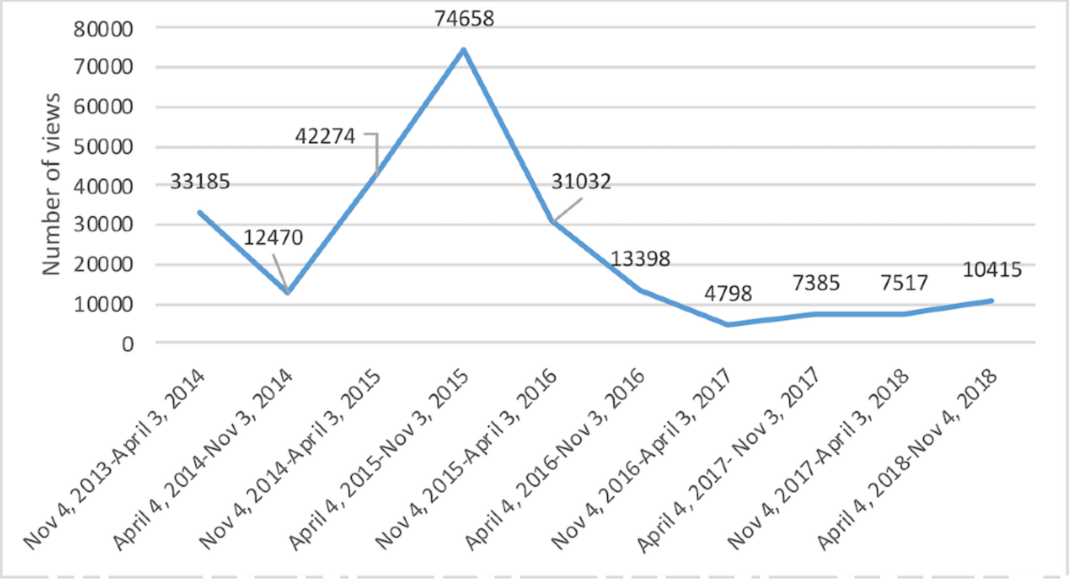
Results

Video Analytics

Five years after the launch, the video had a total of 237,132 unique views and had been viewed in 182 countries. The average view time was 1 min 16 seconds, which is 55.1% (76/138 seconds) of the video and corresponds to the end of the initial presentation of all evidence-based strategies by the little girl to her mother (ie, before recap). The United States (42.5%) and Canada (24.8%) had the most views, followed by Australia (10.2%), New Zealand (8.5%), and the United Kingdom (5.4%). Viewers were primarily females (53.3%), aged between 25 to 34 years (36.6%) and 35 to 44 years (37.5%). Traffic to the video was through YouTube advertising (122,788/237,132, 51.8%), searching on YouTube (28,155/237,132, 11.8%), an external link (28,004/237,132, 11.8%), a suggested video on YouTube (22,752/237,132, 9.6%), or other methods (35,433/237,132, 15.0%). The video was primarily watched on tablets (102,904/237,132, 43.4%), computers (67,564/237,132, 28.5%), mobile devices (62,726/237,132, 26.5%), or other devices (3,938/237,132, 1.6%). The video was shared directly from YouTube a total of 801 times through various channels, including copying the link (266/801, 33.2%), Facebook (122/801, 15.2%), WhatsApp (52/801, 6.5%), Twitter (48/801, 6.0%), and other (313/801, 39.1%). The video was watched without subtitles 91.5% (217,030/237,132) of the time, with Arabic (5,392/237,132, 2.3%), French (4322/237,132, 1.8%), Spanish (2739/237,132, 1.2%), Russian (2304/237,132, 1.0%), and Portuguese (1669/237,132, 0.7%) as the top 5 most selected closed caption subtitles.

Figure 1 shows the number of views the video received over time. The peak in views in 2015 was associated with additional formal promotion of the video at that time. Of note, no additional formal promotion of the video has been done since that time, so subsequent views (including 10,415 views during a 6-month period in 2018) are the result of organic sharing of the video.

Figure 1. Number of views over a 5-year period.



Survey Responses

Table 1 provides the demographics for the subsample of parents (n=163) and HCPs (n=278) who completed the survey. Overall, parents reported strong acceptance of the video (mean 4.06, SD 0.08), greater confidence in their ability to help their child cope (mean 3.62, SD 1.09), and that their child's next needle procedure would be less painful (mean 3.31, SD 1.14; Table 2). Moreover, parents reported a significant increase in the likelihood of future use of pain management strategies such as deep breathing, topical anesthetic cream, and distraction (Table 3). Before watching the video, 84.6% (138/163) of parents reported that they had used reassuring phrases such as "it'll be okay," but after watching the video, 88.3% (144/163) of parents reported that they would avoid using those phases in the future. The majority of parents (110/163, 67.5%) reported that after watching the video, they were interested in learning more about how to manage children's pain from needles, and 77.9% (127/163) of parents said that they planned to share the link with someone else, such as a family member or friend.

HCPs also reported strong acceptance of the video (mean 4.03, SD 1.09) and that the information obtained would be helpful to their practice (mean 3.53, SD 1.24; Table 2). Similar to parents, HCPs reported a significant increase in the likelihood of future use of deep breathing, topical anesthetic cream, and distraction (Table 3). However, the use of alternative interventions was reported by 31.7% (88/278) of HCPs, such as guided imagery, positions for comfort, and sucrose for infants. Before watching the video, 43.5% (121/278) of HCPs reported using reassuring phrases such as "it'll be okay," but after watching the video, 88.8% (247/278) of HCPs reported that they would avoid using those phrases in the future. After watching the video, HCPs reported that they felt more confident about helping children (mean 3.48, SD 1.24) and parents cope (mean 3.70, SD 1.18) with the pain and distress of getting a needle. The majority of HCPs (220/278, 79.4%) reported that after watching the video, they were interested in learning more about how to manage children's pain from needles, and 74.1% (206/278) of HCPs said that they planned to share the link with someone else, such as a family member or friend.

Table 1. Survey demographics for parents and health care professionals.

Participants	Parents (n=163), n (%)	HCPs[a] (n=278), n (%)
Children[b]		
Baby (newborn to 12 months)	22 (9.2)	—[c]
Toddler (1-2 years)	35 (14.6)	—
Preschooler (3-4 years)	53 (22.2)	—
School aged (5-12 years)	79 (33.1)	—
Adolescent (13-17 years)	29 (12.1)	—
Adult (18+ years)	21 (8.8)	—
HCP occupation		
Nurse	—	117 (42.1)
Physician (family, pediatrician, and other)	—	41 (14.7)
Psychologist	—	52 (18.7)
Child life specialist	—	30 (10.8)
Other	—	38 (13.7)
Location[d]		
Canada	118 (72.4)	128 (46.0)
The United States	34 (20.9)	124 (44.6)
Other	11 (6.7)	26 (9.4)
Age[d] (years)		
Under 24	4 (2.5)	16 (5.8)
25-35	39 (23.9)	66 (23.7)
34-44	77 (47.2)	62 (22.3)
44-54	32 (19.6)	67 (24.1)
55-64	9 (5.5)	48 (17. 3)
65 and above	—	12 (4.3)
Sex[d]		
Woman	142 (87.1)	240 (86.3)
Man	17 (10.4)	33 (11.9)

[a] HCP: health care professional.

[b] Parents could select more than 1 age group.

[c] Not applicable/no response.

[d] Percentage may not equal 100% as participants had the option to not answer.

Table 2. Acceptance of video by parents and health care professionals.

Acceptance of video	Response, mean (SD)[a]
Parents (n=163)	
Liked the video	4.06 (0.80)
Felt the video was helpful	3.90 (0.87)
Felt more confident to help child cope	3.62 (1.09)
Felt more confident that the next needle will be less painful	3.31 (1.14)
Health care professionals (n=278)	
Liked the video	4.03 (1.09)
Felt the video was helpful	3.53 (1.24)
Felt more confident in their own practice	3.48 (1.24)
Felt more confident in helping parents	3.70 (1.18)

[a] As reported on a 5-point scale, where 0=*not at all* and 5=*very much*.

Table 3. Past and predicted future use of techniques in the video by parents and health care professionals to reduce needle pain.

Predicted future use	Past, n (%)	Future, n (%)	Difference, %	*P* value
Parents (n=163)				
Deep breathing or bubbles	25 (14.7)	89 (54.6)	39.9	<.001[a]
Distraction	108 (66.3)	126 (77.6)	11.3	.04
Topical anesthetic cream	31 (19.0)	102 (62.6)	43.6	<.001[a]
Health care professionals (n=78)				
Deep breathing or bubbles	165 (59.4)	242 (87.1)	27.7	<.001[a]
Distraction	230 (82.7)	245 (88.1)	5.4	<.05[a]
Topical anesthetic cream	171 (61.5)	213 (76.6)	15.1	<.001[a]

[a] Significant differences.

Qualitative Responses

When parents (n=42) and HCPs (n=98) were provided with the opportunity to offer an open-ended comment, seven themes arose: praise, suggestions for improvements, questions, plans to share video, identifying they already use these strategies, critiques about video or content, or other comments about thoughts and experiences. Multimedia Appendix 3 provides example comments from parents and HCPs in these categories as well as how they map onto implementation outcomes [41,48]. Of note, parents primarily praised the video, with comments including "great work—nice to see research move into practice" while also offering suggestions for the video, such as "It would have been helpful to actually see one of the techniques that you provided being used in the video." Similarly, HCPs also shared praise of the video, such as "It is great to have a video as a tool to use with families…," yet also had critiques of the video, such as "As a pediatric HCP for >25 years I object to the approach [referring to the exaggerate way in which the HCP indicated there would be needles today and put on gloves] that is displayed when the care provider comes into the room."

Discussion

Principal Findings

This paper summarizes an evaluation of the implementation effectiveness of a parent-directed YouTube video about strategies parents can use to minimize their children's procedural pain. The findings of this study suggest that the video is an acceptable method for disseminating evidence-based information regarding pain management with a high likelihood of adoption.

Penetration was high as the YouTube video received significant uptake during the period of analysis with 237,132 views. In similar parent-targeted pain management videos related to newborn pain, penetration rates measured at 12 months and 18 months had 65,478 views and 157,938 views, respectively, with the latter video part of this series receiving similar promotion as the current video [39,40]. Parents and HCPs both showed strong acceptance of the video and intention to adopt evidence-based pediatric pain management behaviors after watching the video. Parents reported significant increases in the degree to which they would use each of the pain management strategies demonstrated in the video, especially for deep breathing and topical anesthetic cream. Alternatively, HCPs reported smaller yet still significant increases in the degree to which they would use each of the pain management strategies. Generally, parents and HCPs were receptive to the evidence-based information provided through the video and were willing to use it to minimize pain, which suggests that the video was effective in gaining acceptability and adoption among parents and HCPs.

Most parents and HCPs felt that the strategies were appropriate to minimize child pain during immunization. However, some concerns related to the feasibility of the strategies were noted in comments from parents and HCPs. One-third of the parents commented that the strategies provided were not practical (ie, topical creams may not be available and unsure as to how long a child should use it), whereas nearly half of all HCPs identified similar barriers, such as cost and application timing for the topical anesthetic cream. Parents also commented on concerns related to their HCP's acceptance of the strategies: "I'm not 100% sure my doctor would be ok with us blowing bubbles at this office." This was reflected in some HCP responses as well: "may find other way to encourage deep breathing to avoid 'bubble mess'."

In terms of the costs associated with this video, it cost Can $10,000 to professionally develop and produce this video and an additional Can $5000 to promote the video. It took considerable effort on the part of the team to promote the video, and further efforts in this area could be improved via partnering with parenting media who already have expertise in creating parenting content and an established reach to parents. Given the cost of video development and promotion in finances and time, this may be a hindrance for individual researchers or health care providers to undertake alone. However, consideration should be undertaken by public health organizations or clinical practice guideline developers that may have the financial resources and desire to create parent-targeted content. On the basis of this study and previous work, parent-targeted videos have the ability to reach a large number of people [39,40] and show evidence of impacting behavior change [49].

Limitations

This study had a number of limitations. First, those parents and HCPs who completed our Web-based survey may not be representative of all parents and HCPs; they may represent groups of individuals who had a particular interest in or willingness to adopt pain management strategies. Second, our study did not examine the actual implementation of pain management strategies by parents and HCPs; we simply assessed their report of whether they would use the strategies. Future prospective research should follow parents and HCPs over time to determine whether the strategies were effectively implemented. Finally, our reach analytics were limited in our reliance on YouTube analytic reports for viewer data (which require viewers to be logged into their personal account to pull demographics on sex and age).

Comparison With Prior Work

Communicating evidence-based recommendations for pain management to parents could be powerful, yet large-scale efforts to disseminate this knowledge to parents are lacking. A recent randomized trial showed that parental exposure to a 5-min educational video significantly increased parental pain management behaviors and decreased child pain [49]. However, the video in this trial was developed for research purposes and is not publicly available to parents.

Building on previous work evaluating publicly available YouTube videos directed at parents for pain management [39,50], this work is the first 5-year evaluation. Previous work has limited evaluation of the YouTube video to 12 months [40] and 18 months [39], leading to the current video having more views because of being available longer. In both previous studies, surveys were conducted with parents and HCPs and also found an increased likelihood of parents and HCPs using the techniques provided in the videos during the next painful procedure [39,40]. What is unique about the current video is its focus on children, whereas the other 2 videos targeted the newborn population, filling a gap in the evidence-based information available to parents on YouTube regarding pain management for procedures.

As identified in an earlier scoping review on publicly available videos on pediatric needle pain management [51], there is a continued need to evaluate the effectiveness of these videos. An effective implementation needs to include and illustrate acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability [41]. Evaluation of the current video illustrates that the video was perceived as acceptable as illustrated by the positive response from parents and HCPs. It also illustrated the likelihood of adoption of behaviors as they were appropriate and feasible to implement by parents. This analysis also illustrates that it was able to achieve penetration with the significant number of views, and this was sustained over time. However, challenges remain in evaluating the true behavior change impact of this KT video as parents were not followed up to determine if parents or HCPs actually used the pain management strategies at a future appointment.

Conclusions

This YouTube video benefited knowledge users, in this case, parents and HCPs, directly by providing them with evidence-based information about pain management for procedures in an engaging and accessible way. Owing to the dissemination method (ie, making the video openly available free of charge on YouTube), the video reached a very wide, international audience. Making evidence-based information on pediatrics available in this way has the potential to result in improved awareness and use of evidence-based practices, including, in this case, reduced pain and distress in children undergoing painful medical procedures and their families. Given the evidence of success in parent-targeted videos to improve pain management, opportunities exist to expand this work to other areas of pediatric health. Future research should consider conducting randomized controlled trials that explore the impact of such videos on behavior change outcomes.

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Authors' Contributions

CC had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. All authors were involved in the design and conduct of the study and preparation and review of the manuscript. CC, JP, and JD were involved in the direct collection, management, analysis, and interpretation of the data. CC is the senior author for this publication.

Conflicts of Interest

AT has received research funding from Pfizer and study supplies from Ferndale and Natus and RGR Pharma for unrelated clinical trials. There are no other conflicts of interest to declare.

Multimedia Appendix 1
Advertisement for promotion of video.
[PDF File (Adobe PDF File), 505 KB - pediatrics_v3i1e13552_app1.pdf]

Multimedia Appendix 2
Surveys.
[PDF File (Adobe PDF File), 311 KB - pediatrics_v3i1e13552_app2.pdf]

Multimedia Appendix 3
Qualitative findings from parents' and health care professionals' comments.
[PDF File (Adobe PDF File), 235 KB - pediatrics_v3i1e13552_app3.pdf]

References

1. Birnie KA, Chambers CT, Fernandez CV, Forgeron PA, Latimer MA, McGrath PJ, et al. Hospitalized children continue to report undertreated and preventable pain. Pain Res Manag 2014;19(4):198-204 [FREE Full text] [doi: 10.1155/2014/614784] [Medline: 24809068]
2. Stevens BJ, Harrison D, Rashotte J, Yamada J, Abbott LK, Coburn G, CIHR Team in Children's Pain. Pain assessment and intensity in hospitalized children in Canada. J Pain 2012 Sep;13(9):857-865. [doi: 10.1016/j.jpain.2012.05.010] [Medline: 22958873]
3. Stevens BJ, Abbott LK, Yamada J, Harrison D, Stinson J, Taddio A, CIHR Team in Children's Pain. Epidemiology and management of painful procedures in children in Canadian hospitals. Can Med Assoc J 2011 Apr 19;183(7):E403-E410 [FREE Full text] [doi: 10.1503/cmaj.101341] [Medline: 21464171]
4. Taddio A, Chambers CT, Halperin SA, Ipp M, Lockett D, Rieder MJ, et al. Inadequate pain management during routine childhood immunizations: the nerve of it. Clin Ther 2009;31(Suppl 2):S152-S167. [doi: 10.1016/j.clinthera.2009.07.022] [Medline: 19781434]
5. Taddio A, Katz J, Ilersich AL, Koren G. Effect of neonatal circumcision on pain response during subsequent routine vaccination. Lancet 1997 Mar 1;349(9052):599-603. [doi: 10.1016/S0140-6736(96)10316-0] [Medline: 9057731]
6. Anand K, Sippell W, Green A. Randomised trial of fentanyl anaesthesia in preterm babies undergoing surgery: Effects on the stress response. The Lancet 1987;329(8527):243-248. [doi: 10.1016/S0140-6736(87)90065-1]
7. Beggs S, Currie G, Salter M, Fitzgerald M, Walker S. Priming of adult pain responses by neonatal pain experience: maintenance by central neuroimmune activity. Brain 2012 Feb;135(Pt 2):404-417 [FREE Full text] [doi: 10.1093/brain/awr288] [Medline: 22102650]
8. Schwaller F, Fitzgerald M. The consequences of pain in early life: injury-induced plasticity in developing pain pathways. Eur J Neurosci 2014 Feb;39(3):344-352 [FREE Full text] [doi: 10.1111/ejn.12414] [Medline: 24494675]

9. Straus S, Tetroe J, Graham ID. Knowledge Translation in Health Care: Moving from Evidence to Practice. Second Edition. Hoboken, NJ: John Wiley & Sons; 2013.
10. Chambers CT. From evidence to influence: dissemination and implementation of scientific knowledge for improved pain research and management. Pain 2018 Sep;159(Suppl 1):S56-S64. [doi: 10.1097/j.pain.0000000000001327] [Medline: 30113948]
11. Stevens BJ, Yamada J, Promislow S, Stinson J, Harrison D, Victor JC, Members of the CIHR Team in Children's Pain. Implementation of multidimensional knowledge translation strategies to improve procedural pain in hospitalized children. Implement Sci 2014 Nov 25;9:120 [FREE Full text] [doi: 10.1186/s13012-014-0120-1] [Medline: 25928349]
12. Stevens B. Challenges in knowledge translation: integrating evidence on pain in children into practice. Can J Nurs Res 2009 Dec;41(4):109-114. [Medline: 20191718]
13. Ospina MB, Taenzer P, Rashiq S, MacDermid JC, Carr E, Chojecki D, et al. A systematic review of the effectiveness of knowledge translation interventions for chronic noncancer pain management. Pain Res Manag 2013;18(6):e129-e141 [FREE Full text] [doi: 10.1155/2013/120784] [Medline: 24308029]
14. Gagnon MM, Hadjistavropoulos T, Hampton AJ, Stinson J. A systematic review of knowledge translation (KT) in pediatric pain: focus on health care providers. Clin J Pain 2016 Nov;32(11):972-990. [doi: 10.1097/AJP.0000000000000345] [Medline: 26710219]
15. Chambers C. The role of family factors in pediatric pain. In: McGrath PJ, Finley GA. editors. Pediatr pain Biol Soc Context Seattle: IASP Press; 2002:99.
16. Gates A, Shave K, Featherstone R, Buckreus K, Ali S, Scott SD, et al. Procedural pain: systematic review of parent experiences and information needs. Clin Pediatr (Phila) 2018 Jun;57(6):672-688. [doi: 10.1177/0009922817733694] [Medline: 28959897]
17. Gagliardi AR, Légaré F, Brouwers MC, Webster F, Badley E, Straus S. Patient-mediated knowledge translation (PKT) interventions for clinical encounters: a systematic review. Implement Sci 2016 Feb 29;11:26 [FREE Full text] [doi: 10.1186/s13012-016-0389-3] [Medline: 26923462]
18. Shah V, Taddio A, Rieder MJ, HELPinKIDS Team. Effectiveness and tolerability of pharmacologic and combined interventions for reducing injection pain during routine childhood immunizations: systematic review and meta-analyses. Clin Ther 2009;31(Suppl 2):S104-S151. [doi: 10.1016/j.clinthera.2009.08.001] [Medline: 19781433]
19. Taddio A, Appleton M, Bortolussi R, Chambers C, Dubey V, Halperin S, et al. Reducing the pain of childhood vaccination: an evidence-based clinical practice guideline. Can Med Assoc J 2010 Dec 14;182(18):E843-E855 [FREE Full text] [doi: 10.1503/cmaj.101720] [Medline: 21098062]
20. Chambers CT, Taddio A, Uman LS, McMurtry C, HELPinKIDS Team. Psychological interventions for reducing pain and distress during routine childhood immunizations: a systematic review. Clin Ther 2009;31(Suppl 2):S77-S103. [doi: 10.1016/j.clinthera.2009.07.023] [Medline: 19781437]
21. Birnie KA, Noel M, Chambers CT, Uman LS, Parker JA. Psychological interventions for needle-related procedural pain and distress in children and adolescents. Cochrane Database Syst Rev 2018 Oct 4;10:CD005179 [FREE Full text] [doi: 10.1002/14651858.CD005179.pub4] [Medline: 30284240]
22. Bibault J, Leroy T, Blanchard P, Biau J, Cervellera M, Diaz O, et al. Mobile technology and social media in the clinical practice of young radiation oncologists: results of a comprehensive nationwide cross-sectional study. Int J Radiat Oncol Biol Phys 2014 Sep 1;90(1):231-237. [doi: 10.1016/j.ijrobp.2014.05.012] [Medline: 24986747]
23. Gorman JR, Roberts SC, Dominick SA, Malcarne VL, Dietz AC, Su HI. A diversified recruitment approach incorporating social media leads to research participation among young adult-aged female cancer survivors. J Adolesc Young Adult Oncol 2014 Jun 1;3(2):59-65 [FREE Full text] [doi: 10.1089/jayao.2013.0031] [Medline: 24940529]
24. Hamm MP, Chisholm A, Shulhan J, Milne A, Scott SD, Given LM, et al. Social media use among patients and caregivers: a scoping review. BMJ Open 2013 May 9;3(5):pii: e002819 [FREE Full text] [doi: 10.1136/bmjopen-2013-002819] [Medline: 23667163]
25. White R, Hayes C, White S, Hodson FJ. Using social media to challenge unwarranted clinical variation in the treatment of chronic noncancer pain: the 'Brainman' story. J Pain Res 2016;9:701-709 [FREE Full text] [doi: 10.2147/JPR.S115814] [Medline: 27703395]
26. Perrin A, Duggan M, Lenhart A, Lampe C, Ellison NB. Pew Research Center. 2015 Oct 8. Social Media Usage: 2005-2015 URL: https://www.pewresearch.org/internet/2015/10/08/social-networking-usage-2005-2015/ [accessed 2020-01-14]
27. Pew Research Center. 2019 Jun 12. Social Media Fact Sheet URL: http://www.pewinternet.org/fact-sheet/social-media/ [accessed 2020-01-14]
28. Duggan M, Lenhart A, Lampe C, Ellison NB. Pew Research Center. Washington; 2015 Jul 16. Parents and Social Media: Mothers Are Especially Likely to Give and Receive Support on Social Media URL: http://www.pewinternet.org/2015/07/16/parents-and-social-media/ [accessed 2020-01-14]
29. Rehman S. Cancer Knowledge Network. 2014 Sep 22. Connecting on Social Media: Resources for Families Caring for a Child Diagnosed With Cancer URL: https://cancerkn.com/connecting-social-media-resources-families-caring-child-diagnosed-cancer/ [accessed 2015-02-26]

30. Moorhead SA, Hazlett DE, Harrison L, Carroll JK, Irwin A, Hoving C. A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. J Med Internet Res 2013 Apr 23;15(4):e85 [FREE Full text] [doi: 10.2196/jmir.1933] [Medline: 23615206]
31. Sim NZ, Kitteringham L, Spitz L, Pierro A, Kiely E, Drake D, et al. Information on the World Wide Web--how useful is it for parents? J Pediatr Surg 2007 Feb;42(2):305-312. [doi: 10.1016/j.jpedsurg.2006.10.003] [Medline: 17270540]
32. Hand F, McDowell DT, Glynn RW, Rowley H, Mortell A. Patterns of internet use by parents of children attending a pediatric surgical service. Pediatr Surg Int 2013 Jul;29(7):729-733. [doi: 10.1007/s00383-013-3317-5] [Medline: 23615872]
33. Moseley KL, Freed GL, Goold SD. Which sources of child health advice do parents follow? Clin Pediatr (Phila) 2011 Jan;50(1):50-56. [doi: 10.1177/0009922810379905] [Medline: 20837618]
34. Madathil KC, Rivera-Rodriguez AJ, Greenstein JS, Gramopadhye AK. Healthcare information on YouTube: a systematic review. Health Informatics J 2015 Sep;21(3):173-194. [doi: 10.1177/1460458213512220] [Medline: 24670899]
35. Harrison D, Sampson M, Reszel J, Abdulla K, Barrowman N, Cumber J, et al. Too many crying babies: a systematic review of pain management practices during immunizations on YouTube. BMC Pediatr 2014 May 29;14:134 [FREE Full text] [doi: 10.1186/1471-2431-14-134] [Medline: 24885559]
36. Guillaume L, Bath PA. A content analysis of mass media sources in relation to the MMR vaccine scare. Health Informatics J 2008 Dec;14(4):323-334. [doi: 10.1177/1460458208096654] [Medline: 19008281]
37. Dol J, Richardson B, Boates T, Campbell-Yeo M. Learning to parent from Google? Evaluation of available online health evidence for parents of preterm infants requiring neonatal intensive care. Health Informatics J 2019 Dec;25(4):1265-1277. [doi: 10.1177/1460458217752564] [Medline: 29361867]
38. Tougas ME, Chambers CT, Corkum P, Robillard JM, Gruzd A, Howard V, et al. Social media content about children's pain and sleep: content and network analysis. JMIR Pediatr Parent 2018 Dec 11;1(2):e11193 [FREE Full text] [doi: 10.2196/11193] [Medline: 31518292]
39. Campbell-Yeo M, Dol J, Disher T, Benoit B, Chambers CT, Sheffield K, et al. The power of a parent's touch: evaluation of reach and impact of a targeted evidence-based YouTube video. J Perinat Neonatal Nurs 2017;31(4):341-349. [doi: 10.1097/JPN.0000000000000263] [Medline: 28520656]
40. Harrison D, Wilding J, Bowman A, Fuller A, Nicholls SG, Pound CM, et al. Using YouTube to disseminate effective vaccination pain treatment for babies. PLoS One 2016;11(10):e0164123 [FREE Full text] [doi: 10.1371/journal.pone.0164123] [Medline: 27695054]
41. Lewis CC, Fischer S, Weiner BJ, Stanick C, Kim M, Martinez RG. Outcomes for implementation science: an enhanced systematic review of instruments using evidence-based rating criteria. Implement Sci 2015 Nov 4;10:155 [FREE Full text] [doi: 10.1186/s13012-015-0342-x] [Medline: 26537706]
42. IWK Health Centre. YouTube. Canada: YouTube; 2013 Nov 4. It Doesn't Have To Hurt URL: https://www.youtube.com/watch?v=KgBwVSYqfps [accessed 2019-03-12]
43. Chambers C, Dol J, Parker J, Caes L, Birnie K, Taddio A, et al. Multimedia Appendix 1: Advertisement for promotion of video. Multimedia 2020.
44. IWK Health Centre. YouTube. Canada: YouTube; 2017 Apr 19. Ça n’a pas besoin de faire mal (It Doesn’t Have To Hurt) URL: https://www.youtube.com/watch?v=wx8XQHYehO0 [accessed 2019-03-12]
45. Chambers C, Dol J, Parker J, Caes L, Birnie K, Taddio A, et al. Multimedia Appendix 2: Surveys. Multimedia 2020.
46. Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness criteria. Int J Qual Methods 2017;16(1):1-13. [doi: 10.1177/1609406917733847]
47. Adedokun OA, Burgess WD. Analysis of paired dichotomous data: a gentle introduction to the McNemar Test in SPSS. J Multidiscip Eval 2011;8(17):125-131 [FREE Full text]
48. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, et al. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. Adm Policy Ment Health 2011 Mar;38(2):65-76 [FREE Full text] [doi: 10.1007/s10488-010-0319-7] [Medline: 20957426]
49. Riddell RP, O'Neill MC, Campbell L, Taddio A, Greenberg S, Garfield H. Featured article: the ABCDs of pain management: a double-blind randomized controlled trial examining the impact of a brief educational video on infants' and toddlers' pain scores and parent soothing behavior. J Pediatr Psychol 2018 Apr 1;43(3):224-233. [doi: 10.1093/jpepsy/jsx122] [Medline: 29145589]
50. Harrison D, Larocque C, Reszel J, Harrold J, Aubertin C. Be sweet to babies during painful procedures: a pilot evaluation of a parent-targeted video. Adv Neonatal Care 2017 Oct;17(5):372-380. [doi: 10.1097/ANC.0000000000000425] [Medline: 28885227]
51. Farkas C, Solodiuk L, Taddio A, Franck L, Berberich FR, LoChiatto J, et al. Publicly available online educational videos regarding pediatric needle pain: a scoping review. Clin J Pain 2015 Jun;31(6):591-598. [doi: 10.1097/AJP.0000000000000197] [Medline: 25551476]

Abbreviations

HCP: health care professional

KT: knowledge translation

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Original Paper

Hidden Communities of Practice in Social Media Groups: Mixed Methods Study

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Abstract

Background: Although most US mothers initiate breastfeeding, suboptimal breastfeeding rates still exist. Although breastfeeding is a complex process, social support has been linked with increases in positive breastfeeding outcomes. Recent technological advances, including the development of social networking sites, provide mothers with convenient access to a unique array of audiences from which to seek advice about parenting, including breastfeeding. However, little is known about how the use of the sites—specifically groups centered around breastfeeding—influences breastfeeding knowledge, attitudes, or behaviors.

Objective: This mixed methods study aimed to explore utilization of an existing probreastfeeding Facebook group and how utilization influences breastfeeding-related knowledge, attitudes, and behaviors.

Methods: Participants were recruited online through Facebook wall posts from within the existing group. Mothers aged between 18 and 50 years who were pregnant and intended to breastfeed, were currently breastfeeding, or had recently weaned their infant in the past 3 years were eligible to participate. Participants engaged in online focus group discussions (n=21) and individual interviews (n=12). Inductive content analysis of qualitative data led to the conceptualization and contextualization of a breastfeeding community of practice (COP). Using qualitative results, a quantitative survey was then developed to assess the prevalence of qualities of a COP as well as how COP usage influenced breastfeeding-related attitudes and knowledge. A total of 314 mothers completed the online survey.

Results: Qualitative findings showed an overall sense of community, with subthemes of group trust, interaction, and the promotion of breastfeeding. A majority (287/314, 91.5%) of mothers initiated breastfeeding, with 69.0% (216/314) of mothers reporting exclusive breastfeeding their infant at 6 months. Approximately 98.5% (309/314) of mothers reported that the Facebook group captured and stored knowledge; therefore, information could be easily accessed and applied. In addition, 96.2% (302/317) of mothers reported that the Facebook group motivated them to share breastfeeding-related knowledge.

Conclusions: The results suggest that this existing probreastfeeding Facebook group exhibits characteristics of an online COP, which was organically formed. Utilization of the Facebook group, in the context of an online COP, could be beneficial in impacting breastfeeding-related knowledge, attitudes, and behaviors. However, further examination and exploration of breastfeeding COPs, including using this type of model as a method of lactation support or as a telemedicine framework, is a clear need.

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KEYWORDS

online social support; breastfeeding; social media; social support system

Introduction

Background

Decades of research have proved breastmilk to not only be the optimal source of nutrition for infants for the first 6 months of life but to also have numerous maternal health benefits. The vast research on the benefits of breastfeeding has lead national child health organizations, including the American Academy of Pediatrics, the World Health Organization, and the Academy for Breastfeeding Medicine, to recommend exclusive breastfeeding for the first 6 months of life, with continued breastfeeding for at least one year and thereafter so long as mutually desired by the mother-infant dyad [1-3]. Despite these recommendations, subpar breastfeeding rates exist in the United States. Although approximately 83% of infants were ever breastfed, only an estimated 24.9% of these infants were exclusively breastfed at 6 months [4]. Disparities exist for breastfeeding rates in the southeast, with breastfeeding initiation rates as low as 63.2% and 6-month breastfeeding exclusivity at an estimated 13.0% for Mississippi. Although Georgia had the highest prevalence in the southeastern states of exclusive breastfeeding at 6 months (22.1%), it is still lower than the national average [4].

The high initiation rate, but low duration of breastfeeding exclusivity rates in the United States, may indicate that mothers lack the necessary support to continue in their breastfeeding journey. Breastfeeding mothers are faced with a plethora of factors that can contribute to high stress in the postpartum period, including lack of sleep, unclear expectations, and the constant learning associated with breastfeeding [5-8]. Just as there are many factors influencing a women’s intention and ability to breastfeed, there are also many ways breastfeeding mothers can be supported through during breastfeeding. Breastfeeding mothers can be actively supported by their partners, families, communities, employers, and peers. Larger-level influences of breastfeeding support include policies, such as paid maternity leave, and insurer-provided lactation support. However, it takes more than active support for breastfeeding mothers to initiate and maintain breastfeeding; maternal self-efficacy, confidence, and anxiety also play a large role. Access to social support, including women-to-women support groups, during the postpartum period has been linked to better maternal health and child health outcomes, including increases in maternal confidence and relationship satisfaction (for both partner-to-partner and parent-child interactions) and decreases in emotional stress [5,9-11]. Furthermore, a recent meta-analysis of social support interventions found these types of interventions to increase breastfeeding initiation by 86% and exclusive breastfeeding by 20% [12].

With recent sociotechnical trends regarding social networking sites (SNSs) and use by mothers, there is a growing field of research centered around the juncture of motherhood and technology. These mechanisms of social interaction in SNSs include peer-to-peer support, knowledge gaining and sharing, establishing friendships, and a sense of belonging, all of which can disappear during the transition to motherhood [11,13,14]. In addition to ease of use, SNSs are convenient and provide mothers with access to a unique array of audiences from which to seek advice about parenting, including infant feeding [11,15,16]. Social media groups, a subset of certain SNSs, rely on user-generated content (UGC) for interaction among users. Existing Facebook groups can be both broadly focused on motherhood and parenting, or more specialized, focusing on one parenting area, such as sleep training or breastfeeding. When social media groups focus on the promotion of one feeding type, such as breastfeeding, it has the potential to create an organically formed community of practice (COP).

Although originally developed as a theory for situational learning, COPs have transformed over the past few decades beyond this meaning [17]. In addition, COPs have expanded beyond previous geographical limitations, presenting an opportunity for the creation of virtual communities based on a shared practice, such as peer-to-peer communities centered on motherhood [18], including Facebook groups. For this study, we define COP as “groups of people who share a concern or passion for something they do and learn how to do it better as they interact regularly” [18]. At their core, COPs are formed by people who engage in a collective learning process and have 3 crucial, defining characteristics: (1) the domain, (2) the community, and (3) the practice [18]. Embedded within COPs are key activities, such as joint problem solving and skill building, which can enhance the formation of social ties [19]. Additional examples of activities include knowledge mapping, requests for information, and advice seeking. When individuals engage in a COP, knowledge flows freely, which supports both knowledge sharing and knowledge seeking behaviors [18,20]. Within the realms of virtual COPs lies an essential component, UGC, which is member generated, and retains components of offline communication [21].

Objective

The recent growth of UGC embedded within social media groups elicits a need to further understand the social support and communication dynamics in these virtual communities. Although numerous studies have laid the foundation for SNSs, including Facebook groups, as a community building tool, there is a lack of knowledge about how these types of online communities can impact breastfeeding-related outcomes, with multiple studies calling for research on the relationship between social media and breastfeeding [12,15]. Only in recent years have these types of online support mechanisms been explored for the transition to motherhood, with limited research examining how they could provide breastfeeding support [14,22,23]. To address this gap, this research aimed to explore the utilization of an existing probreastfeeding Facebook group within the context of a virtual COP and how utilization may influence breastfeeding-related knowledge, attitudes, and behaviors.

Methods

Study Design

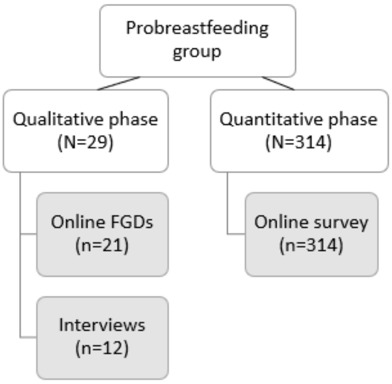
This mixed methods study used a sequential exploratory design [24], which consisted of two critical phases: (1) the qualitative phase and (2) the quantitative phase, with the first phase iteratively guiding the second phase of the study. The exploratory design was particularly helpful in achieving the aims of this study, as little information was known about the conceptualization of a phenomenon and how to measure potential key variables. The emphasis in this design was given to the qualitative strand, as it played an essential role in informing the design of the quantitative phase. This study was conducted with the Institutional Review Board approval and oversight (REC300000306).

Setting and Sample

One existing probreastfeeding Facebook group was used to explore the qualitative and quantitative phases of the study. This group was selected because of the large number of members (>6300), their probreastfeeding approach (as designated by the title of the group), and accessibility to the group (US based). This Facebook group originally stemmed from an in-person support group based at a midsized hospital in Birmingham, Alabama, and was created in 2012. However, there are no restrictions for joining the group; any and all breastfeeding moms are welcome, according to the Facebook group description. As such, the group includes mothers from all over the southeast. There are five administrators of the group, some of whom are International Board Certified Lactation Consultants (IBCLC) and others who do not have any professional training but are experienced in breastfeeding, either from feeding their children or from other experience (eg, work experience as a labor and delivery or neonatal intensive care unit nurse or from being a lactation counselor or dietician).

Study participation was limited to women who were existing members of this Facebook group. Mothers between 18 and 50 years of age who were pregnant and intended to breastfeed (mixed or exclusively), were currently breastfeeding (mixed or exclusively), or had recently weaned their infant in the past 3 years were eligible to participate. Mothers were excluded if they had never breastfed a child, were pregnant and intended to only formula feed, or had weaned their infant off breast milk more than 3 years before recruitment. Please see Figure 1 for a participant flowchart that outlines the number of participants for both the qualitative and quantitative strands of the study.

Figure 1. Participant flowchart. FGD: focus group discussion; UGC: user-generated content.



Study 1: Qualitative Strand

The following research questions guided the qualitative strand of this study: (1) How does the utilization of the probreastfeeding Facebook group support breastfeeding mothers? and (2) Are there COP activities present in the probreastfeeding Facebook group? To fully answer this research question, it was necessary to first broadly explore the overall usage within the social media group through online focus group discussions (FGDs) and further develop emergent themes through individual follow-up interviews. Group posts within the probreastfeeding group were analyzed using USG analysis to examine if and how COP activities were manifested.

Qualitative Instrument Development

To structure the online FGDs, we created a focus group guide that consisted of open-ended questions broadly exploring why mothers use social media groups, their perceptions of utilization on breastfeeding-related outcomes (eg, knowledge, education, behaviors, and duration), and perceived barriers to breastfeeding encountered in the virtual realm (see Multimedia Appendix 1).

Individual interview data collection included the creation of a separate guide developed to further explore topics brought up by mothers in the online FGDs. This guide was developed to be comprehensive of the themes derived from the online FGDs but open ended enough to allow interviewees to describe their experiences in sufficient detail. Topics explored in the interview guide included returning to work, positive and negative facets of social media (both in general and specifically for the probreastfeeding social media group), and if participants felt social media group usage had influenced their breastfeeding relationship and why. The following questions were included in the qualitative interview guide: (1) How do you think the probreastfeeding group has impacted your breastfeeding relationship?, (2) What about the other social media groups?, (3) Discuss a time that a social media breastfeeding group has impacted a decision or choice you made with regard to breastfeeding?, (4) What are some barriers or pitfalls to using social media to post or interact with other mothers about breastfeeding?, and (5) How would you describe the information posted in probreastfeeding group with regard to accuracy? For each question, exploratory prompts were used to guide the interview and encourage greater depth of response from participants.

Qualitative Recruitment

We used convenience and snowball sampling to recruit mothers via a series of wall posts within the Facebook group in the fall of 2017. The series of posts shared information about the aims of the qualitative portion of the study and asked for their interest in participation. Mothers who responded to the recruitment posts were first asked to participate in one of the three online FGDs. The online FGDs were secret online groups consisting of 6 to 9 mothers, as is the best practice for focus group formation. Once the slots for online FGDs were filled, mothers were asked to participate in interviews. Slots for both focus groups and interviews were filled within 48 hours of the first recruitment post. From the wall post, 37 women were recruited and were eligible to participate. Of the 29 participants who consented for the qualitative strand of this study, 21 participated in the online FGDs, with 12 mothers returning to complete follow-up individual interviews. Although there were 22 participants randomized into online FGDs, 1 participant did not engage or post and was excluded from the analysis. There were 4 mothers who were asked to participate in both the online FGDs and interviews to advance our understanding of topics brought up in the online FGDs. Participants were given a US $10 Amazon gift card for their participation in either the online FGDs or interviews.

Qualitative Data Collection

Online Focus Group Discussions

After informed consent was obtained, online FGD participants were asked to complete a demographic questionnaire and then randomized into the online FGDs. Online FGDs were facilitated by a trained focus group moderator within the secret online group. An asynchronous approach to the online FGD allowed participants 4 days to read and respond to the initial posts (questions from the online FGD guide) as well as to respond to and interact with other posts in the group. The researcher posted all questions in the secret group ahead of time to enable participants to respond at their convenience. However, the moderator engaged with participants during the online FGDs through the use of prompts to encourage elaboration on responses. Field notes were made during the online FGDs. Posts and responses from each online FGD were copied and pasted into separate documents. Reflection of utilization of the online FGDs for this study showed that this virtual technique was effective in including this sensitive population in qualitative research [25]. Please see Table 1 for online FGD engagement.

Table 1. Online focus group discussion engagement characteristics.

Engagement	Online FGD[a] 1 (n=6), n	Online FGD 2 (n=9), n	Online FGD 3 (n=6), n
Total engagement	151	244	167
Posts	47	78	46
Responses	22	43	42
Likes	82	123	79

[a] FGD: focus group discussion.

Interviews

To conduct the interviews, participants provided the interviewer with a time that was convenient for them. Eight of the interviews were conducted in person, with the remaining 4 occurring via Skype. Before the start of the interview, consent was obtained from participants. Interviews were then conducted using the interview guide developed from the synthesis of the online FGD findings. On average, interviews lasted 34 min, but ranged from 17 to 49 min. The interviewer made field notes for each interview. Interviews were audio recorded and then transcribed into separate Word documents.

User-Generated Content Analysis

To calculate the sample size for the UGC analysis, the Facebook group was monitored over a 14-day period to get a weekly posting average for a *typical week*. A typical week was considered to be a week in which there were no holidays or school breaks, which could have caused posting to fluctuate. Weekly posting averages were 176 and 188 posts for the first and second weeks, respectively. To obtain a 25% coverage area of average weekly postings, we calculated a random sample size of 44. Any post on the Facebook group page seeking breastfeeding-related advice during a 7-day period was eligible for inclusion, regardless of the number of comments. We collected 44 posts over a 7-day period in November 2017. In addition to the content of posts within the Facebook group, we collected time of posting, number of likes, and number of comments.

Synthesis

Online FGDs and interview transcripts were analyzed using inductive qualitative content analysis. NVIVO version 10 qualitative data analysis software (QSR International, Melbourne, Australia) was used for qualitative synthesis. We used in vivo coding initially for each phrase of the transcript as an approach to stay true to the data, as this approach used participants' own words [26,27]. This methodology is preferred when qualitative data are fragmented, as they are in online FGDs [26]. The coded data were then coded and organized into categories and themes, which led to the creation of a preliminary analysis results document, which was then shared with participants. This member checking was conducted to verify that the researchers' interpretation of the data was accurate. The identified themes were accepted by all 7 participants who were invited for member checking; no changes were suggested by participants during this process.

Study 2: Quantitative Analysis

For the quantitative strand of this mixed methods study, we used the following research questions: (1) How does social media group usage impact breastfeeding-related knowledge, attitudes, and behavior? and (2) Can the existing probreastfeeding social media group be considered an online COP?

As qualitative results of study 1 were used for the development of an online questionnaire within the sequential exploratory mixed methods design, the themes and context (eg, community, shared experiences, and trust) revealed in the first phase of this study, in combination with a thorough literature review on each theme, led to the creation of a series of constructs to be included in the online survey. Thus, the quantitative instrument was developed based on the qualitative results. The qualitative analysis revealed a clear need for grounding the online questionnaire in the social capital theories, which was included through the use of social capital scales. In addition, there was a need to include the following content in the questionnaire: social media group usage; social media factors influencing mothers' breastfeeding-related knowledge, attitudes, and behaviors; and the presence of aspects of a COP within the probreastfeeding Facebook group. After a second literature review to find validated measures of the constructs and content, a survey instrument codebook was created, which mapped the content of the survey, response options, coding schema, source, and validation data.

As there was no published instrument measuring a social media group–based COP, we adapted 3 existing scales: the 2011 survey of Asian Development Bank–Hosted Communities of Practice [28], the Breastfeeding Self-Efficacy Scale-short form [29], and the Iowa Infant Feeding Attitudes Scale [30]. Mothers were also asked about their youngest infant's breastfeeding outcomes. The survey itself took, on average, less than 15 min and was designed to use language to make participants feel comfortable. No identifiable information or personal health information was collected from participants. Adapted scales were evaluated for psychometric properties and found to have internal consistency (alpha=.72). The full results of this psychometric evaluation, including factor analysis of scales, are forthcoming in a separate manuscript.

Recruitment

During the spring of 2019, two recruitment posts within the probreastfeeding Facebook group were used to recruit online survey participants. These posts provided a brief description of topics included in the online questionnaire and included a direct hyperlink to the online questionnaire in Qualtrics. Participants were screened for inclusion through a three-item screener with skip logic embedded within Qualtrics before consent was obtained. Participants who completed the entire online questionnaire were automatically entered to win 1 of the 2 US $50 Amazon gift cards.

Data Collection

Once participants consented, they were able to move forward onto the online questionnaire. A total of 314 mothers completed the online survey.

Data Analysis

All surveys were completed via Qualtrics, an online research and experience software. Qualtrics securely hosted all survey responses until downloaded into a .csv file. All data files were stored on a password-protected computer. Preliminary validation testing was conducted for developed COP scales to determine internal consistency via exploratory factor analysis. The results of the exploratory factor analysis found the developed scales to have internal consistency. For this study, we will report only basic descriptive statistics, including proportions, frequencies, means, and standard deviations for the online survey. We also report mean scale scores and associated standard deviations for the developed COP scales. All descriptive analyses were conducted using SPSS Statistics version 22 software (IBM, Armonk, New York) [31].

Results

Study 1

Demographics

Of 29 mothers who participated in the qualitative strand, 2 were currently pregnant, 25 (86%) were currently nursing, and 4 (14%) had weaned their infant in the past 12 months. A majority of mothers were white (25/29, 86%) and worked either full time or part time (25/29, 86%). The mean age of participants was 29.7 years, with a range of 23 to 40 years. Moreover, 41% (12/29) of the participants had a high school diploma and some college degree, with 58% (17/29) of the participants reporting attainment of at least a bachelor's degree. The majority (21/29, 75%) of mothers in the qualitative strand had been in the probreastfeeding Facebook group for 6 months or longer.

Overarching Theme: Creating Community

The results from FGDs and interviews revealed an overarching theme of community across participants' reported experiences within the Facebook support group. Overall, mothers felt like the probreastfeeding Facebook group was a place where they were able to bond with others by uniting strangers together around one topic: breastfeeding. Participants described their relationship with the group as being "always nice to have a place to go where you are 'understood'." They also reported appreciating the group's ability to "normalize not only breastfeeding but also the troubles that surround breastfeeding moms. It brings us together!"

Shared Experience in Breastfeeding

One subtheme derived from the qualitative analysis was the shared experience among members in the social media group. As 1 participant stated, "Posting [on the social media group] allowed me to reach other moms that were in similar situations or had similar issues." Many mothers mentioned the immense support they felt within the group and their appreciation for this support, which they may have otherwise not received. Furthermore, many mothers mentioned that they did not have anyone within their immediate social network who had breastfed, which left them with a desire to find others who had breastfed. One mother shared:

> *With no mothers in my own family who breastfed, the number of women to whom I can ask questions is very limited. Social media broadens that pool.*

Another mother described the importance of social support during breastfeeding and how this social media group provided that support for her, stating:

> *I believe it is important to interact with other mothers dealing with the same issues and concerns. It's important for a breastfeeding relationship to have some sort of support and social media can provide that to an extent.*

Mothers described their experiences within the Facebook group as mostly uplifting and positive. One mother described her experience with the group and how it helped her to not give up on breastfeeding:

> *I knew I had someone to ask questions to, so it allowed me to not give up when I struggled. I felt like lots of other moms had some of the same struggles I did. I liked that in a world that is only slowly accepting open breastfeeding or accommodations, it felt so normal and so celebrated in this group.*

Another mother described similar encouragement received from the group, stating that:

> *The support I received from a social media group was invaluable. I was encouraged to never quit on a bad day.*

Social Interaction

Most mothers reported that they were interacting within the group in some fashion (23/29, 80%), primarily in the form of knowledge sharing (20/29, 70%) and asking questions (19/29, 66%). For those who did not report regular interaction, the reasons that were cited were because they "searched within the social media group to see if the question had already been answered" or had "recently weaned their infant and no longer breastfed."

Mothers reported that they enjoyed sharing information within the group, feeling that "it's my job, as a member of the group, to comment with a carefully-worded response that is uplifting and kind." In addition to sharing information within the social media group, mothers enjoyed having real-time responses to inquiry and associated feedback:

> *If I have a question about breastfeeding, I have hundreds of women who have experience breastfeeding at my fingertips. I have direct access to at least one IBCLC and several experts. Other moms with the same question can read the post and benefit from the information.*

Confidentiality and Trust

Participants also found a strong sense of confidentiality within the group. Mothers reported that they felt fellow members were focused on promoting best practices for breastfeeding and provided encouragement and support, which led them to developing a strong sense of trust and nonjudgment within a group composed predominantly of strangers. One aspect of trust embedded within this community was the quality of breastfeeding information throughout the group. Mothers felt like the information received in the group was consistent with evidence-based practices for breastfeeding, especially in comparison with other parenting and mom groups they were a part of:

> *In the group, the postings almost always adhere to AAP guidelines and the admins even provide evidence-based articles and studies to support the guidelines. In other groups, I feel most of the advice is very ill-advised in all respects, both in regard to AAP guidelines and in regard to other general breastfeeding and pumping advice.*

Many mothers felt this probreastfeeding Facebook group was of high quality, often comparing it with others they considered less trustworthy. One mother shared her broader experience with social media groups, including why she chose to leave other groups:

> *The experience with social media regarding breastfeeding strongly depends on your social network and which group(s) you're a member of. There was one group that I had initially joined, but later left due to the fact that I felt it put more of a negative stigma on breastfeeding, rather than normalizing it and bringing positivity to it, despite the fact that it was intended as a "pro-breastfeeding" site. Others I've left due to gross misinformation and terrible advice.*

A large portion of the discussion for both online FGDs and interviews centered around the trust and confidentiality within the Facebook group, indicating this type of group as a rich place for knowledge sharing.

Activities of a Community of Practice

The USG content analysis revealed that within the probreastfeeding Facebook group, not only were key themes brought up about community, but key COP activities were also present. These COP activities included reciprocity, joint problem solving, and skill building, to name a few. Textbox 1 shows descriptions and specific examples of COP mechanisms embedded within this probreastfeeding group.

Textbox 1. Community of practice activities present in the probreastfeeding Facebook group.

Problem solving

- “Any tips for a very sore and cracking nipple situation? It hurts so bad to latch”

Requests for information

- “When baby is on solid foods 3x a day, how much breast milk should he be getting?”

Seeking experience

- “Just had my baby at midnight via emergency c section. He is in the NICU. Already pumping. Any advice to make sure I do the best for my supply until I can start feeding him?”

Reusing assets

- “We love the MommyMeds app from the Infant Risk Center- download it!”

Coordination and synergy

- “We will be teaming up with Babywearing International of for a baby wearing meet-up!!!”

Mapping knowledge and identifying gaps

- “I know occasionally we have mamas post they are stranded without their pump or certain parts. What if we had ‘pumping stations’ around town?”

Study 2

Sociodemographic characteristics of mothers who completed the online survey, including maternal characteristics, are shown in Table 2. Approximately 91.5% (287/314) of mothers reported breastfeeding initiation, with 69.8% (216/314) of mothers reporting exclusively breastfeeding their infant at 6 months. Less than half (112/314, 35.6%) of the mothers reported taking a breastfeeding prenatal class. Almost half (140/314, 44.8%) of the mothers had been in the Facebook group more than 12 months, with 18.1% (57/314) and 37.1% (116/314) being in the group between 6 to 12 months and less than 6 months, respectively.

Table 2. Demographic characteristics of the participants who completed the online questionnaire (N=314).

Characteristics	Values
Age (years), mean (range)	29.85 (19-42)
Race, n (%)	
African American	4 (1.3)
American Indian or Alaskan Native	2 (0.6)
White	300 (95.5)
Other	8 (2.5)
Marital status, n (%)	
Single, never married	7 (2.2)
Married	284 (90.4)
In a monogamous relationship	23 (7.3)
Education, n (%)	
High school diploma or some college	106 (33.8)
Bachelor’s degree (4 years)	113 (35.9)
Master’s degree	65 (20.7)
Professional degree (Juris Doctor and Doctor of Medicine)	30 (9.5)
Working status, n (%)	
Full time or part time	234 (74.5)
Not working	80 (25.4)
Previously breastfed a child, n (%)	129 (41.1)
Full-term infant, n (%)	229 (77.6)
Interaction with social media group, n (%)	
Ask questions	240 (76.4)
Give advice	225 (71.6)
Does not interact regularly	51 (16.2)

The COP scale asked participants to answer how they agreed with statements about the probreastfeeding social media group. Responses were in a Likert scale format, ranging from very strongly disagree (1) to strongly agree (4). Please see Table 3 for all items included in the scale to asses social capital within the probreastfeeding group and associated means and standard deviations.

A majority (257/262, 98.1%) of the mothers agreed or strongly agreed that “there was a clear focus on breastfeeding” within this social media group. When asked if mothers felt the Facebook group “built knowledge sharing and learning into the group,” approximately 99.2% (260/262) of mothers reported that they either agreed or strongly agreed with this statement. Approximately 98.4% (258/262) of mothers reported that they either agreed or strongly agreed that the social media group captured and stored knowledge; therefore, it could be easily accessed and applied. Furthermore, 96.6% (253/262) of mothers reported that the social media group motivated them to share breastfeeding-related knowledge. There were 97.0% (254/262) of women who reported that they felt the information and advice shared within the group is accurate. Approximately 96.2% (252/262) of participants felt the group helped them to achieve their breastfeeding outcomes. Only 85.5% (224/262) of mothers reported that they agreed or strongly agreed with the statement, “this Facebook group helps me to build my relationship with others.”

Table 3. Scale to assess social capital within the probreastfeeding group descriptive statistics.

Item	Value, n (%)[a]	Value, mean (SD)
Has a user-friendly communication platform	260 (99.2)	3.32 (0.48)
Build knowledge sharing and learning into the group	260 (99.2)	3.30 (0.47)
Capture and store knowledge so it can be easily applied	258 (98.4)	3.32 (0.50)
Helps me achieve better breastfeeding outcomes	258 (98.4)	3.27 (0.49)
Benefits my breastfeeding outcomes	257 (98.1)	3.27 (0.50)
Helps to build my confidence	257 (98.1)	N/A[b]
Represents a common area of interest for many mothers in the group	257 (98.1)	3.15 (0.40)
There is a clear focus on breastfeeding	257 (98.1)	3.13 (0.37)
Benefits my breastfeeding relationship	257 (98.1)	3.23 (0.48)
Is driven by the willingness of members to participate	255 (97.3)	3.28 (0.53)
I trust the group members	254 (97.0)	3.38 (0.56)
The information/advise shared is accurate	254 (97.0)	3.37 (0.56)
Motivates me to share breastfeeding-related knowledge	253 (96.6)	3.18 (0.46)
The group helped me to achieve my goals for breastfeeding	252 (96.2)	3.26 (0.53)
Gives me a sense of empowerment	252 (96.2)	3.25 (0.53)
Gives me a sense of belonging	250 (95.4)	3.25 (0.56)
Breaks down communication barriers among members	247 (94.3)	3.34 (0.61)
Helps me to build relationships with others	224 (85.5)	3.25 (0.71)

[a] n is reported as the number of women who agreed or strongly agreed with the statement.

[b] N/A: not applicable.

Discussion

Principal Findings

The combined approach to this study enabled us to fully explore an existing probreastfeeding Facebook group as an organically formed online COP and to elaborate both qualitatively and quantitatively on how these mothers felt their involvement with the social media group effected their breastfeeding journey. Looking at both the qualitative and quantitative findings of the study, the following key findings were made: (1) breastfeeding mothers reported the peer-to-peer support from the probreastfeeding Facebook group to be invaluable and that the group itself is a resource for knowledge and interaction that consequently impacts the breastfeeding relationship and (2) this specific Facebook group organically formed a COP, as demonstrated through the presence of key characteristics within the group. These conclusions regarding the organic formation of this online community as a COP would not have been possible without the interaction of the two strands (qualitative and quantitative) of this study, which is a strength of this study. This study helps to fill gaps in the current field regarding social media group usage and breastfeeding practices.

To elaborate on the notion of a hidden COP, we found the following key tenants of a COP in the probreastfeeding Facebook group: (1) commitment, that is, a shared domain (the social media group); (2) a virtual community that distinguishes its members from others (mothers); and (3) the practice (breastfeeding) [18]. Through engagement in joint activities, stories and experience, and knowledge sharing, members of the COP were able to support one another in their breastfeeding journey. Also consistent with communication within a COP, breastfeeding knowledge flowed freely in this Facebook group, without social norms of reciprocity. A shared repertoire of resources is also essential for sharing the practice, which was available to the COP through current and past posts and responses within the Facebook group. The shared domain, practice, and community were dynamically integrated into the probreastfeeding Facebook group; therefore, we can say it is indeed a hidden COP. Within the context of this breastfeeding COP, mothers reported that their breastfeeding-related questions or concerns were addressed with information consistent with clinical breastfeeding guidelines and national recommendations for breastfeeding.

Participants mostly reported positive feedback around the probreastfeeding social media group. More importantly, mothers also reported high agreement with statements showing the breastfeeding group not only as a COP but also as a mechanism of support, empowerment, and trust for all things breastfeeding. Examining breastfeeding prevalence rates in the probreastfeeding Facebook group compared with the national average, there was a higher prevalence of breastfeeding exclusivity at 6 months among mothers in the Facebook group (69%) compared with national data from the 2018 Breastfeeding Report Card (24.9%) [4]. Furthermore, 91.5% (287/314) of mothers who completed the online survey reported initiation of breastfeeding, which is also higher than the national average of 83%. The rates of breastfeeding initiation and exclusivity among members of this probreastfeeding group may indicate that group membership, and specifically the COP activities identified within the Facebook group, influences breastfeeding duration. However, further statistical analyses are warranted to examine differences in prevalence rates.

Findings of this study may have been influenced by the presence of group moderators who were certified lactation consultants, as they deleted posts citing outdated or misinformation. This is a powerful characteristic of the Facebook group under study because although knowledge sharing within social media groups is intended to help, it can often lead to confusing mothers when not aligned with clinical guidelines. There are multiple ways results from this study can impact clinical practice and implementation of breastfeeding-related programming. As mother-to-mother support groups are well known to provide opportunities for breastfeeding mothers to support breastfeeding through sharing of experiences, discussion in overcoming challenges, and through a sense of belonging [10,32-34], these types of groups could be the foundation for evolving telemedicine and electronic health models for lactation support, especially ones that are moderated by professional lactation clinicians, but also include mothers. This type of telemedicine model could be a way for hospitals and lactation consultation practices to expand their reach to mothers, ensuring access to reliable information online. This type of virtual COP could also be a place for referral to other health care professionals when there are other issues suspected (eg, referral to a pediatric dentist if posted picture of baby's frenulum showed a tongue tie and referral to a psychologist for postpartum depression symptoms). However, more foundational work, including interventions with other breastfeeding-related, social media–related technologies and platforms, should be conducted before the provision of concrete recommendations in this area.

These novel findings also have implications for breastfeeding promotion and practice. Regarding breastfeeding promotion, it seems social media groups, especially those that focus on breastfeeding, can disseminate and promote best practices within the group. This is consistent with a recent study conducted in Australia on the social media group use by a national breastfeeding organization, in which they found that the social media group promoted best practices for its members [14]. Furthermore, this social media group was able to provide critical social support that mothers reported they were not receiving elsewhere. Many mothers, especially those with multiple children, do not have the time to go to in-person support groups because of parental or work-related constraints [25]. However, mothers find interacting with others online to be convenient and can lead to the development of relationships over time. Reaching mothers through virtual communities, especially social media groups, has an immense potential to increase the reach of breastfeeding education and programming. Future research should explore how health care professionals can leverage existing social media, mobile health apps, and emerging technologies to promote breastfeeding and provide mothers with support.

Limitations

Although there are many strengths to this study, there are also limitations that must be considered. As this was an exploratory study with a small qualitative sample from a group of mothers located mainly in the southeast, results are not generalizable to all breastfeeding mothers who use social media or all breastfeeding groups. This is traditional of qualitative studies, as they are meant to describe and understand the phenomenon of interest. The smaller sample size was also intentional, as qualitative studies are small because of their in-depth nature. As there was only one coder for the qualitative data, interrater agreement could not be tested. However, member checking was performed to validate thematic analysis. In addition, as focus groups rely on the individuals' perceptions and experiences of social media group use and breastfeeding, these perceptions are also based on sample selection. With regard to sample selection, there is also the potential for self-selection bias in those mothers who participated, meaning those mothers who agreed to participate in the study may have been more likely to see themselves as ideal participants (eg, active participation in the group, success with breastfeeding, and previously breastfed an infant). However, we did have varying degrees of interaction within the group as well as variability in breastfeeding outcomes (eg, exclusively breastfeeding, mixed feeding, and breastfeeding barriers). It is important to note that because of the cross-sectional nature of this study, causality could not be determined.

Conclusions

This mixed methods study explored a novel area: using existing specialized infant feeding Facebook groups as hidden COPs. Mothers reported that they felt their interaction within the probreastfeeding Facebook group benefited their breastfeeding relationship through the formation of a breastfeeding community that empowered them in their breastfeeding journey. However, the findings presented here are preliminary and descriptive. The examination of this probreastfeeding social media group would not have been possible without the *mixing* of the qualitative and quantitative data. We recommend future studies employ this approach to move the field forward. Further analyses on the data from this study are needed to better understand and determine how social media groups may influence breastfeeding-related outcomes. This also includes research that aims to determine how the formation and utilization of a virtual breastfeeding COP can be replicated in other social media groups or virtual communities as well as to explore the casual relationships between group usage and breastfeeding-related knowledge, attitudes, and outcomes.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Focus group guide.
[DOCX File , 14 KB - pediatrics_v3i1e14355_app1.docx]

References

1. Section on Breastfeeding. Breastfeeding and the use of human milk. Pediatrics 2012 Mar;129(3):e827-e841. [doi: 10.1542/peds.2011-3552] [Medline: 22371471]
2. World Health Organization. 2011. Exclusive Breastfeeding for Six Months Best for Babies Everywhere URL: http://www.who.int/mediacentre/news/statements/2011/breastfeeding_20110115/en/ [accessed 2018-12-08]
3. Academy of Breastfeeding Medicine. ABM clinical protocol #10: breastfeeding the late preterm infant (34(0/7) to 36(6/7) weeks gestation) (first revision June 2011). Breastfeed Med 2011 Jun;6(3):151-156. [doi: 10.1089/bfm.2011.9990] [Medline: 21631254]
4. Centers for Disease Control and Prevention. Atlanta, GA: Centers for Disease Control and Prevention; 2018. Breastfeeding Report Card URL: https://www.cdc.gov/breastfeeding/data/reportcard.htm [accessed 2020-02-06]
5. Meadows SO. The association between perceptions of social support and maternal mental health: a cumulative perspective. J Fam Issues 2011;32(2):181-208. [doi: 10.1177/0192513x10375064]
6. Meedya S, Fahy K, Kable A. Factors that positively influence breastfeeding duration to 6 months: a literature review. Women Birth 2010 Dec;23(4):135-145. [doi: 10.1016/j.wombi.2010.02.002] [Medline: 20299299]
7. Barclay L, Everitt L, Rogan F, Schmied V, Wyllie A. Becoming a mother--an analysis of women's experience of early motherhood. J Adv Nurs 1997 Apr;25(4):719-728. [doi: 10.1046/j.1365-2648.1997.t01-1-1997025719.x] [Medline: 9104667]
8. McDonald SW, Benzies KM, Gallant JE, McNeil DA, Dolan SM, Tough SC. A comparison between late preterm and term infants on breastfeeding and maternal mental health. Matern Child Health J 2013 Oct;17(8):1468-1477 [FREE Full text] [doi: 10.1007/s10995-012-1153-1] [Medline: 23054457]
9. Britton C, McCormick F, Renfrew M, Wade A, King S. Support for breastfeeding mothers. Cochrane Database Syst Rev 2007 Jan 24(1):CD001141. [doi: 10.1002/14651858.CD001141.pub3] [Medline: 17253455]
10. Morris MR. Social Networking Site Use by Mothers of Young Children. In: Proceedings of the 17th ACM conference on Computer supported cooperative work & social computing. 2014 Presented at: CSCW'14; February 15 - 19, 2014; Baltimore, MD p. 1272-1282. [doi: 10.1145/2531602.2531603]
11. Gibson L, Hanson VL. Digital Motherhood: How Does Technology Help New Mothers? In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 2470700: ACM; 2013 Presented at: CHI'13; April 27 - May 2, 2013; Paris, France p. 313-322. [doi: 10.1145/2470654.2470700]
12. Rollins NC, Bhandari N, Hajeebhoy N, Horton S, Lutter CK, Martines JC, Lancet Breastfeeding Series Group. Why invest, and what it will take to improve breastfeeding practices? Lancet 2016 Jan 30;387(10017):491-504. [doi: 10.1016/S0140-6736(15)01044-2] [Medline: 26869576]
13. Johns R, English R. Mothers influencing mothers: the use of virtual discussion boards and their influence on consumption. Int J Web Based Commun 2014;10(3):319-338. [doi: 10.1504/ijwbc.2014.062945]
14. Bridges N. The faces of breastfeeding support: experiences of mothers seeking breastfeeding support online. Breastfeed Rev 2016 Mar;24(1):11-20. [Medline: 27188074]
15. Doub AE, Small M, Birch LL. A call for research exploring social media influences on mothers' child feeding practices and childhood obesity risk. Appetite 2016 Apr 1;99:298-305. [doi: 10.1016/j.appet.2016.01.003] [Medline: 26767614]
16. McDaniel BT, Coyne SM, Holmes EK. New mothers and media use: associations between blogging, social networking, and maternal well-being. Matern Child Health J 2012 Oct;16(7):1509-1517. [doi: 10.1007/s10995-011-0918-2] [Medline: 22094592]
17. Ridings CM, Gefen D, Arinze B. Some antecedents and effects of trust in virtual communities. J Strateg Inf Syst 2002;11(3-4):271-295. [doi: 10.1016/s0963-8687(02)00021-5]
18. Wenger E. Semantic Scholar. Communities of Practice: A Brief Introduction URL: https://pdfs.semanticscholar.org/84d6/e4deccf799fbc18c6a2b7a86911e62cbe78d.pdf?_ga=2.188693608.1998517035.1580978333-1679671381.1567599385 [accessed 2020-02-06]
19. Wasko MM, Faraj S. Why should I share? Examining social capital and knowledge contribution in electronic networks of practice. MIS Q 2005;29(1):35-57. [doi: 10.2307/25148667]
20. Brown JS, Duguid P. CiteSeerX. Mysteries of the Region: Knowledge Dynamics in Silicon Valley URL: http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.500.212&rep=rep1&type=pdf [accessed 2020-02-06]
21. Abdul-Rahman A, Hailes S. Supporting Trust in Virtual Communities. In: Proceedings of the 33rd Annual Hawaii International Conference on System Sciences. 2000 Presented at: HICSS'00; January 7, 2000; Hawaii, USA. [doi: 10.1109/hicss.2000.926814]
22. Asiodu IV, Waters CM, Dailey DE, Lee KA, Lyndon A. Breastfeeding and use of social media among first-time African American mothers. J Obstet Gynecol Neonatal Nurs 2015;44(2):268-278 [FREE Full text] [doi: 10.1111/1552-6909.12552] [Medline: 25712127]

23. Skelton KR, Evans R, LaChenaye J, Amsbary J, Wingate M, Talbott L. Exploring social media group use among breastfeeding mothers: qualitative analysis. JMIR Pediatr Parent 2018 Nov 5;1(2):e11344 [FREE Full text] [doi: 10.2196/11344] [Medline: 31518305]
24. Ivankova NV, Creswell JW, Stick SL. Using mixed-methods sequential explanatory design: From theory to practice. Field Methods 2006;18(1):3-20. [doi: 10.1177/1525822x05282260]
25. Skelton K, Evans R, LaChenaye J, Amsbary J, Wingate M, Talbott L. Utilization of online focus groups to include mothers: a use-case design, reflection, and recommendations. Digit Health 2018;4:2055207618777675 [FREE Full text] [doi: 10.1177/2055207618777675] [Medline: 29942638]
26. Smith J, Firth J. Qualitative data analysis: the framework approach. Nurse Res 2011;18(2):52-62. [doi: 10.7748/nr2011.01.18.2.52.c8284] [Medline: 21319484]
27. Saldaña J. The Coding Manual for Qualitative Researchers. Newbury Park, California: SAGE; 2015.
28. Serrat O. Surveying communities of practice. In: Knowledge Solutions. Singapore: Springer; 2017:745-763.
29. Dennis CL. The breastfeeding self-efficacy scale: psychometric assessment of the short form. J Obstet Gynecol Neonatal Nurs 2003;32(6):734-744. [doi: 10.1177/0884217503258459] [Medline: 14649593]
30. Mora A, Russell D, Dungy C, Losch M, Dusdieker L. The Iowa Infant Feeding Attitude Scale: analysis of reliability and validity1. J Appl Social Pyschol 1999;29(11):2362-2380. [doi: 10.1111/j.1559-1816.1999.tb00115.x]
31. SPSS. IBM Corp New York. IBM SPSS Statistics 22 URL: https://www.ibm.com/support/pages/ibm-spss-statistics-22-documentation [accessed 2020-02-06]
32. UNICEF. From the First Hour of Life: Making the Case for Improved Infant and Young Child Feeding Everywhere. New York, New York: UNICEF; 2016.
33. Bunik M, Leifermann J, Ryan J, Furniss A, Bull S. Mother's MILK Messaging: a pilot study of an app to support breastfeeding in first time mothers. Pediatrics 2016;137(Supplement 3):218A. [doi: 10.1542/peds.137.Supplement_3.218A]
34. Meier PP, Engstrom JL, Rossman B. Breastfeeding peer counselors as direct lactation care providers in the neonatal intensive care unit. J Hum Lact 2013 Aug;29(3):313-322. [doi: 10.1177/0890334413482184] [Medline: 23563112]

Abbreviations

COP: community of practice
FGD: focus group discussion
IBCLC: International Board Certified Lactation Consultant
SNS: social networking site
UGC: user-generated content

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Original Paper

Web-Based Technology to Improve Disease Knowledge Among Adolescents With Sickle Cell Disease: Pilot Study

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Abstract

Background: Advancements in treatment have contributed to increased survivorship among children with sickle cell disease (SCD). Increased transition readiness, encompassing disease knowledge and self-management skills before transfer to adult care, is necessary to ensure optimal health outcomes. The Sickle Cell Transition E-Learning Program (STEP) is a public, Web-based, 6-module tool designed to increase transition readiness for youth with SCD.

Objective: The objective of our study was to investigate the participation rate of youth with SCD in STEP and its association with transition readiness.

Methods: This was a single-center, Institution Review Board–approved, retrospective cohort review. A total of 183 youths with SCD, aged between 12 and 15 years, were offered STEP as an adjunct to in-clinic disease education sessions. Participation rate (number of patients who used at least one STEP module divided by those approached) was calculated. The association among the number of STEP modules completed, disease knowledge, and self-management was explored.

Results: Overall, 53 of the 183 approached adolescents completed at least one STEP module, yielding a participation rate in STEP of 29.0%. Of the 53 participants, 37 and 39 adolescents had disease knowledge and self-management confidence rating available, respectively. A positive correlation (r=0.47) was found between the number of STEP modules completed and disease knowledge scores (P=.003). No association was found between the number of modules completed and self-management confidence ratings. Disease knowledge scores were significantly higher among participants who completed ≥3 STEP modules compared with those who completed <3 STEP modules (U=149.00; P=.007).

Conclusions: Improvement in disease knowledge in adolescence is critical to ensure the youth's ability to self-care during the period of transition to adult care. Despite low participation, the cumulative exposure to the STEP program suggested greater promotion of disease knowledge among adolescents with SCD before transfer to adult care.

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KEYWORDS

sickle cell anemia; eHealth; transition to adult care

Introduction

Background

Sickle cell disease (SCD) is a genetic disorder characterized by recurrent vaso-occlusive events, chronic pain, and progressive multisystem end-organ damage [1]. In the United States, SCD affects an estimated 100,000 individuals [2,3]. Over the past 5 decades, survivorship into adulthood for US children with SCD has increased to greater than 95%, mostly attributable to newborn screening programs, greater access to care, and use of disease-modifying therapies [4,5]. Increased survivorship to adulthood underscores the adult health care transition period as an important time for individuals with SCD. The transfer period from pediatric to adult care is a high-risk time with an increase in acute health care utilization and acute complications for many chronic diseases [6]. Poor health outcomes during the transfer period for individuals with SCD, including increased acute health care utilization, is complex and may be attributable in part to poor transition readiness [7].

Transition readiness comprises self-management skills and disease knowledge aimed at increasing self-care skills. Individuals with SCD may have deficits in disease knowledge, and both patients and caregivers are interested in interventions to increase disease knowledge and self-management skills [8,9]. In the SCD population, proper transition readiness is correlated with improved transition outcomes and is recognized as an area for intervention to improve health outcomes during the transition period [10,11]. Improved disease knowledge is associated with lower frequency of emergency room visits and higher frequency of outpatient visits among adults with SCD [12].

Interventions that require the physical presence of patients in clinic to deliver the intervention are limited by access to longitudinal care and low adherence to routine clinic visits [13]. The use of electronic devices allows flexibility in utilization beyond the hospital walls, such as their home, school, and other environments. Adolescents with SCD have expressed desire to use mobile health and other Web-based tools as part of their disease management [14]. Over 80% of adolescents and young adults with SCD have access to a computer or mobile phone [15,16]. Among individuals with SCD, Web-based and mobile apps have been shown to increase adherence to medications [16-18]. Taken together, these findings point toward the increasing acceptability of digital interventions for self-management in the SCD population, particularly among adolescents and young adults.

Structured education interventions for patients with SCD before transfer to adult care is limited, especially those focused on transition readiness. A total of 2 studies utilizing electronic platforms among youth with SCD, 1 with mobile technology and 1 with a CD-ROM education game, have demonstrated an increase in disease knowledge [19,20]. Currently, most mobile interventions favor medication adherence, whereas a few apps focus on targeting disease knowledge and self-management skills [21,22]. There is increasing evidence that electronic health (eHealth) interventions improve self-management outcomes for individuals with SCD [14]. The mobile self-management app, iManage, demonstrated feasibility and acceptance among adolescents with SCD [15]. Furthermore, educational handouts were shown to improve preidentified deficits in self-management skills [23].

Objectives

The Sickle Cell Transition E-Learning Program (STEP) is as a Web-based educational intervention developed to improve SCD knowledge. STEP offers an alternative to the existing disease education interventions as it can be used in any setting and only requires internet access. Thus, our primary objective was to investigate the participation rate in STEP as an intervention to improve transition readiness and to gather preliminary data regarding its correlation with disease knowledge and self-management confidence among adolescents with SCD.

Methods

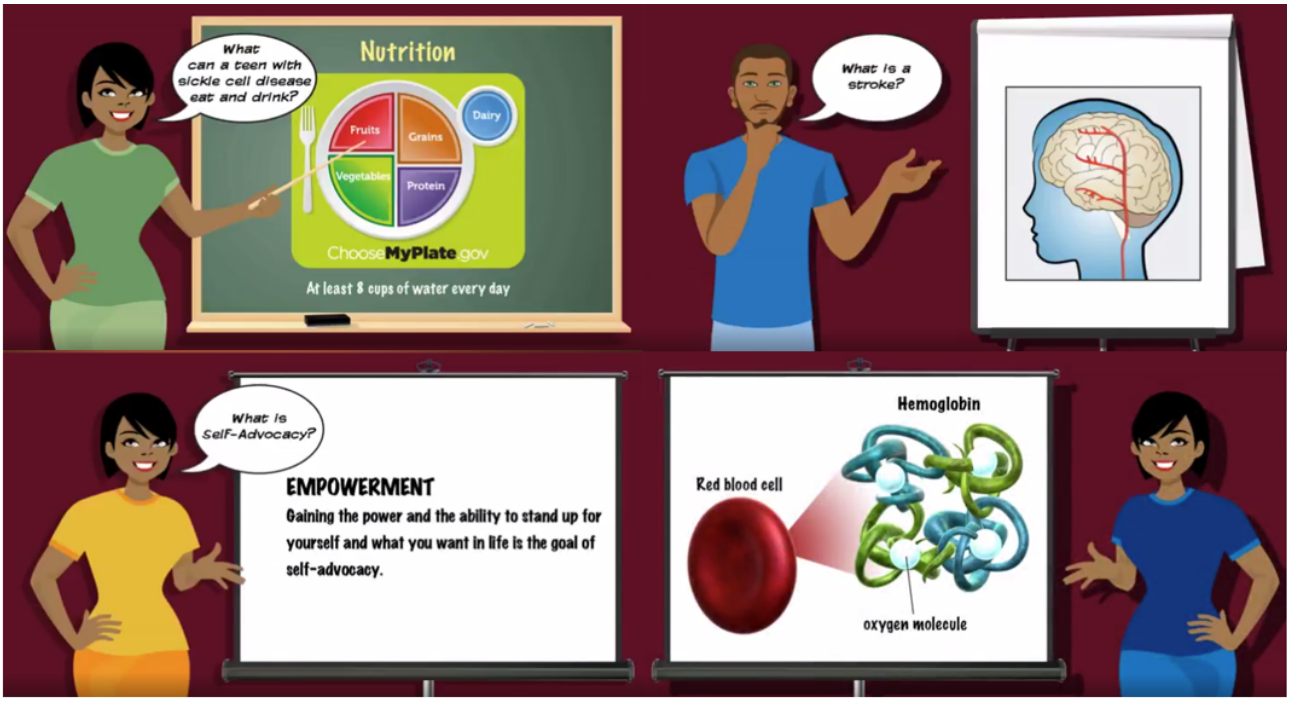
Participant Selection

Individuals with SCD, aged between 12 and 15 years during the first 2 years of STEP implementation, and who were participants of the longitudinal cohort study, Sickle Cell Clinical Research and Intervention Program (SCCRIP) [24], were included. Those who completed 1 or more modules of STEP, in addition to either the disease knowledge or the self-efficacy assessments during pediatric care at St. Jude Children’s Research Hospital were included in the subanalysis of the efficacy of STEP in increasing transition readiness. All participants or their legal guardians (if minors at the time of SCCRIP enrollment) signed the SCCRIP informed consent, which allowed for retrospective data collection for STEP participation.

Sickle Cell Transition Electronic Learning Program Description

The STEP program was developed in 2013 by a nurse from the department of hematology and other SCD program staff as an adjunct to the standard of care in-clinic education sessions offered by the nurse educators. STEP utilizes the electronic learning software Articulate Global Inc, and is an open-access, Web-based tool comprising 6 modules (Figure 1) [25]. It is administered via a tablet device in clinic or at home. Module, video, and quiz contents were developed based on SCD literature and our program’s SCD educational curriculum [21] and includes 6 modules: (1) sickle cell and me; (2) healthy living and SCD; (3) pain, infection, and SCD; (4) other complications of SCD; (5) genes and SCD; and (6) self-advocacy for teens with SCD. Modules 1 and 2 reflect fundamentals of SCD disease knowledge, whereas modules 3 to 6 address advanced topics related to disease complications and necessary transition skills. Each module includes an optional preassessment, educational video of topic, and a scored postassessment (Figure 1). The postassessment scores range between 0 and 100, and STEP participation and score results were recorded after each module completion. Patients with scores of >80 (scale of 1-100) were provided an incentive (eg, small toys and board games). The program did not capture discrete scores within the software, but results were recorded as pass or fail based on scoring 80% or higher.

Figure 1. Panel of 4 module videos of the Sickle Cell Transition E-Learning Program (STEP). STEP is a 6-module, Web-based tool designed to increase disease knowledge in patients with sickle cell disease.



Disease Knowledge and Self-Management Assessments

The disease knowledge assessment is delivered at the pediatric clinic visit between the ages of 12 and 15 years and before the participants are transferred to adult care. This knowledge assessment is paper-based and comprises 12 multiple-choice questions serving as a comprehensive review of the adolescent SCD-specific knowledge (Multimedia Appendix 1). The disease knowledge assessment tool was developed by the staff of the Hematology Department at St. Jude Children's Research Hospital, and it tests knowledge related to the general definition of SCD, complications, and pain (Multimedia Appendix 1) [26]. The scores in the disease knowledge assessment range from 0 to 100, with higher numbers reflecting higher disease knowledge. Self-management confidence was assessed with the Self-Management Skills Checklist (SMSC). The SMSC is a tool modified from the validated Transition Readiness Assessment Questionnaire and assesses perceived disease knowledge and self-management skills (Multimedia Appendix 2) [27,28]. The self-management confidence score is rated on a scale from 1 to 10, such that 1 indicates the lowest and 10 indicates the highest self-confidence levels for self-care.

Statistical Considerations

The rate of acceptance was calculated by dividing the number of patients who were offered and used at least one STEP module by the total of number of those approached. Disease knowledge scores were calculated as a percentage of correct answers. Owing to the data not being normally distributed, the Spearman rho test was used to examine the association between disease knowledge and self-management scores with the completion of at least one STEP module. The Mann-Whitney test was used to compare the association between disease knowledge scores and the number of STEP modules completed [29]. By design, STEP participation always occurred before the knowledge and self-management assessments. This order was intentional and allowed us to collect preliminary data on the relationship between an early disease-education intervention and later disease knowledge and perceived self-efficacy.

Results

A total of 183 adolescents between the ages of 12 and 15 years were offered to participate in STEP between 2013 and 2014. Of these, 53 participants (median age 14 years, range 12-15 years; 33/53, 62% male) utilized at least one STEP module, yielding a rate of participation of 29.0%. Most participants had HbSS or HbSβ^0 thalassemia; all were African American, and the demographic characteristics did not differ among males and females (Table 1). There were no differences in demographics related to race, age, sex, and sickle genotype among the STEP participants (n=53) and nonparticipants (n=130). The median number of STEP modules completed was 3 (range 1-6). All (53/53, 100%), 83% (44/53), 62% (33/53), 43% (23/53), 4% (2/53), and 4% (2/53) of the patients completed 1, 2, 3, 4, 5, and 6 STEP modules, respectively. The time to complete each STEP module was approximately 12 min to 18 min. All modules were completed within 12 months from the first module by those who completed >1 module. All participants scored greater than 80% on the module postassessment test.

Table 1. Sickle Cell Transition E-Learning Program participants' characteristics (N=53).

Characteristics	Statistics
Sex, n (%)	
Male	33 (62)
Female	20 (38)
Genotype, n (%)	
HbSS/ HbSβ^0 thalassemia	35 (66)
HbSC/HbSβ^+ thalassemia	18 (34)
Race (African American), n (%)	53 (100)
Ethnicity (non-Hispanic), n (%)	53 (100)
Sickle Cell Transition E-Learning Program modules completed	
Mean (SD)	2.79 (1.08)
Median (range)	3.00 (1-6)
Grouping of modules completed, n (%)	
1-2 modules	20 (38)
3-6 modules	33 (62)

Out of the 53 adolescents who completed at least one STEP module, 37 completed the disease knowledge assessment and 39 completed the SMSC before transfer to adult care and comprised the subset for whom preliminary STEP efficacy was tested. Their median age upon completion of the disease knowledge assessment and SMSC was 16 years (range 15-17 years) and 15 years (range 13-17), respectively (Table 2). STEP participation occurred a median of 2.6 and 1.3 years before the disease knowledge assessment and SMSC evaluations, respectively. The median self-management confidence score was 8 (range 5-10) and median knowledge assessment score was 79 (range 37-100). A positive correlation (*r*=0.471) was found between the number of STEP modules completed and the disease knowledge score (*P*=.003; Figure 2). No correlation was found between the number of modules completed and the self-management confidence ratings (*P*=.945).

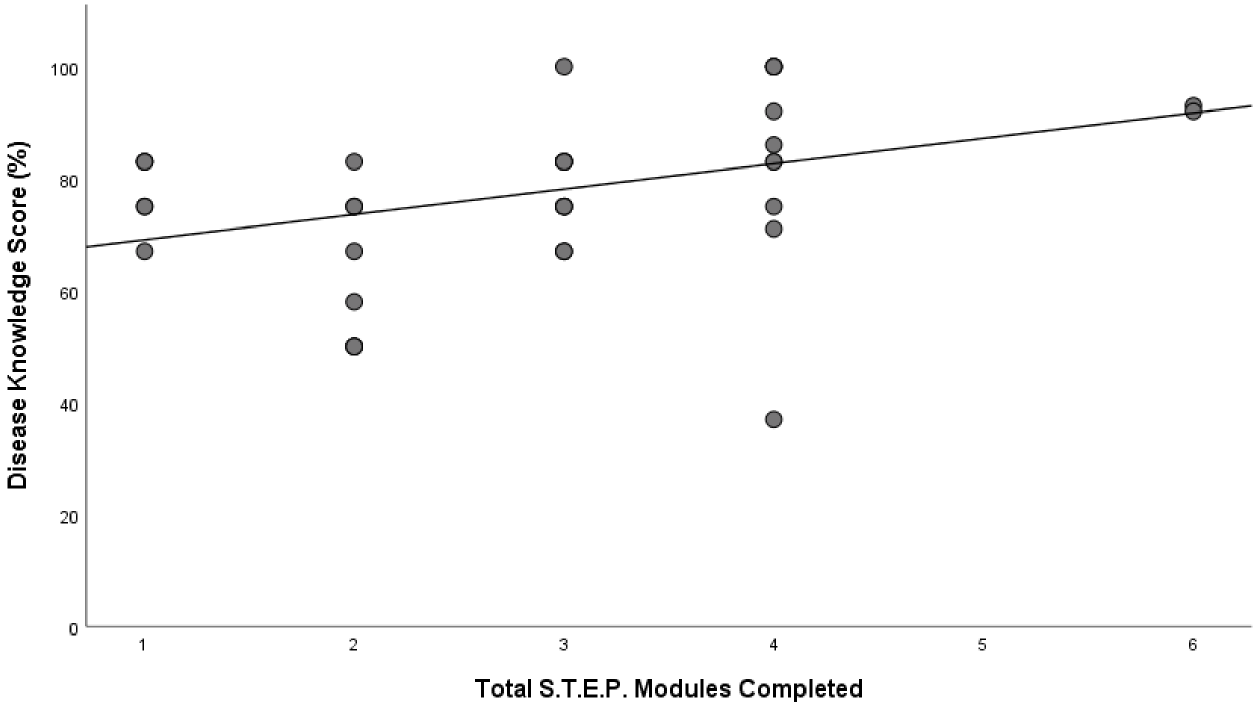
The median disease knowledge score was significantly higher among participants who completed ≥3 STEP modules (82.7 [SD 14.68]) compared with those who completed ≤2 modules (69.57 [SD 12.82]; *U*=149.0; *P*=.007). Furthermore, a positive correlation (*r*=0.502) was found between the disease knowledge score and self-management confidence rating (*P*=.005). We repeated the analysis with the 35 participants who had completed modules 1 to 4 only and the results remained the same such that there was a positive relationship between the number of STEP modules and greater disease knowledge (Multimedia Appendix 3). There were no significant differences in STEP scores, knowledge, or SMSC scores by sex. Of the 130 who did not participate in the STEP program, 57 completed the disease knowledge assessment before they transitioned to adult care. When the 57 youths who did not participate in STEP were compared with the 37 who did, there were no statistical differences with regard to demographics (sex, sickle cell genotype, or disease knowledge score).

Table 2. Transition readiness scores of Sickle Cell Transition E-Learning Program participants (N=53).

Score characteristics	Values
Age at first STEP[a] module (years)	
Mean (SD)	14.07 (1.27)
Median (range)	14.19 (12-15)
Disease knowledge score	
STEP participants with score, n	37
Mean (SD)	77.53 (14.69)
Median (range)	79 (37-100)
Age at disease knowledge score (years)	
Mean (SD)	16.0 (0.263)
Median (range)	16 (15-17)
Self-management confidence score	
STEP participants with score, n	39
Mean (SD)	8.05 (1.58)
Median (range)	8 (5-10)
Age at self-management confidence score (years)	
Mean (SD)	15.18 (0.756)
Median (range)	15 (13-17)
Time between administration of disease knowledge and self-management assessments (months)	
Mean (SD)	11.5 (7.34)
Median (range)	12 (5-38)

[a] STEP: Sickle Cell Transition E-Learning Program.

Figure 2. Relationship between the number of Sickle Cell Transition E-Learning Program (STEP) modules completed and the disease knowledge score. A dose-response relationship was found such that greater number of STEP modules completed positively correlated (r=0.47; P=.003) with disease knowledge scores before transfer to adult care.



Discussion

Principal Findings

Disease knowledge is an important component of transition readiness and low knowledge may serve as a barrier to adequate transition outcomes. Our findings suggest that Web-based technology may improve disease knowledge among adolescents with SCD. Greater transition readiness may mitigate the deterioration of health outcomes for patients with SCD during the transition period; however, there is a paucity of studies investigating the role of structured education interventions to improve transition readiness. Few reported structured education programs for adolescents with SCD have utilized eHealth technologies, although a paper-based format to deliver disease education demonstrated feasibility [23]. In addition, new apps in development offer disease education and self-management strategies but have not yet been formally tested [15]. STEP offers an alternative to existing education interventions as it encompasses basic and advanced SCD knowledge and self-management skills necessary for transition to adult care and can be used on any device with internet connection and without the need for an app.

STEP is a readily accessible free resource that can be used by hematology clinic staff as a primary or adjunct intervention to educate youth in preparation for transition to adult care. The easy accessibility of STEP allows for its use in mobile devices or desktops, facilitating its adoption outside the clinic. Furthermore, assessment for each module allows clinical staff to monitor individual progress and identify potential gaps in knowledge. Although we were able to demonstrate a relationship between STEP participation and disease knowledge retention, we did not find a relationship between participation in the program and higher self-management confidence ratings. However, we did find a relationship between disease knowledge and self-management confidence scores, suggesting that increased disease knowledge may be correlated with greater self-management skills. Furthermore, we only included 1 aspect of the SMSC in our analysis, the confidence rating, which may have reduced our sensitivity to detect any association between STEP participation and perceived self-management. It is possible that there are other aspects of self-management that may have been associated with STEP exposure; however, they were not measured in our study.

Limitations

There were several limitations. The study was a small single-center retrospective cohort study; thus, our findings may not be representative of other adolescent SCD populations. In addition, STEP is embedded within our comprehensive transition program (Saulsberry et al, forthcoming) and the impact of education delivered throughout other aspects of the transition program between time of STEP participation and time of transition readiness assessments is unknown. STEP preassessment and postassessment score documentation was limited as scores were recorded as pass or fail and could not be correlated with comprehensive disease knowledge assessment. Although the rate of participation was low, our sample size was small and limited by completion of both the disease education assessment and the SMSC. This limitation could be because of poor compliance with routine care visits, which is high for many adolescents with chronic diseases [13], and low completion of both the knowledge and the SMSC assessments. It is unclear as to why we did not observe a difference in disease knowledge between the groups participating in STEP and those not participating in STEP, but small sample size in the STEP participant group, a nonrandomized design, and possible differential exposure to other education methods are all plausible reasons. Nonparticipation in the program was not formally measured; therefore, we are unable to provide qualitative reasons for nonparticipation. However, lack of time to complete the STEP modules or lack of interest are possible explanations.

Future Work

We plan to qualitatively assess engagement in STEP as a future phase in our research. In addition, we plan to formally investigate satisfaction (patient and medical provider) and perceived benefit of STEP and the relationship among the use of STEP, educational outcomes (eg, achievement and attainment), and clinical outcomes during adult care (eg, medication adherence or compliance with medical visits as adults). As STEP can be used outside the clinic, future work will also capture how frequently it is being accessed outside the clinic environment. Finally, future work needs to be done to rule out selection bias as we cannot be certain that those who chose not to participate in the STEP intervention have different educational needs or motivation levels than those who chose to participate.

Conclusions

In summary, STEP, a Web-based SCD educational tool, had a suboptimal engagement rate; however, preliminary findings suggested that greater STEP use promoted greater disease knowledge among adolescents with SCD. STEP can potentially be used as an intervention to provide SCD education among adolescents with SCD, with the goal of improving their transition readiness. Future work includes investigating the relationship of STEP with other clinical, educational, and behavioral outcomes and strategies to improve participation.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

The disease knowledge assessment is paper-based and comprises 12 multiple-choice questions serving as a comprehensive review of adolescent sickle cell disease knowledge.

[PDF File (Adobe PDF File), 40 KB - pediatrics_v3i1e15093_app1.pdf]

Multimedia Appendix 2

The Self-Management Skills Checklist for teens is a tool modified from the validated Transition Readiness Assessment Questionnaire and assesses perceived disease knowledge and self-management skills.

[PDF File (Adobe PDF File), 66 KB - pediatrics_v3i1e15093_app2.pdf]

Multimedia Appendix 3

Relationship between the number of Sickle Cell Transition E-Learning Program modules completed and disease knowledge score among participants that completed 1-4 modules.

[PNG File , 20 KB - pediatrics_v3i1e15093_app3.png]

References

1. Kato GJ, Piel FB, Reid CD, Gaston MH, Ohene-Frempong K, Krishnamurti L, et al. Sickle cell disease. Nat Rev Dis Primers 2018 Mar 15;4:18010. [doi: 10.1038/nrdp.2018.10] [Medline: 29542687]
2. Therrell BL, Lloyd-Puryear MA, Eckman JR, Mann MY. Newborn screening for sickle cell diseases in the United States: a review of data spanning 2 decades. Semin Perinatol 2015 Apr;39(3):238-251. [doi: 10.1053/j.semperi.2015.03.008] [Medline: 25979783]
3. Hassell KL. Population estimates of sickle cell disease in the US. Am J Prev Med 2010 Apr;38(4 Suppl):S512-S521. [doi: 10.1016/j.amepre.2009.12.022] [Medline: 20331952]
4. Quinn CT, Rogers ZR, McCavit TL, Buchanan GR. Improved survival of children and adolescents with sickle cell disease. Blood 2010 Apr 29;115(17):3447-3452 [FREE Full text] [doi: 10.1182/blood-2009-07-233700] [Medline: 20194891]
5. Scott RB. Health care priority and sickle cell anemia. J Am Med Assoc 1970 Oct 26;214(4):731-734. [Medline: 5536114]
6. Callahan ST, Cooper WO. Changes in ambulatory health care use during the transition to young adulthood. J Adolesc Health 2010 May;46(5):407-413. [doi: 10.1016/j.jadohealth.2009.09.010] [Medline: 20413075]
7. Modi AC, Pai AL, Hommel KA, Hood KK, Cortina S, Hilliard ME, et al. Pediatric self-management: a framework for research, practice, and policy. Pediatrics 2012 Feb;129(2):e473-e485. [doi: 10.1542/peds.2011-1635] [Medline: 22218838]
8. Zhao MS, Johnson M, Pullen A, Russell KM, Wesley K, Hankins JS. Assessment of personal medical history knowledge in adolescents with sickle cell disease: a pilot study. J Clin Outcomes Manag 2016;6:23 [FREE Full text]
9. Porter JS, Lopez AD, Wesley KM, Magdovitz-Frankfurt P, Anderson SM, Cole AR, et al. Using qualitative perspectives of adolescents with sickle cell disease and caregivers to develop healthcare transition programming. Clin Pract Pediatr Psychol 2017 Dec;5(4):319-329 [FREE Full text] [doi: 10.1037/cpp0000212] [Medline: 31131180]
10. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med 2011 Jul 19;155(2):97-107. [doi: 10.7326/0003-4819-155-2-201107190-00005] [Medline: 21768583]
11. Molter BL, Abrahamson K. Self-efficacy, transition, and patient outcomes in the sickle cell disease population. Pain Manag Nurs 2015 Jun;16(3):418-424. [doi: 10.1016/j.pmn.2014.06.001] [Medline: 25047808]
12. Nolan VG, Anderson SM, Smeltzer MP, Porter JS, Carroll YM, Brooks IM, et al. Pediatric to adult care co-location transitional model for youth with sickle cell disease. Am J Hematol 2018 Jan;93(1):E30-E32 [FREE Full text] [doi: 10.1002/ajh.24953] [Medline: 29067725]
13. Crosby LE, Modi AC, Lemanek KL, Guilfoyle SM, Kalinyak KA, Mitchell MJ. Perceived barriers to clinic appointments for adolescents with sickle cell disease. J Pediatr Hematol Oncol 2009 Aug;31(8):571-576 [FREE Full text] [doi: 10.1097/MPH.0b013e3181acd889] [Medline: 19636266]
14. Badawy SM, Cronin RM, Hankins J, Crosby L, DeBaun M, Thompson AA, et al. Patient-centered eHealth interventions for children, adolescents, and adults with sickle cell disease: systematic review. J Med Internet Res 2018 Jul 19;20(7):e10940 [FREE Full text] [doi: 10.2196/10940] [Medline: 30026178]

15. Crosby LE, Ware RE, Goldstein A, Walton A, Joffe NE, Vogel C, et al. Development and evaluation of iManage: a self-management app co-designed by adolescents with sickle cell disease. Pediatr Blood Cancer 2017 Jan;64(1):139-145. [doi: 10.1002/pbc.26177] [Medline: 27574031]
16. Badawy SM, Thompson AA, Liem RI. Technology access and smartphone app preferences for medication adherence in adolescents and young adults with sickle cell disease. Pediatr Blood Cancer 2016 May;63(5):848-852. [doi: 10.1002/pbc.25905] [Medline: 26844685]
17. Crosby LE, Barach I, McGrady ME, Kalinyak KA, Eastin AR, Mitchell MJ. Integrating interactive web-based technology to assess adherence and clinical outcomes in pediatric sickle cell disease. Anemia 2012;2012:492428 [FREE Full text] [doi: 10.1155/2012/492428] [Medline: 22701785]
18. Estepp JH, Winter B, Johnson M, Smeltzer MP, Howard SC, Hankins JS. Improved hydroxyurea effect with the use of text messaging in children with sickle cell anemia. Pediatr Blood Cancer 2014 Nov;61(11):2031-2036. [doi: 10.1002/pbc.25177] [Medline: 25132074]
19. Anderson LM, Leonard S, Jonassaint J, Lunyera J, Bonner M, Shah N. Mobile health intervention for youth with sickle cell disease: impact on adherence, disease knowledge, and quality of life. Pediatr Blood Cancer 2018 Aug;65(8):e27081. [doi: 10.1002/pbc.27081] [Medline: 29693797]
20. Yoon SL, Godwin A. Enhancing self-management in children with sickle cell disease through playing a CD-ROM educational game: a pilot study. Pediatr Nurs 2007;33(1):60-3, 72. [Medline: 17411004]
21. Saulsberry AC, Porter JS, Hankins JS. A program of transition to adult care for sickle cell disease. Hematology Am Soc Hematol Educ Program 2019 Dec 06;2019(1):496-504. [doi: 10.1182/hematology.2019000054] [Medline: 31808907]
22. Badawy SM, Barrera L, Sinno MG, Kaviany S, O'Dwyer LC, Kuhns LM. Text messaging and mobile phone apps as interventions to improve adherence in adolescents with chronic health conditions: a systematic review. JMIR Mhealth Uhealth 2017 May 15;5(5):e66 [FREE Full text] [doi: 10.2196/mhealth.7798] [Medline: 28506955]
23. Calhoun CL, Abel RA, Pham HA, Thompson S, King AA. Implementation of an educational intervention to optimize self-management and transition readiness in young adults with sickle cell disease. Pediatr Blood Cancer 2019 Jul;66(7):e27722. [doi: 10.1002/pbc.27722] [Medline: 30907500]
24. Hankins JS, Estepp JH, Hodges JR, Villavicencio MA, Robison LL, Weiss MJ, et al. Sickle Cell Clinical Research and Intervention Program (SCCRIP): a lifespan cohort study for sickle cell disease progression from the pediatric stage into adulthood. Pediatr Blood Cancer 2018 Sep;65(9):e27228. [doi: 10.1002/pbc.27228] [Medline: 29797644]
25. St Jude Children's Research Hospital. Sickle Cell Transition E-Learning Program (STEP) for Teens with Sickle Cell Disease. URL: https://www.stjude.org/treatment/disease/sickle-cell-disease/step-program.html [accessed 2019-05-09] [WebCite Cache ID 78F9mIh8d]
26. Saulsberry AC, Hodges J, Williams J, Loew M, Anderson S, Cole A, et al. Caregiver Perceptions of Adolescent Self-Management Skills Predicts Higher Disease Knowledge Among Adolescents with SCD. Blood 2017 Dec 06;130(Supplement 1):3350-3350.
27. Wood DL, Sawicki GS, Miller MD, Smotherman C, Lukens-Bull K, Livingood WC, et al. The Transition Readiness Assessment Questionnaire (TRAQ): its factor structure, reliability, and validity. Acad Pediatr 2014;14(4):415-422. [doi: 10.1016/j.acap.2014.03.008] [Medline: 24976354]
28. Loew M, Williams JL, Russell K, Rupff R, Hankins JS, Porter J. The Adolescent and Caregiver Sickle Cell Disease Self-management Skills Checklist: Preliminary Reliability and Validity. J Pediatr Hematol Oncol 2019 Oct 29. [doi: 10.1097/MPH.0000000000001618] [Medline: 31688630]
29. Elliott AC, Woodward WA. Statistical Analysis Quick Reference Guidebook: With SPSS Examples. Thousand Oaks, California: Sage Publications Pvt Ltd; 2006.

Abbreviations

eHealth: electronic health
SCCRIP: Sickle Cell Clinical Research and Intervention Program
SCD: sickle cell disease
SMSC: Self-Management Skills Checklist
STEP: Sickle Cell Transition E-Learning Program

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Original Paper

Quality of Pregnancy Dating and Obstetric Interventions During Labor: Retrospective Database Analysis

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Abstract

Background: The correct dating of pregnancy is critical to support timely decisions and provide obstetric care during birth. The early obstetric ultrasound assessment before 14 weeks is considered the best reference to assist in determining gestational age (GA), with an accuracy of ±5 to 7 days. However, this information is limited in many settings worldwide.

Objective: The aim of this study is to analyze the association between the obstetric interventions during childbirth and the quality of GA determination, according to the first antenatal ultrasound assessment, which assisted the calculation.

Methods: This is a hospital-based cohort study using medical record data of 2113 births at a perinatal referral center. The database was separated into groups and subgroups of analyses based on the reference used by obstetricians to obtain GA at birth. Maternal and neonatal characteristics, mode of delivery, oxytocin augmentation, and forceps delivery were compared between groups of pregnancies with GA determination at different reference points: obstetric ultrasound assessment 14 weeks, 20 weeks, and ≥20 weeks or without antenatal ultrasound (suboptimal dating). Ultrasound-based GA information was associated with outcomes between the interest groups using chi-square tests, odds ratios (OR) with 95% CI, or the Mann-Whitney statistical analysis.

Results: The chance of nonspontaneous delivery was higher in pregnancies with 14 weeks ultrasound-based GA (OR 1.64, 95% CI 1.35-1.98) and 20 weeks ultrasound-based GA (OR 1.58, 95% CI 1.31-1.90) when compared to the pregnancies with ≥20 weeks ultrasound-based GA or without any antenatal ultrasound. The use of oxytocin for labor augmentation was higher for 14 weeks and 20 weeks ultrasound-based GA, OR 1.41 (95% CI 1.09-1.82) and OR 1.34 (95% CI 1.04-1.72), respectively, when compared to those suboptimally dated. Moreover, maternal blood transfusion after birth was more frequent in births with suboptimal ultrasound-based GA determination (20/657, 3.04%) than in the other groups (14 weeks ultrasound-based GA: 17/1163, 1.46%, P=.02; 20 weeks ultrasound-based GA: 25/1456, 1.71%, P=.048). Cesarean section rates between the suboptimal dating group (244/657, 37.13%) and the other groups (14 weeks: 475/1163, 40.84%, P=.12; 20 weeks: 584/1456, 40.10%, P=.20) were similar. In addition, forceps delivery rates between the suboptimal dating group (17/657, 2.6%) and the other groups (14 weeks: 42/1163, 3.61%, P=.24; 20 weeks: 46/1456, 3.16%, P=.47) were similar. Neonatal intensive care unit admission was more frequent in newborns with suboptimal dating (103/570, 18.07%) when compared with the other groups (14 weeks: 133/1004, 13.25%, P=.01; 20 weeks: 168/1263, 13.30%, P=.01), excluding stillbirths and major fetal malformations.

Conclusions: The present analysis highlighted relevant points of health care to improve obstetric assistance, confirming the importance of early access to technologies for pregnancy dating as an essential component of quality antenatal care.

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KEYWORDS

gestational age; parturition; ultrasound; pregnancy dating; information systems

Introduction

The correct dating of gestation is trigger information for health professionals to make timely decisions for care. Caregivers should be vigilant with the recording and retrieving of gestational age (GA) during antenatal care and birth [1,2], as well as the availability and quality of clinical data impacting caring [3]. Nonetheless, there are different references to assist in determining the GA, which all have varying accuracy [4]. Current methods to calculate GA have disadvantages due to the high costs of ultrasound assessment, inaccurate dates of the last menstrual period, and the lack of precision in neonatal maturity scores [2,4,5]. GA is oftentimes calculated using the difference between the date of birth and the referential daters from the beginning of gestation, such as the last menstrual period, ultrasound assessment, or markers of pregnancy evolution like fundal height. After birth, neonatal maturity scores are used to assist professionals to face unreliable or unknown dating of pregnancy [4]. Ultrasound for fetal assessment in early pregnancy (>7 weeks but <14 weeks) is considered the best dating method for gestational chronology, with a given error of ±5 to 7 days [1]. Despite a ±10-day margin of error, GA determined by ultrasound assessments ≥14 weeks but <20 weeks is still a reasonable antenatal record to estimate the GA when an early fetal ultrasound is missing [1,6,7]. A pregnancy dating based on ultrasonography performed after 20 weeks is considered suboptimally dated [1].

Accurate GA calculation remains a priority in public health [6]. According to the World Health Organization (WHO), several countries are unable to adequately collect minimum data for each birth [4,8]. The quality of data has an impact on prematurity rates (ranging from 6.2%-17.5%) and small-for-gestational-age rates, and varies according to the methodology of GA estimation [9], country, and the quality of the report [10].

At the end of pregnancy, labor induction, oxytocin augmentation, instrumental vaginal delivery, and cesarean sections are clearly necessary for some high-risk situations. Some preterm births are medically induced, and approximately half of preterm births are idiopathic [11]. Nevertheless, unnecessary obstetric interventions are continually increasing around the world; a situation that is made worse when GA is unreliable or unknown [5,11]. The impact that the quality of antenatal references used to support GA determination has on obstetric decisions and perinatal outcomes has not sufficiently been elucidated. We tested the hypothesis that the credibility of GA information retrieved at birth might be associated with the medical choices during obstetric interventions. This study aims to analyze the association between the obstetric interventions during childbirth and the quality of GA determination according to the first antenatal ultrasound assessment used for the calculation.

Methods

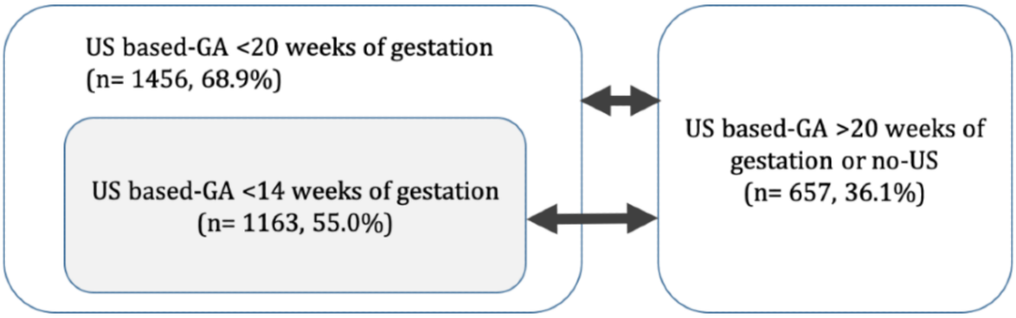
Study Design

This hospital-based cohort study retrospectively evaluated the quality of pregnancy dating and obstetric information in a computerized medical database, SISMater, dedicated to registering inpatient birth records [12]. All 2113 medical records from the dataset of live or stillborn infants delivered between October 2016, and September 2017, at the Hospital das Clínicas of the Universidade Federal de Minas Gerais in Brazil were included. The institutional review boards approved the research protocol (number: CAAE 10286913.3.0000.5149), dismissing individual written informed consent.

Dataset and Data Collection

For the analysis, the database was organized into groups based on ultrasonography reference used by obstetricians to assist in determining GA. The group of childbirths with the first obstetric ultrasound assessment <20 weeks of gestation and their subgroup of the first obstetric ultrasound assessment <14 weeks, were compared to the group of pregnancies suboptimally dated with ultrasound assessment ≥20 weeks or without any ultrasound recorded (Figure 1).

Figure 1. Comparison groups for ultrasound-based gestation age determination (N=2113). GA: gestational age; US: ultrasound.



The medical staff collected data on childbirth scenarios and all maternal and neonatal hospital stays using a system with a structured interface format [12]. The authors intend to share the minimum anonymized dataset necessary to replicate study findings (Multimedia Appendix 1). The data can be used under reasonable request to the corresponding author, as the citation of the original study is required.

The electronic medical record consists of the obstetric care and neonatal care reports. In the obstetric care section, the GA was automatically calculated by the system after input of the first trimester ultrasound findings when available. Cases in which ultrasound information that was <14 weeks of gestation was lacking or when the ultrasound was performed at 14 weeks or later, the GA was primarily calculated by the physician who assisted the birth, and the result was recorded in the electronic medical record system. For this, obstetricians used their best judgment to estimate the GA, either based on the last menstrual period or the ultrasound results. The information was considered missing if GA was reported in the electronic medical record as unknown. We had no access to the date of the last menstrual period in this database.

Perinatal Characteristics

Records on perinatal characteristics were compared between groups of interest to enhance the external validity of primary outcomes. Neonatal resuscitation referred to any of the steps of the recommended actions at birth [13]. The fetal or newborn mortality variable included stillbirths and newborn deaths during the hospital stay. Maternal transfusion after birth considered all derivatives of blood. Fetal and neonatal mortality, neonatal resuscitation, and neonatal intensive care unit (NICU) admission were presented, considering the presence of major malformations. Even in the presence of severe birth defects, elective abortion is not permitted by law in Brazil, except in the case of anencephaly [14].

Primary Outcomes

The obstetric interventions chosen as primary outcomes included maternal admission for nonspontaneous vaginal delivery, oxytocin augmentation during labor, cesarean section, and forceps delivery. Maternal admissions for the interruption of pregnancy without natural labor contractions and induced labors were considered nonspontaneous vaginal deliveries. University hospital protocols to manage labor rely on the best clinical and obstetric practices geared toward maternal-fetal diagnosis, labor management, neonatal care, and hospital or intensive care admissions.

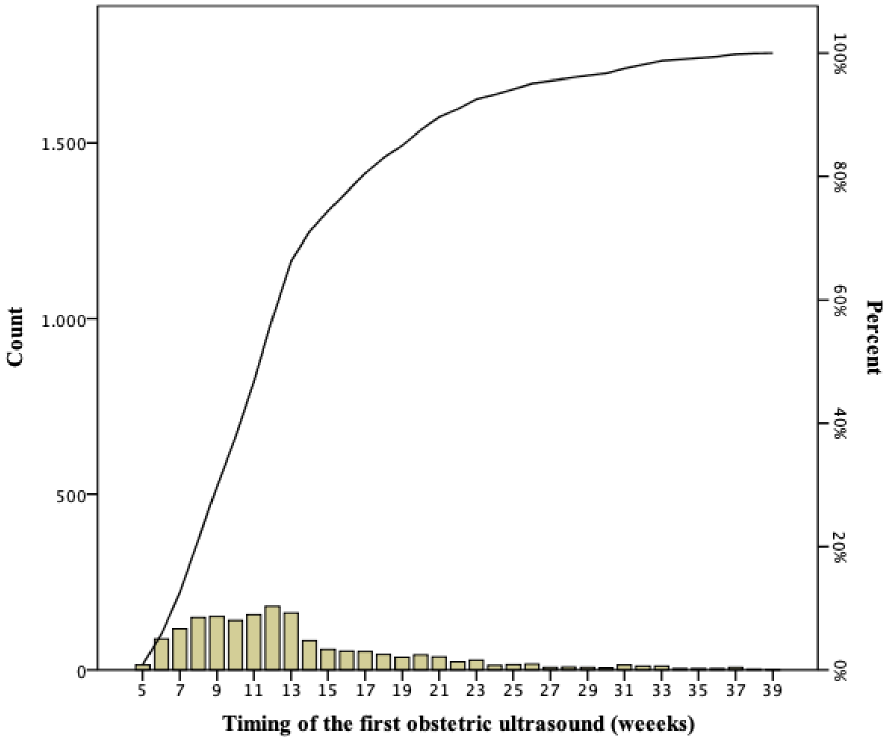
Statistics

Descriptive statistics assessed the variables, depending on data distribution. Quantitative variables were presented as means, SDs, medians, and IQRs. Qualitative variables were presented as absolute values and percentages. The first obstetric ultrasound available was shown using the Pareto chart to overview the moment of GA assessment by ultrasonography in this cohort of childbirths. The quality of GA determination, according to the obstetric ultrasound assessment used to assist the calculation, was associated with the records of labor interventions using the chi-square test, odds ratio (OR) with 95% CI, or the Mann-Whitney statistical analysis. The significance level, adjusted for the hypothesis test, was set at 5%. The statistical program SPSS version 22.0 (IBM Corp, Armonk, NY) was used for analysis.

Results

A substantial proportion of the obstetric histories recorded in the dataset had at least one antenatal ultrasound assessment prior to the hospital admission. The distribution of the first obstetric ultrasound assessment for pregnancy dating is presented in Figure 2.

Figure 2. Pareto chart with the distribution of births according to the first obstetric ultrasound retrieved by clinical histories (n=1695).



Perinatal Characteristics

Table 1 presents the clinical and obstetric characteristics of the cohort, considering valid records. One-third of these newborns (615/2113, 29.11%) were delivered by mothers who received prenatal care at the local unit. The remaining mothers came from city hospitals, referenced to the perinatal center as high-risk pregnancies. Most childbirths were born from a gestation complicated by diseases or by nonspontaneous vaginal delivery. Of the 2113 total samples, there were 2030 (96.07%) live births. In addition, 76 (3.60%) newborns were siblings.

Table 1. Perinatal characteristics of the cohort.

Clinical and obstetrics characteristics	Descriptive statistics	95% CI
Antenatal obstetric ultrasound, n/N (%)	1695/2113 (80.22)	81.9-78.6
Gestation age at the first obstetric ultrasound, median (IQR)	12 (6.29)	11.85-12.14
Maternal-fetal diseases, n/N (%)	1217/2113 (57.60)	55.6-59.7
Hypertensive disorders, n/N (%)	345/2113 (16.33)	14.8-17.9
Major malformations, n/N (%)	228/2113 (10.79)	9.4-12.2
Diabetes, n/N (%)	179/2113 (8.47)	7.3-9.6
Antenatal infections (eg, HIV, syphilis, toxoplasmosis), n/N (%)	123/2113 (5.82)	4.9-6.8
Nonspontaneous vaginal delivery, n/N (%)	1091/2113 (51.63)	48.2-55.6
Oxytocin augmentation, n/N (%)	375/2113 (17.75)	16.1-19.5
Delivery, cesarean section, n/N (%)	828/2113 (39.19)	37.1-41.3
Delivery, vaginal with forceps, n/N (%)	63/2113 (2.98)	2.3-3.7
Maternal blood transfusion after birth, n/N (%)	45/2113 (2.13)	1.6-2.8
Intensive care unit maternal admission, n/N (%)	24/2098 (1.14)	0.7-1.6
Sex[a], male, n/N (%)	1098/2113 (51.96)	50.0-54.1
Live birthweight (g), median (IQR)	3055 (690)	3022.5-3085.0
5-minute Apgar score, median (IQR)	9 (1)	9-9
Neonatal resuscitation[b], n/N (%)	219/2030 (10.79)	9.5-12.2
NICU[c] admissions, n/N (%)	382/2030 (18.82)	17.1-20.4
NICU admissions[d], n/N (%)	271/1885 (14.38)	13.3-16.3
Fetal or newborn mortality[e], n/N (%)	136/2113 (6.44)	5.4-7.6
Fetal or newborn mortality[d,e], n/N (%)	71/1885 (3.77)	2.9-4.7

[a] Undetermined sex: 8 (0.4%).

[b] Received at least one step of neonatal resuscitation [13].

[c] NICU: neonatal intensive care unit.

[d] Excluding major malformations.

[e] During hospital stay, before or after birth.

Perinatal characteristic comparisons between groups of interest are summarized in Table 2. The group of pregnancies with GA <14 weeks had more antenatal diabetes diagnoses, fewer occurrences of maternal blood transfusion after birth, and fewer NICU admissions, excluding newborns with major malformations, in comparison with the suboptimally dated pregnancy group. The group of pregnancies with a GA of 20 weeks or less and the group with a GA less than 14 weeks had fewer occurrences of maternal blood transfusion after birth when compared with the suboptimally dated pregnancy group.

Table 2. Perinatal characteristics according to the quality of gestational age information at birth.

Characteristics	PD[a] with US[b]<14 weeks (N=1163)	PD with US<20 weeks (N=1456)	Suboptimal PD[c] (N=657)	*P* value[d]	*P* value[e]
Maternal-fetal diseases, n (%)	684 (58.81)	843 (57.89)	374 (56.93)	.43[f]	.68[f]
Hypertensive disorders, n (%)	202 (17.38)	243 (16.69)	102 (15.53)	.31[f]	.50[f]
Diabetes, n (%)	116 (9.97)	134 (9.2)	45 (6.85)	.02[f]	.07[f]
Maternal blood transfusion after birth, n (%)	17 (1.46)	25 (1.72)	20 (3.04)	.02[f]	.048[f]
ICU[g] maternal admission, n (%)	12 (1.03)	14 (0.96)	10 (1.52)	.35[f]	.26[f]
5-minute Apgar score, median (IQR)	9 (1)	9 (1)	9 (1)	.64[h]	.47[h]
Live birth weight (g), median (IQR)	3025 (735)	303 (735)	3030 (755)	.79[h]	.70[h]
Major malformations, n (%)	136 (11.69)	162 (11.13)	66 (10.05)	.28[f]	.46[f]
Neonatal resuscitation[i], n (%)	133 (11.44)	162 (11.13)	62 (9.44)	.19[f]	.24[f]
Neonatal resuscitation[i,j], n (%)	100 (9.74)	125 (9.66)	51 (8.63)	.46[f]	.48[f]
NICU[k] admission, n (%)	204 (18.13)	251 (17.85)	131 (20.99)	.15[f]	.095[f]
NICU admission[j], n (%)	133 (13.25)	168 (13.30)	103 (18.07)	.01[f]	.008[f]
Fetal or neonatal mortality, n (%)	70 (6.02)	89 (6.11)	47 (7.15)	.34[f]	.37[f]
Fetal or newborn mortality[j], n (%)	32 (3.12)	43 (3.32)	28 (4.74)	.10[f]	.13[f]

[a] PD: pregnancy dating.

[b] US: ultrasound.

[c] Ultrasound done ≥20 weeks of gestation or not done at all.

[d] Comparison between ultrasound dating <14 weeks and suboptimal dating.

[e] Comparison between ultrasound dating <20 weeks and suboptimal dating.

[f] Chi-square test used.

[g] ICU: intensive care unit.

[h] Mann-Whitney test used.

[i] At least one step of neonatal resuscitation [14].

[j] Excluding major malformations.

[k] NICU: neonatal intensive care unit.

Primary Outcomes

In Table 3, the association between interventions during parturition and the quality of pregnancy dating retrieved at birth is displayed, considering the reference to assist obstetricians in determining GA. Chances of nonspontaneous vaginal delivery were increased by 64% in pregnancies that had the first obstetric ultrasound assessment dating <14 weeks and increased by 58% for ultrasound assessment dating at <20 weeks when compared to the pregnancies with suboptimal dating. Oxytocin augmentation was 41% higher during labor of pregnancies with the first obstetric ultrasound assessment dating <14 weeks and 34% higher for ultrasound assessment dating at <20 weeks in comparison with pregnancies with suboptimal dating. In spite of these results, cesarean section rates and vaginal births with forceps were similar between groups of comparisons.

Table 3. Association between the quality of pregnancy dating retrieved at birth and obstetric interventions in labor.

Obstetric intervention during labor	PD[a] with US[b] <14 weeks (N=1163), n (%)	PD with US<20 weeks (N=1456), n (%)	Suboptimal PD[c] (N=657), n (%)	<14 weeks vs suboptimal dating, OR[d] (95% CI)	*P* value[e]	<20 weeks vs suboptimal dating, OR (95% CI)	*P* value[e]
Nonspontaneous vaginal delivery	652 (56.06)	803 (55.15)	288 (43.84)	1.64 (1.35-1.98)	<.001	1.58 (1.31-1.90)	<.001
Oxytocin augmentation	230 (19.77)	277 (19.03)	98657 (14.92)	1.41 (1.09-1.82)	.01	1.34 (1.04-1.72)	.02
Cesarean section	475 (40.83)	584 (40.11)	244 (37.14)	1.17 (0.96-1.42)	.12	1.13 (0.94-1.37)	.20
Vaginal birth with forceps	42 (3.61)	46 (3.16)	17 (2.59)	0.71 (0.40-1.26)	.24	1.23 (0.69-2.16)	.47

[a] PD: pregnancy dating.

[b] US: ultrasound.

[c] Ultrasound done ≥20 weeks of gestation or not done at all.

[d] OR: odds ratio.

[e] Chi-square test.

Discussion

Main Findings

This study underlines how the quality of GA information is associated with timely obstetric interventions at birth. The main finding was that some aspects in the management of childbirth were significantly distinct according to the available information used to calculate GA at birth. We observed an association between assurances of GA estimates at birth by early ultrasound and nonspontaneous vaginal deliveries, as well as an increased proportion of oxytocin augmentation, without affecting cesarean section rates or the frequency of vaginal delivery with forceps. Higher incidence of neonatal NICU admissions, excluding major fetal malformations, indicated the tendency towards more freedom in NICU admissions when pregnancies were suboptimally dated at birth (Table 2). Moreover, no differences were observed regarding the 5-minute Apgar score or birth weight.

Medical choices and women's parturition preferences are complex, and caregivers try to combine the best practices and available data to achieve the best estimate of GA possible to support clinical decisions [15]. Nonetheless, early ultrasound-based GA is presumed to reduce inductions for postterm pregnancies [6]. Ultrasound examinations are used to confirm the date of the last menstrual period or to assign the due date of birth. However, obtaining adequate references for pregnancy dating remains a challenge in clinical practice and has immediate impact on pregnancy outcomes and direct influence on the accuracy of worldwide prematurity rates, diagnoses of small-for-gestational-age newborns, and perinatal outcomes [5,7,16,17].

Comparison With Prior Work

Previous studies have described the relationship between the reliability of GA and obstetric and neonatal outcomes. Higher risk of maternal death in pregnant women with unreliable vs reliable last menstrual periods (OR 2.0, 95% CI 1.5-2.6) and a higher risk of stillbirth (OR 2.7, 95% CI 1.7-4.3) were reported by Nguyen et al (2000) [5]. Although our analysis did not include maternal death, pregnancies suboptimally dated with ultrasound assessments at more than 20 weeks or without any ultrasound presented a higher frequency of maternal blood transfusion after birth, even with more spontaneous labors. We interpret this association based on the assumption that the timing for appropriate discontinuation of pregnancy was lost in this group, and the severe hemorrhage morbidity, requiring a blood transfusion after birth, could be in part due to unplanned interruptions in risk situations. This outcome deserves more attention considering severe maternal morbidity and maternal near miss concepts [18]. These necessary details are not available in our database for such an analysis; however, this hypothesis deserves future prospective evaluation.

Our results were consistent with previous evidence, showing that different moments of access to ultrasound facilities during prenatal care are associated with perinatal effects [15,17]. However, no difference was found in labor interventions for pregnancies for the first obstetric ultrasound assessment at 20 weeks or earlier of gestation and the subgroup of the first obstetric ultrasound assessment less than 14 weeks when compared with pregnancies suboptimally dated. In the present analysis, both were statistically associated with the same outcome variables. This result corroborated recommendations that a single ultrasound in the second trimester can be used to estimate GA with reasonable accuracy [2,19]. The WHO recently reported that ultrasound exams before 24 weeks of gestation is the gold standard for the estimation of chronology [2]. Moreover, inadequate pregnancy dating is related to limited early access to prenatal care facilities [7], explaining some of the worst obstetric outcomes in such scenarios [15].

Timely and effective care at birth is one of the most challenging aspects of health care worldwide. Undoubtedly, inaccurate GA is an essential topic in low- and middle-income countries [4]. Achieving lower worldwide prematurity rates is one of the goals established in sustainable development to ensure healthy lives and reduce infant mortality [2], a target that requires feasible strategies based on credible pregnancy dating. Part of the issue is due to the inequities of health facilities worldwide [19], insufficient professional training [7], and the lack of governmental commitment to investing in health care systems [20]. Complications during pregnancy and childbirth affect healthy women populations and is dependent on the inequities of health care facilities [21]. Efforts have been joined to compensate imprecise or unknown GA at birth, such as mathematical models derived from a combination of neonatal screening values [22], mixes of antenatal clinical measurements with obstetric ultrasound in any trimester [7], and emerging low-cost technologies for the assessment of neonatal skin maturity [23]. Moreover, electronic medical records that support clinical routines can benefit patients with safe and accessible information when necessary for better health care results [24].

Limitations

Our exploratory study is subject to limitations. The risk of recall bias was low because birth data were collected prospectively. However, outcome variables from antenatal care, such as maternal-fetal diseases, were retrieved from a computerized medical database at birth. Therefore, the precise criteria for diagnoses, such as the frequency of gestational diabetes, recorded from the clinical database at birth in the suboptimally dated pregnancies were unable to be met. The diagnosis of diabetes, mainly when occurring for the first time during pregnancy, depends on the interpretation of the screening test when pregnancy, maternal comorbidities, and differences among detection protocols [25].

Another key point in this aspect is the quality of the ultrasonography. Ultrasound offers clinicians a method to estimate GA with high accuracy and precision. Furthermore, effects of ultrasound pregnancy dating on neonatal morbidity, analyzed by Kullinger et al (2016) [15], shows that early differences in fetal growth do in fact exist, as do differences in gender, showing clinical importance when the gestational length is estimated at birth. At our referral health care unit, 1122/2113 (53.1%) of all recorded births received outpatient antenatal care, calling for public and private attention from both our city or neighboring small towns. We believe that future analyses are still warranted to provide a complete and accurate picture of the impact on labor management.

Finally, this study is based on a referral hospital; therefore, the results may not be generalizable in lower complexity hospitals. One prior Brazilian nationwide sample pointed out a 61.3% coverage of pregnant women by prenatal ultrasound [9]. This reality is even worse in other developing countries [4,7]. Therefore, the comparability of our results is limited by the standards of antenatal obstetric care that were similar to our scenario of study.

Conclusions

A GA of high quality available at birth, assisted by early obstetric ultrasound, was associated with a higher rate of labor interventions for pregnancy interruption, however with lesser maternal blood transfusion and NICU admissions. This study's analysis highlighted relevant points of health care to improve obstetric care and achieve lower maternal and neonatal morbidity at birth, which confirms the importance of early access to technologies for pregnancy dating as an essential component of quality antenatal care.

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Conflicts of Interest

ZR declares a patent deposit of an optoelectronic device to detect gestational age at birth, on behalf of the Universidade Federal de Minas Gerais and Fundação de Amparo a Pesquisa de Minas Gerais public institutions in Brazil. The other authors declare no competing financial interests.

Multimedia Appendix 1
Database.
[PDF File (Adobe PDF File), 690 KB - pediatrics_v3i1e14109_app1.pdf]

References

1. Committee on Obstetric Practice, the American Institute of Ultrasound in Medicine,the Society for Maternal-Fetal Medicine. Committee Opinion No 700: Methods for Estimating the Due Date. Obstet Gynecol 2017 May;129(5):e150-e154. [doi: 10.1097/AOG.0000000000002046] [Medline: 28426621]
2. Lee AC, Blencowe H, Lawn JE. Small babies, big numbers: global estimates of preterm birth. The Lancet Global Health 2019 Jan;7(1):e2-e3. [doi: 10.1016/S2214-109X(18)30484-4]
3. Cantor DE, Macdonald JR. Decision-making in the supply chain: examining problem solving approaches and information availability. Journal of Operations Management 2008 Sep 11;27(3):220-232. [doi: 10.1016/j.jom.2008.09.002]
4. Lee AC, Panchal P, Folger L, Whelan H, Whelan R, Rosner B, et al. Diagnostic accuracy of neonatal assessment for gestational age determination: a systematic review. Pediatrics 2017 Dec;140(6) [FREE Full text] [doi: 10.1542/peds.2017-1423] [Medline: 29150458]

5. Nguyen TH, Larsen T, Engholm G, Møller H. Increased adverse pregnancy outcomes with unreliable last menstruation. Obstet Gynecol 2000 Jun;95(6 Pt 1):867-873. [doi: 10.1016/s0029-7844(99)00639-0] [Medline: 10831983]
6. Butt K, Lim K, Diagnostic Imaging Committee. Determination of gestational age by ultrasound. J Obstet Gynaecol Can 2014 Feb;36(2):171-181. [doi: 10.1016/S1701-2163(15)30664-2] [Medline: 24518917]
7. Karl S, Li Wai Suen CSN, Unger HW, Ome-Kaius M, Mola G, White L, et al. Preterm or not - an evaluation of estimates of gestational age in a cohort of women from Rural Papua New Guinea. PLoS One 2015 May 6;10(5):e0124286 [FREE Full text] [doi: 10.1371/journal.pone.0124286] [Medline: 25945927]
8. Kågesten AE, Tunçalp Ö, Portela A, Ali M, Tran N, Gülmezoglu AM. Programme Reporting Standards (PRS) for improving the reporting of sexual, reproductive, maternal, newborn, child and adolescent health programmes. BMC Med Res Methodol 2017 Aug 03;17(1):117 [FREE Full text] [doi: 10.1186/s12874-017-0384-7] [Medline: 28774287]
9. Pereira APE, Leal MDC, Gama SGND, Domingues RMSM, Schilithz AOC, Bastos MH. Determinação da idade gestacional com base em informações do estudo Nascer no Brasil. Cad. Saúde Pública 2014 Aug;30(suppl 1):S59-S70. [doi: 10.1590/0102-311X00160313]
10. Beck S, Wojdyla D, Say L, Betran AP, Merialdi M, Requejo JH, et al. The worldwide incidence of preterm birth: a systematic review of maternal mortality and morbidity. Bull World Health Organ 2010 Jan;88(1):31-38 [FREE Full text] [doi: 10.2471/BLT.08.062554] [Medline: 20428351]
11. Macfarlane AJ, Blondel B, Mohangoo AD, Cuttini M, Nijhuis J, Novak Z, Euro-Peristat Scientific Committee. Wide differences in mode of delivery within Europe: risk-stratified analyses of aggregated routine data from the Euro-Peristat study. BJOG 2016 Mar;123(4):559-568 [FREE Full text] [doi: 10.1111/1471-0528.13284] [Medline: 25753683]
12. Gaspar J, Chagas J, Osanan G, Cruz-Correa R, Reis Z. Maternal and neonatal healthcare information system: development of an obstetric electronic health record and healthcare indicators dashboard. In: Lecture Notes in Computer Science. Berlin: Springer; 2013 Presented at: International Conference on Information Technology in Bio- and Medical Informatics; August 28 2013; Prague p. 62-76. [doi: 10.1007/978-3-642-40093-3_5]
13. Perlman JM, Wyllie J, Kattwinkel J, Wyckoff MH, Aziz K, Guinsburg R, Neonatal Resuscitation Chapter Collaborators. Part 7: neonatal resuscitation: 2015 international consensus on cardiopulmonary resuscitation and emergency cardiovascular care science with treatment recommendations. Circulation 2015 Oct 20;132(16 Suppl 1):S204-S241. [doi: 10.1161/CIR.0000000000000276] [Medline: 26472855]
14. Diniz D, Vélez ACG. Aborto na Suprema Corte: o caso da anencefalia no Brasil. Rev Estud Fem 2008 Aug;16(2):647-652. [doi: 10.1590/S0104-026X2008000200019]
15. Kullinger M, Haglund B, Kieler H, Skalkidou A. Effects of ultrasound pregnancy dating on neonatal morbidity in late preterm and early term male infants: a register-based cohort study. BMC Pregnancy Childbirth 2016 Oct 31;16(1):335 [FREE Full text] [doi: 10.1186/s12884-016-1129-z] [Medline: 27799069]
16. Ananth CV. Menstrual versus clinical estimate of gestational age dating in the United States: temporal trends and variability in indices of perinatal outcomes. Paediatr Perinat Epidemiol 2007 Sep;21 Suppl 2:22-30. [doi: 10.1111/j.1365-3016.2007.00858.x] [Medline: 17803615]
17. Morin I, Morin L, Zhang X, Platt RW, Blondel B, Bréart G, et al. Determinants and consequences of discrepancies in menstrual and ultrasonographic gestational age estimates. BJOG 2005 Feb;112(2):145-152 [FREE Full text] [doi: 10.1111/j.1471-0528.2004.00311.x] [Medline: 15663577]
18. Pattinson R, Say L, Souza JP, Broek NVD, Rooney C. WHO maternal death and near-miss classifications. Bull World Health Organ 2009 Oct;87(10):734 [FREE Full text] [doi: 10.2471/blt.09.071001] [Medline: 19876533]
19. Papageorghiou AT, Kemp B, Stones W, Ohuma EO, Kennedy SH, Purwar M, et al. Ultrasound-based gestational-age estimation in late pregnancy. Ultrasound Obstet Gynecol 2016 Dec;48(6):719-726 [FREE Full text] [doi: 10.1002/uog.15894] [Medline: 26924421]
20. Reddy KS, Patel V, Jha P, Paul VK, Kumar AS, Dandona L. Towards achievement of universal health care in India by 2020: a call to action. The Lancet 2011 Feb;377(9767):760-768. [doi: 10.1016/s0140-6736(10)61960-5]
21. Graham W, Woodd S, Byass P, Filippi V, Gon G, Virgo S, et al. Diversity and divergence: the dynamic burden of poor maternal health. The Lancet 2016 Oct;388(10056):2164-2175. [doi: 10.1016/S0140-6736(16)31533-1]
22. Wilson K, Hawken S, Potter BK, Chakraborty P, Walker M, Ducharme R, et al. Accurate prediction of gestational age using newborn screening analyte data. Am J Obstet Gynecol 2016 Apr;214(4):513.e1-513.e9 [FREE Full text] [doi: 10.1016/j.ajog.2015.10.017] [Medline: 26519781]
23. Reis ZSN, Vitral GLN, de Souza IMF, Rego MAS, Guimaraes RN. Newborn skin reflection: proof of concept for a new approach for predicting gestational age at birth. A cross-sectional study. PLoS One 2017;12(9):e0184734 [FREE Full text] [doi: 10.1371/journal.pone.0184734] [Medline: 28931040]
24. Reis ZSN, Maia TA, Marcolino MS, Becerra-Posada F, Novillo-Ortiz D, Ribeiro ALP. Is there evidence of cost benefits of electronic medical records, standards, or interoperability in hospital information systems? Overview of systematic reviews. JMIR Med Inform 2017 Aug 29;5(3):e26 [FREE Full text] [doi: 10.2196/medinform.7400] [Medline: 28851681]
25. Lavery JA, Friedman AM, Keyes KM, Wright JD, Ananth CV. Gestational diabetes in the United States: temporal changes in prevalence rates between 1979 and 2010. BJOG 2017 Apr;124(5):804-813 [FREE Full text] [doi: 10.1111/1471-0528.14236] [Medline: 27510598]

Abbreviations

GA: gestational age
IQR: interquartile range
NICU: neonatal intensive care unit
OR: odds ratio
WHO: World Health Organization

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Original Paper

A Web-Based Intervention for Youth With Physical Disabilities: Comparing the Role of Mentors in 12- and 4-Week Formats

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Abstract

Background: Youths with physical disabilities face many barriers in society, including social exclusion, stigma, and difficulties finding employment. Electronic mentoring (e-mentoring) offers a promising opportunity for youths with disabilities and has the potential to improve their inclusion while enhancing career outcomes. However, little is known about the role of mentors in a Web-based e-mentoring format to improve employment outcomes.

Objective: This study aimed to explore the role of mentors in engaging youths in an e-mentoring intervention and to compare and contrast mentors' engagement strategies within a 12- and 4-week format.

Methods: This paper drew on a pilot feasibility study, which is a group, Web-based employment readiness intervention involving a discussion forum for youths with physical disabilities. Our intervention involved having trained youth mentors (ie, near-peers who also had a disability) lead Web-based discussion forums while offering peer support and resources, which involved 12 modules completed over both a 12- or 4-week format. We used a mixed method approach including qualitative data (mentor interviews and discussion forum data) and quantitative data (pre-post survey data) comparison.

Results: A total of 24 youths participated across 3 e-mentoring intervention groups: 9 in the 12-week format (mean age 17.7 years [SD 1.7]) and 15 in the 4-week format (mean age 19.5 years [SD 2.6]), led by 3 trained youth mentors with disabilities, 2 males and 1 female (mean age 22 years [SD 2.64]). Our findings revealed that mentors engaged youths in the e-mentoring program by providing informational, emotional, and tangible support. We noted more instances of mentors providing advice, empathy, and encouragement in the 12-week format compared with the 4-week format. We also found fewer examples of providing advice, developing a rapport, and social support from mentors in the 4-week format. Our findings revealed no significant differences between the 2 groups regarding time spent in the forum, number of logins, number of posts, and self-rated engagement.

Conclusions: Mentors in the 12-week and 4-week format engaged participants differently in providing informational and emotional support, although there were no differences in tangible support provided. Mentors reported that the 12-week format was too long and lacked interaction between participants, whereas the 4-week format felt rushed and had fewer detailed responses from mentees.

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KEYWORDS

social support; mentor; youth; adolescent; employment

Introduction

Background

Youths with disabilities are at risk of living below the poverty line and having poor developmental outcomes [1-5]. They often experience social exclusion and isolation and encounter challenges of being fully included within society. The hurdles that youths encounter are often a result of their social (eg, stigma and discrimination) and physical (eg, inaccessible spaces) environments [6,7]. Approximately 4.4% of youths aged 15 to 24 years in Canada have a disability [8] (defined as impairments, activity limitations, and participation restrictions) [9], and 1% of these youths have a physical disability. Therefore, it is critical to find ways to enhance their inclusion. Focusing on youths with physical disabilities is important because they are considered a vulnerable population with unique social and vocational needs [10]. Youths with physical disabilities often experience different challenges than youths with chronic illnesses, because their condition is often visible and they may face difficulties with mobility, speech, stigma, coping, and social exclusion [6,10,11]. Furthermore, they often experience periods of developmental, emotional, and social changes, which differ from other youths [12-14].

One encouraging approach to improving the inclusion of underrepresented groups, such as youths with disabilities, is through peer mentoring [15]. A mentor is someone who acts as a role model and shares experiences while supporting a protégé in their development [16-18]. Peer mentoring refers to those of similar age who share experiential knowledge and lived experiences as a mechanism for promoting positive outcomes [19]. Peer mentors can offer tangible, informational, and emotional support for youths [20,21]. Mentors typically perform 3 main functions: vocational or instrumental support, psychological support through counseling, friendship, and encouragement [22-26]. Such traits are often linked with positive mentor-related outcomes [27-29]. For example, among youths without disabilities, there is a strong empirical basis showing the effectiveness of mentoring on improved self-efficacy, quality of life, and employment [17,24,30-32]. Mentoring targeted toward a specific achievement or goal is referred to as instrumental mentoring [33]. For instance, mentoring is an important component of career development [34], whereby those who are mentored have better opportunities for advancement, make higher salaries, and report higher career satisfaction [35].

Research on youths with disabilities indicates that mentoring can have beneficial impacts on the development of educational, employment, social skills and on self-esteem [2,30,36-38]. A recent systematic review on disability and mentoring found that mentoring led to improvements in knowledge of employment services and support [39,40] and knowledge of employment preparation [39-41] and employment outcomes [42]. For example, Kolakowsky-Hayner et al [43] had a group-based mentoring program to help youths with acquired brain or spinal cord injury to return to work and school. They found their program helped the youths achieve educational goals [43].

Most studies in this area focus on traditional face-to-face mentoring in a one-to-one or group-based format [17]. Despite the potential benefits of mentoring for youths with disabilities, they may encounter challenges in accessing mentors in person because of geographical or other barriers and limited mobility [17,44]. Therefore, Web-based formats may offer a viable alternative, helping to address some of these limitations.

Electronic mentoring (e-mentoring; ie, computer mediated) is a newer format of mentoring [45] helping to meet the needs of underserved populations, such as youths with disabilities [17,46,47]. Mentoring models have evolved considerably since the original face-to-face relationships [48] toward Web-based relations that are sustained primarily through electronic means [45] and multiple mentoring with 1 protégé having multiple sequential mentoring relations [49].

E-mentoring offers opportunities that are not seen in face-to-face mentoring, such as creating written text, practicing communication skills, and developing relationships without barriers of time and distance [22], along with immediate access to mentors [50]. There is also a chance to be mentored by several people from varying backgrounds [34]. Furthermore, the anonymity of electronic formats can provide a degree of privacy that is not always possible with face-to-face mentors [34]. E-mentoring relationships have the potential to generate a sense of belonging and autonomy, satisfaction, fulfillment, and potential friendships [51]. Some studies highlight that electronic mentors (e-mentors) can help to enhance employment and career-related outcomes. For example, in a Web-based mentoring program for youths with vision impairments, Bell [36] found a significant increase in efficacy to make career-related decisions compared with the beginning of the program. Similarly, Kim-Rupnow and Burgstahler [41] had a community Web-based mentoring program for youths with disabilities and found a significant improvement in knowledge of career options. Other research on mentoring for youths with disabilities to enhance employment or academic outcomes has used face-to-face formats [17,39,42,43]. Little is known about the role of mentors in a Web-based format aiming to improve employment skills.

Rationale

This study addressed several important gaps in the literature. First, there is an underrepresentation of youths with disabilities in mentoring [17], especially where mentors have a disability themselves. Most studies focus on mentors without disabilities. Having youths with a disability who mentor other youths may be valuable, given they have shared lived experiences [15,52]. Second, little is known about the role of e-mentoring for youths with physical disabilities, especially in the context of employment preparation. Third, our study is novel because it compares 2 different lengths (ie, 12 and 4 weeks) of the same mentoring intervention (see studies by Lindsay et al [53-55] for the full description).

Methods

Objectives

The objectives of this study were (1) to explore the role of mentors in engaging youths in an e-mentoring employment preparation intervention for youths with physical disabilities and (2) to compare and contrast mentors' experience and engagement strategies and level of engagement within a 12- and 4-week format.

Design

This paper drew on a feasibility, embedded, qualitative pilot randomized controlled trial design [56], assessing a group, Web-based employment readiness intervention (*Empowering youth towards employment*) involving a discussion forum for youths with physical disabilities [10]. This intervention included (1) experimental groups receiving employment preparation Web-based modules and a peer e-mentor and (2) control groups receiving the Web modules only (with no mentor) but could interact with other participants within their group [10]. The intervention consisted of 12 modules on employment preparation [10]. The discussion forums were hosted on a youth- and disability-friendly website (*Ability Online*, by using Web-hosting *Drupal* platform analytics) through a unique link that only participants could access (for a full description, see the study by Lindsay et al [10]). For this paper, we focused only on the 3 experimental groups that received the intervention with 2 youth mentors (see Multimedia Appendix 1).

12- Versus 4-Week Format

From the 3 experimental groups, the first group ran for 12 weeks, whereas the following 2 groups were condensed to a 4-week format, which we adjusted based on participant feedback [53]. Group 1 included a 12-week long program, which consisted of 1 topic per week. Participants in the 4-week intervention (groups 2 and 3) received the same topics and information, but 3 topics were posted per week for 4 weeks. Mentors divided the discussion topics in half between them, with each mentor posting 6 of the 12 topics, which allowed participants to get to know both mentors equally (see Multimedia Appendix 1).

Mentor Training

All mentors completed mentor training (ie, hospital-based youth peer mentor training program and project-specific training), received research ethics training, and had employment experience at the time of the intervention. Mentors were trained on how to use the *Ability Online* platform, and they had to introduce the topics in the same order. They were trained to respond to participant's comments in a similar manner, providing information, appraisal, and emotional support (eg, active listening, perspective taking, maintaining boundaries, positive modeling, trust building, interactive training, and mentoring) [10]. A research coordinator and project director supervised the mentors.

Procedures

We received institutional research ethics board approval. Eligible participants received an information letter and a phone call from the researchers who screened all participants and obtained informed written consent before enrolling them in the intervention. Once participants consented, they were randomized into an experimental or control group of up to 10 participants in each group [10]. Following that, a researcher contacted participants to inform them of their group assignment and instruct them on the procedures to be followed, including a presurvey and registering for the Web-based discussion forum.

Recruitment and Participants

Participants were recruited in the summer months from June 2016 to August 2018 through invitation letters sent from a pediatric hospital and advertisements. Inclusion criteria were as follows: (1) able to read and write in English, (2) aged 15 to 25 years, (3) have access to a computing device with internet access; (4) currently enrolled in or recently completed a high school diploma in the applied or academic stream (ie, university- or college-bound students), (5) have no paid work experience, and (6) youths with a physical disability [10]. Youths who were thought to meet the inclusion criteria were sent an invitation letter from our hospital database. Our rationale for this age group and for choosing youths without employment experience is that youths with disabilities often start their first job later than youths without disabilities [10]. Exclusion criteria involved those who recently completed or who are currently participating in another employment preparation or peer support intervention.

Data Collection

Mentor Interview Data

A researcher conducted semistructured interviews with each mentor after the completion of forums for each group (from October 2016 to September 2018). There were 6 interviews conducted in total. Questions asked were about what mentors liked most and least from the intervention, how engaged the participants were, and how engaged they were in the group (for interview guide, see Multimedia Appendix 2).

Discussion Forum Data

We drew on the discussion forums for each group, which consisted of 12 topics. Mentors posted an introduction to each topic with information and examples from their personal experiences and a series of discussion questions for the mentees to respond to. Mentees replied to the discussion questions and shared their experiences, which mentors replied to individually. We also analyzed quantitative data from the discussion forums, including the number of logins, number of posts per participant, and total time logged in to the discussion forum.

Pre-Post Survey Data

We drew on quantitative data from the pre-post surveys to compare and contrast differences between those in the 4-week and 12-week groups. Surveys were sent out to all participants via email. All 25 participants completed the presurvey, and 19 participants completed the postsurvey (9 in group 1, 5 in group 2, and 5 in group 3). Of 25 participants, 6 did not complete the survey either because of losing interest in the program or because they could not be reached by the research team for follow-up. We analyzed the following 2 variables: self-rated level of engagement and whether participants would recommend the program to others.

Data Analysis

Mentor Interviews

Mentor interview data were audio recorded, transcribed verbatim, and anonymized and checked for accuracy. The semistructured interviews with mentors were analyzed using a qualitative thematic analysis [57]. With the research question in mind, the interview transcripts were analyzed by both authors independently. Then, a sample transcript was independently read and coded by each individual. Codes were categorized by types of social support given (eg, informational, emotional, and tangible). Codes were collated into larger categories (ie, themes). After this, we met to compare and contrast codes and arrived at consensus to create a final codebook, which were applied to all transcripts using NVivo. We kept an audit trail, documenting all decisions and discrepancies noted throughout the coding and analysis process. The codebook was then used to further analyze transcripts and extract quotes representative of the themes and subthemes of the results.

Discussion Forum Data Analysis

We downloaded the discussion forum data from the host website, stored as a password-protected document, and entered them into NVivo 10 and analyzed them using qualitative thematic analysis. We chose this approach because of its flexibility to analyze a variety of data types and sample sizes [58]. This method is useful when analyzing semistructured interviews and large discussion forum data, where we had 24 unique participants, 3 mentors, and 162 pages of data. We organized and coded the initial dataset using an open coding, iterative approach, which was informed by our research question. Both authors read a sample of the discussion forum transcripts and coded them independently and later met to discuss codes until we reached a final consensus with the coding scheme. The codes were then applied to the entirety of the dataset, where they were categorized into themes and subthemes.

Qualitative Comparison

After forum transcripts and interviews were coded once in entirety, they were compared and contrasted again using a constant qualitative comparative method to analyze differences within and between the 12- and 4-week intervention groups [59]. We developed a thematic comparison table to help analyze what themes were present in each comparison group (see Multimedia Appendix 3), and representative quotes were abstracted of the themes analyzed within and across groups.

Survey Data

Data from the surveys were analyzed using descriptive statistics and *t* tests by using SPSS version 25 to explore differences between the 12- and 4-week format. Forum usage was tracked using the Drupal software built into the Web hosting platform (eg, time spent in the forum was measured as total overall time on the website in hours, number of log-ins, and number of posts). Self-rated engagement was measured on a 10-point scale (1=low engagement and 10=high engagement). Recommendation of the program to others was a dichotomous variable (1=yes and 0=no).

Results

Sample Characteristics

We first outlined the sample characteristics followed by differences between groups with regard to time spent in the forum, number of posts, and self-rated engagement. Then, we explored how mentors engaged youths within the discussion forum.

Our sample consisted of 27 participants: 24 mentees and 3 youth mentors. We had 9 participants in the 12-week format (mean age 17.7 years; 5/9, 55% females) and 15 participants in the 4-week format (mean age 19.5 years, 9/15, 60% females). They had various physical disabilities, including cerebral palsy, muscular dystrophy, Charcot-Marie tooth disease, and spina bifida (see Table 1).

Table 1. Mentee and mentor demographics.

Demographics	Participants		Mentors (n=3)
	12 weeks (n=9)	4 weeks (n=15)	
Age (years), mean (SD)	17.7 (1.7)	19.5 (2.6)	22 (2.64)
Sex, n (%)			
Male	4 (44)	6 (40)	2 (67)
Female	5 (56)	9 (60)	1 (33)
Disability type, n (%)			
Cerebral palsy	4 (44)	7 (47)	2 (67)
Duchenne muscular dystrophy and neuromuscular	5 (56)	3 (20)	0 (0)
Spina bifida	0 (0)	2 (13)	0 (0)
Other physical disabilities	0 (0)	3 (20)	1 (33)
Group, n (%)			
1	9 (100)	0 (0)	2 (67)
2	0 (0)	7 (47)	2 (67)
3	0 (0)	8 (53)	2 (67)

Mentors included 2 males and 1 female with a disability, aged between 19 and 25 years. Each mentored group had 2 mentors (1 male and 1 female), who alternated posting topics. Mentor 1 was a female, aged 20 years, who was enrolled in postsecondary education at the time of the intervention and participated in all 3 groups. Mentor 2 was a male, aged 19 years, who was enrolled in postsecondary education, who mentored groups 1 and 2, but was unable to continue on as a mentor for the last group. Therefore, mentor 3 was introduced in group 3 and included a male, aged 25 years, who completed postsecondary education.

How Mentors Engaged Youths Within the Discussion Forum

Throughout the e-mentoring intervention, youth mentors used several strategies to engage participants and encourage interaction within the discussion forums. We explored strategies that mentors commonly used (ie, informational, emotional, and tangible support) and to what extent they varied between the 12- and 4-week formats.

Our findings showed the type of informational support in the 12-week format (ie, employment, postsecondary, and volunteering) included a greater breadth of topics than the 4-week format (ie, employment; see Multimedia Appendix 3). There were more examples of providing advice in the 12-week group compared with the 4-week format. Meanwhile, emotional support in the 12-week format involved more examples of empathy and understanding, whereas the 4-week format involved offering encouragement. There were no differences in the types of tangible support provided to participants across the 2 formats. Finally, we have outlined the differences in the mentor’s experience in the 12- and 4-week groups.

Informational Support

Mentors provided informational support, which included providing resources for employment-related issues, offering advice, and researching a specific topic for mentees (see Multimedia Appendix 3). All mentors provided informational support in both the 12- and 4-week format; however, the content differed between groups, with mentors providing additional support on employment, postsecondary education, transportation, and volunteering in the 12-week intervention group, whereas only providing additional employment-related support in the 4-week intervention group. We found more instances of providing advice and longer posts in the 12-week format compared with the 4-week format.

In the 4-week format, mentors provided informational support to youths in the form of employment tips and resources, in response to mostly work-related questions and concerns from youths. Although all youth mentors provided informational support, mentors in the 12-week format provided support on multiple topics, whereas the informational support in the 4-week format focused mainly on employment-related topics.

When comparing how mentors provided advice in both the 12- and 4-week formats, mentors gave longer and more detailed advice to mentees in the 12-week format (longer and with more information) compared with the 4-week format. Alternatively, advice given in the 4-week format typically included 1 or 2 sentences and contained less information. The discrepancy in advice given between groups was mentioned in a postintervention interview, where mentor 1 shared why she did not need to provide as much information in the 4-week format:

> *Mentees were saying a lot of the right things; So, I really didn't have too much else to add, other than one girl who didn't know what networking was; So, I explained that to her. I felt like it wasn't really too in-depth, because this group seemed like they knew what they wanted.* [Mentor 1, Group 3]

Our results indicate that the types of social support and advice shared by mentees differed between the 12- and 4-week formats. The ways in which it differed included more types of information shared with mentees in the 12-week group (ie, employment, postsecondary, and volunteering) and more instances of providing advice to mentees in the 12-week intervention group. Meanwhile, only employment-related information was shared in the 4-week format, and posts providing advice were shorter.

Emotional Support

Mentors provided emotional support, which involved encouragement, being vulnerable, and showing empathy to mentees. We noticed differences in the type of emotional support provided by mentors in the 12- and 4-week format. For example, mentors in the 12-week group provided more empathetic and understanding support to mentees while displaying vulnerability. Meanwhile, emotional support in the 4-week group comprised encouragement to mentees and focusing on solutions. Another difference included that although all 3 mentors provided emotional support, in both the 12-week and 4-week format, the female (mentor 1) provided the most variety and instances of emotional support to all mentees.

The instances of emotional support observed in the 4-week intervention group used encouragement rather than empathy. For example, mentor 3 stated:

> *That's amazing! You've really molded yourself some amazing experiences that will help your future goals. These are all amazing things to put on your resume.* [Mentor 3, Group 3, 4-week format]

The emotional support in the 4-week format reinforced the youth’s accomplishments and encouraged them to not give up on their goals. Another type of emotional support in the 12-week format included mentors showing vulnerability with mentees. In the 4-week format, mentors shared their challenges but focused on sharing solutions with mentees.

Mentors provided emotional support in the discussion forums to engage participants, although the methods differed in the 12- and 4-week formats, such as showing empathy, understanding, and vulnerability in the 12-week format and offering encouragement and solutions in the 4-week intervention groups. It is important to note that the female mentor offered more emotional support to mentees (of both genders) than male mentors.

Tangible Support

Mentors provided tangible support, which included offering solutions and additional support. One strategy involved mentors offering an alternative solution to mentees when they may not agree with them (see Multimedia Appendix 3). These occurrences were infrequent but appeared in both the 12-week and 4-week format. Mentor 1 used this strategy only in the 4-week format, whereas mentor 2 provided alternative solutions in both the 12- and 4-week format, and mentor 3 did not use this strategy at all. In particular, on the topic of managing one’s disability in the workplace, a male mentee in group 2 discussed their opinion of *keeping it to themselves* if they were discriminated against in the workplace. Mentor 2 responded:

> *I agree with most of what you said [but] I’m not sure I would handle discrimination in the workplace in the same way...Hopefully, you will never run into these situations, but not reporting them could have negative long-term effects.* [Mentor 2, Group 2, 4-week format]

In this instance, the mentor described that the situation could potentially result negatively and offered an alternative solution to the mentee on how to deal with it.

Another way mentors provided tangible support (in both the 12- and 4-week format) included offering additional help or support to mentees either through a follow-up post or private message. For instance, mentor 1 commonly used this technique. Mentor 2 offered additional support to mentees on occasion. For example:

> *If you have a question you would like to be answered in private or if you would just like to chat, feel free to send Mentor 1 or message.* [Mentor 2, Group 2, 4-week format]

We found no differences in tangible support provided within the 12- and 4-week intervention groups. Tangible support included offering solutions and additional help to mentees, although there were inconsistencies in using this strategy between mentors.

Mentor Experience

Lack of Participation and Engagement

All mentors experienced challenges with engaging participants and shared disappointment in their expectation of the level of engagement (see Multimedia Appendix 4). This theme was evident in the 4-week postintervention interviews and briefly mentioned by mentors in the 12-week program. For example, Mentor 2 expressed:

> *I didn't really get to talk to (participants) as much as I thought I would originally because you encourage people to private message you and reach out, but most of them didn’t.* [Mentor 2, Group 1]

In the 4-week intervention groups, mentors expressed more concern over a lack of engagement despite their efforts. For example, Mentor 3 noted:

> *There was definitely a lack of participation. I tried to facilitate as much conversation back and forth as I could but it was still a lot of one note answers, and I just don’t think there was much across the board engagement.* [Mentor 3, Group 3]

Another concern with the participation in the 4-week intervention group involved the length and detail of posts from the mentees. Mentor 1 shared:

> *The way mentees were answering questions was a bit concerning because they were very quick and wouldn’t elaborate…I would ask them, what’s difficult about finding work? They would say: well my disability has limited me but they wouldn't elaborate.* [Mentor 1, Group 2]

Overall, mentors perceived lower than expected mentee engagement, but particularly in the 4-week intervention groups, where mentees’ posts were brief and less detailed.

Length of the Intervention

The length of the program was another issue that mentors reported affected participation and the quality of mentee posts. In the 12-week format (ie, 1 topic a week), mentors expressed concerns with the program being too long for participants, stating:

> *I would see a few people participate less as we progressed through the week, so they weren't able to get as much out of the program as I would have liked them to because it was such a long commitment.* [Mentor 1, Group 1]

Mentors discussed how the 12-week format affected their own engagement. To illustrate:

> *My motivations started to dip a tiny bit near the 11 and 12th week just because I wasn't getting as much feedback from the participants as (I did) initially.* [Mentor 1, Group 1]

On the basis of feedback from the 12-week intervention group, we amended it to a 4-week format with 3 topics a week. One of the benefits of the 4-week program included:

> *It's a shorter time commitment…and you still get the same amount of material but in a shorter amount of time.* [Mentor 1, Group 2]

Some criticisms of the 4-week program length included not having enough time to elaborate on topics and less interaction.

Mentors highlighted the benefits and limitations of the 12- and 4-week intervention, with an overall consensus that the 12-week format was prone to drop off in participant engagement but had more in-depth responses. Meanwhile, the 4-week format involved a more efficient time commitment for mentees yet felt rushed for mentors and did not allow time for meaningful interactions.

Levels of Engagement

Drawing on our pre- and postsurvey, we found no significant differences between the 2 groups regarding time spent in the Web forum (in the intervention), number of log-ins, number of posts, self-rated engagement, or whether they would recommend the program to others (see Table 2). Despite the lack of significance, there were notable trends where although the 12-week group logged in more often on average, the 4-week group spent more time on the project website. Participants in the 4-week group had a slightly higher self-rated engagement, and all of them recommended the program to others.

Table 2. Differences between 12- and 4-week formats (*t* tests).

Variables	12-week group, mean (SD)	4-week group, mean (SD)	*t* test (df)	*P* value
Time spent on the website (hours)	1.10 (1.30)	4.51 (5.68)	−1.65 (23)	.11
Number of log-ins	34.33 (59.00)	5.40 (5.98)	1.91 (23)	.07
Number of posts and messages	6.77 (6.49)	6.40 (6.25)	0.14 (23)	.89
Self-rated engagement	5.22 (2.48)	6.50 (2.41)	0.27 (23)	.22
Recommend program to others	0.89 (0.33)	1.00 (0.0)	0.03 (23)	.41

Discussion

Principal Findings

Youths with disabilities are a vulnerable population with an increased risk of social exclusion and, therefore, could benefit from mentoring [60]. Peer mentoring could help youths with disabilities to build social networks while improving academic and employment outcomes [10]. Our study addressed an important gap in the literature by exploring how mentors engage youths in an e-mentoring program while also comparing 2 different formats of the same intervention. Exploring this is important because a recent review highlighted that further work should explore what delivery formats work best [17,60].

Our findings reveal that mentors engaged youths in the e-mentoring program by providing informational, emotional, and tangible support. We noted more instances of mentors providing advice, empathy, and encouragement in the 12-week format compared with the 4-week format. We found fewer examples of providing advice, developing rapport, and social support from mentors in the 4-week format. It was interesting to note that we did not find significant differences between the 2 groups regarding the time spent in the Web forum, number of logins, number of posts, and self-rated engagement. The self-rated engagement of participants was lower than expected and lower than other mentoring studies; however, these studies used a different format (ie, Skype) [61]. The lower engagement in our study could be linked with the asynchronous nature of our forum and participants perhaps wanting more live interaction. Future studies should consider building in activities to help increase engagement [39,62].

Our results highlight that mentors experienced challenges with engaging participants, particularly in the 4-week format. These findings are consistent with other face-to-face and e-mentoring studies, showing that mentors had difficulties engaging youths and developing a rapport [47,62]. Other research similarly indicates that mentors play an essential role in engaging participants in a program [60]. Achieving successful outcomes through a mentoring relationship depends on the quality of the relationship [15]. Key components of peer mentor interventions include trained mentors, monitored implementation, structured activities, routine contact, and parental support [24,41,63,64]. A study by Cohen and Light [65] reports that the frequency and length of communications between mentors and mentees might be influenced by the availability of mentors and the quality of the match.

Our results revealed that the 12-week format seemed too long for mentors, whereas the 4-week format felt too rushed. Future studies should consider balancing mentors' schedules along with the time it takes to develop a good rapport with mentees. The examples of advice provided by mentors in the 12-week format may have resulted from them having more time to elaborate on posts compared with the 4-week format where 3 topics were posted per week. Other research reports that the strength of communication between mentors can impact mentoring [37,60]. Indeed, it often takes time to develop a rapport with mentees.

Other e-mentoring studies reveal quite a range in the length of interventions from 4 to 24 weeks [66]. Both short- and long-term outcomes showed positive outcomes for youths with disabilities. It remains unclear which mentoring formats work best for youths with disabilities. Further work is needed to explore this in detail.

With regard to mediating factors and, specifically, gender of the mentors, our results indicated that our female mentor provided more emotional support than the male mentors, although one of the male mentors provided more informational support to mentees. This finding is consistent with a study from Allen and Eby [67], where female mentors were more likely to provide psychosocial support and males provided more career-related mentoring to mentees. These authors suggest that it is important to cultivate mentorship relationships with mentors of different genders to gain the most from mentoring [67], which supports our model of having a male and female mentor run the program together.

Other research indicates that in same-gender mentor relationships, the pairs are more likely to identify with each other, be more comfortable, and communicative [68]. For example, Ryan et al [69] found that in mentoring relationships with youths with developmental disabilities, the strongest connections included dyads where the mentee and peer mentor were the same gender. Ryan et al [69] also found that female mentees were more frequently in relationships with stronger connections as determined by mentor and mentee engagement and enthusiasm [69]. Further research should explore how a mentor's gender might influence the mentee's experience within a group-based environment.

Limitations

It is important to highlight the limitations of our study. First, the data were drawn from a pilot feasibility study, which was collected from 1 site and had only 3 mentors and, therefore, may have limited generalizability. Second, there were several technical difficulties with the website over the course of the study (ie, difficulties logging in and glitches because of website upgrades) that may have impacted mentee engagement. Third, mentors may have felt rushed in responding to mentees, given their schedules and involvement in school and other activities. Fourth, there was staff turnover in mentors leading the discussion forum; however, they were provided the same training and had a similar level of experience; this could have affected outcomes. Fifth, we only had access to the total overall time that participants spent on the website and not daily or weekly averages. It would be important for future research to include this to test for any differences over time. Finally, there is a potential threat to validity, given that the 12-week program was delivered first followed by 2 implementations of the 4-week program. It is possible that mentors provided less information or shorter responses either because of boredom or forgetting their training.

Future Directions

Future studies should consider exploring whether the timing of the year running the intervention (eg, summer months vs during the school year) affects the level of engagement in the mentoring program. It may be worthwhile for future research to compare and contrast peer versus professional mentors and explore any differences in the types of support provided by mentors. Other studies on e-mentoring for youths with disabilities involve email, virtual environments, *Skype* video calls, and phone calls [66]. A recent review of e-mentoring for youths with disabilities found that the majority of studies involved one-to-one mentoring and some had a combination of both one-to-one and group-based mentoring [66]. Thus, future studies should consider offering more than 1 approach to maximize youth engagement.

Conclusions

Our study explored the role of mentors engaging youths with disabilities in an e-mentoring employment intervention. We also compared and contrasted mentors' engagement strategies within a 12- and 4-week format. Our findings showed that mentors in the 12- and 4-week format engaged participants differently in providing informational and emotional support, although there were no differences in tangible support provided. Mentors reported the 12-week format was too long and lacked interaction between participants, whereas the 4-week format felt rushed and had fewer detailed responses from mentees. Further research should explore which mentoring formats work best for engaging youths with disabilities.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Format of 12- and 4-week mentoring intervention.
[DOCX File , 16 KB - pediatrics_v3i1e15813_app1.docx]

Multimedia Appendix 2
Mentor interview guide.
[DOCX File , 16 KB - pediatrics_v3i1e15813_app2.docx]

Multimedia Appendix 3
Types of mentor support within the discussion forum.
[DOCX File , 18 KB - pediatrics_v3i1e15813_app3.docx]

Multimedia Appendix 4
Mentor experience with the program.
[DOCX File , 17 KB - pediatrics_v3i1e15813_app4.docx]

References

1. UNICEF. The State of the World’s Children 2013: Children with Disabilities. New York: UNICEF; 2013.
2. DuBois DL, Karcher M. Handbook of Youth Mentoring. Thousand Oaks, CA: Sage; 2014.
3. Lindsay S, McDougall C, Sanford R, Menna-Dack D, Kingsnorth S, Adams T. Exploring employment readiness through mock job interview and workplace role-play exercises: comparing youth with physical disabilities to their typically developing peers. Disabil Rehabil 2015;37(18):1651-1663. [doi: 10.3109/09638288.2014.973968] [Medline: 25323394]
4. The Organisation for Economic Co-operation and Development. 2015. Education at a Glance. URL: https://www.oecd.org/education/education-at-a-glance/ [accessed 2019-11-26]
5. Mitra S, Posarac A, Vick B. Disability and poverty in developing countries: a multidimensional study. World Dev 2013;41:1-18. [doi: 10.1016/j.worlddev.2012.05.024]
6. Lindsay S, McPherson AC. Experiences of social exclusion and bullying at school among children and youth with cerebral palsy. Disabil Rehabil 2012;34(2):101-109. [doi: 10.3109/09638288.2011.587086] [Medline: 21870932]
7. Lindsay S. Discrimination and other barriers to employment for teens and young adults with disabilities. Disabil Rehabil 2011;33(15-16):1340-1350. [doi: 10.3109/09638288.2010.531372] [Medline: 21067349]
8. Bizier C, Fawcett G, Gilbert S. Mobility Disabilities Among Canadians Aged 15 Years and Older, 2012. Ottawa: Statistics Canada; 2016.
9. Disabilities. Geneva: World Health Organization; 2015. URL: http://www.who.int/topics/disabilities/en/ [accessed 2019-11-26]
10. Lindsay S, Stinson J, Stergiou-Kita M, Leck J. Improving transition to employment for youth with physical disabilities: protocol for a peer electronic mentoring intervention. JMIR Res Protoc 2017 Nov 16;6(11):e215 [FREE Full text] [doi: 10.2196/resprot.8034] [Medline: 29146566]
11. Lindsay S, Kingsnorth S, Hamdani Y. Barriers and facilitators of chronic illness self-management among adolescents: a review and future directions. J Nurs Healthc Chronic Illn 2011;3(3):186-208. [doi: 10.1111/j.1752-9824.2011.01090.x]
12. Lindsay S, Adams T, McDougall C, Sanford R. Skill development in an employment-training program for adolescents with disabilities. Disabil Rehabil 2012;34(3):228-237. [doi: 10.3109/09638288.2011.603015] [Medline: 21977978]
13. Lindsay S. Child and youth experiences and perspectives of cerebral palsy: a qualitative systematic review. Child Care Health Dev 2016 Mar;42(2):153-175. [doi: 10.1111/cch.12309] [Medline: 26754030]
14. Lindsay S, McPherson AC, Maxwell J. Perspectives of school-work transitions among youth with spina bifida, their parents and health care providers. Disabil Rehabil 2017 Apr;39(7):641-652. [doi: 10.3109/09638288.2016.1153161] [Medline: 26987863]
15. Schwartz AE, Kramer JM. 'I just had to be flexible and show good patience': management of interactional approaches to enact mentoring roles by peer mentors with developmental disabilities. Disabil Rehabil 2018 Oct;40(20):2364-2371. [doi: 10.1080/09638288.2017.1334835] [Medline: 28592154]
16. McDonald K, Balcazar F, Keys C. Youth with disabilities. In: Dubois D, Karcher MJ, editors. Handbook of Youth Mentoring. New York: Sage; 2005.
17. Lindsay S, Hartman LR, Fellin M. A systematic review of mentorship programs to facilitate transition to post-secondary education and employment for youth and young adults with disabilities. Disabil Rehabil 2016 Jul;38(14):1329-1349. [doi: 10.3109/09638288.2015.1092174] [Medline: 26497325]
18. Shpigelman C, Reiter S, Weiss PL. A conceptual framework for electronic socio-emotional support for people with special needs. Int J Rehabil Res 2009 Dec;32(4):301-308. [doi: 10.1097/MRR.0b013e32831e4519] [Medline: 19901617]
19. Dennis C. Peer support within a health care context: a concept analysis. Int J Nurs Stud 2003 Mar;40(3):321-332. [doi: 10.1016/s0020-7489(02)00092-5] [Medline: 12605954]

20. Antle BJ, Montgomery G, Stapleford C. The many layers of social support: capturing the voices of young people with spina bifida and their parents. Health Soc Work 2009 May;34(2):97-106. [doi: 10.1093/hsw/34.2.97] [Medline: 19425339]
21. La Greca AM, Bearman KJ, Moore H. Peer relations of youth with pediatric conditions and health risks: promoting social support and healthy lifestyles. J Dev Behav Pediatr 2002 Aug;23(4):271-280. [doi: 10.1097/00004703-200208000-00013] [Medline: 12177575]
22. Shpigelman C, (Tamar) Weiss PL, Reiter S. E-mentoring for all. Comput Human Behav 2009;25(4):919-928. [doi: 10.1016/j.chb.2009.03.007]
23. Ensher E, Craig T, Susan E. Comparison of traditional, sets-ahead and peer mentoring on proteges support, satisfaction, and perceptions of career success: A social exchange perspective. J Bus Psychol 2001;15(3):419-438. [doi: 10.1023/A:1007870600459]
24. DuBois DL, Holloway BE, Valentine JC, Cooper H. Effectiveness of mentoring programs for youth: a meta-analytic review. Am J Community Psychol 2002 Apr;30(2):157-197. [doi: 10.1023/A:1014628810714] [Medline: 12002242]
25. Bunting B, Dye B, Pinnegar S. Understanding the dynamics of peer mentor learning: a narrative study. J First-year Exp Stud Transit 2012;24(1):61-78 [FREE Full text]
26. Ward EG, Thomas EE, Disch WB. Mentor service themes emergent in a holistic, undergraduate peer-mentoring experience. J Coll Stud Dev 2014;55(6):563-579. [doi: 10.1353/csd.2014.0058]
27. Deutsch NL, Spencer R. Capturing the magic: assessing the quality of youth mentoring relationships. New Dir Youth Dev 2009;2009(121):47-70. [doi: 10.1002/yd.296] [Medline: 19358185]
28. Spencer R. A working model of mentors' contributions to youth mentoring relationship quality: insights from research on psychotherapy. Learn Landsc 2012;5(2):295-312. [doi: 10.36510/learnland.v5i2.567]
29. Karcher MJ, Nakkula MJ. Youth mentoring with a balanced focus, shared purpose, and collaborative interactions. New Dir Youth Dev 2010;2010(126):13-32. [doi: 10.1002/yd.347] [Medline: 20665829]
30. Powers L, Sowers J, Stevens T. An exploratory randomized study of the impact of mentoring on the self-efficacy and community-based knowledge of adolescents with severe physical challenges. J Rehabil 1995;61(1):33-41 [FREE Full text]
31. Southwick SM, Morgan CA, Vythilingam M, Charney D. Mentors enhance resilience in at-risk children and adolescents. Psycholanal Inq 2007;26(4):577-584. [doi: 10.1080/07351690701310631]
32. Lindstrom L, Doren B, Post C, Lombardi A. Building career PATHS (postschool achievement through higher skills) for young women with disabilities. Career Dev Q 2013;61(4):330-338. [doi: 10.1002/j.2161-0045.2013.00059.x]
33. Karcher MJ, Kuperminc GP, Portwood SG, Sipe CL, Taylor AS. Mentoring programs: a framework to inform program development, research, and evaluation. J Commun Psychol 2006;34(6):709-725. [doi: 10.1002/jcop.20125]
34. Knouse S. Virtual mentors: mentoring on the internet. J Employ Couns 2001;38(4):162-169. [doi: 10.1002/j.2161-1920.2001.tb00498.x]
35. Dreher GF, Cox TH. Race, gender, and opportunity: a study of compensation attainment and the establishment of mentoring relationships. J Appl Psychol 1996 Jun;81(3):297-308. [doi: 10.1037/0021-9010.81.3.297] [Medline: 8690690]
36. Bell EC. Mentoring transition-age youth with blindness. J Spec Educ 2012;46(3):170-179. [doi: 10.1177/0022466910374211]
37. Jones MM, Goble Z. Creating effective mentoring partnerships for students with intellectual disabilities on campus. J Policy Pract Intellect Disabil 2012;9(4):270-278. [doi: 10.1111/jppi.12010]
38. Fruiht VM, Wray-Lake L. The role of mentor type and timing in predicting educational attainment. J Youth Adolesc 2013 Sep;42(9):1459-1472. [doi: 10.1007/s10964-012-9817-0] [Medline: 22948939]
39. Francis G, Gross J, Turnbull A, Turnbull R. The Family Employment Awareness Training (FEAT): a mixed-method follow-up. J Vocat Rehabil 2013;39(3):167-181. [doi: 10.3233/JVR-130652]
40. Francis G, Gross JM, Turnbull R, Parent-Johnson W. Evaluating the effectiveness of the family employment awareness training in Kansas: a pilot study. Res Pract Persons Severe Disabl 2013;38(1):44-57. [doi: 10.2511/027494813807046953]
41. Kim-Rupnow WS, Burgstahler S. Perceptions of students with disabilities regarding the value of technology-based support activities on postsecondary education and employment. J Spec Educ Technol 2016 Aug;19(2):43-56. [doi: 10.1177/016264340401900204]
42. O'Mally J, Antonelli K. The effect of career mentoring on employment outcomes for college students who are legally blind. J Vis Impair Blind 2016;110(5):295-307. [doi: 10.1177/0145482X1611000502]
43. Kolakowsky-Hayner SA, Wright J, Shem K, Medel R, Duong T. An effective community-based mentoring program for return to work and school after brain and spinal cord injury. NeuroRehabilitation 2012;31(1):63-73. [doi: 10.3233/NRE-2012-0775] [Medline: 22523017]
44. Lindsay S, Yantzi N. Weather, disability, vulnerability, and resilience: exploring how youth with physical disabilities experience winter. Disabil Rehabil 2014;36(26):2195-2204. [doi: 10.3109/09638288.2014.892158] [Medline: 24564361]
45. Hamilton BA, Scandura TA. E-mentoring: implications for organizational learning and development in a wired world. Organ Dyn 2003;31(4):388-402. [doi: 10.1016/S0090-2616(02)00128-6]
46. Britner PA, Balcazar FE, Blechman EA, Blinn-Pike L, Larose S. Mentoring special youth populations. J Commun Psychol 2006;34(6):747-763. [doi: 10.1002/jcop.20127]

47. Kramer JM, Ryan CT, Moore R, Schwartz A. Feasibility of electronic peer mentoring for transition-age youth and young adults with intellectual and developmental disabilities: Project Teens making Environment and Activity Modifications. J Appl Res Intellect Disabil 2018 Jan;31(1):e118-e129 [FREE Full text] [doi: 10.1111/jar.12346] [Medline: 28247558]
48. Kram KE. Phases of the mentor relationship. Acad Manag J 1983;26(4):608-625. [doi: 10.2307/255910]
49. Baugh S, Scandura T. The effect of multiple mentors on protege attitudes toward the work setting. J Soc Behav Pers 2000;14(4):503-521 [FREE Full text]
50. Wah L. Workplace of the future. Manage Rev 2000;89(1):1-12.
51. Shpigelman C, Gill CJ. The characteristics of unsuccessful e-mentoring relationships for youth with disabilities. Qual Health Res 2013 Apr;23(4):463-475. [doi: 10.1177/1049732312469115] [Medline: 23221100]
52. Balcazar F, Keys C. Goals in mentoring relationships. In: DuBois D, Karcher M, editors. Handbook of Youth Mentoring. Thousand Oaks, California: Sage Publications; 2014:83-98.
53. Lindsay S, Stinson J, Stergiou-Kita M, Leck J. Improving transition to employment for youth with physical disabilities: protocol for a peer electronic mentoring intervention. JMIR Res Protoc 2017 Nov 16;6(11):e215 [FREE Full text] [doi: 10.2196/resprot.8034] [Medline: 29146566]
54. Lindsay S, Cagliostro E, Stinson J, Leck J. A 4-week electronic-mentoring employment intervention for youth with physical disabilities: pilot randomized controlled trial. JMIR Pediatr Parent 2019 Apr 24;2(1):e12653 [FREE Full text] [doi: 10.2196/12653] [Medline: 31518302]
55. Lindsay S, Cagliostro E, Leck J, Stinson J. A 12-week electronic mentoring employment preparation intervention for youth with physical disabilities: pilot feasibility randomized controlled trial. JMIR Pediatr Parent 2019 Mar 29;2(1):e12088 [FREE Full text] [doi: 10.2196/12088] [Medline: 31518315]
56. Clark VL, Schumacher K, West C, Edrington J, Dunn LB, Harzstark A, et al. Practices for embedding an interpretive qualitative approach within a randomized clinical trial. J Mix Methods Res 2013;7(3):219-242. [doi: 10.1177/1558689812474372]
57. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
58. Clarke V, Braun V. Thematic analysis. J Posit Psychol 2017;12(3):297-298. [doi: 10.1080/17439760.2016.1262613]
59. Lindsay S. Five approaches to qualitative comparison groups in health research: a scoping review. Qual Health Res 2019 Feb;29(3):455-468. [doi: 10.1177/1049732318807208] [Medline: 30501574]
60. Lindsay S, Munson M. National Mentoring Resource Center. 2018 Oct. Mentoring for Youth With Disabilities: National Mentoring Resource Center Population Review. URL: http://nationalmentoringresourcecenter.org/images/PDF/Mentoring_for_Youth_with_Disabilities_Population_Review.pdf [accessed 2019-11-26]
61. Stinson J, Kohut SA, Forgeron P, Amaria K, Bell M, Kaufman M, et al. The iPeer2Peer Program: a pilot randomized controlled trial in adolescents with Juvenile Idiopathic Arthritis. Pediatr Rheumatol Online J 2016 Sep 2;14(1):48 [FREE Full text] [doi: 10.1186/s12969-016-0108-2] [Medline: 27590668]
62. Powers LE, Schmidt J, Sowers J, McCracken K. Qualitative investigation of the influence of STEM mentors on youth with disabilities. Career Dev Transit Except Individ 2015;38(1):25-38. [doi: 10.1177/2165143413518234]
63. Stumbo NJ, Martin J, Nordstrom D, Rolfe T, Burgstahler S, Whitney J, et al. Evidence-based practices in mentoring students with disabilities: four case studies. J Sci Educ Stud Disabil 2010;14(1):33-54. [doi: 10.14448/jsesd.03.0003]
64. Burgstahler S, Cronheim D. Supporting peer-peer and mentor-protege relationships on the internet. J Res Technol Educ 2001;34(1):59-74. [doi: 10.1080/15391523.2001.10782334]
65. Cohen K, Light J. Use of electronic communication to develop mentor-protégé relationships between adolescent and adult AAC users: pilot study. Augment Altern Commun 2009;16(4):227-238. [doi: 10.1080/07434610012331279084]
66. Lindsay S, Kolne K, Cagliostro E. Electronic mentoring programs and interventions for children and youth with disabilities: systematic review. JMIR Pediatr Parent 2018 Oct 24;1(2):e11679 [FREE Full text] [doi: 10.2196/11679] [Medline: 31518310]
67. Allen TD, Eby LT. Factors related to mentor reports of mentoring functions provided: Gender and relational characteristics. Sex Roles 2004;50(1-2):129-139. [doi: 10.1023/B:SERS.0000011078.48570.25]
68. Mullen EJ. Framing the mentoring relationship as an information exchange. Hum Resour Manage Rev 1994;4(3):257-281. [doi: 10.1016/1053-4822(94)90015-9]
69. Ryan CT, Kramer JM, Cohn ES. Exploring the self-disclosure process in peer mentoring relationships for transition-age youth with developmental disabilities. Intellect Dev Disabil 2016 Aug;54(4):245-259. [doi: 10.1352/1934-9556-54.4.245] [Medline: 27494124]

Abbreviations

e-mentor: electronic mentor
e-mentoring: electronic mentoring

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Original Paper

College Student Problematic Internet Use and Digital Communication Medium Used With Parents: Cross-Sectional Study

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Abstract

Background: Problematic internet use (PIU) is associated with mental health concerns such as depression and affects more than 12% of young adults. Few studies have explored potential influences of parent–college student digital communication on college students' risk of PIU.

Objective: This study sought to understand the relationship between parent–college student digital communication frequency via phone calls, text messages, and Facebook contacts and PIU among college students.

Methods: Incoming first-year students were randomly selected from registrar lists of a midwestern and northwestern university for a 5-year longitudinal study. Data from interviews conducted in summer 2014 were used. Measures included participants' daily Facebook visits, communication frequency with parents via phone call and text message, and 3 variables related to Facebook connection status and communication: (1) parent–college student Facebook friendship status, (2) college student blocking personal Facebook content from parent, and (3) Facebook communication frequency. PIU risk was assessed using the Problematic and Risky Internet Use Screening Scale. Analysis included participants who reported visiting Facebook at least once per day. Multiple linear regression was used, followed by a post hoc mediation with Hayes process macro to further investigate predictive relationships among significant variables.

Results: A total of 151 participants reported daily Facebook use and were included in analyses. Among these participants, 59.6% (90/151) were female, 62.3% (94/151) were from the midwestern university, and 78.8% (119/151) were white. Mean Facebook visits per day was 4.3 (SD 3.34). There was a collective significant effect between participant daily Facebook visits, college student–parent phone calls, texts, and all 3 Facebook connection variables ($F_{6,144}$=2.60, P=.02, R^2=.10). Phone calls, text messages, and Facebook contacts were not associated with PIU risk. However, two individual items were significant predictors for PIU: participant daily Facebook visits were positively associated with increased PIU risk (b=0.04, P=.006) and being friends with a parent on Facebook was negatively associated with PIU risk (b=–0.66, P=.008). Participant daily Facebook visits were not a significant mediator of the relationship between college student–parent Facebook friendship and PIU risk (b=–0.04; 95% CI –0.11 to 0.04).

Conclusions: This study did not find support for a relationship between parent–college student digital communication frequency and PIU among college students. Instead, results suggested Facebook friendship may be a protective factor. Future studies should examine how a parent-child Facebook friendship might protect against PIU among children at varying developmental stages.

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KEYWORDS

parents; young adults; social media

Introduction

Problematic internet use (PIU) is an emerging health concern among young adults, defined as technology use that may involve impulsive and risky internet use; internet use dependency; social, physical, and emotional impairment; and psychological risks [1]. Numerous mental health concerns, including attention deficit hyperactivity disorder, social phobia, hostility, depression, and increased likelihood and severity of suicidal ideation, have been linked to PIU [2,3]. Studies suggest that college students experience PIU at rates of 4% to 22% [4-7]. These findings support the need for an understanding of influences on the development of PIU among young adult college students to inform prevention efforts.

Parents may play roles in college students’ development of PIU. Parent characteristics such as low education level, young age, and lifetime use of tobacco and illicit drugs have been linked to college students’ excessive internet use [8]. In addition, parental relations, such as those involving rejection and overprotection, are associated with increased risk for PIU [9]. Another influential factor may be parents’ own technology behaviors. Parents’ use of social networking and mobile phones has been found to predict their children’s engagement with these media [10,11]. Given the importance of both the parental relationship and parent-child technology behaviors, it is essential to understand mechanisms by which parents can exert influence over their children’s internet use, even at the young adult stage.

Technology itself may offer a vehicle for parents to influence college students’ technology use through modeling their own. According to social cognitive theory, new behaviors may originate from noting how others act [12]. Observing parents’ use of technology could therefore influence college students’ behaviors. Further, relevant cues about parents’ technology use may be transmitted through devices themselves. Parents who initiate frequent, high-volume text message exchanges with their college student children, for example, may unintentionally convey suggestions about acceptable technology use rates. This mode of conveying norms could hold particular relevance for college-attending youth, who often live away from parents and could rely on digital communication frequently. For this reason, rates of parent-child digital communication could be important to college students’ risk of PIU.

Digital communication between parents and college students is common and has increased in recent years [13]. Many college students not only allow the creation of friendship links between themselves and their parents but also use social networking sites such as Facebook to stay in touch [14]. Following the establishment of a social media link, few students report ever blocking parents from seeing individual content they have posted [15]. Increasing digital connectedness between parents and their college student children warrants exploring the effects of these changing relationships.

While parent-child digital connectedness could have an effect on PIU among college students, few studies have explored this possibility. Some evidence suggests that parental mediation around children’s use of the internet is associated with reductions in excessive internet use [16,17]. Thus, it may be that parent-child digital communication provides an opportunity for mediation and modeling of healthy internet use behaviors. However, as parent-child digital communication increases, so too may modeling of unhealthy internet use by parents [10]. Toward clarifying this relationship, this study aimed to understand the relationship between parental digital communication and PIU risk among college students. This purpose was addressed by considering possible effects of three different digital communication media: phone calls, text messages, and Facebook contacts via public timeline post or private message. Phone calls, text messages, and Facebook contacts were the focus of this study given evidence that many adults use all three media [13,18].

Methods

Design

This cross-sectional study used data from a 5-year, longitudinal study involving yearly phone interviews of college students starting at the time of matriculation. For this secondary analysis, phone interview data from a single time point when questions about parent communication were integrated into yearly interviews were used.

Setting

This study took place at two universities, one midwestern and the other northwestern. Data were collected in the summer of 2014, when participants were entering their fourth year of college. The relevant institutional review boards reviewed and approved this study.

Participants

In the summer of 2011, researchers randomly selected incoming first-year students from registrar lists of the targeted midwestern and northwestern universities. Potential participants received a postcard introducing them to the 5-year, longitudinal study, followed by four rounds of recruitment contacts by email, phone, and Facebook message. Eligible potential participants included first-year students with full-time status who owned Facebook profiles, spoke English, and did not move to campus before fall as part of an early enrollment program. For this secondary analysis study, participants were included if they completed a phone interview following their third year of college and they were at least daily users of Facebook.

Phone Interviews

After the third year of college, participants in this study completed phone interviews. This approach allowed for data collection from participants living more than a half hour away from the study site. Phone interviews have been successfully implemented in past studies to collect sensitive health information [19,20]. Interviews were conducted at convenient times for participants and lasted 30 to 60 minutes. Participants received an incentive of $40 after the interview.

Measures

Digital Communication With Parents

Interviews assessed predictor variables around frequency of communication with parents via phone calls, text messages, and

Facebook contacts. To assess phone calls, researchers asked the question, “In an average week, how many times did you talk on the phone with one or both of your parents while at college?” For text messages, participants answered the questions, “In an average week, on how many days did you send or receive a text from your parents?” and “On the days that you texted with your parents, about how many texts were sent back and forth during that day/those days?”

To measure frequency of Facebook contacts, it was necessary to assess the parent-student Facebook connection status (ie, whether the student’s account was made visible to parents). To this end, participants indicated whether at least one parent or guardian owned a Facebook account and if they had at least one parent as a friend on the site. Further, participants indicated whether they blocked any content from their parent Facebook friends. Those who reported having at least one parent who was a Facebook account owner and Facebook friend were asked, “In an average week, how many times did you communicate with your parents or guardians using Facebook?” Interviewers clarified that communication via Facebook included public timeline posts or private messages.

Problematic Internet Use

This study assessed the outcome variable of risk of problematic internet use during the third year of college using the Problematic and Risky Internet Use Screening Scale (PRIUSS) [21]. This scale includes 18 items addressing problematic internet use. This measure has been shown to have strong reliability and content validity in the college population [22]. Participants chose a response of never, rarely, sometimes, often, or very often for each of the 18 items. Each response was assigned a numerical value from 0 (never) to 5 (very often); all items were summed. A score of 25 or greater indicated risk of problematic internet use.

Demographics and Facebook Use Variables

Demographic variables included age, gender, race/ethnicity, and university; Facebook use during the third year of college was also reported. Participants indicated their Facebook account ownership status and whether they visited the site daily. Those who made daily visits indicated how many times they typically did so per day.

Analysis

Toward examining predictors among participants most likely to experience PIU, we included only participants who reported at least daily use of Facebook in analyses. Digital communication with parents, PIU, and demographic and Facebook use variables were analyzed using descriptive statistics. Multiple linear regression was used to test the predictive relationship of digital communication with parents and social media use toward PRIUSS scores. Results were considered statistically significant when $P<.05$. A post hoc mediation analysis with Hayes process macros allowed further investigation into predictive relationships among significant variables [23].

Results

Participants

Among the 329 participants enrolled in the larger study in the summer of 2014, 151 completed phone interviews and indicated daily use of Facebook and were thus included in analyses. These participants had an average of 4.3 (SD 3.34) Facebook visits per day. The majority were female (90/151, 59.6%), from the midwestern university (94/151, 62.3%), and white (119/151, 78.8%). A PRIUSS score of 25 or greater (indicating risk of PIU) was met by 15.9% (24/151) of participants with daily Facebook use. See Table 1 for full demographic results.

Table 1. Participant demographics.

Characteristic	Value, n (%)
Gender	
Female	90 (59.6)
Male	61 (40.4)
University	
Midwestern	94 (62.3)
Northwestern	57 (37.7)
Race/ethnicity	
White	119 (78.8)
Asian	14 (9.3)
Multiracial	8 (5.3)
Hispanic	5 (3.3)
African American	2 (1.3)
East Indian	1 (0.7)
Native American/Alaskan	1 (0.7)
Other	1 (0.7)

Digital Communication With Parents

Most participants (145/151, 96.0%) reported that on a weekly basis they had at least one phone call with their parents. These participants had an average of 3.0 (SD 3.5) calls with parents per week. All participants (151/151, 100%) indicated at least one weekly exchange of text messages with parents and did so an average of 3.5 (SD 2.1) days per week.

Nearly all participants (146/151, 96.7%) reported that at least one parent owned a Facebook account. Among them, the majority (136/146, 93.2%) indicated that they had at least one parent as a Facebook friend. Few (24/136, 17.6%) reported blocking Facebook content from a parent. Less than half (64/136, 47.0%) suggested they used Facebook contacts, such as a timeline post or private message, to communicate with parents. These participants reported using Facebook to interact with parents an average of 1.8 (SD 1.4) times per week.

Associations Between Parent-Child Digital Communication and Risk of Problematic Internet Use

The multiple linear regression indicated that there was a collective significant effect between participant daily Facebook visits, participant-parent phone calls, text messages, parent Facebook friendships, weekly parent Facebook contacts, and blocking content from parents ($F_{6,144}$=2.60, P=.02, R^2=.10; model fit: R=.321; R^2=.097; adjusted R^2=.06). Weekly phone calls, text messages, and Facebook contacts were not associated with risk of PIU. The number of daily Facebook visits was found to be associated with increased risk of PIU (P=.006), while a parent Facebook friendship was associated with decreased PIU risk (P=.008). Weekly parent phone calls, text messages, and Facebook contacts were not significantly associated with risk of PIU. See Table 2 for full multiple linear regression results.

Table 2. Predictors of risk of problematic internet use.

Characteristics	B	SE B	β	*t* value	*P* value
Number of daily Facebook visits	0.036	0.013	0.223	2.808	.006
Weekly parent phone calls	–0.006	0.012	–0.041	–0.517	.61
Weekly parent text messages	–0.008	0.010	–0.066	–0.826	.41
Parent Facebook friendship	–0.661	0.244	–0.219	–2.708	.008
Weekly parent Facebook contacts	0.003	0.034	0.007	0.093	.93
Blocking Facebook content from parents	–0.101	0.121	-0.006	–0.079	.94

The post hoc mediation analysis with Hayes process macro did not show the number of daily Facebook visits to be a significant mediator between parent Facebook friendship and PIU risk (b=–0.04; 95% CI –0.11 to 0.04).

Discussion

Principal Findings

The purpose of this cross-sectional, 2-site phone interview study was to understand the relationship between parent–college student digital communication and PIU among these young adults. Findings did not support digital communication—via parent-child phone calls, text messages, and Facebook contacts—as a risk factor for PIU. Further, the study suggested parent–college student Facebook friendships are associated with decreased risk of PIU among college students who use Facebook daily and that text messages and phone calls are commonly used digital communication media.

In this study, parent–college student phone calls, text messages, and Facebook contacts were not associated with college students' risk of PIU. Thus, support was not found for the possibility that parents convey norms of excessive technology use when they communicate with their college student children on digital platforms at high rates. Instead, it may be that the immersive nature of content exchanged through digital media affects the student's risk of PIU. If a peer sends their friend a meme via text message, for example, the recipient may be prompted to find additional content to share in return, thereby engaging with the internet further. Meanwhile, if parents primarily contact their children for practical purposes, such as coordinating plans, interactions with them may not motivate additional phone and internet use. This explanation is consistent with an emerging body of literature suggesting that the manner of engagement with social media, not just the duration, is associated with well-being [24-26].

An unexpected, additional finding was that Facebook friendships with parents were associated with decreased risk of PIU and that the number of daily Facebook visits among college students who used Facebook daily did not mediate this relationship. It is also worth noting that a large majority of participants were Facebook friends with at least one parent. Thus, results did not yield evidence that a parent's online presence leads to lower engagement with social media on the part of the many college students who have parents as Facebook friends. Instead, it may be that a parent–college student Facebook friendship allows mediating and modeling of safe, healthy internet use. Another possible reason for this finding is that some aspects of the parent–college student relationship affect both these young adults' likelihood of being Facebook friends with their parents and having increased risk of PIU. This possibility is consistent with previous studies suggesting a connection between parenting factors, such as parenting and attachment style, and adolescents' and young adults' use of mobile phones [27-32]. Similarly, college students have reported ways that social media connection benefits their relationship with parents, including sharing important life events and memories [14]. Thus, an additional possibility is that Facebook friendship with parents could decrease risk of PIU in college students by improving parental relationships. While the reason for the association between

Facebook friendships with parents and college students' reduced risk of PIU remains unclear, this finding provides additional support for the importance of parents, and their potential protective effect, in college students' development of PIU.

An important third finding was that participants frequently communicated with parents via text messages and phone calls but seldom via Facebook contacts. This finding is consistent with a previous study showing text messages to be among the most frequently used parent–young adult communication media and suggesting that adopting a new platform for family communication requires the development of technologies that improve how families communicate with each other [33]. It may be that college students and their parents find text messages and phone calls adequate for the nature of their digital communications, if interaction often serves practical purposes such as coordinating plans. Further, compared with other media, texting message and phone call platforms may be viewed as simple, infrequently updated, and easy to use.

Limitations

This study has limitations to consider. Data were collected from large state universities. It is not clear whether findings generalize to other institution types such as small private colleges. Nevertheless, our study population included two geographically diverse schools, and participants had similar demographic makeup to that of the involved universities. Further, participants were predominantly white. Since parent-child relationships occur in differing cultural contexts [34-37], it is not clear whether findings generalize to nonwhite families. In addition, in this cross-sectional study, the direction of significant relationships found is unknown. There is a need for culturally specific research investigating causal pathways between parent–college student digital communication and college students' risk of PIU. Finally, this study's self-reported findings may be subject to recall bias. Future studies may use ecological momentary assessment approaches to circumvent this limitation.

Conclusion

This study did not find evidence that digital communication with parents is a risk factor for PIU among college students. Instead, findings suggest a possibility that social media connections between parents and college students may be protective. Implications are relevant to guidelines that pediatricians may offer to parents regarding digital communication with their children. It may not be necessary to advise limiting use of digital communication with children, particularly among the many parents who have already established social media connections with their children. In fact, parents should be informed of potential benefits of social media connection.

Additional research is needed toward developing guidelines for parents around digital communication with their children. Future studies should examine the role that a parent-child Facebook friendship may play in protecting against PIU among college students, such as allowing modeling of healthy internet use by parents or promoting regular contact and therefore supportive relationships and well-being. Further, investigations into risks and benefits of social media interactions among parents and children across development stages are important to inform guidelines for parents on this topic. What protects against PIU at one developmental stage may not at another. A third important area to consider is the nature of content shared between parents and children in digital communications. Meme sharing, coordination of plans, and serious conversations facilitated by digital communication may have differing effects on their recipients. These future inquiries may support parents in using digital communication as a tool to promote their children's well-being.

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Conflicts of Interest

None declared.

References

1. Moreno MA, Jelenchick LA, Christakis DA. Problematic internet use among older adolescents: a conceptual framework. Comput Hum Behav 2013 Jul;29(4):1879-1887. [doi: 10.1016/j.chb.2013.01.053]
2. Yen J, Ko C, Yen C, Wu H, Yang M. The comorbid psychiatric symptoms of Internet addiction: attention deficit and hyperactivity disorder (ADHD), depression, social phobia, and hostility. J Adolesc Health 2007 Jul;41(1):93-98. [doi: 10.1016/j.jadohealth.2007.02.002] [Medline: 17577539]
3. Cheng Y, Tseng P, Lin P, Chen T, Stubbs B, Carvalho AF, et al. Internet addiction and its relationship with suicidal behaviors: a meta-analysis of multinational observational studies. J Clin Psychiatry 2018 Jun 05;79(4). [doi: 10.4088/JCP.17r11761] [Medline: 29877640]
4. Tateno M, Teo AR, Shiraishi M, Tayama M, Kawanishi C, Kato TA. Prevalence rate of Internet addiction among Japanese college students: two cross-sectional studies and reconsideration of cut-off points of Young's Internet Addiction Test in Japan. Psychiatry Clin Neurosci 2018 Sep;72(9):723-730 [FREE Full text] [doi: 10.1111/pcn.12686] [Medline: 29845676]
5. Shao Y, Zheng T, Wang Y, Liu L, Chen Y, Yao Y. Internet addiction detection rate among college students in the People's Republic of China: a meta-analysis. Child Adolesc Psychiatry Ment Health 2018;12:25 [FREE Full text] [doi: 10.1186/s13034-018-0231-6] [Medline: 29849754]

6. Christakis DA, Moreno MM, Jelenchick L, Myaing MT, Zhou C. Problematic internet usage in US college students: a pilot study. BMC Med 2011 Jun 22;9:77 [FREE Full text] [doi: 10.1186/1741-7015-9-77] [Medline: 21696582]
7. Derbyshire KL, Lust KA, Schreiber LRN, Odlaug BL, Christenson GA, Golden DJ, et al. Problematic Internet use and associated risks in a college sample. Compr Psychiatry 2013 Jul;54(5):415-422. [doi: 10.1016/j.comppsych.2012.11.003] [Medline: 23312879]
8. Mellouli M, Zammit N, Limam M, Elghardallou M, Mtiraoui A, Ajmi T, et al. Prevalence and predictors of internet addiction among college students in Sousse, Tunisia. J Res Health Sci 2018 Jan 02;18(1):e00403 [FREE Full text] [Medline: 29445049]
9. Yao MZ, He J, Ko DM, Pang K. The influence of personality, parental behaviors, and self-esteem on Internet addiction: a study of Chinese college students. Cyberpsychol Behav Soc Netw 2014 Feb;17(2):104-110 [FREE Full text] [doi: 10.1089/cyber.2012.0710] [Medline: 24003966]
10. Ramsay J, Terras M. The relationship between parent and child digital technology use. 2016 Presented at: BPS Annual Conference; 2016; Nottingham URL: https://research-portal.uws.ac.uk/en/publications/the-relationship-between-parent-and-child-digital-technology-use
11. Hefner D, Knop K, Schmitt S, Vorderer P. Rules? Role Model? Relationship? The impact of parents on their children’s problematic mobile phone involvement. Media Psychology 2018 Feb 12;22(1):82-108. [doi: 10.1080/15213269.2018.1433544]
12. Bandura A. Social Foundations of Thought and Action: A Social Cognitive Theory. Upper Saddle River: Prentice-Hall, Inc; 1986.
13. Ramsey MA, Gentzler AL, Morey JN, Oberhauser AM, Westerman D. College students' use of communication technology with parents: comparisons between two cohorts in 2009 and 2011. Cyberpsychol Behav Soc Netw 2013 Oct;16(10):747-752. [doi: 10.1089/cyber.2012.0534] [Medline: 23679572]
14. Yang C. Social media as more than a peer space: college freshmen encountering parents on Facebook. J Adoles Res 2016 Jul 21;33(4):442-469. [doi: 10.1177/0743558416659750]
15. Abar CC, Farnett S, Mendola K, Koban K, Sarra S. Relationships between parent–child social media interactions and health behaviors. J Substance Use 2017 Dec 08;23(3):335-337. [doi: 10.1080/14659891.2017.1410586]
16. Kalmus V, Blinka L, Ólafsson K. Does it matter what mama says: evaluating the role of parental mediation in European adolescents’ excessive internet use. Child Soc 2013 Apr 18;29(2):122-133. [doi: 10.1111/chso.12020]
17. Chen L, Shi J. Reducing harm from media: a meta-analysis of parental mediation. Journalism Mass Comm Q 2018 Mar 12;96(1):173-193. [doi: 10.1177/1077699018754908]
18. Perrin A, Anderson M. Share of U.S. adults using social media, including Facebook, is mostly unchanged since. Washington: Pew Internet and American Life Project; 2018. URL: https://tinyurl.com/yya2afsf [accessed 2020-03-08]
19. Fortney J, Mukherjee S, Curran G, Fortney S, Han X, Booth BM. Factors associated with perceived stigma for alcohol use and treatment among at-risk drinkers. J Behav Health Serv Res 2004;31(4):418-429. [doi: 10.1097/00075484-200410000-00006]
20. Meyer IH, Rossano L, Ellis JM, Bradford J. A brief telephone interview to identify lesbian and bisexual women in random digit dialing sampling. J Sex Res 2002 May;39(2):139-144. [doi: 10.1080/00224490209552133]
21. Jelenchick L, Christakis D, Benson M, Moreno M. Development and validation of the Problematic and Risky Internet Use Screening Scale (PRIUSS). 2013 Presented at: Pediatric Academic Societies; 05/2013; Washington, DC. [doi: 10.1037/t32450-000]
22. Jelenchick LA, Eickhoff J, Zhang C, Kraninger K, Christakis DA, Moreno MA. Screening for adolescent problematic internet use: validation of the Problematic and Risky Internet Use Screening Scale (PRIUSS). Acad Pediatr 2015;15(6):658-665. [doi: 10.1016/j.acap.2015.07.001] [Medline: 26547545]
23. Hayes A. Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach. New York: Guilford Publications; 2017.
24. Thorisdottir IE, Sigurvinsdottir R, Asgeirsdottir BB, Allegrante JP, Sigfusdottir ID. Active and passive social media use and symptoms of anxiety and depressed mood among Icelandic adolescents. Cyberpsychol Behav Soc Netw 2019 Aug;22(8):535-542. [doi: 10.1089/cyber.2019.0079]
25. Macrynikola N, Miranda R. Active Facebook use and mood: when digital interaction turns maladaptive. Comput Hum Behav 2019 Aug;97:271-279. [doi: 10.1016/j.chb.2019.02.012]
26. Verduyn P, Lee DS, Park J, Shablack H, Orvell A, Bayer J, et al. Passive Facebook usage undermines affective well-being: experimental and longitudinal evidence. J Experimental Psychol Gen 2015;144(2):480-488. [doi: 10.1037/xge0000057]
27. Oldmeadow JA, Quinn S, Kowert R. Attachment style, social skills, and Facebook use amongst adults. Comput Hum Behav 2013 May;29(3):1142-1149. [doi: 10.1016/j.chb.2012.10.006]
28. Kwan H, Leung M. The path model of parenting style, attachment style, self-regulation and Smartphone addiction. Appl Psychol 2016:196-214. [doi: 10.1142/9789814723398_0011]
29. Yeo J, Kang S, Kim D. The impact of attachment anxiety on smart phone addiction with a mediating effect of impulsivity and loneliness: focused on the group of SNS and GAME. Korea J Youth Couns 2014 Jun;22(1):47-69. [doi: 10.35151/kyci.2014.22.1.003]
30. Kim E, Cho I, Kim EJ. Structural equation model of smartphone addiction based on adult attachment theory: mediating effects of loneliness and depression. Asian Nurs Res 2017 Jun;11(2):92-97. [doi: 10.1016/j.anr.2017.05.002]

31. Hibbard A. The Relationship of Attachment Styles and Self-Control on Cell Phone Reliance [Thesis]. Northridge: California State University; 2015.
32. Kim E, Koh E. Avoidant attachment and smartphone addiction in college students: the mediating effects of anxiety and self-esteem. Comput Hum Behav 2018 Jul;84:264-271. [doi: 10.1016/j.chb.2018.02.037]
33. Stein CH, Osborn LA, Greenberg SC. Understanding young adults' reports of contact with their parents in a digital world: psychological and familial relationship factors. J Child Fam Stud 2016 Jan 27;25(6):1802-1814. [doi: 10.1007/s10826-016-0366-0]
34. Sahithya BR, Manohari SM, Vijaya R. Parenting styles and its impact on children: a cross cultural review with a focus on India. Mental Health Relig Culture 2019 Jun 18;22(4):357-383. [doi: 10.1080/13674676.2019.1594178]
35. Mah JWT, Johnston C. Cultural variations in mothers' acceptance of and intent to use behavioral child management techniques. J Child Fam Stud 2011 May 5;21(3):486-497. [doi: 10.1007/s10826-011-9502-z]
36. Klarin M, Sasic S. Differences in family interactions between adolescents from the Republic of Croatia and Bosnia and Herzegovina: cross-cultural perspective. Drustvena Istrazivanja 2009 Apr;18(1-2):243-261 [FREE Full text]
37. Chen B, Soenens B, Vansteenkiste M, Van Petegem S, Beyers W. Where do the cultural differences in dynamics of controlling parenting lie? Adolescents as active agents in the perception of and coping with parental behavior. Psychol Belg 2016 Jul 13;56(3):169-192 [FREE Full text] [doi: 10.5334/pb.306] [Medline: 30479435]

Abbreviations

PIU: problematic internet use
PRIUSS: Problematic and Risky Internet Use Screening Scale

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Original Paper

Association of Social Media Use and High-Risk Behaviors in Adolescents: Cross-Sectional Study

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Abstract

Background: Previous studies have demonstrated the prevalence of social media use and identified the presence of high-risk behaviors among adolescents, including self-harm and sharing of sexually explicit messages.

Objective: This study aimed to identify patterns in the amount of time spent on social media by adolescents who engage in high-risk behavior and the extent to which they use social media as a platform for sharing such behaviors.

Methods: This was a descriptive cross-sectional study of 179 adolescents seen in a pediatric clinic at an urban medical center. We used an anonymous self-report survey to obtain demographic characteristics, rates of self-harm thoughts and behaviors, sharing of sexually explicit messages, and social media use as determined by total hours spent on social media per day and the number of applications used.

Results: Most adolescents reported spending 3 to 5 hours on social media each day and using 3 or more social media applications. Almost 1 in 8 (22/179, 12.3%) adolescents self-reported having ever engaged in self-injury with a mean age of onset of 11.8 years. Over a quarter (49/179, 27.4%) of adolescents reported sharing sexually explicit messages. Relative risk of engaging in self-injury and or sharing sexually explicit messages increased with the use of 4 or more social media applications (1.66; CI 1.11-2.48).

Conclusions: Results show a relationship between the number of social media applications used and increased rates of high-risk behaviors. We identified relevant risk factors that clinicians can use to screen for high-risk behavior and parents can monitor to encourage education about healthy online practices.

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KEYWORDS

self-harm; social media; nonsuicidal self-injury; sexting

Introduction

The degree to which social media has permeated our culture has led to growing concerns among parents and clinicians regarding how best to protect young people from vulnerabilities unique to the modern social media landscape [1-4]. Some of the most commonly used social media platforms originated when today's adolescents were infants [5]. As a result, this type of technology has essentially been woven into their developmental experience, with unknown long-term impacts. Several studies have explored how internet and social media use influence adolescent behavior [6-9]. Social media platforms may be an important means to expose young people to the concept of self-harm and may provide a sense of normalcy or belonging via online communities of peers engaging in similar behaviors, thereby perpetuating these harmful behaviors [10-14]. Researchers have sought to identify trends in social media use and how they may relate to the concomitantly growing rates of self-injurious and suicidal behaviors, sharing of sexually explicit messages and photos, and other forms of potentially harmful activities [12,13,15].

Deliberate self-harm or nonsuicidal self-injury (NSSI) is the intentional and direct destruction or alteration of body tissue resulting in tissue damage without conscious suicidal intent [12,16]. This behavior is recognized in literature in both North America and Europe [16,17]. Experts estimate the prevalence of NSSI ranges from 4% to 35%, with higher rates found in psychiatric patients and significant variation depending on definition and measurements used [16,17]. Previous studies of adolescents who reported a history of self-injury found more than 50% had engaged in internet searches for self-injury material [8]. Qualitative interviews revealed while some adolescents reported discovering the concept of self-injury online and subsequently engaging in self-injurious behaviors, most used online platforms to support preexisting behaviors [13]. Existing evidence also shows online communities can perpetuate potentially dangerous behaviors through increased exposure and normalization [12-14]. A survey-based study of more than 700 participants demonstrated that youth who self-reported “unmet need for mental health support” had an adjusted relative risk ratio of 3.15 for spending more than 2 hours per day on social media and that adolescents who reported more than 2 hours of social media use per day also had an independent association with psychological distress including suicidal ideation [9,14,18]. Social media and online communities present opportunities for adolescents to seek validation and a sense of belonging around these behaviors. The ability to identify sources of potentially harmful content on the internet can be exceedingly difficult for parents and providers, highlighted by research specifically examining the presence of self-injury on the social media site Instagram, where users disguised posts with ambiguous hashtags making them difficult to detect and content warnings were often not reliable [12].

Sexting is a term used to refer to the act of sending or receiving sexually explicit or sexually suggestive photos, videos, or messages. Prior studies estimated the prevalence of adolescents sharing sexually explicit images and/or videos via text messaging or social media ranges from 5% to 7%, with rates of sharing sexually explicit messages (without images) as high as 22% [19,20]. Studies found the most commonly reported reasons for sexting among teenagers include responding to a request from a partner or seeking to attract interest or increase popularity [21]. The same studies showed girls are more likely to be pressured, coerced, or blackmailed into sexting, particularly by male peers [21]. Sexting has been shown to be associated with both sexual activity and substance use [22]. Researchers have not fully studied relationships between sexting and self-injurious behaviors. A 2014 research review suggested that, despite common perceptions, rates of cyberbullying, contact with strangers, and sharing of sexually explicit content did not appear to rise with increased access to the internet or mobile technology, and these behaviors were more likely attributable to psychosocial risk factors. Authors have postulated that mass media campaigns for widespread social awareness and safety initiatives may mitigate risk for engaging in such behaviors [23].

A more comprehensive understanding of current social media practices among adolescents is essential to implement efforts to identify adolescents in crisis, educate parents and adolescents about how to respond to high-risk behaviors, and protect vulnerable adolescents both from self-destructive behaviors and victimization. Our study aimed to identify patterns in time spent on social media by adolescents who engage in NSSI and/or sexually explicit sharing on social media compared with those who do not and the extent to which adolescents use social media as a platform for sharing and thereby possibly perpetuating such behaviors.

Methods

Study Design

We recruited study participants from the outpatient general pediatric and adolescent medicine clinic at an academic urban medical center from August 2016 to May 2018. The institutional review board approved this study and granted a waiver for parental consent of participants aged younger than 18 years. We defined adolescents according to those outlined by the age limitations of the American Academy of Pediatrics (AAP) [24,25]. Adolescents were eligible to participate if they were attending clinic for any visit, were between the ages of 12 and 21 years, understood spoken and written English, and had no documented intellectual disability. Participants 18 years or older provided verbal and written informed consent prior to participation. For participants aged younger than 18 years, we obtained verbal and written assent to participate. We administered a survey to eligible participants onsite in clinic and collected them at the end of their appointment. Self-reported survey responses were anonymous, and we coded surveys with deidentified information. Researchers reviewed surveys upon collection for any concern of actively occurring self-injurious behavior and discussed any concerns with the participant’s provider to determine need for additional safety intervention. Participants could withdraw from the study at any time.

Measures

Authors designed a 40-question survey tool that collected basic demographic information (age, gender, ethnicity), grade level in school, history of being bullied, NSSI thoughts and behaviors, behaviors related to sharing of sexually explicit messages (sexting), and social media use. We based questions related to NSSI thoughts and behaviors on validated survey tools including the Self-Harm Inventory and the Self-Injurious Thoughts and Behaviors Interview [26,27]. These questions recorded responses related to frequency, duration, method, and communication of NSSI thoughts and behaviors. Survey questions also recorded responses to frequency, duration, and type of sexually explicit messages shared with questions based on the proposed Sexting Behaviors Scale [28]. This proposed survey tool was used as a guide as validated measures of sexting behaviors have not been well developed or studied [29]. Questions regarding social media, recorded total time spent on social media per day, and the number and type of social media applications used were also included. We also surveyed adolescents on how they use social media (messaging/texts, photos, videos, meeting people, or other). All survey responses for high-risk behaviors were self-reported.

Statistical Analysis

Statistical analysis was performed using SPSS Statistics version 22 (IBM Corp). We used descriptive statistics to summarize numerical survey data. We used chi-square tests to assess for associations between categorical variables and computed the association of social media use with high-risk behaviors as relative risks and reported confidence intervals as 95%. Due to missing data, there is some variability in denominators across variables.

Results

Participant Demographics

A total of 179 adolescents completed anonymous surveys. Most survey respondents were female (120/179, 67.0%). The mean age of respondents was 16.8 (SD 2.5) years. The sample of adolescents was ethnically diverse and included white, black, Hispanic, and Asian adolescents, with Asian adolescents making up the largest percentage of respondents (53/179, 29.6%). The highest percentage of respondents reported parents as married (76/179, 42.4%). Table 1 provides additional demographic data.

A total of 41.3% (74/179) of adolescents reported being bullied, with verbal threats, taunting, or teasing as the most common type of bullying (53/179, 29.6%). A statistically significant difference was found in the number of bullied male respondents versus the number of bullied female respondents (24.0% [14/58] vs 49.0% [59/118]; *P*=.001). There was no statistically significant difference in being bullied reported across race.

Table 1. Participant demographics (n=179).

Variable	Value
Gender, n (%)	
Male	58 (32.4)
Female	120 (67.0)
Other	1 (0.6)
Age in years, mean (SD)	16.8 (2.2)
Grade level, n (%)	
Sixth	4 (2.2)
Seventh	4 (2.2)
Eighth	17 (9.5)
Ninth	14 (7.8)
Tenth	16 (8.9)
Eleventh	28 (15.6)
Twelfth	21 (11.7)
College	33 (18.4)
Missing	42 (23.5)
Average grades, n (%)	
Mostly As	46 (25.7)
Mostly Bs	90 (50.3)
Mostly Cs	25 (14.0)
Mostly Ds	0 (0)
Missing	18 (10.0)
Race/ethnicity, n (%)	
White, non-Hispanic	36 (20.1)
White, Hispanic	16 (8.9)
Black, Hispanic	13 (7.3)
Black, non-Hispanic	41 (22.9)
American Indian/Alaska Native	0 (0)
Asian	53 (29.6)
Other	15 (8.4)
Missing	5 (2.8)
Being bullied, n (%)	
Yes	74 (41.3)
No	103 (57.5)
Missing	2 (1.1)
Parent marital status, n (%)	
Married	76 (42.5)
Single	43 (24..0)
Separated	24 (13.4)
Divorced	24 (13.4)
Widowed	3 (1.7)
Other	5 (2.8)
Missing	4 (2.2)

Social Media Use

A total of 93.8% (168/179) of adolescent respondents reported at least 1 hour of social media use per day, with 3 to 5 hours of social media use per day being the most common (63/179, 35.2%).

Most adolescents reported mixed use of social media with 75.4% (135/179) using social media for messaging, texting, or online chatting. Of those adolescents who reported using social media, nearly 40% (71/179, 39.7%) used 4 or more social media platforms. There was no difference in social media use by race or gender.

Self-Harm (Nonsuicidal Self-Injury)

One in five adolescents endorsed a history of having thoughts of self-harm (35/179, 19.6%). The mean age of first thoughts of self-harm was 11.8 (SD 2.5) years. Of those adolescents who reported having thoughts of self-harm, more than half (20/35, 57%) reported those thoughts occurring a few times per year, and 69% (24/35) had shared those thoughts with their friends. More than 40% (78/179, 43.6%) of adolescents reported knowing their friends had self-harm thoughts. Of the adolescents who reported thoughts of self-harm, 74% (26/35) reported being bullied compared to 33.3% (47/141) of adolescents who reported no thoughts of self-harm (*P*<.001). Females reported more self-harm thoughts than males (82% [28/34] vs 18% [6/34]; *P*=.01). Asian adolescents reported more self-harm thoughts than adolescents of any other racial group (12/31, 39%, *P*=.01).

Nearly 1 in 8 (22/179, 12.3%) adolescents endorsed a history of engaging in self-injurious behaviors and reported cutting as the most common behavior (17/22, 77%). The mean age of first engaging in self-harm was 11.8 (SD 4.6) years. Of those adolescents who reported engaging in self harm, 41% (9/22) engaged in self-harm a few times per year. Almost one-third (56/179, 31.2%) of adolescents reported knowing their friends engaged in self-injurious behaviors. Of those adolescents who communicated with their friends about engaging in self-harm, more than a quarter (10/34, 29%) communicated those thoughts via social media. Of the adolescents who reported engaging in self-injurious behaviors, 68% (15/22) reported being bullied, compared with 36.7% (47/128) of adolescents with no self-injurious behaviors (*P*=.06). Females reported more self-injurious behaviors than males (77% [17/22] vs 18% [4/22]; *P*=.001). Other race adolescents reported more self-harm compared adolescents of any other racial group (10/22, 45%; *P*<.001).

Sexting

Two-thirds (120/179, 67.0%) of adolescents reported texting with friends more than once per day. Over a quarter (49/179, 27.4%) of adolescents reported that they shared sexually explicit messages with others, with texting as the most common form of communication (41/49, 84%). Adolescents shared sexually explicit messages with multiple people, with boyfriends and girlfriends as the most common (34/49, 69%). Of those adolescents who shared sexually explicit messages, most responded they did it when someone asked for them (12/49, 25%). Almost one-third (57/179, 31.8%) of adolescents knew of someone who had a bad experience from sharing sexually explicit messages. There was no difference in sexting across race or gender. Tables 2 and 3 provide a summary of self-harm and sexting behavior reported in adolescents.

Table 2. Summary of self-harm behaviors reported by adolescents (n=22).

Characteristic	Value, n (%)
Self-harm subtype	
Cutting	17 (77)
Burning	3 (14)
Scratching	10 (46)
Hitting	14 (64)
Skin picking	7 (32)
Other	0 (0)
Frequency	
Every day	0 (0)
A few times per week	5 (23)
A few times per month	6 (27)
A few times per year	9 (41)

Table 3. Summary of sexting behaviors reported by adolescents (n=49).

Characteristic	Value, n (%)
Sexting subtype	
Text	41 (84)
Photo of self	25 (51)
Photo of someone else	29 (59)
Video of self	7 (14)
Video of someone else	8 (16)
Recipient	
Classmates	11 (22)
Boyfriend/girlfriend	34 (69)
Other friends/neighbors	10 (20)
Online friends	4 (8)
Reason	
Someone asked	12 (25)
Without being asking	6 (12)
In return for photos	11 (22)
Peer pressure	2 (4)
Other	19 (39)

Risk of Self-Harm (Nonsuicidal Self-Injury)

Table 4 shows the relative risks for thoughts of self-injury, self-injurious behaviors, sexting, or any of those behaviors compared with the amount of social media use, including hours per day and number of applications used. The relative risk of any high-risk behavior (self-harm, sexting, or both) was 1.66 in adolescents who used 4 or more social media applications at a time (95% CI 1.11-2.48). Relative risk of high-risk behaviors was greater than 1.00 for social media use of more than 5 hours per day, but these findings were not statistically significant.

Table 4. Risk of self-harm/risk-taking behavior with social media use.

Social media use and self-harm/risk-taking behavior	Relative risk (95% CI)
Any social media use	
Thoughts of self-harm	0.48 (0.16-1.46)
Self-harm behaviors	0.45 (0.09-2.32)
Sexting	0.69 (0.63-0.77)
Self-harm, sexting, or both	1.22 (0.24-6.13)
Use of 4 or more social media applications	
Thoughts of self-harm	1.02 (0.55-1.87)
Self-harm behaviors	1.33 (0.62-2.88)
Sexting	1.96 (1.00-3.87)
Self-harm, sexting, or both	1.66 (1.11-2.48)
>5 hours of social media use per day	
Thoughts of self-harm	1.11 (0.59-2.06)
Self-harm behaviors	1.31 (0.60-2.84)
Sexting	1.57 (0.99-2.50)
Self-harm, sexting, or both	1.32 (0.8-1.98)

Discussion

Principal Findings

Our results suggest a positive association between the number of social media platforms used and increased rates of high-risk behaviors in adolescents, including NSSI and sharing of sexually explicit content. This was evidenced by the relative risk of 1.66 (95% CI 1.11-2.48) for any high-risk behavior (self-harm, sexting, or both) in adolescents who reported use of 4 or more social media applications. Although not statistically significant, our data implies increased rates of sharing of sexually explicit messages in respondents who reported more than 5 hours of social media use per day (relative risk 1.57; 95% CI 0.99-2.495). These findings are particularly relevant as adolescents overall reported a large amount of daily social media use, with nearly all of those surveyed meeting the criteria for heavy use [30].

The amount of social media use that adolescents self-reported in this study is not surprising given the findings of the latest report issued by the Pew Research Center in 2018 where 45% of teens reported being online almost constantly, an increase of more than 20% from 2014-2015 [31]. Diverse use and engagement in multiple online social media platforms as reported by the adolescents in our study are also consistent with data from the same report by the Pew Research Center in which teens reported rates of use across multiple platforms [31]. With the advent of social media applications directed for text-based communication, adolescents also have the capacity to exchange greater numbers of texts and messages [32].

Increased screen time and digital media use have previously been associated with other health risks in children and adolescents, including obesity and cardiovascular risk as well as decreased sleep and poorer sleep quality [32,33]. Greater attention has also been brought to the mental health risks of social media use including higher rates of depression (also known as Facebook depression) and anxiety [34,35]. High-risk behaviors including rates of alcohol consumption have been associated with increased social media use as well [36]. It is therefore not surprising that engaging in additional high-risk behaviors such as those examined in this study would have a similar association with increased social media exposure.

While our study surveyed patients ages 12 to 21 years, the results indicate that the average age at which young people first experienced thoughts of self-harm and the average age at which they report first engaging in self-injurious behaviors was 11.8 years. This is consistent with existing literature which generally reports age at onset of self-injurious behaviors to range from 11 to 15 years and suggests a need for further study among younger patients [37,38]. Also similar to prior studies, we found youth identified cutting as the most common method of self-harm and females were substantially more likely than males to endorse thoughts of self-harm and report a history of engaging in NSSI [39].

Adolescents in our study reported awareness of friends engaging in self-harm, and social media was identified as method by which adolescents self-reported sharing thoughts and actions of self-harm with others. Some social media platforms have taken steps to limit the sharing of explicit photos or messages of self-harm [1,40]. Adolescents who are aware of and exposed to posts about self-harm on social media may experience changes in their perception or attitude toward self-harm behavior including normalization [41]. Given the speed at which new social media platforms are being developed, a significant challenge remains for developers to be able to moderate content and promote safety for all users.

In addition to identifying these specific risk factors, our study generates concern for the growing rates of these high-risk behaviors seen in adolescents of all ages, genders, and backgrounds—not just adolescents referred for psychiatric evaluation or treatment [42]. Our results found the prevalence of non-suicidal self-injurious behaviors consistent with existing evidence but revealed higher rates of sharing of sexually explicit messages than previously estimated [12,17].

There is concern that adolescents may not fully appreciate the consequences of sharing sexually explicit content through texting or social media and are particularly uneducated regarding issues related to privacy [32]. There are discrepancies in what adolescents believe to be public vs private content [43]. Teens may also be taking advantage of hidden apps or storage apps in an effort to shield online behavior from parents [43]. This may limit the knowledge parents have about adolescent behavior online, which in turn could significantly limit the opportunity for discussion between parents and teens regarding safe internet practices. The AAP has promoted raising awareness of healthy online behaviors and offers a guide to parents on how to create a family media use plan [44].

Additional studies to expand upon our findings and further explore how specific patterns of social media use relate to increased risk of high-risk behaviors will help to delineate more concrete thresholds (ie, duration daily of use, number of platforms used) that can be used for counseling and screening purposes. Areas of future study may include evaluation of the relationship between social media use and psychiatric comorbidities, with additional focus on preadolescent behavior, as well as identification of protective factors that might inform clinicians and parents how best to foster healthy use of social media in children and adolescents. Due to previously identified risk, efforts to screen for social media and internet use have been recommended by American College of Obstetrics and Gynecology as well as the AAP for adolescents during clinical visits [45,46].

Limitations

Limitations of our study include the small sample size based on a nonrandom sample and lack of generalizability due to our sample population being taken from a single urban medical center. A larger sample size could potentially show a stronger association between the extent of social media use and incidence of high-risk behaviors. While we had a relatively racially heterogeneous sample, our results may not necessarily be generalizable to the population at large as our study was conducted in an urban medical center and our sample consisted of a majority of females and higher proportion of Asian adolescents. In addition, respondents were limited to those able to understand written and spoken English, which likely introduced further bias to our results. Although participants were able to self-report behaviors anonymously, due to the sensitive nature of some survey questions, some reporting bias is expected. Lastly, we did not assess for comorbidities. Further studies may assess whether adolescents with psychiatric comorbidities such as anxiety or depression are more likely to engage in more extensive social media use and whether there are discrepancies in risk when comparing adolescents with and without psychiatric comorbidities.

Conclusion

Social media access is ubiquitous among adolescents. With high rates of self-reported use, there is also concern for engagement in other high-risk behaviors. This study demonstrates the potential for increased risk of NSSI and exchange of sexually explicit messages with higher levels of social media use. Sharing of self-harm practices on social media or using social media to share sexually explicit content as reported by adolescents in this study may essentially normalize these high-risk behaviors. Although there are notable limitations to this study, it highlights the importance of screening for social media use, including duration of daily use and number of applications used, so that clinicians and parents may have an opportunity to address concerns and provide guidance and education on safe internet use for adolescents and their families.

Conflicts of Interest

None declared.

References

1. Leonard K. US News & World Report. 2015 May 29. Is social media making self-harm worse for teens? URL: https://www.usnews.com/news/articles/2015/05/29/is-social-media-making-self-harm-worse-for-teens [accessed 2020-03-17]
2. George M. The importance of social media content for teens' risks for self-harm. J Adolesc Health 2019 Jul;65(1):9-10. [doi: 10.1016/j.jadohealth.2019.04.022] [Medline: 31229057]
3. House A. Social media, self-harm and suicide. BJPsych Bull 2020 Jan 20:1-3 [FREE Full text] [doi: 10.1192/bjb.2019.94] [Medline: 31957627]
4. Editorial. Social media, screen time, and young people's mental health. Lancet 2019 Feb 16;393(10172):611. [doi: 10.1016/S0140-6736(19)30358-7] [Medline: 30782327]
5. Van Dijk J. Engineering sociality in a culture of connectivity. In: The Culture of Connectivity: A Critical History of Social Media. New York: Oxford University Press; 2013.
6. Belfort EL, Miller L. Relationship between adolescent suicidality, self-injury, and media habits. Child Adolesc Psychiatr Clin N Am 2018 Apr;27(2):159-169. [doi: 10.1016/j.chc.2017.11.004] [Medline: 29502743]
7. Richards D, Caldwell PH, Go H. Impact of social media on the health of children and young people. J Paediatr Child Health 2015 Dec;51(12):1152-1157. [doi: 10.1111/jpc.13023] [Medline: 26607861]
8. Mars B, Heron J, Biddle L, Donovan JL, Holley R, Piper M, et al. Exposure to, and searching for, information about suicide and self-harm on the Internet: prevalence and predictors in a population based cohort of young adults. J Affect Disord 2015 Oct 01;185:239-245 [FREE Full text] [doi: 10.1016/j.jad.2015.06.001] [Medline: 26150198]
9. Sampasa-Kanyinga H, Hamilton HA. Social networking sites and mental health problems in adolescents: the mediating role of cyberbullying victimization. Eur Psychiatry 2015 Nov;30(8):1021-1027. [doi: 10.1016/j.eurpsy.2015.09.011] [Medline: 26512450]
10. Hökby S, Hadlaczky G, Westerlund J, Wasserman D, Balazs J, Germanavicius A, et al. Are mental health effects of internet use attributable to the web-based content or perceived consequences of usage? A longitudinal study of European adolescents. JMIR Ment Health 2016 Jul 13;3(3):e31 [FREE Full text] [doi: 10.2196/mental.5925] [Medline: 27417665]
11. Daine K, Hawton K, Singaravelu V, Stewart A, Simkin S, Montgomery P. The power of the web: a systematic review of studies of the influence of the internet on self-harm and suicide in young people. PLoS One 2013;8(10):e77555 [FREE Full text] [doi: 10.1371/journal.pone.0077555] [Medline: 24204868]
12. Moreno MA, Ton A, Selkie E, Evans Y. Secret society 123: understanding the language of self-harm on Instagram. J Adolesc Health 2016 Jan;58(1):78-84 [FREE Full text] [doi: 10.1016/j.jadohealth.2015.09.015] [Medline: 26707231]
13. Jacob N, Evans R, Scourfield J. The influence of online images on self-harm: a qualitative study of young people aged 16-24. J Adolesc 2017 Oct;60:140-147 [FREE Full text] [doi: 10.1016/j.adolescence.2017.08.001] [Medline: 28881214]
14. Memon AM, Sharma SG, Mohite SS, Jain S. The role of online social networking on deliberate self-harm and suicidality in adolescents: a systematized review of literature. Indian J Psychiatry 2018;60(4):384-392 [FREE Full text] [doi: 10.4103/psychiatry.IndianJPsychiatry_414_17] [Medline: 30581202]
15. Shanahan N, Brennan C, House A. Self-harm and social media: thematic analysis of images posted on three social media sites. BMJ Open 2019 Feb 19;9(2):e027006 [FREE Full text] [doi: 10.1136/bmjopen-2018-027006] [Medline: 30782950]
16. Fliege H, Kocalevent R, Walter OB, Beck S, Gratz KL, Gutierrez PM, et al. Three assessment tools for deliberate self-harm and suicide behavior: evaluation and psychopathological correlates. J Psychosom Res 2006 Jul;61(1):113-121. [doi: 10.1016/j.jpsychores.2005.10.006] [Medline: 16813853]

17. O'Connor RC, Rasmussen S, Hawton K. Adolescent self-harm: a school-based study in Northern Ireland. J Affect Disord 2014 Apr;159:46-52. [doi: 10.1016/j.jad.2014.02.015] [Medline: 24679388]
18. Lewis SP, Santor DA. Self-harm reasons, goal achievement, and prediction of future self-harm intent. J Nerv Ment Dis 2010 May;198(5):362-369. [doi: 10.1097/NMD.0b013e3181da8500] [Medline: 20458199]
19. Mitchell KJ, Finkelhor D, Jones LM, Wolak J. Prevalence and characteristics of youth sexting: a national study. Pediatrics 2012 Jan;129(1):13-20. [doi: 10.1542/peds.2011-1730] [Medline: 22144706]
20. Houck CD, Barker D, Rizzo C, Hancock E, Norton A, Brown LK. Sexting and sexual behavior in at-risk adolescents. Pediatrics 2014 Feb;133(2):e276-e282 [FREE Full text] [doi: 10.1542/peds.2013-1157] [Medline: 24394678]
21. Englander E. Low risk associated with most teenage sexting: a study of 617 18-year-olds. Bridgewater: Massachusetts Aggression Reduction Center, Bridgewater State University; 2012. URL: https://vc.bridgew.edu/cgi/viewcontent.cgi?article=1003&context=marc_reports [accessed 2020-04-23]
22. Henderson L. Sexting and sexual relationships among teens and young adults. McNair Scholars Res J 2011;7(1):31-39 [FREE Full text]
23. Livingstone S, Smith PK. Annual research review: harms experienced by child users of online and mobile technologies: the nature, prevalence and management of sexual and aggressive risks in the digital age. J Child Psychol Psychiatry 2014 Jun;55(6):635-654. [doi: 10.1111/jcpp.12197] [Medline: 24438579]
24. AAPCCAH. American Academy of Pediatrics Council on Child and Adolescent Health: age limits of pediatrics. Pediatrics 1988 May;81(5):736. [Medline: 3357740]
25. Bright Futures/American Academy of Pediatrics. Recommendations for preventative pediatric health care. 2017. URL: https://downloads.aap.org/AAP/PDF/periodicity_schedule.pdf [accessed 2020-04-23]
26. Sansone RA, Sansone LA. Measuring self-harm behavior with the self-harm inventory. Psychiatry (Edgmont) 2010 Apr;7(4):16-20 [FREE Full text] [Medline: 20508804]
27. Nock MK, Holmberg EB, Photos VI, Michel BD. Self-Injurious Thoughts and Behaviors Interview: development, reliability, and validity in an adolescent sample. Psychol Assess 2007 Sep;19(3):309-317. [doi: 10.1037/1040-3590.19.3.309] [Medline: 17845122]
28. Dir AL. Understanding sexting behaviors, sexting expectancies, and the role of impulsivity in sexting behaviors [Thesis]. Indianapolis: Purdue University; May 2012.
29. DiClemente RJ. Validity of self-reported sexual behavior among adolescents: where do we go from here? AIDS Behav 2016 Jan;20 Suppl 1:S215-S217. [doi: 10.1007/s10461-015-1217-5] [Medline: 26459333]
30. Common Sense Research Study. Common Sense Media. Social media, social live: how teens view their digital lives URL: https://www.commonsensemedia.org/file/socialmediasociallife-final-061812pdf-0/download [accessed 2020-04-23]
31. Anderson A, Jiang J. Teens social media and technology 2018. Washington: Pew Internet and American Life Project; 2018. URL: https://www.pewresearch.org/internet/wp-content/uploads/sites/9/2018/05/PI_2018.05.31_TeensTech_FINAL.pdf [accessed 2020-04-23]
32. Reid CYL, Radesky J, Christakis D, Moreno MA, Cross C, Council on Communications and Media. Children and adolescents and digital media. Pediatrics 2016 Nov;138(5) [FREE Full text] [doi: 10.1542/peds.2016-2593] [Medline: 27940795]
33. Woods HC, Scott H. #Sleepyteens: social media use in adolescence is associated with poor sleep quality, anxiety, depression and low self-esteem. J Adolesc 2016 Aug;51:41-49. [doi: 10.1016/j.adolescence.2016.05.008] [Medline: 27294324]
34. Yoon S, Kleinman M, Mertz J, Brannick M. Is social network site usage related to depression? A meta-analysis of Facebook-depression relations. J Affect Disord 2019 Apr 01;248:65-72. [doi: 10.1016/j.jad.2019.01.026] [Medline: 30711871]
35. Muzaffar N, Brito EB, Fogel J, Fagan D, Kumar K, Verma R. The association of adolescent Facebook behaviours with symptoms of social anxiety, generalized anxiety, and depression. J Can Acad Child Adolesc Psychiatry 2018 Nov;27(4):252-260 [FREE Full text] [Medline: 30487941]
36. Brunborg GS, Andreas JB, Kvaavik E. Social media use and episodic heavy drinking among adolescents. Psychol Rep 2017 Jun;120(3):475-490. [doi: 10.1177/0033294117697090] [Medline: 28558617]
37. Stallard P, Spears M, Montgomery AA, Phillips R, Sayal K. Self-harm in young adolescents (12-16 years): onset and short-term continuation in a community sample. BMC Psychiatry 2013 Dec 02;13:328 [FREE Full text] [doi: 10.1186/1471-244X-13-328] [Medline: 24294921]
38. Vega D, Sintes A, Fernández M, Puntí J, Soler J, Santamarina P, et al. Review and update on non-suicidal self-injury: who, how and why? Actas Esp Psiquiatr 2018 Jul;46(4):146-155 [FREE Full text] [Medline: 30079928]
39. Zhu L, Westers NJ, Horton SE, King JD, Diederich A, Stewart SM, et al. Frequency of exposure to and engagement in nonsuicidal self-injury among inpatient adolescents. Arch Suicide Res 2016;20(4):580-590. [doi: 10.1080/13811118.2016.1162240] [Medline: 26983456]
40. Jacobs J. New York Times. 2019 Feb 07. Instagram bans graphic images of self-harm after teenager’s suicide URL: https://www.nytimes.com/2019/02/07/technology/instagram-self-harm-ban.html [accessed 2020-04-23]
41. Record RA, Straub K, Stump N. #Selfharm on #Instagram: examining user awareness and use of Instagram's self-harm reporting tool. Health Commun 2019 Apr 08:1-8. [doi: 10.1080/10410236.2019.1598738] [Medline: 30961389]

42. Shafi RMA, Nakonezny PA, Romanowicz M, Nandakumar AL, Suarez L, Croarkin PE. The differential impact of social media use on middle and high school students: a retrospective study. J Child Adolesc Psychopharmacol 2019 Dec;29(10):746-752. [doi: 10.1089/cap.2019.0071] [Medline: 31233343]
43. Homayoun A. New York Times. 2017 Jun 07. The secret social media lives of teenagers URL: https://www.nytimes.com/2017/06/07/well/family/the-secret-social-media-lives-of-teenagers.html [accessed 2020-01-01]
44. American Academy of Pediatrics. 2019 Nov 05. How to make a family media use plan URL: https://www.healthychildren.org/English/family-life/Media/Pages/How-to-Make-a-Family-Media-Use-Plan.aspx [accessed 2020-04-23]
45. American College of Obstetricians and Gynecologists' Committee on Adolescent Health Care. Committee Opinion No. 653: Concerns regarding social media and health issues in adolescents and young adults. Obstet Gynecol 2016 Feb;127(2):e62-e65. [doi: 10.1097/AOG.0000000000001313] [Medline: 26942388]
46. Clark DL, Raphael JL, McGuire AL. HEADS4: social media screening in adolescent primary care. Pediatrics 2018 Jun;141(6):e201736555 [FREE Full text] [doi: 10.1542/peds.2017-3655] [Medline: 29716979]

Abbreviations

AAP: American Academy of Pediatrics
NSSI: nonsuicidal self-injury

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Original Paper

Perspectives of Nurses and Doulas on the Use of Information and Communication Technology in Intercultural Pediatric Care: Qualitative Pilot Study

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Abstract

Background: Sweden is rapidly becoming an increasingly multicultural and digitalized society. Encounters between pediatric nurses and migrant mothers, who are often primary caregivers, are impeded by language problems and cultural differences. To support mothers, doulas, who are women having the same linguistic and cultural backgrounds, serve as cultural bridges in interactions with health care professionals. In addition, information and communication technology (ICT) can potentially be used to manage interactions owing to its accessibility.

Objective: The objective of this study was to investigate the role of ICT in managing communicative challenges related to language problems and cultural differences in encounters with migrant mothers from the perspectives of Swedish pediatric nurses and doulas.

Methods: Deep semistructured interviews with five pediatric nurses and four doulas from a migrant-dense urban area in western Sweden were audio recorded, transcribed, and analyzed using thematic content analysis.

Results: The results showed that ICT contributes to mitigating communicative challenges in interactions by providing opportunities for nurses and migrant mothers to receive distance interpreting via telephones and to themselves interpret using language translation apps. Using images and films from the internet is especially beneficial while discussing complex and culturally sensitive issues to complement or substitute verbal messages. These findings suggest that ICT helps enable migrant mothers to play a more active role in interactions with health care professionals. This has important implications for their involvement in other areas, such as child care, language learning, and integration in Sweden.

Conclusions: The findings of this study suggest that ICT can be a bridging tool between health care professionals and migrants. The advantages and disadvantages of translation tools should be discussed to ensure that quality communication occurs in health care interactions and that health information is accessible. This study also suggests the development of targeted multimodal digital support, including pictorial and video resources, for pediatric care services.

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KEYWORDS

child care; migrant mother; nurse; doula; smartphone; mobile phone; Google Translate; internet, mHealth; digital health; intercultural communication

Introduction

Migration and Child Care in Sweden

At present, about 20% of the Swedish population is foreign-born [1]. Because of increased migration, intercultural encounters in pediatric care are becoming common. Many families of non-European background who migrate to Sweden with small children live in disadvantaged areas that are characterized by poor socioeconomic conditions [2,3]. Low income, insufficient Swedish language competence, and poor knowledge about health programs may have adverse impacts on the health of children in terms of mortality, morbidity, and injuries, and they could be determinants of physical and mental ill health in the future [4].

Being a parent and a migrant is a complex and challenging experience. Facing different health and social systems and lacking supporting social networks, such as relatives and friends, may result in psychological distress and depression [5]. This often causes migrants to avoid contact with locals in general and health care providers in particular, thereby deepening social exclusion [6,7]. As in many non-Western societies, mothers are the primary caregivers, and their contact and communication with pediatric nurses are essential for their health and the health of their children and families [8,9].

Child health care (CHC) centers led by a pediatric nurse or a district nurse offer free preventive health care to 99% of children in Sweden. Nurses assess child development, vaccines, nutrition issues, and parental health, including sleeping and breastfeeding, as well as social and family issues [10]. In meetings between migrants and health care staff, language problems are known to be a major barrier for communication, resulting in a lack of understanding, insecurity, and low engagement during interactions [11,12]. Although people without the ability to communicate in Swedish have a statutory right to interpreters [13,14], the use of interpreters is often challenging owing to patient refusal, lack of authorized interpreters, time shortage, etc [11,15-17]. Apart from language problems, cultural differences regarding beliefs, values, and practices often have a considerable impact on interactions in health care contexts [18-20]. Cultural competence and sensitivity when staff engage with migrant parents, as well as respectfulness, understanding, and cultural knowledge of the large ethnic minority groups living in the country are prerequisites for developing a trustful relationship and providing quality care in a multicultural society [8,21-23].

To support migrant parents’ interactions with individuals in the Swedish health care system, doula culture interpreters are available during pregnancy and birth and in the postpartum period. Doula (from Greek δοὐλα, doula, [pron. / ðula/], “servant woman”) is a migrant mother, who has Swedish knowledge and is willing to act as a “cultural bridge“ between mothers with the same cultural background and individuals in the Swedish health care system. The tasks of doulas include offering support during and after pregnancy, giving informal advice and information about health care services, and providing assistance during interactions with health care staff [24-26]. At this moment, 35 doulas are available in Gothenburg, and they are financially supported by the county council Region Västra Götaland (Western Sweden) [26,27].

Digitalization and Migrant Care

Increasing digitalization in Europe, particularly in Sweden, is another barrier in terms of the digital skills gap that many low-skilled migrants must overcome when entering the host society [28-30]. Yet, from another perspective, information and communication technology (ICT), defined as a “diverse set of technological tools and resources used to transmit, store, create, share, or exchange information” [31], which includes computers, the internet, broadcasting, and telephony, provides integration support for developing contacts with locals [32], learning language and culture [33-35], and obtaining information about health care services [36].

With the purpose of mitigating linguistic barriers in communication between migrants with limited language competence and health care providers, mobile medical translation apps, such as American Canopy speak [37], Spanish Universal doctor [38], Australian CALD assist [39], and Swedish Care to Translate [40], provide translations, phonetic scripts, and audio recordings in minority languages for the different phases of consultation (eg, greeting and diagnosis). Although these types of apps are useful for communicating preset phrases, they are not able to replace professional interpreters [39,41]. To manage interactions with illiterate migrants, picture-based information and communication boards, partially available online, have been developed [42]. In addition, Google Translate, though criticized, is often used to manage language problems in intercultural interactions [32,43].

Currently, little is known about the use of ICT for managing communication between migrants with limited language competence and staff in pediatric contexts. More specifically, research on the role of technology for handling cultural differences in interactions is also limited [41,44]. This study explores the role of ICT in managing communicative challenges related to language and cultural barriers in interactions with migrant mothers from the perspectives of Swedish nurses and doulas.

Methods

Study Location

The study was conducted in a migrant-dense urban area in western Sweden. A qualitative inductive approach was chosen to identify patterns in data in an unprejudiced way [45]. Purposive sampling [46] was used for participant recruitment to obtain respondents with experience in communicating with migrant mothers.

Recruitment

The author RRP contacted the chief nurses in three CHC centers in the chosen area of Gothenburg by email to inform them about the study. One center showed interest in participating in the project. The main reason for refusal by the other centers was time constraints.

Both authors received an invitation to present the study to nurses, who had experience working with migrant mothers, at a morning meeting. Five female Swedish nurses (aged 34-65 years), who were native Swedish speakers, agreed to participate in the interviews.

The author RRP also contacted the Doulas and Cultural Interpreters center via email and was invited to present the study to the doulas. Four doulas (aged 35-60 years) from Somalia, Iran, and Iraq, who had worked for 2-10 years as doulas, volunteered to participate.

Data Collection

Semistructured interviews with five nurses and four doulas were conducted from February to May 2018. The interviews with nurses were conducted by both authors at the CHC center, whereas the author RRP conducted interviews with the doulas at the Doulas and Cultural Interpreters center. A semistructured interview guide for nurses and doulas was developed and piloted in five students, which resulted in minor changes (Table 1).

The interviews were audio recorded upon receiving written consent. Each interview lasted between 45 and 60 minutes. The total interview time was 417 minutes. The interviews focused on the experiences of doulas and nurses when communicating with migrant mothers and on the use of ICT for managing interactions.

Table 1. Interview guide.

Questions	Probes
What communicative problems influence your interaction with migrant mothers?	Word finding problems? Understanding problems? Cultural differences? Which ones?
How do you solve these problems?	By yourself? Getting help from interpreters? From mothers?
How is technology used in your interactions with migrant mothers to manage communicative problems?	The Internet? Stationary phones? Smartphones? Computers? Other tools? To manage language problems? To communicate culturally related issues?

The research was a part of the “Integration With Mobiles: Developing Language and Intercultural Communication Support for Integration of Newly Arrived Migrants” project approved by the Ethics Review Board of the Department of Applied Information Technology, University of Gothenburg, Gothenburg, Sweden (registration number: 538-17).

Data Analysis

The interviews were transcribed verbatim in Swedish, translated into English by the author RRP, and checked against the original audio recording by the author NBL. Thematic content analysis was used for evaluation [47]. Data analysis involved an iterative process of listening to the interviews, reading the transcriptions, assigning codes, and finally determining patterns in the material. Both authors read the transcripts independently several times and assigned codes. Thereafter, the codes were sorted into different categories. The codes that had a high degree of agreement between the coders were discussed and sorted into subthemes. The subthemes were organized into overarching themes.

Results

Identified Themes

The following three broad themes were derived from the data in relation to the use of ICT to manage language problems and cultural differences in interactions: (1) using formal and informal distance interpreting; (2) using mobile translation apps; and (3) using images and films as a substitute for or complement to verbal messages.

Using Formal and Informal Distance Interpreting

Nurses mentioned that many mothers they met on a daily basis had limited or no command of the Swedish language. A common view was that language problems were the most frequent challenge to overcome. Although professional interpreters were often available, in some situations, it was not possible to get them to come to the CHC center, and distance interpreting was arranged via stationary phones. Nurses acknowledged that this approach solved immediate communication needs, but they expressed skepticism about the quality of the interpreting service as follows:

> *The (phone) interpreter is unable to see what the children, nurse, and mother are doing in the room. It doesn't work so well. Especially when the child is older; there are so many things to do: to talk a little with her, to sit and draw with her here... the young sister screaming at the back. The interpreter misses a part...* [Nurse #2]

Lack of visual cues in combination with disturbances due to the presence of children and other family members was mentioned. Distance interpreting was also perceived as impersonal, which resulted in many mothers refusing this communication medium. Some interviewees argued that being unwilling to talk about health problems with interpreters owing to their perception as strangers and the fear that they would breach confidentiality was another reason for migrants avoiding professional interpreters. Both nurses and doulas reported that many mothers preferred to call their relatives, friends, or doulas using private smartphones and ask for mediating interactions rather than using professional interpreters. Mobile apps, such as WhatsApp and Viber, were commonly used. The following statement was made:

> *Many call their friends and their husbands who are at work and ask for help.* [Nurse #1]

Although nurses were critical about mothers involving informal interpreters, they had to accept the situation to avoid conflicts. The main concerns, apart from the quality of interpreting (often it was the older children in the family who acted as informal interpreters because they spoke better Swedish than their mothers, fathers, or mothers’ friends), were the lack of face-to-face contact and poor connection quality, which complicated understanding.

Doulas spoke about getting calls from mothers (ie, the mothers they were responsible for) and requests to interpret interactions with nurses, without prior notice. One doula commented as follows:

> *Sometimes we just get a call from the Child Health Center when they (a mother and a nurse) don't have an interpreter, and we interpret for them.* [Doula #1]

For doulas, an unplanned interpreting request was an additional task to perform, which led to frustration resulting from the blurred line between work as a doula and their private life. As mothers could call them on their private numbers and ask for help at any time, some doulas felt pressed to be constantly “connected” on their smartphones. All doulas commented on feeling bad about refusing to help mothers coming from the same country, as it could jeopardize their relationship. Concerns about not always being able to provide spontaneous support and being worried about not having enough knowledge to interpret appropriately were also expressed.

Using Mobile Translation Apps

Participants mentioned migrant mothers refusing both formal and informal interpreting in meetings with nurses, which was motivated by having sufficient linguistic competence, as well as an unwillingness to involve anyone else in the interaction. Some mothers overestimated their Swedish proficiency, which required nurses to speak slower, use shorter simplified phrases, repeat their statements, and use gestures to illustrate what was meant. Drawing/writing on paper, writing the names of medicines, and using English or other languages was also mentioned. Concerning technology use, Google Translate was reported to be the most common (apart from Lexin, which is a Swedish online dictionary for Swedish and main minority languages in the country) and often the only translation app used. Nurses and doulas were positive about this translation app and mentioned encouraging mothers to “Google” and translate Swedish words into their native language. One doula said the following:

> *Sometimes I ask them (mothers) to Google translate, for instance the word mucus plug (into their language). I show that they can manage themselves (without my help).* [Doula #3]

In some cases, if longer text needed to be translated (eg, a website), nurses reported mothers “copying and pasting” it directly into Google. Talking about this issue, a nurse said the following:

> *I have parents who speak good Swedish, but when they need to write something, they use Google Translate. They scan the text and then you get the translation.* [Nurse #3]

Using Images and Films as a Substitute for or Complement to Verbal Messages

Although Google Translate was primarily used to manage language problems, doulas and nurses reported showing images and videos from the internet on computer screens and mothers doing the same on their smartphones for managing language problems, as well as facilitating communication about cultural issues.

In situations where there was insufficient language or uncertainty about understanding, images from the internet served as a substitute for or complement to verbal communication to ensure understanding. A nurse commented as follows about using an image to illustrate baby food in a jar to complement the verbal message when she was unsure if mothers new in Sweden could understand her:

> *I can show the picture sometimes from my computer, so they understand what a prune is. I look for images of jars with beans and broccoli.* [Nurse #2]

Doulas and nurses were concerned about having limited time for interactions with mothers, which, in combination with language difficulties, resulted in stress and problems with allocating time for providing lengthy explanations concerning complex and sensitive issues. Many migrant mothers, especially those with less education, were perceived as having a more traditional perspective on their role as compared with native-born Swedish mothers. Being the primary and only responsible parent for child care resulted in a lack of time for learning Swedish and finding employment. All nurses commented that the CHC center, which was situated in a migrant-dense urban area, was often the only “window” for many mothers to the Swedish society. Not surprisingly, according to both doulas and nurses, many migrant mothers retained their cultural beliefs and values, which were often different from the Swedish cultural beliefs and values that were advocated by nurses. Thus, apart from time pressure and language difficulties, participants feared problems with understanding and mothers taking offence when Swedish cultural values regarding child care collided with the values from their countries of origin.

When talking about culture-sensitive issues in child care, both doulas and nurses reported using images and films from the internet to illustrate what they were trying to say, thereby complementing or substituting verbal messages. One of the most common cultural differences many migrant mothers experience in Sweden is related to nutrition, overweight, and obesity. Both doulas and nurses commented on the preferences of many mothers (eg, those from Somalia and Afghanistan) regarding the use of formula instead of breastfeeding or as a complement to breastfeeding, the addition of sugar to baby food, and the belief that a chubby baby was a sign of well-being, whereas there were differing views in Sweden. Participants reported that showing images of Swedish food from the internet on a computer screen was common when talking about healthy food habits. One nurse said the following:

> *You look for it (food) in Google and show not only the name but how it looks. When you're talking about porridge, for example, not everyone eats porridge as we do in Sweden. I Google and show how it looks. “This is a good porridge. There are others that have a lot of sugar. Avoid this kind!”* [Nurse #4]

The excerpt above shows the nurse using an image as a complement to the recommended porridge name. In addition, she also uses images of other products that contain more sugar, thereby making clear recommendations concerning limiting sugar intake and choosing the right foods.

In relation to weight problems, a doula mentioned using a projector in the center and showing mothers images about the changes to a woman's body after delivery and breastfeeding, inspiring them to exercise for weight loss and go to the gym, which is an issue considered too sensitive to openly discuss. She said the following:

> *We show pictures. We have a projector. We illustrate how you should breastfeed, and we talk about parent education in Sweden, you know. How your body will go back to normal after delivery, going to the gym, etc.* [Doula #1]

Images are also used to help mothers understand more complex concepts, such as maternal-infant bonding. The participants mentioned that many migrant mothers consider bonding with babies in terms of keeping eye contact, playing, reading, and talking as being less important when compared with providing food and care. A doula commented as follows on attempting to show what skin-to-skin contact is using pictures from Google:

> *If I want to show what skin-to-skin contact is, then I Google it. I also ask them (the mothers) to Google. I show that they can do it themselves.* [Doula #3]

A nurse also mentioned regularly using a short film about safety available on the internet to both illustrate the risks at home and rules for child protection expected in Sweden. She said the following:

> *I have a good film on www.dinsakerhet.se ("yoursafety.se"), which is 4 minutes long because it shows burning wounds or a child climbing up on the sofa. In many countries, you do not have car seats. You have no bicycle helmets. You do not have child protection. We have to talk about it…* [Nurse #2]

This respondent stated that it was not easy to explain child protection measures, as many migrant mothers did not understand the difference between car seats for children of different ages and how to use bicycle helmets. As these measures are required by law in Sweden, the nurse felt obliged to inform migrant mothers about these measures. The short film about safety from the website was used to substitute explanations in order to save time. She also commented asking mothers to show the film to their partners and other family members. Another resource mentioned was www.1177.se (Vårdguiden–Health Care Guide), which is available in many languages and could be accessed during and after interactions. Both doulas and nurses complained about sometimes spending too much time on searching for suitable and good quality images and films on the internet (eg, YouTube). They also expressed a need for the development of multimedia resources that were targeted at the pediatric practice for managing intercultural interactions.

Discussion

Principal Findings

This qualitative pilot study explored the experiences of doulas and nurses using ICT to mitigate language problems and cultural differences in interactions with migrant mothers in an immigrant-dense urban area in Sweden.

The results of this study show that ICT contributes to mitigating communicative challenges in interactions by providing opportunities for nurses and migrant mothers to obtain distance interpreting via stationary phones and smartphones if interpreters are not physically present in the CHC center for different reasons [48]. While distance interpreting by professionals is preferred by nurses, migrant mothers prefer to call their friends, relatives, or doulas via private smartphones for informal interpreting [49]. In both cases, although distance interpreting has disadvantages, specifically in terms of sound quality due to poor connection (migrant mothers reported primarily using Voice over Internet Protocol apps, such as WhatsApp and Viber, which require an internet connection) and lack of visual messages [48], technology still helps to solve immediate communication problems. Interestingly, even though both WhatsApp and Viber provide opportunities for video calls, the respondents in this study did not mention using video calls, despite the fact that they can potentially contribute to communicating more visually [50] and possibly improving interpretation quality. The findings that migrant mothers use their smartphones and make active choices to contact informal interpreters indicate that mobile technology and the internet contribute to increased patient-centeredness and empowerment [51] by providing opportunities for solving communication challenges and enabling migrant mothers to take more responsibility for their own care and their children's care. However, apart from corroborating the disadvantages of informal interpreting described earlier [52], this study indicates that informal interpreters (eg, husbands at work and doulas), who are perceived as a close, friendly, and supportive resource, are often contacted and expected to interpret without prior notice. The disturbance and pressure resulting from unplanned interpreting can additionally compromise the interpretation quality.

Another finding of this study was the extensive use of Google Translate for managing language problems in interactions, and it contributed to providing more opportunities for migrant mothers, nurses, and doulas to manage interactions themselves, without the assistance of a professional interpreter. Both nurses and doulas were positive about using Google Translate and reported asking mothers to "just Google," believing that in this way, they encouraged them to become more involved in conversations. In accordance with the present results, previous studies have demonstrated that mobile translation and language apps are successful in relating language learning to a person's physical context and are beneficial for informal learning of the language relevant to a specific context (pediatric encounters in this case) [33]. Although the fallacies and inaccuracies in automatic translations are well-known, especially for less common languages and for medical vocabulary [43,53], the use of Google Translate can potentially contribute to mothers acquiring the Swedish language and integrating into Swedish society.

While providing culturally competent pediatric care for minority populations is essential [54,55], as in many busy practices, a lack of time for in-depth conversations limits opportunities to understand patients in all their complexities, including culture-related differences [56]. In terms of cultural differences, the risks for understanding problems and conflicts increase, which in combination with time pressure, may negatively influence the provider-patient relationship. The study shows that nurses, doulas, and mothers search and show images and films from the internet for illustration, as well as to substitute or complement verbal messages when culturally sensitive topics requiring complex and time-consuming explanations are discussed. This study confirms that pictorial information used for supporting interactions with people having limited or no knowledge of language (eg, newly arrived refugees in neonatal care and migrant workers) [42,57] is beneficial for managing communicative challenges.

The study participants were concerned about spending time searching for images and films on the internet. This finding, although preliminary, suggests that the development of targeted multimodal digital support, including pictorial and video resources, for the issues mentioned by the participants, such as nutrition, child bonding strategies, and safety, can potentially save time from “googling” [39] and make interactions more efficient. Further, the availability and accessibility of internet resources provide opportunities for accessing information after interactions and sharing it with other family members not present during the interactions. For example, fathers who have to work can still obtain information, which contributes to involving them in child care and to their integration in the host society [58].

Despite its exploratory nature, the results of this study indicate that ICT, including telephones, smartphones, computers, and the internet, provides opportunities for mitigating communication challenges and allows migrants to become actively involved in child care. Despite its limitations, this study adds to our knowledge of the use of ICT in pediatric encounters. However, further research with nurses, doulas, and migrant mothers to better understand their experiences of using ICT in pediatric encounters is needed. In addition, to obtain an in-depth understanding of the cultural differences for specific cultural groups, evaluations involving the perspectives of mothers and doulas from different cultural backgrounds are necessary.

Conclusions

Considering the limited research available, this study is an important contribution to literature regarding the use of ICT by doulas and nurses in intercultural pediatric care. Taken together, the findings of this study show the complexity of providing culturally competent care. The research highlights that there is a need to embrace the advancement of technological artifacts and to gain more knowledge about the possibilities and limitations of the implementation of ICT and its role in managing language barriers and intercultural communication challenges, which are becoming increasingly relevant in a global society. Advancements in intelligent translation algorithms are important for increasing translation reliability and ensuring mutual understanding between patients and health care providers. The research contributes to theory by providing multidisciplinary findings in multiple research fields, such as information technology, mobile-assisted language learning, and intercultural health care communication.

Limitations and Future Research

With regard to study limitations, more work needs to be done to determine how ICT can be adapted to the needs of professionals and users in the different sectors of health care. Further, the present article reflects the perspectives of a limited number of nurses and doulas. Finally, future research should focus on the perspectives of migrant parents.

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Authors' Contributions

NBL designed the study, collected and analyzed the data, and drafted the manuscript and RRP designed the study, collected and analyzed the data, and contributed to writing the manuscript.

Conflicts of Interest

None declared.

References

1. Statistics Sweden. SCB. Stockholm; 2019 Sep 18. Summary of population statistics 1960-2019 URL: https://www.scb.se/en/finding-statistics/statistics-by-subject-area/population/population-composition/population-statistics/pong/tables-and-graphs/yearly-statistics--the-whole-country/summary-of-population-statistics/ [accessed 2019-09-18]
2. Wallby T, Hjern A. Child health care uptake among low-income and immigrant families in a Swedish county. Acta Paediatr 2011 Nov;100(11):1495-1503. [doi: 10.1111/j.1651-2227.2011.02344.x] [Medline: 21535134]
3. Oudin A, Richter JC, Taj T, Al-Nahar L, Jakobsson K. Poor housing conditions in association with child health in a disadvantaged immigrant population: a cross-sectional study in Rosengård, Malmö, Sweden. BMJ Open 2016 Jan 06;6(1):e007979 [FREE Full text] [doi: 10.1136/bmjopen-2015-007979] [Medline: 26739718]
4. Hjern A, Ringbäck-Weitoft G, Andersson R. Socio-demographic risk factors for home-type injuries in Swedish infants and toddlers. Acta Paediatr 2001 Jan;90(1):61-68. [doi: 10.1080/080352501750064897] [Medline: 11227336]

5. Skoog M, Berggren V, Hallström IK. 'Happy that someone cared'-Non-native-speaking immigrant mothers' experiences of participating in screening for postpartum depression in the Swedish child health services. J Child Health Care 2019 Mar;23(1):118-130. [doi: 10.1177/1367493518778387] [Medline: 29804463]
6. Barclay L, Kent D. Recent immigration and the misery of motherhood: a discussion of pertinent issues. Midwifery 1998 Mar;14(1):4-9. [doi: 10.1016/s0266-6138(98)90108-5] [Medline: 9633371]
7. Råssjö EB, Byrskog U, Samir R, Klingberg-Allvin M. Somali women's use of maternity health services and the outcome of their pregnancies: a descriptive study comparing Somali immigrants with native-born Swedish women. Sex Reprod Healthc 2013 Oct;4(3):99-106. [doi: 10.1016/j.srhc.2013.06.001] [Medline: 24041730]
8. Berlin A, Johansson S, Törnkvist L. Working conditions and cultural competence when interacting with children and parents of foreign origin--Primary Child Health Nurses' opinions. Scand J Caring Sci 2006 Jun;20(2):160-168. [doi: 10.1111/j.1471-6712.2006.00393.x] [Medline: 16756521]
9. Almqvist K, Broberg AG. Mental health and social adjustment in young refugee children 3 1/2 years after their arrival in Sweden. J Am Acad Child Adolesc Psychiatry 1999 Jun;38(6):723-730. [Medline: 10361791]
10. Wettergren B, Blennow M, Hjern A, Söder O, Ludvigsson JF. Child Health Systems in Sweden. J Pediatr 2016 Oct;177S:S187-S202. [doi: 10.1016/j.jpeds.2016.04.055] [Medline: 27666267]
11. Rydström I, Dalheim Englund A. Meeting Swedish Health Care System: Immigrant Parents of Children With Asthma Narrate. Clin Nurs Res 2015 Aug;24(4):415-431. [doi: 10.1177/1054773814534439] [Medline: 24853374]
12. Klassen AF, Gulati S, Watt L, Banerjee AT, Sung L, Klaassen RJ, et al. Immigrant to Canada, newcomer to childhood cancer: a qualitative study of challenges faced by immigrant parents. Psychooncology 2012 May;21(5):558-562. [doi: 10.1002/pon.1963] [Medline: 21425390]
13. Fatahi N, Hellström M, Skott C, Mattsson B. General practitioners' views on consultations with interpreters: a triad situation with complex issues. Scand J Prim Health Care 2008;26(1):40-45 [FREE Full text] [doi: 10.1080/02813430701877633] [Medline: 18297562]
14. Sveriges Riksdag (the Swedish Government). 2014 Jun 19. The Patient Act 2014:821 URL: https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/patientlag-2014821_sfs-2014-821 [accessed 2019-09-20]
15. Sallinen J. Svenska Dagbladet. Stockholm; 2015 Nov 06. Akut tolkbrist kan bli livsfarlig för patienter (Acute lack of interpreters can be fatal for patients) URL: https://www.svd.se/akut-tolkbrist-kan-bli-livsfarlig-for-patienter [accessed 2019-10-02]
16. Hilder J, Gray B, Dowell A, Macdonald L, Tester R, Stubbe M. 'It depends on the consultation': revisiting use of family members as interpreters for general practice consultations - when and why? Aust J Prim Health 2017 Jul;23(3):257-262. [doi: 10.1071/PY16053] [Medline: 27832830]
17. Nailon RE. Nurses' concerns and practices with using interpreters in the care of Latino patients in the emergency department. J Transcult Nurs 2006 Apr;17(2):119-128. [doi: 10.1177/1043659605285414] [Medline: 16595399]
18. Napier AD, Ancarno C, Butler B, Calabrese J, Chater A, Chatterjee H, et al. Culture and health. Lancet 2014 Nov 01;384(9954):1607-1639. [doi: 10.1016/S0140-6736(14)61603-2] [Medline: 25443490]
19. Wikberg A, Eriksson K, Bondas T. Intercultural caring from the perspectives of immigrant new mothers. J Obstet Gynecol Neonatal Nurs 2012;41(5):638-649. [doi: 10.1111/j.1552-6909.2012.01395.x] [Medline: 22823102]
20. Betancourt JR, Green AR, Carrillo JE, Park ER. Cultural competence and health care disparities: key perspectives and trends. Health Aff (Millwood) 2005;24(2):499-505. [doi: 10.1377/hlthaff.24.2.499] [Medline: 15757936]
21. Tavallali AG, Jirwe M, Kabir ZN. Cross-cultural care encounters in paediatric care: minority ethnic parents' experiences. Scand J Caring Sci 2017 Mar;31(1):54-62. [doi: 10.1111/scs.12314] [Medline: 26800093]
22. Mangrio E, Persson K. Immigrant parents' experience with the Swedish child health care system: A qualitative study. BMC Fam Pract 2017 Mar 01;18(1):32. [doi: 10.1186/s12875-017-0604-6] [Medline: 28249606]
23. Karoly LA, Gonzalez GC. Early care and education for children in immigrant families. Future Child 2011;21(1):71-101. [doi: 10.1353/foc.2011.0005] [Medline: 21465856]
24. Akhavan S, Edge D. Foreign-born women's experiences of Community-Based Doulas in Sweden--a qualitative study. Health Care Women Int 2012;33(9):833-848. [doi: 10.1080/07399332.2011.646107] [Medline: 22891742]
25. Berg M, Terstad A. Swedish women's experiences of doula support during childbirth. Midwifery 2006 Dec;22(4):330-338. [doi: 10.1016/j.midw.2005.09.006] [Medline: 16603283]
26. Näsfeldt M. Angered Hospital. Gothenburg; 2016. Doula/Kulturtolk i nordöstra Göteborg. En utvärdering av avtalet mellan Angereds Närsjukhus (ANS) och Födelsehuset (Doula/ Culture interpreter in northeast Gothenburg. An evaluation of the agreement between Angered Hospital (ANS) and the Birth House) URL: https://alfresco.vgregion.se/alfresco/service/vgr/storage/node/content/workspace/SpacesStore/b9f0c7df-3f75-4910-a3d3-d0e0500f325c/doula-kulturtolk-i-nordostra-goteborg-utvardering.pdf?a=false&guest=true [accessed 2020-01-15]
27. Doula and kulturtolk (Doula and cultural interpreter). Support for non-Swedish speaking women during pregnancy and childbirth URL: https://www.doulakulturtolk.se/ [accessed 2020-01-18]
28. Ebbers W, Jansen M, van Deursen AJ. Impact of the digital divide on e-government: Expanding from channel choice to channel usage. Government Information Quarterly 2016 Oct;33(4):685-692 [FREE Full text] [doi: 10.1016/j.giq.2016.08.007]

29. Stiller J, Trkulja V. Assessing Digital Skills of Refugee Migrants During Job Orientation in Germany. In: Chowdhury G, McLeod J, Gillet V, Willett P, editors. Transforming Digital Worlds. iConference 2018. Lecture Notes in Computer Science. Transforming Digital Worlds iConference: Springer Cham; 2018.
30. Alam K, Imran S. The digital divide and social inclusion among refugee migrants. Info Technology & People 2015 Jun;28(2):344-365 [FREE Full text] [doi: 10.1108/itp-04-2014-0083]
31. UNESCO. Information and communication technologies (ICT). Guide to Measuring Information and Communication Technologies (ICT) in Education URL: http://uis.unesco.org/en/glossary-term/information-and-communication-technologies-ict [accessed 2019-09-29]
32. Berbyuk Lindström N, Sofkova Hashemi S, Bartram L, Bradley L. Mobile Resources for Integration: How Availability Meets the Needs of Newly Arrived Arabic-Speaking Migrants in Sweden. In: Borthwick K, Bradley L, Thouësny S, editors. CALL in a climate of change: adapting to turbulent global conditions: Short papers from EUROCALL 2017. University of Southampton: Research-publishing.net; 2017:40-44.
33. Kukulska-Hulme A. Mobile Language Learning Innovation Inspired by Migrants. Journal of Learning For Development (JL4D) 2019;6(2):116-129 [FREE Full text]
34. Collin S, Karsenti T. Facilitating Linguistic Integration of Immigrants: An Overview of ICT Tools. IISIT 2012;9:243-251 [FREE Full text] [doi: 10.28945/1619]
35. Berbyuk Lindström N, Sofkova Hashemi S. Mobile Technology for Social Inclusion of Migrants in the Age of Globalization: A Case Study of Newly Arrived Healthcare Professionals in Sweden. The International Journal of Technology, Knowledge, and Society 2019;15(2):1-18. [doi: 10.18848/1832-3669/cgp/v15i02/1-18]
36. Goodall K, Ward P, Newman L. Use of information and communication technology to provide health information: what do older migrants know, and what do they need to know? Qual Prim Care 2010;18(1):27-32. [Medline: 20359410]
37. Mani NS, Ottosen T, Wright ST, McCall RC, Conklin JL, Adapa K. Strategies for Integrating Technology as a Team Member. N C Med J 2018;79(4):245-249 [FREE Full text] [doi: 10.18043/ncm.79.4.245] [Medline: 29991618]
38. Khander A, Farag S, Chen KT. Identification and Evaluation of Medical Translator Mobile Applications Using an Adapted APPLICATIONS Scoring System. Telemed J E Health 2018 Aug;24(8):594-603. [doi: 10.1089/tmj.2017.0150] [Medline: 29271702]
39. Freyne J, Bradford D, Pocock C, Silvera-Tawil D, Harrap K, Brinkmann S. Developing Digital Facilitation of Assessments in the Absence of an Interpreter: Participatory Design and Feasibility Evaluation With Allied Health Groups. JMIR Form Res 2018 Jan 09;2(1):e1 [FREE Full text] [doi: 10.2196/formative.8032] [Medline: 30684405]
40. Care to Translate. 2018. A digital translator for healthcare personnel: Language barriers should not be an obstacle to good healthcare URL: https://caretotranslate.com/ [accessed 2019-09-26]
41. Panayiotou A, Gardner A, Williams S, Zucchi E, Mascitti-Meuter M, Goh AM, et al. Language Translation Apps in Health Care Settings: Expert Opinion. JMIR Mhealth Uhealth 2019 Apr 09;7(4):e11316 [FREE Full text] [doi: 10.2196/11316] [Medline: 30964446]
42. Thunberg G, Ferm U, Blom Å, Karlsson M, Nilsson S. Implementation of pictorial support for communication with people who have been forced to flee: Experiences from neonatal care. J Child Health Care 2019 Jun;23(2):311-336. [doi: 10.1177/1367493518819210] [Medline: 30587003]
43. Patil S, Davies P. Use of Google Translate in medical communication: evaluation of accuracy. BMJ 2014 Dec 15;349:g7392 [FREE Full text] [doi: 10.1136/bmj.g7392] [Medline: 25512386]
44. Becker D. What's App? An Overview of Medical Mobile Apps. Journal of Electronic Resources in Medical Libraries 2019 Mar 20;15(3-4):165-171 [FREE Full text] [doi: 10.1080/15424065.2018.1554465]
45. Neuman W. Social Research Methods: Pearson New International Edition: Qualitative And Quantitative Approaches. Harlow, United Kingdom: Pearson Higher Education; 2013.
46. Palys T. Purposive sampling. In: Given ML, editor. The Sage Encyclopedia of Qualitative Research Methods. Los Angeles: Sage Publications, Inc; 2008:697-698.
47. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
48. Masland MC, Lou C, Snowden L. Use of communication technologies to cost-effectively increase the availability of interpretation services in healthcare settings. Telemed J E Health 2010;16(6):739-745 [FREE Full text] [doi: 10.1089/tmj.2009.0186] [Medline: 20626299]
49. Nkulu Kalengayi FK, Hurtig A, Nordstrand A, Ahlm C, Ahlberg BM. Perspectives and experiences of new migrants on health screening in Sweden. BMC Health Serv Res 2016 Jan 15;16:14 [FREE Full text] [doi: 10.1186/s12913-015-1218-0] [Medline: 26772613]
50. Locatis C, Williamson D, Gould-Kabler C, Zone-Smith L, Detzler I, Roberson J, et al. Comparing in-person, video, and telephonic medical interpretation. J Gen Intern Med 2010 Apr;25(4):345-350 [FREE Full text] [doi: 10.1007/s11606-009-1236-x] [Medline: 20107916]
51. Daruwalla Z, Thakkar V, Aggarwal M, Kiasatdolatabadi A, Guergachi A, Keshavjee K. Patient Empowerment: The Role of Technology. Stud Health Technol Inform 2019;257:70-74. [Medline: 30741175]

52. Jacobs EA, Shepard DS, Suaya JA, Stone E. Overcoming language barriers in health care: costs and benefits of interpreter services. Am J Public Health 2004 May;94(5):866-869. [doi: 10.2105/ajph.94.5.866] [Medline: 15117713]
53. Chang DT, Thyer IA, Hayne D, Katz DJ. Using mobile technology to overcome language barriers in medicine. Ann R Coll Surg Engl 2014 Sep;96(6):e23-e25 [FREE Full text] [doi: 10.1308/003588414X13946184903685] [Medline: 25198966]
54. Dabney K, McClarin L, Romano E, Fitzgerald D, Bayne L, Oceanic P, et al. Cultural Competence in Pediatrics: Health Care Provider Knowledge, Awareness, and Skills. Int J Environ Res Public Health 2015 Dec 22;13(1):ijerph13010014 [FREE Full text] [doi: 10.3390/ijerph13010014] [Medline: 26703672]
55. Flores G. Providing culturally competent pediatric care: integrating pediatricians, institutions, families, and communities into the process. The Journal of Pediatrics 2003 Jul;143(1):1-2. [doi: 10.1016/s0022-3476(03)00145-8] [Medline: 12915812]
56. Turner L. Is cultural sensitivity sometimes insensitive? Can Fam Physician 2005 Apr;51:478-80, 483 [FREE Full text] [Medline: 15856962]
57. Connor A, Layne L, Thomisee K. Providing care for migrant farm worker families in their unique sociocultural context and environment. J Transcult Nurs 2010 Apr;21(2):159-166. [doi: 10.1177/1043659609357631] [Medline: 20301816]
58. Boucher JL. Technology and Patient-Provider Interactions: Improving Quality of Care, But Is It Improving Communication and Collaboration? Diabetes Spectrum 2010 Aug 19;23(3):142-144. [doi: 10.2337/diaspect.23.3.142]

Abbreviations

CHC: child health care
ICT: information and communications technology

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Original Paper

Families' Degree of Satisfaction With Pediatric Telehomecare: Interventional Prospective Pilot Study in Catalonia

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Abstract

Background: Pediatric home hospitalization improves the quality of life of children and their families, involving them in their children's care, while favoring the work-life balance of the family. In this context, technology guarantees accessibility to assistance, which provides security to users. From the perspective of the health care system, this could lower the demand for hospital services and reduce hospitalization costs.

Objective: This study aimed to assess families' degree of satisfaction and acceptability of pediatric telehomecare and explore the clinical characteristics of children benefiting from the program.

Methods: A total of 95 children and their families participated in the home-hospitalization pilot program operated by Sant Joan de Déu Hospital in Barcelona, Spain. Families were visited once a day and patients were monitored using a kit consisting of a scale, a thermometer, a pulse oximeter, and a blood pressure monitor. Data on parental experience, satisfaction, safety, and preference for care was collected by means of a questionnaire. Data about the children's characteristics were collected from medical records. Descriptive and comparative statistics were used to analyze the data.

Results: A total of 65 survey respondents expressed very high levels of satisfaction. Families reported their experiences as being very positive, preferring home hospitalization in 94% (61/65) of cases, and gave high scores regarding the use of telemonitoring devices. The program did not record any readmissions after 72 hours and reported a very low number of adverse incidents. The user profile was very heterogeneous, highlighting a large number of respiratory patients and patients with infections that required endovenous antibiotic therapy.

Conclusions: Pediatric home hospitalization through telemonitoring is a feasible and desirable alternative to traditional hospitalization, both from the perspective of families and the hospital. The results of this analysis showed a very high degree of satisfaction with the care received and that the home-based telemonitoring system resulted in few adverse incidents.

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KEYWORDS

home health monitoring; pediatrics; telehomecare; videoconferencing; satisfaction with care; remote sensing technology; telemedicine; telehealth

Introduction

Pediatric home-based care is a good alternative to conventional hospitalization insofar as it is consistent with a care model that places a high value on a more humanized form of health care and encourages self-care and children's rights. The provision of this type of care for children with acute and chronic illnesses is increasing in western countries due to technological developments [1], improvements in support services [2], rising health care costs [3], and the potential psychosocial benefit for children and their families [4].

The technology available today allows for remote and real-time monitoring of a patient's clinical status and regular follow-up with families. Developments in health care equipment means that many diagnostic and treatment procedures normally conducted in a clinical environment can be provided at home [5,6]. Likewise, the increase in the survival of severe processes (ie, complicated interventions that have caused death in the past) and the greater availability of treatments for patients affected by rare diseases has increased the cohort of fragile patients and/or those who are in need of follow-up care; in all likelihood, the hospital environment is not the best place to look after them. This means there is a contingent of stable patients, who are not outpatients, who need prolonged hospital stays in order to complete treatments. Home-based hospitalization care can prevent hospital admission or shorten the average stay.

Home is a child's natural environment. The European Association for Children in Hospital Charter establishes that a child should only be admitted to hospital if it is absolutely necessary and must be discharged as soon as possible [7]. Earlier studies show a high degree of satisfaction among pediatric patients and their families when hospitalized at home [8-14]. Additionally, hospital facilities, especially those located in urban and highly complex environments, see the need to rationalize their spaces. Freeing up some hospital beds by sending patients home could be a good response to the growing demand and the increase in the complexity of the cases dealt with [15,16].

In this context, the Sant Joan de Déu Hospital in Barcelona decided to initiate a pilot program on pediatric home-based hospitalization care. This study aims to (1) measure the impact of the intervention on the satisfaction of patients and their families and (2) determine the clinical and sociodemographic characteristics of the children benefiting from the program in view of the possible deployment of the intervention.

Methods

Setting

The Sant Joan de Déu Hospital in Barcelona is a third-level university hospital located in Catalonia, Spain, which specializes in the fields of pediatrics, gynecology, and obstetrics. It is a privately owned hospital that operates as part of the public health system and the Catalan hospital network. It sees approximately 27,000 cases annually, with around 250,000 outpatient consultations; 15,000 surgical interventions; and 160,000 emergencies. The study involving the pediatric home-based care pilot program took place between April 1 and June 30, 2019. The candidate users were selected in accordance with the criteria outlined in Textbox 1.

Textbox 1. Selection criteria for pediatric home hospitalization.

- Distance: patient's home is no more than 30 minutes from the hospital
- Clinical stability: patient is stable without forecasting decompensations in the short term
- Voluntary consent is given by the family and, where applicable, by the child
- Habitability conditions of the home: composition of the family group, individual room for the patient, cleanliness condition of the home, availability of the minimum infrastructure for the patient's personal hygiene, and the ability to comply with the prescribed diet, environmental conditions of noise, and ambient temperature
- Prior family training to ensure continuity in the care process
- Possibility of establishing permanent telephone communication

When the medical team detected a potential case, they contacted the home-hospitalization team, who assessed it and made sure it met the selection criteria. In that case, the family was informed of what home hospitalization involves and was provided with information in writing. If the family agreed, they were asked to give informed consent. Finally, the team's nurse trained the family and empowered them to carry out the necessary care; when leaving, they were issued a kit (see Table 1) containing devices for remote telemonitoring—thermometer, pulse oximeter, blood pressure monitor, and scale—together with a tablet, which used Bluetooth and special software to record information registered by the devices and enabled videocalls.

Table 1. Contents of the remote telemonitoring kit.

Device	Brand (manufacturer)	Model	Medical device certification
Blood pressure monitor	iHealth View (iHealth Labs)	BP75	Yes
Pulse oximeter	iHealth Air (iHealth Labs)	P03M	Yes
Scale	iHealth Lina (iHealth Labs)	HS2	No
Thermometer	OMRON (Omron Healthcare)	GentleTemp 521	Yes
Tablet	iPad (Apple)	MR6P2TY/A	No

The intervention considered two types of complementary health care: face-to-face, with a daily visit, and telecare (ie, 24/7 continuous care via remote real-time monitoring, phone calls, and videoconferencing). The human resources devoted to the project were 1 pediatrician, 2.7 nurses, technical support, and part-time administrative staff. Clinicians traveled from the hospital by means of a car and there were 10 remote telemonitoring kits.

Data Collection and Outcome Measures

Once the intervention was finished, an ad hoc, nonvalidated, and self-administered survey was conducted using Google's online survey tool (see Multimedia Appendix 1); the survey included multiple variables related to satisfaction and participants used the tablet provided to complete the survey. This questionnaire did not include names, medical record numbers, or any data that could identify the participants. The analysis of the results did not require any kind of user identification. The following user clinical and sociodemographic information data were extracted from the administrative database and transferred to a designated form: age, sex, source of referral, medical specialty, main caregiver, child location, type of intravenous line, administration schedule, readmission date, and reason for readmission.

This was a unicentric, single-arm, interventional prospective study with no control group. The statistical program R, version 3.6.1 (The R Foundation), was used for the statistical analyses.

Ethical Considerations

The study was approved by Sant Joan de Déu Hospital's Ethical Committee for Clinical Research (registration No. 88-19) and was carried out in accordance with the Helsinki Declaration [17].

Results

Characteristics of the Beneficiaries

Participant characteristics are shown in Table 2. The typical profile of a home-based hospitalized patient in our study was a 4-year-old boy (53/95, 56%) who lived 12 km from the hospital, was previously hospitalized (85/95, 89%) in the pediatrics department (80/95, 84%), and whose main caregiver was their mother (54/95, 57%). They returned home with an intravenous inserted (48/95, 51%) and their administration schedule was every 24 hours (36/89, 40%). A total of 89% (85/95) of patients included in this study came from hospitalization, 8% (8/95) came from outpatient visits, and 2% (2/95) came from the emergency department. The clinical profile was diverse, with the most frequent pathologies being infectious diseases that required endovenous antibiotic therapy, head and neck infections (ie, adenitis, adenophlegmons, and mastoiditis), pneumonia, urinary tract infections, and respiratory infections requiring bronchodilator nebulization and/or oxygen therapy (1 L/min or less, administered via nasal cannula). To a lesser extent, fever without a focus was treated in infants under observation, atypical febrile convulsion was treated under observation, and endovenous serotherapy was given in cases of dehydration.

The cohort studies did not show any security incidents related to medication administration. However, there were 4 readmitted patients out of 95 (4%). In 2 cases, readmission was due to the evolution of the disease (ie, a nephrotic syndrome that developed into a bronchospasm and a peritonsillar phlegmon due to poor control of pain). After these 2 readmissions, some adjustments were made to minimize problems that could have been prevented; this included a deeper interview with families, explaining how the program works and what the terms and conditions are. Also, patients who required oxygen were not discharged from hospital until the oxygen supply was at home.

In 1 case, a bronchospasm occurred because a supply of oxygen was not provided during the home hospitalization. In this case, the bronchospasm occurred due to a nephrotic syndrome caused by the lack of compliance with the medical indications at home. The patients who were hospitalized with the peritonsillar phlegmon due to poor control of pain, and the bronchospasm due to lack of oxygen, returned home the next day. These readmissions should be interpreted as a sign of program success, because each family freely decided to resume home hospitalization. In the cases of poor control of pain and the lack of oxygen supply, once controlled, the family felt secure to go home.

Satisfaction Results

Survey results regarding general satisfaction with the intervention are reported in Table 3. Of the 95 patients included in the program, 65 completed the satisfaction survey (68%); of these, only 3% (2/65) indicated they had more work than what they had expected, only 3% (2/65) would have preferred conventional hospitalization, and 100% (63/63) would repeat the experience. Level of care was scored overall as *Excellent* (60/65, 92%); the information provided by the staff during home hospitalization was also scored as *Excellent* (54/65, 83%).

Most of the respondents (49/64, 77%) received their first home visit less than 24 hours following their home hospitalization and did not have to call to ask for help (35/65, 54%); for those who did ask for help, the problem was resolved quickly (30/33, 91%). They valued the fact that the pediatrician and the nurses worked in a coordinated way and that their home visit lasted a sufficient amount of time (65/65, 100%).

Table 2. Sociodemographic characteristics of the sample.

Characteristic	Values (N=95)
Gender, n (%)	
Total	95 (100)
Boy	53 (56)
Girl	42 (44)
Age (years), mean (SD)	4.22 (4.57)
Source of referral, n (%)	
Total	95 (100)
Hospitalization	85 (89)
Outpatient visits	8 (8)
Emergencies	2 (2)
Medical field, n (%)	
Total	95 (100)
Pediatrics	80 (84)
Nephrology	6 (6)
Surgery	5 (5)
Orthopedic surgery and traumatology	2 (2)
Gastroenterology	1 (1)
Others	1 (1)
Distance (km) to hospital, mean (range)	11.72 (10-50)
Main caregiver, n (%)	
Total	95 (100)
Mother	54 (57)
Mother and father	35 (37)
Father	5 (5)
Other	1 (1)
Type of intravenous line, n (%)	
Total	48 (100)
Peripheral route	44 (92)
Peripherally inserted central catheter	2 (4)
Broviac	1 (2)
Midline	1 (2)
Schedule of administration, n (%)	
Total	89 (100)
Every 24 hours	36 (40)
Every 8 hours	22 (25)
Every 4 hours	21 (24)
Every 6 hours	7 (8)
Every 12 hours	2 (2)
Continuous	1 (1)

Table 3. Survey results regarding general satisfaction with the intervention.

Survey question and responses	Participants (N=65), n (%)
How many days passed since your child was discharged from hospital until their first visit home?	
Total	64 (100)
Between 1 and 3 days	15 (23)
Less than 1 day	49 (77)
Did you have to call to ask for help in relation to any problem with your child while he or she was hospitalized at home?	
Total	65 (100)
Yes	30 (46)
No	35 (54)
If so, was the problem resolved quickly?	
Total	33 (100)
Yes	30 (91)
No	3 (9)
Do you think that the pediatrician and the nurses worked in a coordinated way?	
Total	65 (100)
Yes	65 (100)
No	0 (0)
Do you think that the staff spent enough time with your child and family during their home visits?	
Total	65 (100)
Yes	65 (100)
No	0 (0)
How would you rate the way in which the staff has taken care of your child and family?	
Total	65 (100)
Excellent	60 (92)
Very good	5 (8)
How would you rate the information provided to you by the home-hospitalization team during the home-based care?	
Total	65 (100)
Excellent	54 (83)
Very good	11 (17)
In relation to your child’s home-based care and regarding the duties that you normally assume, what has the amount of work been like?	
Total	65 (100)
As expected	49 (75)
Less than expected	14 (22)
More than expected	2 (3)
Would you have preferred conventional hospitalization instead of your child being at home?	
Total	65 (100)
Yes	2 (3)
No	61 (94)
I don’t know	2 (3)
If necessary, would you like your child to be taken care of by the home-based care team again?	
Total	63 (100)
Yes	63 (100)
No	0 (0)

Survey results regarding satisfaction with the devices are reported in Table 4. Regarding the use of the telemonitoring devices—thermometer, pulse oximeter, blood pressure monitor, scale, and tablet—results show that the software was perceived as *Easy* (47/58, 81%) and 91% of respondents (49/54) were able to take the corresponding vitals easily. The scores, measured from 0 (*Very bad*) to 5 (*Excellent*), regarding communication with the clinical team and regarding the devices—scale, thermometer, pulse oximeter, and blood pressure monitor—were very high (range 3.79-4.61). In a qualitative assessment space, it was mentioned that the scale was the least useful device and respondents experienced problems with the thermometer because it was not fully adapted to the physiology of the pediatric users.

Table 4. Survey results regarding satisfaction with the devices.

Survey question and responses	Values (N=65)
How would you rate the software's accessibility? n (%)	
Total	58 (100)
Easy	47 (81)
Neither easy nor difficult	3 (5)
I did not access the program	8 (14)
Have you been able to easily take the vitals that you have been asked to take? n (%)	
Total	54 (100)
Yes	49 (91)
No	5 (9)
How would you rate the communication with the clinical team using this tool? (n=59), mean score[a] (SD)	4.61 (0.65)
How would you rate the utility of the videoconferencing sessions? (n=57), mean score (SD)	4.28 (1.02)
Of the devices you were issued, together with the tablet, how would you rate the scale? (n=38), mean score (SD)	4.25 (1.02)
Of the devices you were issued, together with the tablet, how would you rate the thermometer? (n=48), mean score (SD)	3.79 (1.36)
Of the devices you were issued, together with the tablet, how would you rate the pulse oximeter? (n=45), mean score (SD)	4.21 (1.12)
Of the devices you were issued, together with the tablet, how would you rate the blood pressure monitor? (n=45), mean score (SD)	4.19 (1.17)

[a] Scores were measured on a scale from 0 (*Very bad*) to 5 (*Excellent*).

The results of this analysis showed a high degree of satisfaction with the care received and highlight the fact that the telehomecare system did not generate significant adverse incidents. Overall, the intervention (ie, training, face-to-face visits, and telemonitoring) enabled the families to be self-sufficient regarding their children's care. Their satisfaction with the devices was very good and their perception of accessibility was regarded as excellent.

Discussion

Principal Findings

This study assessed the impact of the pediatric, home-hospitalization, pilot program of the Sant Joan de Déu Hospital in Barcelona on the satisfaction of patients and their families; the study also assessed the clinical and sociodemographic characteristics of the children benefiting from the program in view of the potential deployment of the intervention. Although a small sample has been studied, the experience suggests that the intervention could be extended to patients originating from specialties other than the pediatric specialty (ie, surgery, orthopedic surgery and traumatology, gastroenterology, and nephrology).

Limitations

During the pilot study, a problem with the size of the devices was identified, as they are not always suited to the physiology of pediatric patients, meaning the families used them less. This factor should be taken into account in view of the possible extension of the intervention in the hospital itself or in any replication of the experience.

Finally, the guarantee of the anonymity of the information gathered by the survey has made it impossible to cross-reference this data with administrative data. Future studies should examine the differential impacts on satisfaction according to type of illness or other sociodemographic factors.

Conclusions

Pediatric home-based care is preferred by patients and their families. Remaining in their homes and staying in their environments contributes to patient-centered care, while empowering the patients and their families in the care and control of their illnesses. In keeping with the evidence already published, this study shows that home-based hospitalization is associated with an improvement in the quality of life of the child and the family and with a potential decrease in the demand for hospital services. Telemonitoring tools are one of the essential elements that make this possible. The high degree of acceptance of the devices—thermometer, pulse oximeter, blood pressure monitor, and scale—is an opportunity to study the implementation of new tools that reinforce and offer guarantees of certain types of care.

In terms of the impact on clinical outcomes, future studies should determine whether, as with the adult population, clinical outcomes are comparable to or better than those of conventional hospitalization by analyzing the impact on readmission or mortality with respect to the usual path of hospitalization. Likewise, we must study the cost-effectiveness of this type of intervention, by comparing the cost of travel and that of the devices with the savings derived from the reduction of days in hospital, reduction of conventional hospitalization costs, and the increase in hospital capacity resulting from the freeing up of beds.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Self-administered study survey.
[DOCX File , 24 KB - pediatrics_v3i1e17517_app1.docx]

References

1. Burke BL, Hall RW, Section on Telehealth Care. Telemedicine: Pediatric applications. Pediatrics 2015 Jul;136(1):e293-e308 [FREE Full text] [doi: 10.1542/peds.2015-1517] [Medline: 26122813]
2. Parker G, Spiers G, Gridley K, Atkin K, Birks Y, Lowson K, et al. Systematic review of international evidence on the effectiveness and costs of paediatric home care for children and young people who are ill. Child Care Health Dev 2013 Jan;39(1):1-19. [doi: 10.1111/j.1365-2214.2011.01350.x] [Medline: 22329427]
3. Simon TD, Berry J, Feudtner C, Stone BL, Sheng X, Bratton SL, et al. Children with complex chronic conditions in inpatient hospital settings in the United States. Pediatrics 2010 Oct;126(4):647-655 [FREE Full text] [doi: 10.1542/peds.2009-3266] [Medline: 20855394]
4. Cooper S, Valleley RJ, Polaha J, Begeny J, Evans JH. Running out of time: Physician management of behavioral health concerns in rural pediatric primary care. Pediatrics 2006 Jul;118(1):e132-e138. [doi: 10.1542/peds.2005-2612] [Medline: 16818528]
5. Garne Holm K, Brødsgaard A, Zachariassen G, Smith AC, Clemensen J. Parent perspectives of neonatal tele-homecare: A qualitative study. J Telemed Telecare 2018 May 23;25(4):221-229. [doi: 10.1177/1357633x18765059]
6. Notario PM, Gentile E, Amidon M, Angst D, Lefaiver C, Webster K. Home-based telemedicine for children with medical complexity. Telemed J E Health 2019 Nov;25(11):1123-1132. [doi: 10.1089/tmj.2018.0186] [Medline: 30628860]
7. The EACH Charter With Annotations.: EACH European Association for Children in Hospital; 2016. URL: https://www.each-for-sick-children.org/images/stories/2016/Charter_AUG2016_oSz.pdf [accessed 2020-02-20]
8. Castor C, Hallström IK, Landgren K, Hansson H. Accessibility, utilisation and acceptability of a county-based home care service for sick children in Sweden. Scand J Caring Sci 2019 Dec;33(4):824-832. [doi: 10.1111/scs.12678] [Medline: 30865330]
9. Eskola K, Bergstraesser E, Zimmermann K, Cignacco E. Maintaining family life balance while facing a child's imminent death: A mixed methods study. J Adv Nurs 2017 Oct;73(10):2462-2472. [doi: 10.1111/jan.13304] [Medline: 28329430]
10. Parab C, Cooper C, Woolfenden S, Piper S. Specialist home-based nursing services for children with acute and chronic illnesses. Cochrane Database Syst Rev 2013;6:1-32 [FREE Full text] [doi: 10.1002/14651858.cd004383.pub3]
11. Hansson H, Kjaergaard H, Johansen C, Hallström I, Christensen J, Madsen M, et al. Hospital-based home care for children with cancer: Feasibility and psychosocial impact on children and their families. Pediatr Blood Cancer 2013 May;60(5):865-872. [doi: 10.1002/pbc.24474] [Medline: 23335455]
12. Hansson H, Kjaergaard H, Schmiegelow K, Hallström I. Hospital-based home care for children with cancer: A qualitative exploration of family members' experiences in Denmark. Eur J Cancer Care (Engl) 2012 Jan;21(1):59-66. [doi: 10.1111/j.1365-2354.2011.01280.x] [Medline: 21848580]
13. von Lützau P, Otto M, Hechler T, Metzing S, Wolfe J, Zernikow B. Children dying from cancer: Parents’ perspectives on symptoms, quality of life, characteristics of death, and end-of-life decisions. J Palliat Care 2018 Dec 19;28(4):274-281. [doi: 10.1177/082585971202800406]
14. Kassam A, Skiadaresis J, Alexander S, Wolfe J. Parent and clinician preferences for location of end-of-life care: Home, hospital or freestanding hospice? Pediatr Blood Cancer 2014 May;61(5):859-864. [doi: 10.1002/pbc.24872] [Medline: 24265171]

15. Hamline MY, Speier RL, Vu PD, Tancredi D, Broman AR, Rasmussen LN, et al. Hospital-to-home interventions, use, and satisfaction: A meta-analysis. Pediatrics 2018 Nov;142(5):e20180442 [FREE Full text] [doi: 10.1542/peds.2018-0442] [Medline: 30352792]
16. Estrada Cuxart O, Massa Domínguez B, Ponce González MA, Mirón Rubio M, Torres Corts A, Mujal Martínez A, Sociedad Española de Hospitalización a Domicilio (SEHAD). Hospital a Domicilio (HAD); 1(2). 2017. Proyecto HAD 2020: Una propuesta para consolidar la hospitalización a domicilio en España [HAD 2020 Project: A proposal to consolidate hospital-based home care in Spain] URL: https://revistahad.eu/index.php/revistahad/article/view/13/11 [accessed 2020-02-26]
17. WMA Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. Ferney-Voltaire, France: The World Medical Association (WMA); 2013. URL: https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/ [accessed 2020-02-20]

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Original Paper

Using Digital Media to Empower Adolescents in Smoking Prevention: Mixed Methods Study

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Abstract

Background: There is a critical need for effective health education methods for adolescent smoking prevention. The coproduction of antismoking videos shows promising results for adolescent health education.

Objective: This study explored the feasibility of a smoking prevention program using the coproduction of antismoking videos in order to empower adolescents in smoking prevention and tobacco control. A smoking prevention program based on coproduction of antismoking videos over eight sessions was implemented in a low-income neighborhood.

Methods: A mixed methods design with a concurrent embedded approach was used. In total, 23 adolescents participated in the program. During the prevention program, small groups of participants used video cameras and laptops to produce video clips containing antismoking messages. Quantitative data were analyzed using the Wilcoxon signed-rank test to examine changes in participants' psychological empowerment levels between pre- and postintervention; qualitative interview data were analyzed using content analysis.

Results: Pre- and postcomparison data revealed that participants' psychological empowerment levels were significantly enhanced for all three domains—intrapersonal, interactional, and behavioral—of psychological empowerment ($P<.05$). Interviews confirmed that the coproduction of antismoking videos is feasible in empowering participants, by supporting nonsmoking behaviors and providing them with an opportunity to help build a smoke-free community.

Conclusions: Both quantitative and qualitative data supported the feasibility of the coproduction of antismoking videos in empowering adolescents in smoking prevention. Coproduction of antismoking videos with adolescents was a beneficial health education method.

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KEYWORDS

adolescent; children; digital media production; technology; empowerment; smoking prevention

Introduction

Background

Preventing adolescents from becoming smokers is a crucial public health issue. Although the adolescent smoking rate has decreased overall, a significant majority (88%) of smokers have reported taking up the habit as adolescents [1]. Once having become an established smoker, quitting is difficult because of the addictive chemicals in tobacco products, often involving repeated attempts [1,2]. In addition, the adverse impacts of smoking can be more serious for adolescence-initiated long-term smokers because health outcomes last for the rest of their lives [3,4]. Therefore, it is important for prevention efforts to target adolescents who have not yet started smoking or who are just beginning to experiment with it [1,5]. Furthermore, adolescent smoking is particularly serious in minority populations residing in low-income neighborhoods [6,7]. However, prevention efforts have been challenging because this population is hard to reach, difficult to maintain engagement with, and typically suffers from a low level of health literacy and a chronic lack of resources [8,9]. Thus, it is vital to develop and provide socioculturally relevant interventions that take into account the characteristics of this population [10-13].

Engagement can be important for successful adolescent smoking prevention programs [14-16]. Engagement is defined as “the quality of effort students themselves devote to educational activities” [17] in an educational context. Learning outcomes are better achieved when youth are more engaged with pedagogically appropriate approaches [18-20]. There has been much effort focused on developing relevant content concerning adolescent smoking prevention; however, educational methods in delivering those topics have not been widely explored [4]. For example, researchers have suggested topics to be taught for smoking prevention, such as refusal skills, based on a cognitive behavioral approach [8,21,22]; these efforts have yielded some successful outcomes, but results have been mixed [1]. Thus, there is a critical need for more research on effective educational methods (eg, effective teaching methods and active learning methods) to better engage participants in the programs [14,15,23-25]. For adolescents, their developmental characteristics of seeking proper stimuli and fun activities with tasks containing level-appropriate challenges should be considered [20,26-28]. Technology and multimedia-related components are particularly useful to provide more engaging activities in this respect [27,29-31].

Empowerment is another important key that needs to be emphasized in smoking prevention programs in an effort to better help adolescents become advocates for tobacco control [32,33]. Youth empowerment approaches have been adopted for a number of adolescent health promotion interventions, including smoking prevention efforts, and have shown considerable promise [14,34-36]. This approach is known to be helpful in increasing adolescent engagement and in providing a voice, particularly for marginalized populations [37,38]. By adopting this approach, adolescents not only opt to resist smoking behaviors of their own volition but also become advocates for nonsmoking communities [34-37]. As smoking is a sociocritical issue, it is necessary to empower nonsmoking adolescents to become active advocates for a smoke-free society. This approach can be helpful to equip them with the information they need to understand smoking policy issues, how tobacco companies manipulate these issues, and how socioeconomic status influences smoking status.

Participatory media production or coproduction of films with participants has been used for educating adolescents about a number of social and health issues [39-42]. The coproduction process provides not only a method of engagement but also serves as a valuable tool to empower youth with regard to health and social issues [39,40,43-45]. In this study, we explored a newly developed adolescent smoking prevention program grounded in theory-based empowerment, using the coproduction of videos as a tool to facilitate adolescents’ engagement with self-expression and critical thinking. The purpose of this study was to examine whether coproduction of antismoking videos is feasible in empowering adolescent participants in smoking prevention.

Theoretical Framework

This study was grounded in the Youth Empowerment Framework, adapted from Youth Empowerment Theory [46-48]. This framework was derived from the Nomological Network for Psychological Empowerment Model [49] and adapted for tobacco control. According to the Youth Empowerment Framework, psychological empowerment, which is rooted in social action theory, is defined as “empowerment at [the] individual level that integrates perceptions of personal control, a proactive approach to life, and a critical understanding of the sociopolitical environment” [50] and is composed of intrapersonal, interactional, and behavioral domains [47,48]. According to this framework, opportunities to gain control, mobilize resources, and critically understand sociopolitical issues enhance the psychological empowerment of young people [49]. The intrapersonal domain includes domain-specific efficacy, perceived sociopolitical control, and participatory competence; the interactional domain is composed of knowledge of resources, assertiveness, and advocacy; and the behavioral domain includes psychological empowerment-related actions (see Table MA1-1 in Multimedia Appendix 1) [50].

Methods

Study Design

The study protocol was approved by the affiliated Institutional Review Board, and consent from parents and minors was obtained. A mixed methods design with a concurrent, embedded experimental approach was used [51-53]. This mixed methods study concurrently collected both quantitative and qualitative data at the beginning and end of the intervention within the experimental design. However, the quantitative data from this concurrent, embedded experimental approach provided primary findings used to examine changes in primary outcomes before and after the intervention. The qualitative data were used to provide context and to support the quantitative findings. This study design is appropriate in the intervention test phase, as quantitative data will measure the primary outcomes of the intervention and qualitative data will provide participants’ feedback for an in-depth understanding of why and how those outcomes occur [53].

This design is suited to our objective of exploring the empowerment process involved with the intervention. Quantitative data from this study allow us to test the changes in psychological empowerment, which is the major outcome of this study. Additionally, qualitative data enable us to confirm whether findings from the quantitative analysis are related to the intervention and to explain how changes in the main outcome are related to components of the intervention. Quantitative data test the major hypothesis and the qualitative analysis provides additional insight and confirms findings based on quantitative data. Special care was taken to minimize potential threats to validity of the concurrent embedded design.

Participants and Setting

This study was conducted in Pontiac, Michigan, USA, an urban, low-income neighborhood. The median household income was US $30,152 in 2012-2016, which is about half the US national average of US $55,322 [54]. The percentage of the population under the poverty level was 34.3%, about three times higher than the national average of 12.7%. Among those 25 years of age or older, 75.9% had a high school diploma or its equivalent, well below the US average of 85.2%. The unemployment rate in Pontiac was 10.90%, twice the national average of 5.20%. African Americans made up the single-largest ethnic group at 49.9%, well above the US average of 13.3%.

This study was conducted at a neighborhood, nonprofit community center in Pontiac that provides youth summer programs, and the intervention was embedded within their existing summer schedule. Participants who enrolled in the center's summer program were approached for recruitment via flyers and handouts; 23 youths in grades 4-8 chose to participate in the study. The demographic survey indicated that 57% (13/23) of the participants were African American, 35% (8/23) were Latin American, and 9% (2/23) were Caucasian American. All the participants were nonsmokers, although 9% (2/23) had tried cigarettes before. The majority (15/23, 65%) were female and 35% were male (8/23). Gift cards valued at US $10 were given to the participants who completed the data collection.

Intervention

The program consisted of eight sessions over a period of 4 weeks (see Table MA1-2 in Multimedia Appendix 1). Each session lasted 60 minutes. Groups of 3-5 students worked together to make a video clip over the course of the eight sessions. Instructors provided reading materials and access to websites for smoking-related content from reliable sources, such as the US Centers for Disease Control and Prevention, and each group of students discussed the determinants of smoking, the health consequences, and smoking prevention and cessation strategies. The instructors were experienced with children and were trained by the research team. Each group then picked their own topic and genre for their video clips. The resulting video clips lasted from 3 to 5 minutes, and every student had an opportunity to play a number of different roles, including camera person, actor, director, and/or writer. Based on the scenarios and storyboards they created, participants recorded different scenes using flip cameras and then edited the scenes using Windows Movie Maker 2014 (Microsoft). In the final session, they showed the video clips they had created to the teachers and other students at the center.

Measures

Psychological empowerment is the major outcome of this study. The Youth Group Member Survey (YGMS) [47,48] was used to measure psychological empowerment for tobacco control. The YGMS was developed for adolescents, 10-21 years of age, and its validity and reliability have been supported with a Cronbach alpha of .86. The survey uses a Likert-type scale and consists of 19 items with three subscales: intrapersonal, interactional, and behavioral domains.

The intrapersonal domain considers an individual's beliefs about their capacity to influence others' lives, including their family, friends, surrounding environment, and sociopolitical context. This domain includes items such as "How sure are you that you can convince family members not to smoke?" The interactional domain refers to an individual's understanding about the problems faced by their community and their assertiveness, and includes items such as "I can start discussions with others about tobacco issues." The behavioral domain refers to an individual's actions with empowerment, including nonsmoking intentions, advocacy actions toward a smoke-free community, and general actions that may influence other people's lives. This domain includes items such as "Do you think you will smoke a cigarette at any time during the next year?" Quantitative measures only allowed us to assess their individual intentions to exhibit smoking behavior. Their advocacy actions or community actions were assessed via qualitative interviews.

Data Collection

Quantitative data were collected using a pen-and-pencil survey at the beginning of the program and immediately after the program finished. Each survey lasted about 30 minutes. Immediately upon completion of the survey, a semistructured interview was conducted using an interview guide. The interview was conducted by a team member with previous experience interviewing children. The preintervention interview assessed adolescents' motivation regarding the intervention, and the postintervention interview explored their experiences with the intervention process. Each interview lasted about 30 minutes.

Data Analysis

A concurrent data analysis approach was used [52], with the quantitative and qualitative data being analyzed separately (Stage 1). The results were then compared for two datasets to explore whether and how the results supported each other (Stage 2) and were displayed jointly in the matrix using the theoretical framework (see Table 1). For the quantitative findings, we conducted a Wilcoxon signed-rank test as the normal distribution was not met, while the qualitative data was subjected to a content analysis based on the theoretical framework [55]. For the interviews, verbatim transcriptions were coded by two different coders for attributes (primary coding) and patterns (secondary coding). The primary coding followed an inductive approach, and the categories and themes that emerged were then organized using a deductive approach based on the theoretical framework in the secondary coding. Where there were discrepancies between coders, we discussed and resolved the disagreements in consultation with a third member of the research team. We utilized strategies to ensure trustworthiness [52].

Results

Overview

The statistical results from the pre- and postcomparison and representative quotes from the postinterviews that support the findings for each domain—intrapersonal, interactional, and behavioral—are presented in Table 1. The qualitative and quantitative data support each other well. In this study, all the domains of psychological empowerment were significantly enhanced, and the qualitative data facilitated the interpretation of these results by providing the context and meaning of these changes within this intervention. The narratives contributed to our understanding of the nature of the interventions. In particular, it was revealed that the participatory process, which was focused on the making of the health-related videos to show to others, lies at the heart of this intervention and was a key factor in the empowerment process for participants.

Table 1. Comparison of pre- and posttest results and example interview quotes for psychological empowerment.

Domain	Preintervention score, mean (SD)	Postintervention score, mean (SD)	*P* value	Example interview quotes
Intrapersonal domain	—[a]	—	—	• "Smoking makes your teeth get yellow." • "I learned that smoking is bad for you." • "I just learned that smoking is bad and it could hurt your lungs and could affect your voice." • "Now I can actually tell people not to smoke." • "I can help other people not to smoke." • "I know not to smoke and to actually tell people not to smoke and stuff." • "I liked that I got to talk to [my friend] for her not to smoke just like in the video."
Perceived sociopolitical control	12.85 (2.37)	14.92 (2.37)	.01	—
Participatory competence	7.23 (1.30)	9.00 (0.90)	.01	—
Self-efficacy	10.18 (3.61)	14.79 (1.92)	.01	—
Interactional domain	—	—	—	• "Really the only concern I have is that it might not affect some people the way that I think it will. That's mainly my only concern I have." • "We're making videos that helps people to stop smoking." • "I want to help and try to help any way I can though this program."
Advocacy	4.27 (2.91)	5.17 (2.92)	.01	—
Assertiveness	10.55 (1.50)	13.60 (1.92)	.01	—
Behavioral domain	—	—	—	• "This program has influenced me not to smoke." • "I am going to share this video to my friends and family, and some people who smoke." • "I would like to share. I have a cousin and I have friends that I still talk to. So I would definitely tell them about it and see if they can come or share the video that I make with them." • "...everybody in the world. I want to put this up on the YouTube." • "I like to do other videos too [about] substance use or drugs." • "I do community service with my school."
Smoking intention	12.91 (3.42)	14.70 (0.69)	.02	—

[a] Not applicable.

Intrapersonal Domain

Our findings indicate that all subconstructs of the intrapersonal domain, including perceived sociopolitical control, participatory competence, and self-efficacy, were enhanced after the intervention ($P<.05$). By participating in the program, the youths showed enhanced self-competence and self-efficacy in remaining nonsmokers. Supported by the qualitative findings, most participants described how they had learned a great deal about the causes and consequences of smoking and had consequently become more confident in their ability to remain a nonsmoker. One participant stated, "Now I can actually tell people not to smoke," in the postprogram interview. It was interesting to find that one of the main reasons given by many of the adolescents for participating in this study was that they were afraid they would start smoking due to influences from their surrounding environment. Participants also indicated that the video-making process helped them gain confidence in completing tasks and they expressed their pleasure in being the ones "in control," unlike other programs that just "tell them what to do." In addition, they showed self-efficacy in helping others not to smoke.

Interactional Domain

In the interactional domain, advocacy and assertiveness also changed in a positive way ($P<.05$; see Table 1). Our qualitative findings showed that participants expressed a greater interest in and awareness of teenagers' smoking issues and that they understood the complexity of the whole smoking issue, both of which helped them explore ways to help other people not to smoke. The participants suggested that making the videos could be a key way for them to engage in advocacy action, and they considered that this would be an effective way to persuade others. One participant stated:

> *We're making videos that help people to stop smoking. Videos that will help people that might be going through something, they don't know how to get out or to help somebody get out of a situation they were struggling in.*

It was obvious that even after the program was finished, participants were thinking about ways to make the videos more effective. One participant stated:

> *Really the only concern I have is that it [the video produced] might not affect some people the way that I think it will. That's mainly my only concern I have.*

Behavioral Domain

Positive changes were shown in participants' intention to smoke in that they were less likely to initiate smoking after participating in this program (P<.05; see Table 1). Most participants strongly expressed their intention not to smoke in the future during the interview, as described by one participant: "This program has influenced me not to smoke." Furthermore, they were interested in sharing the videos that they had made as an advocacy action for smoke-free communities. Participants wanted to share the videos with others, primarily their friends, family, relatives, and others they knew. They also wanted to show the videos they created to people beyond their extended social network and to make similar videos in the future to help other people not to smoke, as well as videos about other community issues. The intention to engage in empowered actions to help other people is clearly shown with video-making activities. This empowerment action was extended beyond video-making activities, as several of the participants indicated that they had started volunteering in their community, as shown by a participant's statement: "I like to do other videos too [about] substance use or drugs." Most of the participants wanted to become more actively involved in community issues, particularly with regard to drug use or violence-related issues, which indicates voluntary, empowered actions related to the surrounding community.

Discussion

This study demonstrates how a participatory video approach, particularly using coproduction of antismoking videos, can empower adolescents in tobacco control. The study findings support the usefulness of technology in adolescent health education, particularly when exploring the video-making process for adolescent health education. Previously, technology was used as a delivery method and adolescents were treated as passive consumers of content, as digital media was emphasized as a final product delivered to adolescents in health education. This study advances the past approach by using coproduction of video clips for a smoking prevention program. The prevention program in this study allowed adolescent participants to be creative producers and active communicators using video cameras and laptops to create antismoking messages and to share those messages with others. In this way, technology was used for an active learning method in health education.

This study provides empirical evidence for the Youth Empowerment Framework [48]. In this study, the quantitative data showed statistically significant changes in all domains of psychological empowerment—intrapersonal, interactional, and behavioral—from before and after the smoking prevention program using an antismoking video-making process. In particular, the qualitative data confirmed that the adolescent participants experienced enhanced self-efficacy and competence for tobacco control, and their intention not to smoke was strengthened while participating in this smoking prevention program. In addition, the process of coproduction to create antismoking messages provided them with opportunities to become more aware of the resources available to them and the determinants of smoking. In the context of controlling tobacco use, the adolescents were able to identify ways to help others not to smoke and to make their community a smoke-free environment. Furthermore, the participants appreciated how this program allowed them to engage in advocacy actions for other smokers and teenagers and encouraged them to initiate further actions to help others in their communities, using both a digital media approach and other forms of voluntary activity. To our knowledge, this is the first study to explore the process of coproduction of antismoking videos for empowering adolescents in smoking prevention and the feasibility of the program utilizing a mixed methods approach.

However, there are limitations to note within the interpretation of the study findings. With convenience sampling, all the participants were recruited from a single site. This creates limitations concerning external validity, and the fact that it is based on the context of a summer camp in the United States needs to be noted in interpreting the findings. In addition, participants were a self-selected group, which introduced the selection bias of those who volunteered to participate in the study. They could have been highly motivated for smoking prevention and tobacco control. In addition, health literacy and reading skills of participants were not assessed, which could have influenced the findings of this study. Although the main purpose of this study was to test the feasibility of a newly developed prevention program using a coproduction approach, the lack of a control group limits our ability to confirm the effects of the program. We tried to minimize this limitation by using mixed methods so that both quantitative and qualitative data provided context and supported the outcomes of this intervention. In addition, though all levels of domain empowerment exhibited significant positive changes, we were not able to directly observe participants' behaviors. The data sources of this study were from self-reported questionnaires and interviews; this may have introduced bias related to social desirability, meaning participants may have wished to please the investigators when completing the quantitative and qualitative data. Particularly, the behavioral domain was measured with one item that measured the intention to smoke, which does not provide information on advocacy actions or community actions; only qualitative data provide those aspects.

Future studies with a larger sample and a control group (eg, coproduction of other types of videos) are needed. It would also be helpful to explore the long-term effects, especially in studies that involve the direct observation of behavioral domain outcomes for empowered youth behavior and their impact as nonsmokers and advocates for a nonsmoking society, as well as their potential future as good citizens. With this methodological improvement, the efficacy or effect of coproduction on empowering participants in smoking prevention can be explored. Moreover, future studies can explore potential mechanisms by exploring any potential mediators or moderators. In addition, it will be interesting to explore whether the coproduction approach may influence other outcomes, such as critical thinking ability or leadership skills. Furthermore, it will be worthwhile to expand the components of coproducing the video clips to the generation and sharing of content by adolescents using two-way communication methods, such as social media for health education [31,56]. In addition, since e-cigarettes are an emerging issue for adolescents, developing an e-cigarette prevention program using participatory video production may need to be considered.

This study has major implications for health care practice and policy. Our findings suggest that coproduction of video clips about antismoking messages are able to empower adolescents to remain nonsmokers and become advocates for a smoke-free society in a low-income community. This study reports on a feasible way to use technology by incorporating appropriate pedagogical strategies for health education. With the process of coproduction of videos, participants may voice their opinions about specific social issues and become active participants for critical health issues. The findings suggest that the coproduction of videos was seen by participants as an opportunity to actively participate in social issues and help other people. The participatory video-making process may provide an example to help them understand health issues in depth. At the policy level, providing more resources or providing opportunities to better engage adolescents in smoking prevention programs could potentially have a significant impact, particularly for minority populations in low-income neighborhoods. The findings of this study suggest that coproduction of antismoking videos can be a useful and feasible educational method to engage this hard-to-reach population and empower these adolescents to be active participants in sociocritical health issues, such as tobacco control.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary tables.
[DOCX File , 16 KB - pediatrics_v3i1e13031_app1.docx]

References

1. Centers for Disease Control and Prevention. Youth Risk Behavior Surveillance System (YRBSS) URL: http://www.cdc.gov/yrbs [accessed 2018-05-24]
2. US Department of Health and Human Services. Preventing Tobacco Use Among Youth and Young Adults: A Report of the Surgeon General. Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; 2012. URL: https://www.ncbi.nlm.nih.gov/books/NBK99237/pdf/Bookshelf_NBK99237.pdf [accessed 2020-02-06]
3. Kendler KS, Myers J, Damaj MI, Chen X. Early smoking onset and risk for subsequent nicotine dependence: A monozygotic co-twin control study. Am J Psychiatry 2013 Apr;170(4):408-413 [FREE Full text] [doi: 10.1176/appi.ajp.2012.12030321] [Medline: 23318372]
4. Thombs BD, Jaramillo Garcia A, Reid D, Pottie K, Parkin P, Kate M, Canadian Task Force on Preventive Health Care. Recommendations on behavioural interventions for the prevention and treatment of cigarette smoking among school-aged children and youth. CMAJ 2017 Feb 27;189(8):E310-E316 [FREE Full text] [doi: 10.1503/cmaj.161242] [Medline: 28246224]
5. Buchmann AF, Blomeyer D, Jennen-Steinmetz C, Schmidt MH, Esser G, Banaschewski T, et al. Early smoking onset may promise initial pleasurable sensations and later addiction. Addict Biol 2013 Nov;18(6):947-954. [doi: 10.1111/j.1369-1600.2011.00377.x] [Medline: 21966958]
6. Ray M, Buka S, Clark M, Hitsman B, Molnar B, Niaura R, et al. Socioeconomic status and risk of youth regular smoking: Findings from a three-generation study. In: Proceedings of the American Thoracic Society 2014 International Conference. 2014 Presented at: American Thoracic Society 2014 International Conference; May 16-21, 2014; San Diego, CA p. A5083.
7. Wellman RJ, Sylvestre M, O'Loughlin EK, Dutczak H, Montreuil A, Datta GD, et al. Socioeconomic status is associated with the prevalence and co-occurrence of risk factors for cigarette smoking initiation during adolescence. Int J Public Health 2018 Jan;63(1):125-136. [doi: 10.1007/s00038-017-1051-9] [Medline: 29116338]
8. Thomas RE, McLellan J, Perera R. School-based programmes for preventing smoking. Cochrane Database Syst Rev 2013 Apr 30(4):CD001293. [doi: 10.1002/14651858.CD001293.pub3] [Medline: 23633306]
9. Twyman L, Bonevski B, Paul C, Bryant J. Perceived barriers to smoking cessation in selected vulnerable groups: A systematic review of the qualitative and quantitative literature. BMJ Open 2014 Dec 22;4(12):e006414 [FREE Full text] [doi: 10.1136/bmjopen-2014-006414] [Medline: 25534212]

10. Cella DF, Tulsky DS, Sarafian B, Thomas CR, Thomas CR. Culturally relevant smoking prevention for minority youth. J Sch Health 1992 Oct;62(8):377-380. [doi: 10.1111/j.1746-1561.1992.tb02327.x] [Medline: 1479830]
11. Chen MS. Challenges in tobacco use prevention among minority youth. Cancer Epidemiol Biomarkers Prev 2003 Mar;12(3):253s-255s [FREE Full text] [Medline: 12646522]
12. Cremers H, Mercken L, de Vries H, Oenema A. A longitudinal study on determinants of the intention to start smoking among non-smoking boys and girls of high and low socioeconomic status. BMC Public Health 2015 Jul 13;15:648 [FREE Full text] [doi: 10.1186/s12889-015-1917-9] [Medline: 26163878]
13. Landrine H, Corral I. Sociocultural correlates of cigarette smoking among African-American men versus women: Implications for culturally specific cessation interventions. J Health Psychol 2016 Jun;21(6):954-961. [doi: 10.1177/1359105314542821] [Medline: 25104780]
14. Center for Tobacco Policy Research, George Warren Brown School of Social Work, Washington University. Youth Engagement: State and Community Interventions. Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; 2010. URL: https://stacks.cdc.gov/view/cdc/5628/ [accessed 2020-02-06]
15. Heminger CL, Boal AL, Zumer M, Abroms LC. Text2Quit: An analysis of participant engagement in the mobile smoking cessation program. Am J Drug Alcohol Abuse 2016 Jul;42(4):450-458. [doi: 10.3109/00952990.2016.1149591] [Medline: 27120396]
16. Aveyard P, Markham WA, Almond J, Lancashire E, Cheng KK. The risk of smoking in relation to engagement with a school-based smoking intervention. Soc Sci Med 2003 Feb;56(4):869-882. [doi: 10.1016/s0277-9536(02)00088-6] [Medline: 12560019]
17. Beer C, Clark K. Indicators of engagement. In: Curriculum, Technology & Transformation for an Unknown Future: Proceedings ascilite Sydney 2010. Brisbane, Australia: The University of Queensland; 2010 Presented at: Curriculum, Technology & Transformation for an Unknown Future: ascilite Sydney 2010; December 5-8, 2010; Sydney, Australia p. 76.
18. Soep E. Beyond literacy and voice in youth media production. McGill J Educ 2006;41(3):197-213 [FREE Full text]
19. Baskerville NB, Struik LL, Hammond D, Guindon GE, Norman CD, Whittaker R, et al. Effect of a mobile phone intervention on quitting smoking in a young adult population of smokers: Randomized controlled trial study protocol. JMIR Res Protoc 2015 Jan 19;4(1):e10 [FREE Full text] [doi: 10.2196/resprot.3823] [Medline: 25599695]
20. de Graaf A, van den Putte B, Nguyen M, Zebregs S, Lammers J, Neijens P. The effectiveness of narrative versus informational smoking education on smoking beliefs, attitudes and intentions of low-educated adolescents. Psychol Health 2017 Jul;32(7):810-825. [doi: 10.1080/08870446.2017.1307371] [Medline: 28366018]
21. Michie S, West R, Sheals K, Godinho CA. Evaluating the effectiveness of behavior change techniques in health-related behavior: A scoping review of methods used. Transl Behav Med 2018 Mar 01;8(2):212-224 [FREE Full text] [doi: 10.1093/tbm/ibx019] [Medline: 29381786]
22. Botvin GJ, Dusenbury L, Baker E, James-Ortiz S, Kerner J. A skills training approach to smoking prevention among Hispanic youth. J Behav Med 1989 Jun;12(3):279-296. [doi: 10.1007/bf00844872] [Medline: 2634104]
23. Solhi M, Abasi H, Hazavehei MG. Effect of educational intervention on empowerment of high school student in prevention of smoking. Razi J Med Sci 2014;21(118):52-63.
24. Nagelhout GE, Popova L, Kuipers MA. Why are new tobacco control interventions needed? Int J Environ Res Public Health 2018 Apr 02;15(4):658 [FREE Full text] [doi: 10.3390/ijerph15040658] [Medline: 29614798]
25. Gubrium A. Digital storytelling: An emergent method for health promotion research and practice. Health Promot Pract 2009 Apr;10(2):186-191. [doi: 10.1177/1524839909332600] [Medline: 19372280]
26. Park E, Drake E. Systematic review: Internet-based program for youth smoking prevention and cessation. J Nurs Scholarsh 2015 Jan;47(1):43-50. [doi: 10.1111/jnu.12104] [Medline: 25130325]
27. Park E, Jang BG. Youth substance use prevention using disciplinary literacy strategies: A pilot study. J Addict Nurs 2018;29(4):235-243. [doi: 10.1097/JAN.0000000000000253] [Medline: 30507819]
28. Norman CD, Yip AL. eHealth promotion and social innovation with youth: Using social and visual media to engage diverse communities. Stud Health Technol Inform 2012;172:54-70. [Medline: 22910502]
29. Elaheebocus SM, Weal M, Morrison L, Yardley L. Peer-based social media features in behavior change interventions: Systematic review. J Med Internet Res 2018 Feb 22;20(2):e20 [FREE Full text] [doi: 10.2196/jmir.8342] [Medline: 29472174]
30. Leatherdale ST, Cole A. Examining the impact of changes in school tobacco control policies and programs on current smoking and susceptibility to future smoking among youth in the first two years of the COMPASS study: Looking back to move forward. Tob Induc Dis 2015;13(1):8 [FREE Full text] [doi: 10.1186/s12971-015-0031-1] [Medline: 25834482]
31. Wong CA, Merchant RM, Moreno MA. Using social media to engage adolescents and young adults with their health. Healthc (Amst) 2014 Dec;2(4):220-224 [FREE Full text] [doi: 10.1016/j.hjdsi.2014.10.005] [Medline: 25984444]
32. Zimmerman MA. Empowerment theory: Psychological, organizational, and community levels of anaylsis. In: Rappaport J, Seidman E, editors. Handbook of Community Psychology. New York, NY: Springer Science+Business Media; 2000:43-64.
33. Glantz SA, Mandel LL. Since school-based tobacco prevention programs do not work, what should we do? J Adolesc Health 2005 Mar;36(3):157-159. [doi: 10.1016/j.jadohealth.2005.01.001] [Medline: 15737768]

34. Wilson LM, Avila Tang E, Chander G, Hutton HE, Odelola OA, Elf JL, et al. Impact of tobacco control interventions on smoking initiation, cessation, and prevalence: A systematic review. J Environ Public Health 2012;2012:961724 [FREE Full text] [doi: 10.1155/2012/961724] [Medline: 22719777]
35. Winkleby MA, Feighery E, Dunn M, Kole S, Ahn D, Killen JD. Effects of an advocacy intervention to reduce smoking among teenagers. Arch Pediatr Adolesc Med 2004 Mar;158(3):269-275. [doi: 10.1001/archpedi.158.3.269] [Medline: 14993087]
36. Ramirez AG, Velez LF, Chalela P, Grussendorf J, McAlister AL. Tobacco control policy advocacy attitudes and self-efficacy among ethnically diverse high school students. Health Educ Behav 2006 Aug;33(4):502-514. [doi: 10.1177/1090198106287694] [Medline: 16740511]
37. Carver V, Reinert B, Range LM, Campbell C. Adolescents' attitudes and self-perceptions about anti-tobacco advocacy. Health Educ Res 2003 Aug;18(4):453-460. [doi: 10.1093/her/cyf030] [Medline: 12939127]
38. Ager RD, Parquet R, Kreutzinger S. The youth video project: An innovative program for substance abuse prevention. J Soc Work Pract Addict 2008 Jul 23;8(3):303-321. [doi: 10.1080/15332560802223313]
39. De Lange N, Mitchell C, Moletsane R, Stuart J. Youth as knowledge producers in community-based video in the age of AIDS (Sidebar). In: Hoechsmann M, Poyntz SR, editors. Media Literacies: A Critical Introduction. Chichester, UK: Blackwell Publishing; 2012:119.
40. de Lange N, Geldenhuys M. Youth envisioning safe schools: A participatory video approach. SAJE 2012 Nov 07;32(4):494-511. [doi: 10.15700/saje.v32n4a734]
41. Park E, Kulbok PA, Keim-Malpass J, Drake E, Kennedy MJ. Adolescent smoking prevention: Feasibility and effect of participatory video production. J Pediatr Nurs 2017;36:197-204. [doi: 10.1016/j.pedn.2017.07.001] [Medline: 28888503]
42. Haynes K, Tanner TM. Empowering young people and strengthening resilience: Youth-centred participatory video as a tool for climate change adaptation and disaster risk reduction. Child Geogr 2013 Oct 31;13(3):357-371. [doi: 10.1080/14733285.2013.848599]
43. Zemits B, Maypilama L, Wild K, Mitchell A, Rumbold A. Moving beyond "health education": Participatory filmmaking for cross-cultural health communication. Health Commun 2015;30(12):1213-1222. [doi: 10.1080/10410236.2014.924792] [Medline: 25411999]
44. Marr-Lyon L, Young K, Quintero G. An evaluation of youth empowerment tobacco prevention programs in the Southwest. J Drug Educ 2008;38(1):39-53. [doi: 10.2190/DE.38.1.d] [Medline: 18592806]
45. Holleran LK, Reeves L, Dustman P, Marsiglia FF. Creating culturally grounded videos for substance abuse prevention. J Soc Work Pract Addict 2002 Jan;2(1):55-78. [doi: 10.1300/j160v02n01_04]
46. Holden DJ, Crankshaw E, Nimsch C, Hinnant LW, Hund L. Quantifying the impact of participation in local tobacco control groups on the psychological empowerment of involved youth. Health Educ Behav 2004 Oct;31(5):615-628. [doi: 10.1177/1090198104268678] [Medline: 15358893]
47. Holden DJ, Messeri P, Evans WD, Crankshaw E, Ben-Davies M. Conceptualizing youth empowerment within tobacco control. Health Educ Behav 2004 Oct;31(5):548-563. [doi: 10.1177/1090198104268545] [Medline: 15358889]
48. Holden DJ, Evans WD, Hinnant LW, Messeri P. Modeling psychological empowerment among youth involved in local tobacco control efforts. Health Educ Behav 2005 Apr;32(2):264-278. [doi: 10.1177/1090198104272336] [Medline: 15749971]
49. Perkins DD, Zimmerman MA. Empowerment theory, research, and application. Am J Community Psychol 1995 Oct;23(5):569-579. [doi: 10.1007/bf02506982] [Medline: 8851340]
50. Zimmerman MA. Psychological empowerment: Issues and illustrations. Am J Community Psychol 1995 Oct;23(5):581-599. [doi: 10.1007/bf02506983] [Medline: 8851341]
51. Andrew S, Halcomb EJ, editors. Mixed Methods Research for Nursing and the Health Sciences. Chichester, UK: Blackwell Publishing; 2009.
52. Creswell JW, Plano-Clark VL. Designing and Conducting Mixed Methods Research. Thousand Oaks, CA: SAGE Publications; 2007.
53. Sandelowski M. Using qualitative methods in intervention studies. Res Nurs Health 1996 Aug 19;19(4):359-364. [doi: 10.1002/(sici)1098-240x(199608)19:4<359::aid-nur9>3.0.co;2-h]
54. United States Census Bureau. QuickFacts: Pontiac City, Michigan; United States URL: https://www.census.gov/quickfacts/fact/table/pontiaccitymichigan,US/PST045218 [accessed 2018-05-24]
55. Hsieh H, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005 Nov;15(9):1277-1288. [doi: 10.1177/1049732305276687] [Medline: 16204405]
56. Andrade EL, Evans WD, Barrett N, Edberg MC, Cleary SD. Strategies to increase Latino immigrant youth engagement in health promotion using social media: Mixed methods study. JMIR Public Health Surveill 2018 Dec 19;4(4):e71 [FREE Full text] [doi: 10.2196/publichealth.9332] [Medline: 30567689]

Abbreviations

YGMS: Youth Group Member Survey

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Original Paper

Using Social Media and Technology to Communicate in Pediatric HIV Research: Qualitative Study With Young Adults Living With or Exposed to Perinatal HIV

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Abstract

Background: As young adults living with perinatal HIV (PHIV) or perinatal HIV exposure but uninfected (PHEU) grow older and manage the challenges and competing demands of young adulthood, new approaches are needed to facilitate their retention in longitudinal research and clinical care beyond in-person clinic visits. Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the novel virus that causes coronavirus disease (COVID-19), emerged in the United States in January 2020 and has underscored this need; studies are adapting to remote communication with and data collection from participants. However, there are limited data on communication preferences among young adults who are living with PHIV or PHEU.

Objective: The objectives of this qualitative study were to describe participants' perceptions and use of social media and technology in their personal lives and in the context of participating in longitudinal pediatric HIV research and to describe the implications of the use of technology and social media for communication and retention purposes within a longitudinal pediatric study about HIV.

Methods: We conducted 6 focus group discussions with 31 young adults living with PHIV and 13 in-depth interviews with 6 young adults living with PHIV and 7 living with PHEU. We asked about their preferences for the use of social media and digital technology in the Adolescent Master Protocol, a US-based longitudinal cohort study of youth affected by HIV.

Results: Participants' willingness to use social media platforms, telephone calls, SMS text messages, and video calls within the context of HIV research varied due to fears of HIV stigma and inadvertent disclosure. However, trusting relationships with clinical staff positively impacted their willingness to use these platforms.

Conclusions: Our findings offer insight into how pediatric studies and clinics can communicate with participants as they age, even as new technologies and social media platforms emerge and replace old ones. For optimal retention, pediatric clinical staff should consider communication approaches offering flexible and tailored options for young adults participating in HIV research.

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KEYWORDS

pediatric HIV; perinatal HIV; youth; young adults; social media; study retention; COVID-19

Introduction

As young adults living with perinatal HIV (PHIV) or perinatal HIV exposure but uninfected (PHEU) grow older and manage the challenges and competing demands of young adulthood, new approaches are needed to facilitate their retention in longitudinal research studies and clinical care beyond in-person clinic visits. Recent events have underscored this need. Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the novel virus that causes coronavirus disease (COVID-19), emerged in the United States in January 2020 and has quickly forced studies to adapt their procedures to enable remote communication with and collect data from participants. Young adults living with PHIV or PHEU may be navigating increased autonomy, careers, school, and relationships while managing HIV, stigma, and disclosure [1-4], medication fatigue from lifelong antiretroviral regimens [5], and family relationships in the context of HIV. Using digital communication methods holds potential for retaining the participation of these young adults in studies. Although their aging has coincided with a rapid expansion of health care and health communication technology options, little is known about their specific communication preferences in the context of HIV research.

The evidence demonstrating the effectiveness of strategies utilizing social media or digital technology to retain youth living with HIV in research is limited [6]. However, an increasing number of health promotion and peer-to-peer programs have engaged youth living with HIV using text messaging, websites, games, and smartphone apps [7-14]. The general success of these methods may indicate some willingness among youth living with HIV to engage with social and digital media around HIV prevention, treatment-related communication, and peer support. However, these interventions have mostly focused on youth who acquired HIV later in life, who may differ in key health outcomes from youth who acquired HIV perinatally [15-17]. It is not well understood whether young adults living with PHIV or PHEU have unique communication preferences due to lifelong experiences with HIV, antiretrovirals, and stigma, and this topic is in need of further exploration.

The Adolescent Master Protocol (AMP) of the Pediatric HIV/AIDS Cohort Study (PHACS) network [18] follows the physical, cognitive, social, and behavioral development of youth and adolescents living with PHIV and PHEU in the US. Due to declining retention rates in AMP as participants approach young adulthood, there is urgent need to optimize communication with young adults in PHACS for their continued study participation. PHACS therefore launched the AMP Up protocol for young adults in early 2014; this protocol uses a flexible internet-based and clinic-based approach [19]. Novel communication approaches that respond to participants' preferences are critical to ensure that PHACS can continue its research into the long-term impact of PHIV and antiretroviral exposure among young adults living with PHIV or PHEU.

To our knowledge, no other study has examined specific digital communication and information preferences from the direct perspectives of youth living with PHIV and PHEU. The objectives of this qualitative study were to describe participants' perceptions and use of social media and technology in their personal lives and in the context of participating in longitudinal pediatric HIV research and to describe the implications of the use of technology and social media for communication and retention purposes within a longitudinal pediatric study about HIV. It is our hope that the insights described below will help inform digital strategies to retain participants and patients in study protocols and care during and beyond the COVID-19 pandemic.

Methods

This formative qualitative study was conducted among young adults living with PHIV or PHEU at PHACS AMP clinics in 8 cities across the United States: New York, New York; Denver, Colorado; Philadelphia, Pennsylvania; Fort Lauderdale, Florida; San Diego, California; Houston, Texas; Chicago, Illinois; and San Juan, Puerto Rico.

Recruitment and Sampling

Young adults were eligible for this study if they were between 18 and 25 years of age; living with PHIV and aware of their HIV status or living with PHEU and aware of their biological mother's HIV status; enrolled at the time in AMP or receiving HIV care at a clinic with experience participating in an HIV-related longitudinal study in the past four years; and able to provide written informed consent in either English or Spanish. PHACS clinic staff at local AMP sites recruited participants using purposive sampling [20].

Institutional Review Boards at each site and the Harvard TH Chan School of Public Health approved the protocol for this qualitative study. All participants provided written informed consent in their preferred language (English or Spanish).

Data Collection

From June 2013 to May 2014, trained facilitators (CB, DK, and JB) conducted 6 focus group discussions with 31 young adults living with PHIV and one-on-one in-depth interviews with 6 young adults living with PHIV and 7 living with PHEU. The focus groups ranged in size from 3 to 8 (mean 5) participants. Six young adults living with PHIV opted for a one-on-one interview instead of participating in a focus group. All young adults living with PHEU participated in one-on-one interviews due to insufficient numbers of eligible youth per site to hold focus groups. All participants completed a 90-minute audio-recorded focus group discussion or interview followed by a 15-minute self-administered survey. The survey assessed demographics, access to digital technology, social media preferences, and frequency of use.

One or two of the three facilitators trained in qualitative research named above conducted the focus group discussions and interviews. In Puerto Rico, the interviews were conducted by a Spanish-speaking facilitator (JB). At each clinic, the focus group discussions and interviews were held in private rooms. Facilitators used a structured discussion guide covering the following topics: personal use of and access to mobile phones, computers, the internet, and social media; perceptions of adulthood; attitudes towards connecting with other young adults affected by HIV; participant concerns and hopes in their current stage of life; information needs and preferences during their transition to adulthood; motivations for participating in PHACS and HIV research; willingness to use social media to communicate with PHACS; and design and content preferences for a new private website portal for study participants.

Data Analysis

Focus groups and interviews were audio recorded and transcribed verbatim in English, except for those held in Puerto Rico, which were transcribed verbatim in Spanish and then translated into English. To preserve anonymity, all identifying data were removed. Therefore, the quotations in this paper only identify participants' HIV status and whether the response was recorded during a focus group or one-on-one interview. Facilitators took notes and prepared debriefing reports to record insights into dynamics that were not easily captured from the transcripts alone.

Analysis of the survey data included calculating percentages and frequencies of the sociodemographic characteristics of the participants and their digital communication and device use and preferences. Analysis of the qualitative data used a thematic approach [21,22]. All transcripts were coded by the study team using Atlas.ti software [23]. Drawing themes from both focus groups and interviews, the team developed a codebook, which was refined iteratively. The first 20% of the transcripts were double-coded to assess and ensure consistency across coders; discrepancies in coding were resolved by updating codebook definitions or creating new codes where necessary, and the final codes were entered into Atlas.ti and applied to all transcripts.

Results

Characteristics of the Participants

Of the 44 young adults living with PHIV or PHEU participating in the focus groups and one-on-one interviews, 40 (91%) completed the study survey. Of these 40 participants, 26 (65%) identified as female, 35 (87%) were aged 18 to 21 years, 25 (63%) identified as Black/African American, 15 (38%) identified as Hispanic/Latino, 33 (83%) were living with PHIV, and 7 (17%) were living with PHEU (Table 1).

Table 1. Selected participant characteristics (N=40).

Characteristic	n (%)
Gender	
Male	14 (35)
Female	26 (65)
Transgender	0 (0)
Age (years)	
18 to 21	35 (87)
22 to 24	5 (13)
Race	
White	9 (23)
Black/African American	25 (63)
American Indian	2 (5)
Native Hawaiian/Pacific Islander	2 (5)
Other	6 (15)
Hispanic/Latino	15 (38)
HIV status	
PHIV[a]	33 (83)
PHEU[b]	7 (17)

[a] PHIV: perinatal HIV.

[b] PHEU: perinatal HIV exposure but uninfected.

Personal Use of Social Media and Technology

Young adults reported frequent use of smartphones and computers to access the internet (Table 2).

A few participants reported limited internet access due to poor network connectivity, lack of home Wi-Fi connectivity, or lack of an internet-enabled device. Most reported accessing the internet “everywhere” on devices they carried, and they “never” or “rarely” used a work or public library computer. Most reported using Facebook and Instagram; some cited Tumblr, Skype, or Twitter, as well as more solitary forms of entertainment (eg, YouTube and video games). One focus group participant with PHIV described the factors that influence which platform they used:

> *If it’s a quick message, somebody might text someone—send a Facebook message…whereas with, like if you’re having an event or something, you can post it on Facebook…or put it on Twitter.*

Table 2. Frequency of device use among young adults (N=40).

Device type	Frequency, n (%)					
	Daily	Weekly	Monthly	A few times	Any use[a]	Never
Mobile phone	28 (70)	0 (0)	2 (5)	0 (0)	8 (20)	2 (5)
Home computer	11 (28)	4 (10)	3 (8)	7 (18)	3 (8)	12 (30)
School computer	0 (0)	4 (10)	2 (5)	7 (18)	0 (0)	27 (68)
Work computer	1 (3)	1 (3)	2 (5)	0 (0)	0 (0)	36 (90)
Friend or family member’s computer	2 (5)	5 (13)	2 (5)	8 (20)	1 (3)	22 (55)
Public computer	0 (0)	2 (5)	1 (3)	9 (23)	1 (3)	27 (68)
Other device	1 (3)	0 (0)	0 (0)	0 (0)	0 (0)	39 (98)

[a] Any use: use is indicated but the frequency is not specified.

Attitudes towards different forms of social media varied. For instance, while some participants mentioned using Twitter as a way to keep up to date with news (eg, activities of celebrities they liked), most expressed negative attitudes towards it. Of all social media platforms, Facebook elicited the most divided opinions. While some participants stated that they liked Facebook, others said that Facebook was no longer popular among people their age and that they used Facebook somewhat reluctantly to keep in touch with people in their lives. Conversely, Instagram was identified as more popular and was viewed by many participants as a positive way to connect with people, the optimal way to promote a brand, more tailored to user preferences, more “personal” than Facebook, and more entertaining. Most participants stated they did not use email as often as texting. Some perceived email as a more “serious” form of communication compared to texting and reserved it for work, while others had created separate email addresses for personal use, work, and school. The participants described using phone apps if they were easy to navigate; however, they noted that apps often ran too slowly, froze, or were unintuitive to navigate. Regarding this point, one focus group participant with PHIV also noted:

> *It just depends on what kind of website you’re looking at…or what you actually want to do on that website. ’Cause, like, sometimes, like, the mobile version’s more hassle than if you just went to the desktop version and do it the long way.*

Phone and Device Sharing Among Peers

Many young adults reported phone-sharing (passing their mobile phones back and forth while spending time together) among peers. Because of this, many expressed concern that their HIV-affected status could be inadvertently disclosed if their peers saw smartphone alerts from texts, emails, or social media posts about HIV, including study-related messages. One focus group participant with PHIV stated:

> *Say you’re at your friend’s house, or whatever…and the PHACS [study] thing pops up on your phone, and then your friend’s sitting next to you, they’ll know about you. And that’s, like, how the disclosure part come up in there.*

Young adults living with PHIV expressed stronger fear than those living with PHEU of inadvertent disclosure of their HIV-affected status, although some young adults living with PHEU also mentioned concerns that their mother’s HIV status, or their own HIV-affected status, could be disclosed.

Privacy and Confidentiality Concerns

Many participants expressed concern about using digital forms of communication in the context of a long-term study about HIV due to privacy and confidentiality concerns. Some expressed feeling less inclined to visit a social media page on their mobile phones in public due to concerns that their online activity could be viewed by others. Many were averse to seeking information about HIV on their mobile phones in public for the same reason. Young adults reported managing their online presence carefully, aware that privacy protections could quickly change as the Terms of Service on social media sites were updated. For this reason, most participants were hesitant or unwilling to join even a private and invisible Facebook group related to HIV. For some, this concern outweighed the potential benefits of using social media to connect with peers living with HIV. Regarding this point, one interview participant with PHIV stated:

> *My concern is confidentiality there. Never know who's going to…many things can happen. You can lose your phone, people go through your phone…I've had my email hacked before…That shit happens.*

Relationship With Clinic Staff

Participants reported higher willingness to use texting or social media to stay in touch with study staff with whom they had close and trusting relationships. Having participated in research throughout their lives, many young adults described strong connections to PHACS clinical staff. These young adults described staff as "family" they looked forward to seeing during study visits. One focus group participant with PHIV stated:

> *They know everything about you, know everything you've ever done…known you since birth…it literally is your second family.*

Another interview participant with PHEU noted:

> *…'cause these people here are like my family. Like, they've known me from the minute I came out of the womb.*

Another focus group participant with PHIV stated:

> *…I have a doctor that I can—that's been taking care of me since I was a baby…and to see the doctor smile that you've known since you were a baby…it feels good, because you know you're still alive, and they see you're still alive and you're still here surviving and living.*

The high level of trust in these longstanding relationships was cited by participants as a significant factor in their willingness to use social media and texting to communicate in an HIV-related study.

Communication Preferences Within Research

Most participants stated that they preferred that study staff contact them by telephone or email (Table 3), which they perceived as more private and secure.

Table 3. Communication preferences of young adults in PHACS in personal life vs in pediatric HIV research (N=40).

Communication type	Frequency, n (%)				
	Very often	Somewhat often	Not often	Any use[a]	Never
Texting					
Use in personal life[b]	26 (65)	4 (10)	0 (0)	5 (13)	5 (13)
Preferred use with the study[c]	9 (23)	9 (23)	1 (3)	1 (3)	20 (51)
Email					
Use in personal life	2 (5)	9 (23)	9 (23)	1 (3)	19 (48)
Preferred use with the study	11 (28)	9 (23)	1 (3)	5 (13)	14 (36)
Facebook					
Use in personal life	20 (50)	9 (23)	0 (0)	3 (8)	8 (20)
Preferred use with the study	5 (13)	3 (8)	3 (8)	0 (0)	29 (73)
Twitter					
Use in personal life	2 (5)	2 (5%)	6 (15)	1 (3)	29 (73)
Preferred use with the study	1 (3)	0 (0%)	3 (8)	0 (0)	36 (90)
Telephone call					
Use in personal life	18 (45)	6 (15)	2 (5)	3 (8)	11 (28)
Preferred use with the study	7 (18)	4 (10)	4 (10)	5 (13)	20 (51)

[a] Any use: use is indicated but the frequency is not specified.

[b] Survey question: "How often do you and your friends use the following to communicate with each other?"

[c] Survey question: "How often would you prefer to get study-related information from PHACS using the following?"

Some participants expressed a willingness to text or message privately on a social media platform, as they trusted clinic staff to ensure the messages would be secure. However, many stated that they would not feel comfortable using social media to stay in contact with an HIV-related study due to fear of inadvertent disclosure of their HIV-affected status. Some participants expressed that omitting the acronym "HIV" and using code words for the study (or framing messages as simple "appointment reminders") was a compromise that might increase their comfort with written modes of communication. Others stated that this would still feel intrusive or risky, possibly inviting uncomfortable questions from their peers.

Some participants reported reluctance to communicate about the study outside of the clinic because they preferred to forget about HIV in their everyday lives. As one focus group participant with PHIV noted:

> *See, when I'm not [at the clinic], I forget that I have HIV at all…So I never, like, have a need to look it up. I don't know if that makes sense. But I'm never, like, curious about something…'cause I'm like, "Nah." It's not in, like, the front of my mind at all, ever.*

As another interview participant with PHIV stated:

> *The only thing I don't like about the study is that it reminds me…it's a blast to the past of where this all started with me….80% is me helping, the other 20% is me being reminded [of how] this all started.*

When asked whether they would take advantage of a new flexible study format that would allow them to take surveys online from home and reduce clinic visits, the participants' responses were mixed. Some participants stated they would still want to come to the clinic to complete their surveys, while others felt they would benefit from the remote option. Participants who preferred taking surveys remotely expressed that it was convenient, time-saving, and cost-effective. However, those who preferred to complete surveys in the clinic expressed a desire to visit with study staff and ensure the privacy of their responses.

Participants expressed a desire to access study information, especially information on findings from the research they participated in (eg, lay summaries of study results, study announcements). Regarding this point, one interview participant with PHEU stated:

> *I just like feeling like I'm a part of something, like…bigger than me.*

As another focus group participant with PHIV stated:

> *I would like to know…because we do these [studies]…and I would like to know how that information benefitted you, because you never hear about what happened afterwards…and how it helped.*

Participants also stated a desire for a private app or website for the study participants that would not be solely focused on HIV. Most expressed a desire for resources related to young adulthood, including employment, school, housing, health care and health insurance, and maintaining healthy relationships.

Discussion

Principal Findings

While previous studies have more broadly illuminated the experiences of youth living with HIV, our study investigated the unique preferences of young adults living with PHIV or PHEU regarding social media use in longitudinal pediatric HIV research communication. Our findings suggest that tailoring both the mode and content of communication to participants' individual preferences, as well as remaining flexible to allow changes in communication preferences over time, may yield better study retention. In this qualitative study, young adults living with PHIV or PHEU reported frequent use of internet-enabled devices (especially smartphones) and social media in their personal lives, mirroring young adults in the United States more generally [24,25]. However, they expressed varying degrees of willingness to engage with these technologies in the context of an HIV-focused study. For some, a private Facebook message felt acceptable; for others, SMS text messages or email were preferable; others were comfortable only with a telephone call to minimize the digital trail of their connection to HIV. In our study, a fear of inadvertent disclosure of an HIV-affected status through social media or technology use was consistent with other studies of youth living with HIV [11,26]. Most participants expressed caution about connecting with an HIV study online. Participants living with PHIV expressed strong concerns about HIV stigma and inadvertent disclosure, similar to other youth living with HIV worldwide [1-4,27-30], more often than participants living with PHEU. These concerns, combined with the common practice of sharing devices and actively engaging with each other's social media accounts, influenced their social media and technology preferences in the context of longitudinal HIV research.

As with previous research into transition from pediatric to adult health care among young people living with HIV [31-36], participants in this study reported close relationships with their pediatric providers and study staff. Some expressed that their established relationships with clinicians mitigated privacy concerns and increased their willingness to consider using social media and texting to communicate with trusted providers about HIV research. However, many also expressed preferences for private communication channels. Studies should therefore provide staff with the time and resources they need to build and maintain trusting relationships with participants. Study staff should also consider offering participants flexible communication options, asking for consent first, using coded language in messages to protect privacy, tailoring messages to specific participants, and giving participants the option to change their communication preferences over time. It is critical for staff to be aware that even seemingly benign texts or social media messages from study staff that do not mention HIV may be perceived as intrusive or distressing by young adults living with PHIV or PHEU. These messages may still trigger questions from peers, with whom they may share smartphones and other devices. Importantly, using these methods of communication in the context of a pediatric HIV study carries the double risk of disclosing not only the young adult participant's but also their mother's HIV status.

Young adults living with PHIV explicitly named various aspects of emerging young adulthood beyond their health and HIV as key priorities in life, such as housing, employment, school, and relationships, building on previous research and resources focused on living and coping with an HIV diagnosis [5,7-9,31-36]. Many participants expressed a desire to receive results from the studies they participate in. Study staff should consider discussing or offering resources and information on these topics as part of remote communication.

The results of our study underscore the myriad ways that individuals may experience being affected by HIV from birth. Having grown up with a mother living with HIV and having potentially been receiving antiretroviral treatment since childhood, some young adults living with PHIV or PHEU may wish to avoid thinking about HIV in their day-to-day lives. Others may find HIV to be a strong focus in their lives that feels either neutral or even positive. Young adults' responses emphasize the importance of mirroring their varied experiences in communication strategies. Communication that focuses holistically on individuals within a broader constellation of joys, transitions, and challenges inherent to emerging young adulthood—and which provides young adults with the autonomy to decide how HIV fits into this constellation—may be most effective when considering approaches to study retention.

Limitations

There are a number of limitations of this research. The final transcripts of the focus group discussions denoted only male and female-sounding voices, limiting the ability to contextualize key themes according to race, age, gender identity, or location. While our sample was demographically similar to the overall population of the AMP Up protocol [37], participants who were willing to participate in focus groups or interviews may not be representative of the general PHACS population or of participants in other pediatric HIV studies in their views and opinions. For example, it is possible that they have experienced and navigated stigma differently or have had different opportunities to develop coping strategies compared to study participants who chose not to join our study. We conducted this research at only 8 of the 14 PHACS AMP sites; participants in unrepresented parts of the country may have different access to the internet, prefer different communication methods, or operate within a different local context of HIV stigma. The majority of PHACS sites are located in urban settings, and of all eligible youth, those living closer to the clinic may have been more likely to participate. The results of this qualitative study, conducted in 2013 and 2014, may not reflect current attitudes or newer technologies and social media platforms; however, the results can inform fundamental steps staff can take to safely introduce the use of newer and evolving technologies as study communication tools.

Conclusions

Our findings offer insights into how HIV-focused studies can communicate with young adult participants even as new technologies and social media platforms emerge and replace old ones. While participants in our study were young adults living with PHIV or PHEU engaged in longitudinal pediatric HIV research, our results could inform strategies for using social media and technology to recruit new participants into HIV research or treatment. They could also be applied to retaining young adults living with PHIV or PHEU in care during and after the COVID-19 pandemic, should remote communication and telehealth become an enduring norm in HIV care. Finally, these results may have implications for health communication approaches with young adults managing other perinatally or nonhorizontally acquired chronic illnesses or culturally stigmatized diagnoses.

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Conflicts of Interest

None declared.

References

1. Persson A, Newman C, Miller A. Caring for ‘underground’ kids: qualitative interviews with clinicians about key issues for young people growing up with perinatally acquired HIV in Australia. International Journal of Adolescence and Youth 2014 Jan 27;22(1):1-15. [doi: 10.1080/02673843.2013.866149]
2. Philbin MM. "What I got to go through": normalization and HIV-positive adolescents. Med Anthropol 2014;33(4):288-302 [FREE Full text] [doi: 10.1080/01459740.2013.847436] [Medline: 24964722]
3. Bogart LM, Cowgill BO, Kennedy D, Ryan G, Murphy DA, Elijah J, et al. HIV-related stigma among people with HIV and their families: a qualitative analysis. AIDS Behav 2008 Mar;12(2):244-254. [doi: 10.1007/s10461-007-9231-x] [Medline: 17458691]
4. Murphy DA. HIV-positive mothers' disclosure of their serostatus to their young children: a review. Clin Child Psychol Psychiatry 2008 Jan;13(1):105-122 [FREE Full text] [doi: 10.1177/1359104507087464] [Medline: 18411869]
5. Fields EL, Bogart LM, Thurston IB, Hu CH, Skeer MR, Safren SA, et al. Qualitative Comparison of Barriers to Antiretroviral Medication Adherence Among Perinatally and Behaviorally HIV-Infected Youth. Qual Health Res 2017 Jul;27(8):1177-1189 [FREE Full text] [doi: 10.1177/1049732317697674] [Medline: 28682737]
6. Casale M, Carlqvist A, Cluver L. Recent Interventions to Improve Retention in HIV Care and Adherence to Antiretroviral Treatment Among Adolescents and Youth: A Systematic Review. AIDS Patient Care STDS 2019 Jun;33(6):237-252 [FREE Full text] [doi: 10.1089/apc.2018.0320] [Medline: 31166783]
7. Cantrell KA, Sutton S, Gaur AH. A piece of my mind. Pause, listen, share. JAMA 2014;312(4):345-346. [doi: 10.1001/jama.2014.6201] [Medline: 25038350]
8. Flicker S, Goldberg E, Read S, Veinot T, McClelland A, Saulnier P, et al. HIV-positive youth's perspectives on the Internet and e-health. J Med Internet Res 2004 Sep 29;6(3):e32 [FREE Full text] [doi: 10.2196/jmir.6.3.e32] [Medline: 15471758]
9. Ramos D. Reaching Youth Online through HIV-Positive Youth Peer Educators. hiv.gov. 2011 May 31. URL: https://www.hiv.gov/blog/reaching-youth-online-through-hiv-positive-youth-peer-educators [accessed 2020-06-17]
10. Winstead-Derlega C, Rafaly M, Delgado S, Freeman J, Cutitta K, Miles T, et al. A pilot study of delivering peer health messages in an HIV clinic via mobile media. Telemed J E Health 2012;18(6):464-469 [FREE Full text] [doi: 10.1089/tmj.2011.0236] [Medline: 22732025]
11. Taggart T, Grewe ME, Conserve DF, Gliwa C, Roman Isler M. Social Media and HIV: A Systematic Review of Uses of Social Media in HIV Communication. J Med Internet Res 2015 Nov 02;17(11):e248 [FREE Full text] [doi: 10.2196/jmir.4387] [Medline: 26525289]
12. Castel AD, Qasmieh S, Greenberg D, Ellenberger N, Howell TH, Griffith C, et al. Digital Gaming to Improve Adherence Among Adolescents and Young Adults Living With HIV: Mixed-Methods Study to Test Feasibility and Acceptability. JMIR Serious Games 2018 Oct 15;6(4):e10213 [FREE Full text] [doi: 10.2196/10213] [Medline: 30322838]
13. Tanner AE, Song EY, Mann-Jackson L, Alonzo J, Schafer K, Ware S, et al. Preliminary Impact of the weCare Social Media Intervention to Support Health for Young Men Who Have Sex with Men and Transgender Women with HIV. AIDS Patient Care STDS 2018 Nov;32(11):450-458 [FREE Full text] [doi: 10.1089/apc.2018.0060] [Medline: 30398955]
14. Dowshen N, Kuhns LM, Johnson A, Holoyda BJ, Garofalo R. Improving adherence to antiretroviral therapy for youth living with HIV/AIDS: a pilot study using personalized, interactive, daily text message reminders. J Med Internet Res 2012;14(2):e51 [FREE Full text] [doi: 10.2196/jmir.2015] [Medline: 22481246]
15. Judd A, Davies M. Adolescent transition among young people with perinatal HIV in high-income and low-income settings. Curr Opin HIV AIDS 2018 May;13(3):236-248 [FREE Full text] [doi: 10.1097/COH.0000000000000448] [Medline: 29528851]
16. MacDonell K, Naar-King S, Huszti H, Belzer M. Barriers to medication adherence in behaviorally and perinatally infected youth living with HIV. AIDS Behav 2013 Jan;17(1):86-93 [FREE Full text] [doi: 10.1007/s10461-012-0364-1] [Medline: 23142855]
17. Mellins CA, Tassiopoulos K, Malee K, Moscicki A, Patton D, Smith R, Pediatric HIV/AIDS Cohort Study. Behavioral health risks in perinatally HIV-exposed youth: co-occurrence of sexual and drug use behavior, mental health problems, and nonadherence to antiretroviral treatment. AIDS Patient Care STDS 2011 Jul;25(7):413-422 [FREE Full text] [doi: 10.1089/apc.2011.0025] [Medline: 21992620]
18. Pediatric HIV/AIDS Cohort Study. URL: http://www.phacsstudy.org/ [accessed 2020-05-01]
19. Tassiopoulos K, Patel K, Alperen J, Kacanek D, Ellis A, Berman C, Pediatric HIV/AIDS Cohort Study. Following young people with perinatal HIV infection from adolescence into adulthood: the protocol for PHACS AMP Up, a prospective cohort study. BMJ Open 2016 Jun 09;6(6):e011396 [FREE Full text] [doi: 10.1136/bmjopen-2016-011396] [Medline: 27288383]
20. Palys T. Purposive Sampling. In: Given LM, editor. The Sage Encyclopedia of Qualitative Research Methods. Newbury Park, CA: SAGE Publications; 2008:697-698.
21. Boyatzis RE. Transforming Qualitative Information: Thematic analysis and Code Development. Newbury Park, CA: SAGE Publications; 1998.
22. Guest G, MacQueen KM, Namey EE. Applied Thematic Analysis. Newbury Park, CA: SAGE Publications; 2012.
23. atlas.ti. atlas.ti Qualitative Data Analysis. 2011. URL: https://atlasti.com/ [accessed 2020-06-17]

24. Mobile Fact Sheet. Pew Research Center. 2019 Jun 12. URL: http://www.pewinternet.org/fact-sheet/mobile/ [accessed 2020-06-17]
25. Smith A, Anderson M. Social media use in 2018. Pew Research Center. 2018 Mar 01. URL: http://www.pewinternet.org/2018/03/01/social-media-use-in-2018/ [accessed 2020-06-17]
26. Byron P, Albury K, Evers C. "It would be weird to have that on Facebook": young people's use of social media and the risk of sharing sexual health information. Reprod Health Matters 2013 May;21(41):35-44 [FREE Full text] [doi: 10.1016/S0968-8080(13)41686-5] [Medline: 23684185]
27. Bennett DS, Hersh J, Herres J, Foster J. HIV-Related Stigma, Shame, and Avoidant Coping: Risk Factors for Internalizing Symptoms Among Youth Living with HIV? Child Psychiatry Hum Dev 2016 Aug;47(4):657-664. [doi: 10.1007/s10578-015-0599-y] [Medline: 26458909]
28. Earnshaw VA, Kidman RC, Violari A. Stigma, Depression, and Substance Use Problems Among Perinatally HIV-Infected Youth in South Africa. AIDS Behav 2018 Dec;22(12):3892-3896 [FREE Full text] [doi: 10.1007/s10461-018-2201-7] [Medline: 29909588]
29. Lall P, Lim SH, Khairuddin N, Kamarulzaman A. Review: an urgent need for research on factors impacting adherence to and retention in care among HIV-positive youth and adolescents from key populations. J Int AIDS Soc 2015;18(2 Suppl 1):19393 [FREE Full text] [doi: 10.7448/IAS.18.2.19393] [Medline: 25724503]
30. McAteer CI, Truong NT, Aluoch J, Deathe AR, Nyandiko WM, Marete I, et al. A systematic review of measures of HIV/AIDS stigma in paediatric HIV-infected and HIV-affected populations. J Int AIDS Soc 2016;19(1):21204 [FREE Full text] [doi: 10.7448/IAS.19.1.21204] [Medline: 27717409]
31. Pinzón-Iregui MC, Ibanez G, Beck-Sagué C, Halpern M, Mendoza RM. "…like because you are a grownup, you do not need help": Experiences of Transition from Pediatric to Adult Care among Youth with Perinatal HIV Infection, Their Caregivers, and Health Care Providers in the Dominican Republic. J Int Assoc Provid AIDS Care 2017;16(6):579-587. [doi: 10.1177/2325957417729749] [Medline: 28895487]
32. Fair C, Albright J, Lawrence A, Gatto A. “The pediatric social worker really shepherds them through the process”: Care team members' roles in transitioning adolescents and young adults with HIV to adult care. Vulnerable Child Youth Stud 2012 Dec;7(4):338-346. [doi: 10.1080/17450128.2012.713533]
33. Hussen SA, Chahroudi A, Boylan A, Camacho-Gonzalez AF, Hackett S, Chakraborty R. Transition of youth living with HIV from pediatric to adult-oriented healthcare: a review of the literature. Future Virol 2015;9(10):921-929 [FREE Full text] [doi: 10.2217/fvl.14.73] [Medline: 25983853]
34. Sharma N, Willen E, Garcia A, Sharma TS. Attitudes toward transitioning in youth with perinatally acquired HIV and their family caregivers. J Assoc Nurses AIDS Care 2014;25(2):168-175. [doi: 10.1016/j.jana.2013.01.007] [Medline: 23809660]
35. Vijayan T, Benin AL, Wagner K, Romano S, Andiman WA. We never thought this would happen: transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. AIDS Care 2009 Oct;21(10):1222-1229 [FREE Full text] [doi: 10.1080/09540120902730054] [Medline: 20024697]
36. Wiener LS, Kohrt B, Battles HB, Pao M. The HIV experience: youth identified barriers for transitioning from pediatric to adult care. J Pediatr Psychol 2011 Mar;36(2):141-154 [FREE Full text] [doi: 10.1093/jpepsy/jsp129] [Medline: 20040607]
37. Tassiopoulos K, Huo Y, Patel K, Kacanek D, Allison S, Siminski S, Pediatric HIV/AIDS Cohort Study (PHACS). Healthcare Transition Outcomes Among Young Adults With Perinatally Acquired Human Immunodeficiency Virus Infection in the United States. Clin Infect Dis 2019 Aug 16. [doi: 10.1093/cid/ciz747] [Medline: 31584617]

Abbreviations

AMP: Adolescent Master Protocol
COVID-19: coronavirus disease
PHACS: Pediatric HIV/AIDS Cohort Study
PHIV: perinatal HIV
PHEU: perinatal HIV exposure but uninfected
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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Viewpoint

Digital Approaches to Remote Pediatric Health Care Delivery During the COVID-19 Pandemic: Existing Evidence and a Call for Further Research

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Abstract

The global spread of the coronavirus disease (COVID-19) outbreak poses a public health threat and has affected people worldwide in various unprecedented ways, both personally and professionally. There is no question that the current global COVID-19 crisis, now more than ever, is underscoring the importance of leveraging digital approaches to optimize pediatric health care delivery in the era of this pandemic. In this perspective piece, we highlight some of the available digital approaches that have been and can continue to be used to streamline remote pediatric patient care in the era of the COVID-19 pandemic, including but not limited to telemedicine. *JMIR Pediatrics and Parenting* is currently publishing a COVID-19 special theme issue in which investigators can share their interim and final research data related to digital approaches to remote pediatric health care delivery in different settings. The COVID-19 pandemic has rapidly transformed health care systems worldwide, with significant variations and innovations in adaptation. There has been rapid expansion of the leveraging and optimization of digital approaches to health care delivery, particularly integrated telemedicine and virtual health. Digital approaches have played and will play major 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 for more patients and families. However, a number of challenges remain to be addressed, and further research is needed. Optimizing digital approaches to health care delivery and integrating them into the public health response will be an ongoing process during the current COVID-19 outbreak and during other possible future pandemics. Regulatory changes are essential to support the safe and wide adoption of these approaches. Involving all relevant stakeholders in addressing current and future challenges as well as logistical, technological, and financial barriers will be key for success. Future studies should consider evaluating the following research areas related to telemedicine and other digital approaches: cost-effectiveness and return on investment; impact on quality of care; balance in use and number of visits needed for the management of both acute illness and chronic health conditions; system readiness for further adoption in other settings, such as inpatient services, subspecialist consultations, and rural areas; ongoing user-centered evaluations, with feedback from patients, families, and health care providers; strategies to optimize health equity and address disparities in access to care related to race and ethnicity, socioeconomic status, immigration status, and rural communities; privacy and security concerns for protected health information with Health Insurance Portability and Accountability Act (HIPAA)–secured programs; confidentiality issues for some specific populations, especially adolescents and those in need of mental health services; early detection of exposure to violence and child neglect; and integration of training into undergraduate and graduate medical education and subspecialty fellowships. Addressing these research areas is essential to understanding the benefits, sustainability, safety, and optimization strategies of telemedicine and other digital approaches as key parts of modern health care delivery. These efforts will inform long-term adoption of these approaches with expanded dissemination and implementation efforts.

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KEYWORDS

coronavirus; COVID-19; SARS-CoV-2; pandemic; outbreak; public health; pediatric; children; adolescents; telehealth; telemedicine; digital; interventions; digital health; digital medicine; mobile health; mHealth; eHealth; health care delivery

The Burden of the COVID-19 Pandemic

The global spread of COVID-19, the disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has posed a public health threat and has affected people worldwide in various unprecedented ways, both personally and professionally. COVID-19 infection is asymptomatic in many cases; however, in more serious cases, it can lead to severe acute respiratory syndrome, which requires mechanical ventilation, circulatory support, and intensive care unit management. Overall, children have been much less affected than adults in terms of both prevalence and disease severity [1], although the long-term effects are as yet unknown and the evidence base is evolving. The World Health Organization declared COVID - 19 a pandemic on March 11, 2020 [2]. COVID-19 has been spreading rapidly worldwide among children and adults in 187 countries; according to the Johns Hopkins Coronavirus Resource Center, there have been 7,397,349 confirmed cases and 417,133 global deaths as of June 11, 2020 [3]. These numbers continue to increase every day, especially with the high reproductive number of SARS-CoV-2 [4]. Countries with the highest disease burden, particularly fatalities, include the United States, United Kingdom, Brazil, Italy, France, Spain, and Mexico [3].

Several strategies have been implemented worldwide to limit the spread of COVID-19 infection, such as social (ie, physical) distancing and local or national stay-at-home mandates. These strategies, although necessary, have led not only to disruption of people's normal routines or daily life in different ways but also to significant financial challenges to our society and economy across almost all sectors, including health care. Just a few of the many disruptions that are more relevant to pediatrics are lower availability of child care sources due to the closure of day care centers, preschool centers, and schools; homeschooling of children and adolescents; parents or caregivers who are working remotely, have been furloughed, or have temporarily or permanently lost their jobs; limited ability to decrease individual density in outpatient settings, such as pediatricians' private offices and hospital clinics; postponement of elective surgeries, procedures, and imaging studies; avoidance of emergency rooms by children and families who may be in need of health care; and missed appointments for routine children's vaccinations. All these challenges have resulted in increased levels of stress and uncertainty in the lives of our patients and their families.

Digital Approaches to Pediatric Health Care Delivery

There is no question that the current global COVID-19 crisis, now more than ever, is underscoring the importance of leveraging digital approaches to optimize pediatric health care delivery in the era of this pandemic. Given the restrictions and limitations of in-person or face-to-face visits, many patients, families, and clinicians, including pediatricians, are increasingly realizing the potential of these tools. Additionally, access to personal technology is increasingly ubiquitous [5-7]. Moreover, there is growing evidence to support the feasibility, acceptability, and efficacy of digital behavioral interventions in pediatric populations [8-16], although economic evaluations are lacking [17]. However, concerns remain related to inequity of access to the internet, especially broadband connections; therefore, promotion of digital and telehealth equity is urgently needed. In this perspective piece, we highlight some of the available digital approaches that have been and can continue to be used to streamline remote pediatric patient care in the era of the COVID-19 pandemic, including and beyond telemedicine alone. *JMIR Pediatrics and Parenting* is currently publishing a COVID-19 special theme issue for investigators to share their interim and final research data related to digital approaches to remote pediatric health care delivery in different settings, such as telemedicine or telehealth, web-based interventions, mobile apps, wearable devices, and other novel digital strategies [Multimedia Appendix 1] [18].

Telemedicine

Telemedicine has been the main approach to deliver pediatric health care during the COVID-19 pandemic when it is accessible, available, and appropriate to address the present problem. Only 8% of Americans had used telemedicine at one point in 2019 [19]; however, this number has significantly increased during the recent pandemic. A number of barriers to wide adoption were reported earlier, such as discomfort of patients, parents, and providers using telemedicine technology, lower reimbursement rates, and preference for in-person visits. The only exception has been people in remote or rural areas with limited access to care, especially from specialists and subspecialists [20,21]. Due to the lack of an effective vaccine or therapy for COVID-19 as well as social distancing and stay-at-home lockdown orders, exploring alternatives for in-person visits is inevitable. On March 17, 2020, the US government issued a key temporary waiver for several rules related to Health Insurance Portability and Accountability Act (HIPAA) regulations around telemedicine for both audio and video communications [22,23]. This waiver is a recognition of the value and the urgent need to use telemedicine as well as the existing high-quality evidence supporting its utility. Additionally, insurers in the United States have expanded their coverage and reimbursement of various types of home (ie, direct to consumer) telemedicine visits [22]. Telemedicine has clear benefits and unique potential for scalability for general pediatricians as well as pediatric specialists in academic, community, and private sectors as well as in urban and rural settings [24-40]. However, clinics and institutions should pay careful attention to establishing plans to provide required technical support for these services and to integrate them with their workflows. This workflow process involves not only providers but also administrative support staff, nurses, social workers, case managers, other team members, patients, and patients' families. Telemedicine is being used more frequently in pediatric care, and a number of studies have examined its quality of care. In a home-based telehealth videoconferencing group of adolescent transplant recipients living a median of 57 miles from a transplant center, medication adherence generally improved, although technological difficulties limited participation [41]. A telemedicine approach is appropriate for several indications, ranging from prevention of long-term or chronic health conditions by promoting well-being to management of acute illness and provision of mental health services.

Psychosocial Support

Technology itself can be used for therapeutic benefit; in children and adolescents, this application has mostly been directed toward improving mental health and decreasing substance use. A recent systematic review and meta-analysis that included 29 different programs found a medium effect size for internet-based cognitive behavioral therapy (iCBT) for depression and anxiety in children and adolescents compared to waitlist control groups [42]. At least 10 evidence-based iCBT programs are available for adolescent anxiety [43]. Importantly, these programs showed moderate to high use, especially with adjunct support from coaches, teachers, or therapists, to demonstrate credibility and to help users complete their target behavior [43]. Interestingly, even without support, when evidence-based iCBT is open-access and self-directed, engagement is lower than in controlled trials; however, many adolescents still achieved significant reductions in anxiety levels [44]. iCBT is also being adapted for more populations, such as adolescents with intellectual disability and anxiety [45]; youth insomnia [46]; sickle cell disease [47]; and chronic pain [48], including functional abdominal pain or dyspepsia [49]. The latter, in particular, was found to result in cost savings and lower health care utilization [50].

A systematic review examining the use of remotely delivered psychological therapies for chronic pain conditions in children and adolescents included 10 eligible studies [51]. These studies involved patients with headache, juvenile idiopathic arthritis, sickle cell disease, irritable bowel syndrome, and mixed pain syndromes [51]. Reduced headache severity was the only positive finding [51]. An innovative motivational intervention for young people with schizophrenia involving a virtual community of peers with schizophrenia and motivational coaches enhanced social motivation and decreased depressive symptoms [52]. Further, some interventions have been tailored with the goal of delivery at more pertinent moments; these are called just-in-time adaptive interventions (JITAIs). For example, a mobile health intervention for homeless adolescent mothers involves a wearable wristband that measures electrodermal activity as a marker of stress and times the notification of stress signals to prompt the adolescent to use emotion regulation support [53]. It also important to note that evaluating minimal clinically important, relevant, and meaningful differences or effects as a result of these psychosocial interventions, rather than only focusing on effect sizes, is a key consideration when evaluating their effectiveness [54]. Despite the overall promising outcomes related to digital psychosocial interventions, broad and public dissemination and implementation of these interventions is still limited, and more research is needed in this area.

Supporting Preventive Behaviors

One specific population that is amenable to digital health interventions is adolescents, who are avid users of technology. Adolescence is a life period in which the majority of individuals are relatively healthy. It is also a time to establish healthy behaviors and prevent the development of future chronic illnesses. A review of less intensive SMS text messaging interventions for prevention, treatment, and knowledge outcomes for sexually transmitted infections (STIs) has shown equivocal results [55]. Additionally, other digital media interventions only showed effects on STI knowledge [56] as well as condom attitudes and self-efficacy [57]. Further, electronic STI testing was also found to be feasible and acceptable to young people and to increase uptake of testing [58]. Multiple technology interventions have been developed to address other behaviors in adolescents, such as alcohol use, smoking, and drug use. A meta-analysis of SMS text messaging interventions to reduce young adult binge drinking did not show effectiveness [59], while brief interventions and mobile applications showed some improvement in knowledge [60,61]. Intervening earlier in adolescence may provide a greater window of opportunity to enact effective, long-lasting behavior changes.

Medication Adherence and Self-Management

Digital interventions targeting adherence and disease management provide opportunities to enhance communication between patients and their health care teams. Multiple technologies have been used to support disease monitoring and self-management outside clinical settings and outside the purview of parents. In two recent systematic reviews, adherence-promoting interventions have been shown to be efficacious among children and adolescents with or without chronic medical conditions. However, most of the studies were low to moderate in quality; most were pilot studies, only a few were randomized controlled trials, and all had variable follow-up periods [8,10]. Monitoring patients' moods using technology may have several benefits. It can improve self-awareness of emotions and behaviors, decrease the amount of time to seek mental health help due to symptom awareness, and enhance clinicians' understanding of their patients' symptoms and functioning [62]. Several interventions use SMS text message–based support, such as for HIV medication adherence [63,64]; however, these interventions are not always effective [65]. Further, remote monitoring of asthma through an electronic health intervention led to similar asthma control to a usual care group, with fewer in-person visits [66]. Self-management interventions for type 1 diabetes may be more effective with clinician support [67] or when they involve videogames [68]. Further, to address childhood obesity, self-monitoring is often a key treatment component in behavioral interventions for weight loss. However, for these mobile interventions, a small but significant effect size has been reported [69]. Moreover, other novel digital interventions are being developed and tested in various health care fields, such as interactive power toothbrushes to improve plaque removal [70] and eye-gaze control technology for cerebral palsy [71].

Peer Support

Digital approaches to optimize peer support are another interesting area of research that could improve pediatric health and well-being and also provide career and educational support. For example, for youth with physical disabilities, various formats of electronic mentoring from near peers were found to be helpful in making career decisions, coping with daily life, and advancing social skills; these benefits were a result of garnering support from other young people who understood their health challenges [72,73]. Social media has been used for healthy nutrition interventions [74], most notably for increasing desirable food consumption (fruits and vegetables) [75]; however, the effectiveness of these interventions remains unclear, and there are concerns related to social undesirability of posting health-related weight goals publicly as opposed to in private online groups [76].

A Call for Further Research

Although the field of digital intervention continues to grow at a fast pace, several unanswered questions and knowledge gaps remain and should be explored further [77-81]. In particular, telemedicine and other digital approaches for pediatric health care delivery across different settings (eg, academic and community) are expected to continue, especially after their wide adoption during the COVID-19 pandemic. Patients, families, and providers are more comfortable with these approaches [82,83], and several financial barriers related to system adoption and reimbursement concerns have been resolved. Furthermore, in 2008, the American Academy of Pediatrics (AAP) established a Section on Telehealth Care (SOTC) [84]. In 2019, the AAP-SOTC launched a telemedicine initiative: SPROUT (Supporting Pediatric Research on Outcomes and Utilization of Telehealth) [85]. SPROUT is a Collaborative Telehealth Research Network funded by the National Institutes of Health (NIH) [85]. These efforts and the current widespread use of telemedicine in pediatrics reflect the importance and the need for further research to leverage and optimize remote and digital pediatric health care delivery.

Future studies should consider evaluating the following research areas related to telemedicine and other digital approaches: cost-effectiveness return on investment; impact on quality of care; balance of the use and number of visits needed for the management of both acute illness and chronic health conditions; system readiness for further adoption in other settings, such as inpatient services, subspecialist consultations, and rural areas; ongoing user-centered evaluations with feedback from patients, families, and health care providers; strategies to optimize health equity and address disparities in access to care related to race and ethnicity, socioeconomic status, immigration status, and for rural communities; privacy and security concerns for protected health information with HIPAA-secured programs; confidentiality issues for some specific populations, especially adolescents and people in need of mental health services; early detection of violence exposure and child neglect; and finally, integration of training into undergraduate and graduate medical education and subspecialty fellowships. Addressing these research areas is essential to understanding the benefits, sustainability, safety, and optimization strategies of telemedicine and other digital approaches as key parts of modern health care delivery. These efforts will inform long-term adoption of these approaches with expanded dissemination and implementation efforts.

Conclusions

The aforementioned interventions only offer a glimpse into the future of technology for pediatric health; now, a pathway to their wider utilization has been established due to greatly increased need. The COVID-19 pandemic has rapidly transformed health care systems worldwide, with significant variations and innovations in adaptation. There has been rapid expansion of the leveraging and optimization of digital approaches to health care delivery, particularly integrated telemedicine and virtual health. The fight against the COVID-19 pandemic is ongoing and will continue to be a top priority for national and international health organizations as well as health care systems worldwide. Digital approaches including but not limited to telemedicine, such as those described in this viewpoint, have played and will play major 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 patients and families. Increasing numbers of providers, nurses, administrative staff, and institutions are building experience and comfort using these digital approaches, which have undoubtedly changed the way we practice medicine. However, a number of challenges remain when optimizing and integrating digital approaches for health care delivery into the public health response to the current COVID-19 outbreak and other possible future pandemics. Regulatory changes are essential to support the safe and wide adoption of these approaches. Involving all relevant stakeholders in addressing ongoing and future challenges as well as logistical, technological, and financial barriers will be key for success. This includes support for research funding to develop a sound evidence base for the efficacy of pediatric digital interventions as well as to understand their reach to heterogeneous pediatric patient populations to limit exacerbation of health care disparities. Digital approaches to health care delivery, particularly telemedicine, are ideal strategies to optimize general pediatric and subspecialty care for all children and adolescents regardless of their location.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
JMIR Pediatrics and Parenting (JPP) COVID-19 Call for Papers.
[PDF File (Adobe PDF File), 95 KB - pediatrics_v3i1e20049_app1.pdf]

References

1. Dong Y, Mo X, Hu Y, Qi X, Jiang F, Jiang Z, et al. Epidemiology of COVID-19 Among Children in China. Pediatrics 2020 Jun;145(6). [doi: 10.1542/peds.2020-0702] [Medline: 32179660]
2. World Health Organization. Coronavirus (COVID-19) outbreak URL: https://www.who.int/westernpacific/emergencies/covid-19 [accessed 2020-05-06]
3. Johns Hopkins Coronavirus Resource Center. COVID-19 Dashboard URL: https://coronavirus.jhu.edu/map.html [accessed 2020-05-06]
4. Liu Y, Gayle AA, Wilder-Smith A, Rocklöv J. The reproductive number of COVID-19 is higher compared to SARS coronavirus. J Travel Med 2020 Mar 13;27(2) [FREE Full text] [doi: 10.1093/jtm/taaa021] [Medline: 32052846]
5. Andersen M, Jiang J. Pew Research Center. 2018 May 31. Teens, Social Media & Technology 2018 URL: https://www.pewresearch.org/internet/2018/05/31/teens-social-media-technology-2018/ [accessed 2020-01-17]
6. Pew Research Center. 2019 Jun 12. Mobile Fact Sheet URL: https://www.pewresearch.org/internet/fact-sheet/mobile/ [accessed 2020-01-17]
7. Badawy SM, Thompson AA, Liem RI. Technology Access and Smartphone App Preferences for Medication Adherence in Adolescents and Young Adults With Sickle Cell Disease. Pediatr Blood Cancer 2016 May;63(5):848-852. [doi: 10.1002/pbc.25905] [Medline: 26844685]
8. Badawy SM, Barrera L, Sinno MG, Kaviany S, O'Dwyer LC, Kuhns LM. Text Messaging and Mobile Phone Apps as Interventions to Improve Adherence in Adolescents With Chronic Health Conditions: A Systematic Review. JMIR Mhealth Uhealth 2017 May 15;5(5):e66 [FREE Full text] [doi: 10.2196/mhealth.7798] [Medline: 28506955]
9. Badawy SM, Cronin RM, Hankins J, Crosby L, DeBaun M, Thompson AA, et al. Patient-Centered eHealth Interventions for Children, Adolescents, and Adults With Sickle Cell Disease: Systematic Review. J Med Internet Res 2018 Jul 19;20(7):e10940 [FREE Full text] [doi: 10.2196/10940] [Medline: 30026178]
10. Badawy SM, Kuhns LM. Texting and Mobile Phone App Interventions for Improving Adherence to Preventive Behavior in Adolescents: A Systematic Review. JMIR Mhealth Uhealth 2017 Apr 19;5(4):e50 [FREE Full text] [doi: 10.2196/mhealth.6837] [Medline: 28428157]
11. Badawy SM, Thompson AA, Kuhns LM. Medication Adherence and Technology-Based Interventions for Adolescents With Chronic Health Conditions: A Few Key Considerations. JMIR Mhealth Uhealth 2017 Dec 22;5(12):e202 [FREE Full text] [doi: 10.2196/mhealth.8310] [Medline: 29273573]
12. Radovic A, Badawy SM. Technology Use for Adolescent Health and Wellness. Pediatrics 2020 May;145(Suppl 2):S186-S194. [doi: 10.1542/peds.2019-2056G] [Medline: 32358210]
13. Ramsey WA, Heidelberg RE, Gilbert AM, Heneghan MB, Badawy SM, Alberts NM. eHealth and mHealth interventions in pediatric cancer: A systematic review of interventions across the cancer continuum. Psychooncology 2020 Jan;29(1):17-37. [doi: 10.1002/pon.5280] [Medline: 31692183]
14. Majeed-Ariss R, Baildam E, Campbell M, Chieng A, Fallon D, Hall A, et al. Apps and Adolescents: A Systematic Review of Adolescents' Use of Mobile Phone and Tablet Apps That Support Personal Management of Their Chronic or Long-Term Physical Conditions. J Med Internet Res 2015 Dec 23;17(12):e287 [FREE Full text] [doi: 10.2196/jmir.5043] [Medline: 26701961]
15. Fedele DA, Cushing CC, Fritz A, Amaro CM, Ortega A. Mobile Health Interventions for Improving Health Outcomes in Youth: A Meta-analysis. JAMA Pediatr 2017 May 01;171(5):461-469 [FREE Full text] [doi: 10.1001/jamapediatrics.2017.0042] [Medline: 28319239]
16. Marcolino MS, Oliveira JAQ, D'Agostino M, Ribeiro AL, Alkmim MBM, Novillo-Ortiz D. The Impact of mHealth Interventions: Systematic Review of Systematic Reviews. JMIR Mhealth Uhealth 2018 Jan 17;6(1):e23 [FREE Full text] [doi: 10.2196/mhealth.8873] [Medline: 29343463]
17. Badawy SM, Kuhns LM. Economic Evaluation of Text-Messaging and Smartphone-Based Interventions to Improve Medication Adherence in Adolescents with Chronic Health Conditions: A Systematic Review. JMIR Mhealth Uhealth 2016 Oct 25;4(4):e121 [FREE Full text] [doi: 10.2196/mhealth.6425] [Medline: 27780795]

18. Badawy S, Radovic A. JMIR Pediatrics and Parenting. Call for Papers: "Theme Issue 2020: Digital Approaches for Pediatric Healthcare Delivery during the Coronavirus (Covid-19) Pandemic" in the JMIR Pediatrics and Parenting (JPP) Special Theme Issue/E-Collection URL: https://pediatrics.jmir.org/announcement/view/204 [accessed 2020-05-06]
19. American Well. 2019. Telehealth Index: 2019 Consumer Survey URL: https://static.americanwell.com/app/uploads/2019/07/American-Well-Telehealth-Index-2019-Consumer-Survey-eBook2.pdf [accessed 2020-05-07]
20. Dorsey ER, Topol EJ. State of Telehealth. N Engl J Med 2016 Jul 14;375(2):154-161. [doi: 10.1056/NEJMra1601705] [Medline: 27410924]
21. Turner A, Ricketts T, Leslie LK. Comparison of Number and Geographic Distribution of Pediatric Subspecialists and Patient Proximity to Specialized Care in the US Between 2003 and 2019. JAMA Pediatr 2020 May 18. [doi: 10.1001/jamapediatrics.2020.1124] [Medline: 32421165]
22. CMS. Centers for Medicare & Medicaid Services. 2020 Mar 17. Medicare Telemedicine Health Care Provider Fact Sheet URL: https://www.cms.gov/newsroom/fact-sheets/medicare-telemedicine-health-care-provider-fact-sheet [accessed 2020-05-06]
23. US Department of Health & Human Services. Notification of Enforcement Discretion for Telehealth Remote Communications During the COVID-19 Nationwide Public Health Emergency URL: https://www.hhs.gov/hipaa/for-professionals/special-topics/emergency-preparedness/notification-enforcement-discretion-telehealth/index.html [accessed 2020-05-06]
24. Ardura M, Hartley D, Dandoy C, Lehmann L, Jaglowski S, Auletta JJ, Transplant-Associated Learning Network Team (TALNT). Addressing the Impact of the Coronavirus Disease 2019 (COVID-19) Pandemic on Hematopoietic Cell Transplantation: Learning Networks as a Means for Sharing Best Practices. Biol Blood Marrow Transplant 2020 Apr 24 [FREE Full text] [doi: 10.1016/j.bbmt.2020.04.018] [Medline: 32339662]
25. Brough HA, Kalayci O, Sediva A, Untersmayr E, Munblit D, Rodriguez Del Rio P, et al. Managing childhood allergies and immunodeficiencies during respiratory virus epidemics - The 2020 COVID-19 pandemic: A statement from the EAACI-section on pediatrics. Pediatr Allergy Immunol 2020 Apr 22 [FREE Full text] [doi: 10.1111/pai.13262] [Medline: 32319129]
26. Cini C, Bortot G, Sforza S, Mantovani A, Landi L, Esposito C, et al. Paediatric urology practice during COVID-19 pandemic. J Pediatr Urol 2020 Apr 25 [FREE Full text] [doi: 10.1016/j.jpurol.2020.04.023] [Medline: 32359910]
27. Espinoza J, Crown K, Kulkarni O. A Guide to Chatbots for COVID-19 Screening at Pediatric Health Care Facilities. JMIR Public Health Surveill 2020 Apr 30;6(2):e18808 [FREE Full text] [doi: 10.2196/18808] [Medline: 32325425]
28. Finkelstein JB, Nelson CP, Estrada CR. "Ramping up telemedicine in pediatric urology - Tips for using a new modality". J Pediatr Urol 2020 Apr 17. [doi: 10.1016/j.jpurol.2020.04.010] [Medline: 32327290]
29. Frieden IJ, Püttgen KB, Drolet BA, Garzon MC, Chamlin SL, Pope E, Hemangioma Investigator Group. Management of infantile hemangiomas during the COVID pandemic. Pediatr Dermatol 2020 Apr 16 [FREE Full text] [doi: 10.1111/pde.14196] [Medline: 32298480]
30. Garg SK, Rodbard D, Hirsch IB, Forlenza GP. Managing New-Onset Type 1 Diabetes During the COVID-19 Pandemic: Challenges and Opportunities. Diabetes Technol Ther 2020 Jun;22(6):431-439. [doi: 10.1089/dia.2020.0161] [Medline: 32302499]
31. Mann DM, Chen J, Chunara R, Testa PA, Nov O. COVID-19 transforms health care through telemedicine: evidence from the field. J Am Med Inform Assoc 2020 Apr 23 [FREE Full text] [doi: 10.1093/jamia/ocaa072] [Medline: 32324855]
32. Ohannessian R, Duong TA, Odone A. Global Telemedicine Implementation and Integration Within Health Systems to Fight the COVID-19 Pandemic: A Call to Action. JMIR Public Health Surveill 2020 Apr 02;6(2):e18810 [FREE Full text] [doi: 10.2196/18810] [Medline: 32238336]
33. Patel PD, Cobb J, Wright D, Turer R, Jordan T, Humphrey A, et al. Rapid Development of Telehealth Capabilities within Pediatric Patient Portal Infrastructure for COVID-19 Care: Barriers, Solutions, Results. J Am Med Inform Assoc 2020 Apr 17 [FREE Full text] [doi: 10.1093/jamia/ocaa065] [Medline: 32302395]
34. Ray KN, Kahn JM. Connected Subspecialty Care: Applying Telehealth Strategies to Specific Referral Barriers. Acad Pediatr 2020;20(1):16-22. [doi: 10.1016/j.acap.2019.08.002] [Medline: 31404707]
35. Sawalha AH, Manzi S. Coronavirus Disease-2019: Implication for the care and management of patients with systemic lupus erythematosus. Eur J Rheumatol 2020 Apr 08. [doi: 10.5152/eurjrheum.2020.20055] [Medline: 32352359]
36. Szperka CL, Ailani J, Barmherzig R, Klein BC, Minen MT, Halker Singh RB, et al. Migraine Care in the Era of COVID-19: Clinical Pearls and Plea to Insurers. Headache 2020 May;60(5):833-842 [FREE Full text] [doi: 10.1111/head.13810] [Medline: 32227596]
37. Veerapandiyan A, Wagner KR, Apkon S, McDonald CM, Mathews KD, Parsons JA, et al. The care of patients with Duchenne, Becker, and other muscular dystrophies in the COVID-19 pandemic. Muscle Nerve 2020 Apr 24. [doi: 10.1002/mus.26902] [Medline: 32329920]
38. Woo Baidal JA, Chang J, Hulse E, Turetsky R, Parkinson K, Rausch JC. Zooming Toward a Telehealth Solution for Vulnerable Children with Obesity During Coronavirus Disease 2019. Obesity (Silver Spring) 2020 Apr 30 [FREE Full text] [doi: 10.1002/oby.22860] [Medline: 32352650]

39. Wosik J, Fudim M, Cameron B, Gellad ZF, Cho A, Phinney D, et al. Telehealth transformation: COVID-19 and the rise of virtual care. J Am Med Inform Assoc 2020 Jun 01;27(6):957-962 [FREE Full text] [doi: 10.1093/jamia/ocaa067] [Medline: 32311034]
40. Ray KN, Mehrotra A, Yabes JG, Kahn JM. Telemedicine and Outpatient Subspecialty Visits Among Pediatric Medicaid Beneficiaries. Acad Pediatr 2020 Apr 08 [FREE Full text] [doi: 10.1016/j.acap.2020.03.014] [Medline: 32278078]
41. Kelly SL, Steinberg EA, Suplee A, Upshaw NC, Campbell KR, Thomas JF, et al. Implementing a Home-Based Telehealth Group Adherence Intervention with Adolescent Transplant Recipients. Telemed J E Health 2019 Nov;25(11):1040-1048. [doi: 10.1089/tmj.2018.0164] [Medline: 30681398]
42. Grist R, Croker A, Denne M, Stallard P. Technology Delivered Interventions for Depression and Anxiety in Children and Adolescents: A Systematic Review and Meta-analysis. Clin Child Fam Psychol Rev 2019 Jun;22(2):147-171 [FREE Full text] [doi: 10.1007/s10567-018-0271-8] [Medline: 30229343]
43. Radomski AD, Wozney L, McGrath P, Huguet A, Hartling L, Dyson MP, et al. Design and Delivery Features That May Improve the Use of Internet-Based Cognitive Behavioral Therapy for Children and Adolescents With Anxiety: A Realist Literature Synthesis With a Persuasive Systems Design Perspective. J Med Internet Res 2019 Feb 05;21(2):e11128 [FREE Full text] [doi: 10.2196/11128] [Medline: 30720436]
44. March S, Spence SH, Donovan CL, Kenardy JA. Large-Scale Dissemination of Internet-Based Cognitive Behavioral Therapy for Youth Anxiety: Feasibility and Acceptability Study. J Med Internet Res 2018 Jul 04;20(7):e234 [FREE Full text] [doi: 10.2196/jmir.9211] [Medline: 29973338]
45. Hronis A, Roberts R, Roberts L, Kneebone I. Fearless Me! : A feasibility case series of cognitive behavioral therapy for adolescents with intellectual disability. J Clin Psychol 2019 Jun;75(6):919-932. [doi: 10.1002/jclp.22741] [Medline: 30659608]
46. Werner-Seidler A, Johnston L, Christensen H. Digitally-delivered cognitive-behavioural therapy for youth insomnia: A systematic review. Internet Interv 2018 Mar;11:71-78 [FREE Full text] [doi: 10.1016/j.invent.2018.01.007] [Medline: 30135762]
47. Palermo TM, Dudeney J, Santanelli JP, Carletti A, Zempsky WT. Feasibility and Acceptability of Internet-delivered Cognitive Behavioral Therapy for Chronic Pain in Adolescents With Sickle Cell Disease and Their Parents. J Pediatr Hematol Oncol 2018 Mar;40(2):122-127 [FREE Full text] [doi: 10.1097/MPH.0000000000001018] [Medline: 29176462]
48. Tang W, Zhang L, Ai Y, Li Z. Efficacy of Internet-delivered cognitive-behavioral therapy for the management of chronic pain in children and adolescents: A systematic review and meta-analysis. Medicine (Baltimore) 2018 Sep;97(36):e12061 [FREE Full text] [doi: 10.1097/MD.0000000000012061] [Medline: 30200086]
49. Bonnert M, Olén O, Lalouni M, Hedman-Lagerlöf E, Särnholm J, Serlachius E, et al. Internet-Delivered Exposure-Based Cognitive-Behavioral Therapy for Adolescents With Functional Abdominal Pain or Functional Dyspepsia: A Feasibility Study. Behav Ther 2019 Jan;50(1):177-188 [FREE Full text] [doi: 10.1016/j.beth.2018.05.002] [Medline: 30661558]
50. Lalouni M, Ljótsson B, Bonnert M, Ssegonja R, Benninga M, Bjureberg J, et al. Clinical and Cost Effectiveness of Online Cognitive Behavioral Therapy in Children With Functional Abdominal Pain Disorders. Clin Gastroenterol Hepatol 2019 Oct;17(11):2236-2244.e11. [doi: 10.1016/j.cgh.2018.11.043] [Medline: 30502501]
51. Fisher E, Law E, Dudeney J, Eccleston C, Palermo TM. Psychological therapies (remotely delivered) for the management of chronic and recurrent pain in children and adolescents. Cochrane Database Syst Rev 2019 Apr 02;4:CD011118 [FREE Full text] [doi: 10.1002/14651858.CD011118.pub3] [Medline: 30939227]
52. Schlosser DA, Campellone TR, Truong B, Etter K, Vergani S, Komaiko K, et al. Efficacy of PRIME, a Mobile App Intervention Designed to Improve Motivation in Young People With Schizophrenia. Schizophr Bull 2018 Aug 20;44(5):1010-1020 [FREE Full text] [doi: 10.1093/schbul/sby078] [Medline: 29939367]
53. Leonard NR, Casarjian B, Fletcher RR, Praia C, Sherpa D, Kelemen A, et al. Theoretically-Based Emotion Regulation Strategies Using a Mobile App and Wearable Sensor Among Homeless Adolescent Mothers: Acceptability and Feasibility Study. JMIR Pediatr Parent 2018;1(1):e1 [FREE Full text] [doi: 10.2196/pediatrics.9037] [Medline: 30637376]
54. Cuijpers P, Turner EH, Koole SL, van Dijke A, Smit F. What is the threshold for a clinically relevant effect? The case of major depressive disorders. Depress Anxiety 2014 May;31(5):374-378. [doi: 10.1002/da.22249] [Medline: 24677535]
55. Taylor D, Lunny C, Lolić P, Warje O, Geldman J, Wong T, et al. Effectiveness of text messaging interventions on prevention, detection, treatment, and knowledge outcomes for sexually transmitted infections (STIs)/HIV: a systematic review and meta-analysis. Syst Rev 2019 Jan 08;8(1):12 [FREE Full text] [doi: 10.1186/s13643-018-0921-4] [Medline: 30621784]
56. Wadham E, Green C, Debattista J, Somerset S, Sav A. New digital media interventions for sexual health promotion among young people: a systematic review. Sex Health 2019 Apr;16(2):101-123. [doi: 10.1071/SH18127] [Medline: 30819326]
57. Widman L, Golin CE, Kamke K, Burnette JL, Prinstein MJ. Sexual Assertiveness Skills and Sexual Decision-Making in Adolescent Girls: Randomized Controlled Trial of an Online Program. Am J Public Health 2018 Jan;108(1):96-102. [doi: 10.2105/AJPH.2017.304106] [Medline: 29161072]
58. Wilson E, Free C, Morris TP, Syred J, Ahamed I, Menon-Johansson AS, et al. Internet-accessed sexually transmitted infection (e-STI) testing and results service: A randomised, single-blind, controlled trial. PLoS Med 2017 Dec;14(12):e1002479 [FREE Full text] [doi: 10.1371/journal.pmed.1002479] [Medline: 29281628]

59. Bastola MM, Locatis C, Maisiak R, Fontelo P. The Effectiveness of Mobile Phone-Based Text Messaging to Intervene with Problem Drinking in Youth and Younger Adult Population: A Meta-Analysis. Telemed J E Health 2020 Mar;26(3):270-277. [doi: 10.1089/tmj.2018.0307] [Medline: 30985258]
60. Ganz T, Braun M, Laging M, Schermelleh-Engel K, Michalak J, Heidenreich T. Effects of a stand-alone web-based electronic screening and brief intervention targeting alcohol use in university students of legal drinking age: A randomized controlled trial. Addict Behav 2018 Feb;77:81-88. [doi: 10.1016/j.addbeh.2017.09.017] [Medline: 28985586]
61. Hides L, Quinn C, Cockshaw W, Stoyanov S, Zelenko O, Johnson D, et al. Efficacy and outcomes of a mobile app targeting alcohol use in young people. Addict Behav 2018 Feb;77:89-95. [doi: 10.1016/j.addbeh.2017.09.020] [Medline: 28992580]
62. Dubad M, Winsper C, Meyer C, Livanou M, Marwaha S. A systematic review of the psychometric properties, usability and clinical impacts of mobile mood-monitoring applications in young people. Psychol Med 2018 Jan;48(2):208-228. [doi: 10.1017/S0033291717001659] [Medline: 28641609]
63. Liu AY, Vittinghoff E, von Felten P, Rivet Amico K, Anderson PL, Lester R, et al. Randomized Controlled Trial of a Mobile Health Intervention to Promote Retention and Adherence to Preexposure Prophylaxis Among Young People at Risk for Human Immunodeficiency Virus: The EPIC Study. Clin Infect Dis 2019 May 30;68(12):2010-2017 [FREE Full text] [doi: 10.1093/cid/ciy810] [Medline: 30239620]
64. Navarra AD, Gwadz MV, Whittemore R, Bakken SR, Cleland CM, Burleson W, et al. Health Technology-Enabled Interventions for Adherence Support and Retention in Care Among US HIV-Infected Adolescents and Young Adults: An Integrative Review. AIDS Behav 2017 Nov;21(11):3154-3171 [FREE Full text] [doi: 10.1007/s10461-017-1867-6] [Medline: 28776275]
65. Linnemayr S, Huang H, Luoto J, Kambugu A, Thirumurthy H, Haberer JE, et al. Text Messaging for Improving Antiretroviral Therapy Adherence: No Effects After 1 Year in a Randomized Controlled Trial Among Adolescents and Young Adults. Am J Public Health 2017 Dec;107(12):1944-1950. [doi: 10.2105/AJPH.2017.304089] [Medline: 29048966]
66. van den Wijngaart LS, Roukema J, Boehmer ALM, Brouwer ML, Hugen CAC, Niers LEM, et al. A virtual asthma clinic for children: fewer routine outpatient visits, same asthma control. Eur Respir J 2017 Oct;50(4) [FREE Full text] [doi: 10.1183/13993003.00471-2017] [Medline: 28982775]
67. Deacon AJ, Edirippulige S. Using mobile technology to motivate adolescents with type 1 diabetes mellitus: A systematic review of recent literature. J Telemed Telecare 2015 Dec;21(8):431-438. [doi: 10.1177/1357633X15605223] [Medline: 26377124]
68. Theng Y, Lee JWY, Patinadan PV, Foo SSB. The Use of Videogames, Gamification, and Virtual Environments in the Self-Management of Diabetes: A Systematic Review of Evidence. Games Health J 2015 Oct;4(5):352-361. [doi: 10.1089/g4h.2014.0114] [Medline: 26287926]
69. Darling KE, Sato AF. Systematic Review and Meta-Analysis Examining the Effectiveness of Mobile Health Technologies in Using Self-Monitoring for Pediatric Weight Management. Child Obes 2017 Oct;13(5):347-355. [doi: 10.1089/chi.2017.0038] [Medline: 28471699]
70. Erbe C, Klees V, Braunbeck F, Ferrari-Peron P, Ccahuana-Vasquez RA, Timm H, et al. Comparative assessment of plaque removal and motivation between a manual toothbrush and an interactive power toothbrush in adolescents with fixed orthodontic appliances: A single-center, examiner-blind randomized controlled trial. Am J Orthod Dentofacial Orthop 2019 Apr;155(4):462-472 [FREE Full text] [doi: 10.1016/j.ajodo.2018.12.013] [Medline: 30935601]
71. Karlsson P, Allsop A, Dee-Price B, Wallen M. Eye-gaze control technology for children, adolescents and adults with cerebral palsy with significant physical disability: Findings from a systematic review. Dev Neurorehabil 2018 Nov;21(8):497-505. [doi: 10.1080/17518423.2017.1362057] [Medline: 28862491]
72. Lindsay S, Cagliostro E, Leck J, Stinson J. A 12-Week Electronic Mentoring Employment Preparation Intervention for Youth With Physical Disabilities: Pilot Feasibility Randomized Controlled Trial. JMIR Pediatr Parent 2019 Mar 29;2(1):e12088 [FREE Full text] [doi: 10.2196/12088] [Medline: 31518315]
73. Lindsay S, Kolne K, Cagliostro E. Electronic Mentoring Programs and Interventions for Children and Youth With Disabilities: Systematic Review. JMIR Pediatr Parent 2018 Oct 24;1(2):e11679 [FREE Full text] [doi: 10.2196/11679] [Medline: 31518310]
74. Chau MM, Burgermaster M, Mamykina L. The use of social media in nutrition interventions for adolescents and young adults-A systematic review. Int J Med Inform 2018 Dec;120:77-91 [FREE Full text] [doi: 10.1016/j.ijmedinf.2018.10.001] [Medline: 30409348]
75. Hsu MSH, Rouf A, Allman-Farinelli M. Effectiveness and Behavioral Mechanisms of Social Media Interventions for Positive Nutrition Behaviors in Adolescents: A Systematic Review. J Adolesc Health 2018 Nov;63(5):531-545. [doi: 10.1016/j.jadohealth.2018.06.009] [Medline: 30197198]
76. Klassen KM, Douglass CH, Brennan L, Truby H, Lim MSC. Social media use for nutrition outcomes in young adults: a mixed-methods systematic review. Int J Behav Nutr Phys Act 2018 Jul 24;15(1):70 [FREE Full text] [doi: 10.1186/s12966-018-0696-y] [Medline: 30041699]
77. Burke BL, Hall RW, Section on Telehealth Care. Telemedicine: Pediatric Applications. Pediatrics 2015 Jul;136(1):e293-e308 [FREE Full text] [doi: 10.1542/peds.2015-1517] [Medline: 26122813]

78. Committee on Pediatric Workforce, Marcin JP, Rimsza ME, Moskowitz WB. The Use of Telemedicine to Address Access and Physician Workforce Shortages. Pediatrics 2015 Jul;136(1):202-209 [FREE Full text] [doi: 10.1542/peds.2015-1253] [Medline: 26122802]
79. Olson CA, McSwain SD, Curfman AL, Chuo J. The Current Pediatric Telehealth Landscape. Pediatrics 2018 Mar;141(3) [FREE Full text] [doi: 10.1542/peds.2017-2334] [Medline: 29487164]
80. Tomines A. Pediatric Telehealth: Approaches by Specialty and Implications for General Pediatric Care. Adv Pediatr 2019 Aug;66:55-85. [doi: 10.1016/j.yapd.2019.04.005] [Medline: 31230700]
81. Utidjian L, Abramson E. Pediatric Telehealth: Opportunities and Challenges. Pediatr Clin North Am 2016 Apr;63(2):367-378. [doi: 10.1016/j.pcl.2015.11.006] [Medline: 27017042]
82. Haddad RN, Sakr C, Khabbaz L, Azouri H, Eid B. Telephone Consultation and Prescription in Pediatrics: Contributing Factors and Impact on Clinical Outcomes. Front Pediatr 2019;7:515 [FREE Full text] [doi: 10.3389/fped.2019.00515] [Medline: 32010647]
83. López Seguí F, Batlle Boada A, García García JJ, López Ulldemolins A, Achotegui Del Arco A, Adroher Mas C, et al. Families' Degree of Satisfaction With Pediatric Telehomecare: Interventional Prospective Pilot Study in Catalonia. JMIR Pediatr Parent 2020 Mar 26;3(1):e17517 [FREE Full text] [doi: 10.2196/17517] [Medline: 32213471]
84. American Academy of Pediatrics. Section on Telehealth Care (SOTC) URL: https://services.aap.org/en/community/aap-sections/telehealth-care/ [accessed 2020-06-11]
85. American Academy of Pediatrics. Supporting Pediatric Research on Outcomes and Utilization of Telehealth (SPROUT) URL: https://services.aap.org/en/community/aap-sections/telehealth-care/sprout/ [accessed 2020-06-11]

Abbreviations

AAP: American Academy of Pediatrics
COVID-19: coronavirus disease
HIPAA: Health Insurance Portability and Accountability Act
iCBT: internet-based cognitive behavioral therapy
JITAI: just-in-time adaptive intervention
NIH: National Institutes of Health
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
SOTC: Section on Telehealth Care
SPROUT: Supporting Pediatric Research on Outcomes and Utilization of Telehealth
STI: sexually transmitted infection

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Original Paper

An App for Identifying Children at Risk for Developmental Problems Using Multidimensional Computerized Adaptive Testing: Development and Usability Study

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Abstract

Background: The use of multidomain developmental screening tools is a viable strategy for pediatric professionals to identify children at risk for developmental problems. However, a specialized multidimensional computer adaptive testing (MCAT) tool has not been developed to date.

Objective: We developed an app using MCAT, combined with Multidimensional Screening in Child Development (MuSiC) for toddlers, to help patients and their family members or clinicians identify developmental problems at an earlier stage.

Methods: We retrieved 75 item parameters from the MuSiC literature item bank for 1- to 3-year-old children, and simulated 1000 person measures from a normal standard distribution to compare the efficiency and precision of MCAT and nonadaptive testing (NAT) in five domains (ie, cognitive skills, language skills, gross motor skills, fine motor skills, and socioadaptive skills). The number of items saved and the cutoff points for the tool were determined and compared. We then developed an app for a Web-based assessment.

Results: MCAT yielded significantly more precise measurements and was significantly more efficient than NAT, with 46.67% (=(75-40)/75) saving in item length when measurement differences less than 5% were allowed. Person-measure correlation coefficients were highly consistent among the five domains. Significantly fewer items were answered on MCAT than on NAT without compromising the precision of MCAT.

Conclusions: Developing an app as a tool for parents that can be implemented with their own computers, tablets, or mobile phones for the online screening and prediction of developmental delays in toddlers is useful and not difficult.

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KEYWORDS

computer adaptive testing; developmental delay; multidimensional; mobile phone; screening

Introduction

Preschooler developmental delay has been defined to occur when a child does not reach developmental milestones, including gross motor, fine motor, language, cognitive, and social skills, at the expected times [1] or when a child's developmental milestones appear more slowly compared to those of typically developing children [2]. There is usually a more specific condition causing this delay, such as fragile X syndrome or other chromosomal abnormalities. However, it is sometimes difficult to identify the underlying condition [3].

Substantial variations in the prevalence of developmental delay have been reported, including 5.7%-7.0% in Norwegian infants [4], 3.3% in American children [5], and 6%-8% in Taiwanese preschoolers [6]. Some methodologies do not facilitate comparison of prevalence rates because of differences in case definitions and criteria, type of measures used, age, and whether the studies included low- or high-risk populations [4]. Therefore, more standardized developmental screening tools are required [7].

Increase in Screening Rate

In 2001, the American Academy of Pediatrics (AAP) recommended that all children undergo standardized developmental screening as part of their well-child care [8]. However, there are barriers preventing pediatricians from using such screening tools, including lack of personnel, time, or effective screening tools [9]. Therefore, busy practitioners (or parents) should be provided with a quick, simple, valid, and reliable screening tool to allow for quick and efficient screening [10].

Between 1994 and 2002, only 23%-30% of pediatricians screened their patients for developmental delays [11,12]. After a series of enhanced research and educational programs were launched and such screening tools were recommended, there has been an upward trend in the use of screening, reaching up to 48% in 2009 [9] and exceeding 90% in 2011 [13,14] in the United States.

Need for Efficiency and Precision

Many types of screening tools have been designed to detect possible global developmental problems [15-20] and to provide a quick overview of the development of children's communication, gross and fine motor, social, and problem-solving skills. Choosing an appropriate and age-matched checklist for parents to fill out is an added burden.

A search of PubMed on November 13, 2019 with the term "multidimensional computerized adaptive testing" (MCAT) yielded 45 articles, and searching with the term "computerized adaptive testing" (CAT) yielded 483 articles. By the end of 2019, more than 8674 abstracts were retrieved from the PubMed database using the search term "cutoff point." However, none of these articles discussed methods of determining the cutoff points for CAT (or MCAT) in the use of screening tools for assessing developmental delay in children.

Using a Multidimensional Developmental Screening Tool

Although the Multidimensional Screening in Child Development (MuSiC) tool for children 0-3 years old has been reported [7], to our knowledge, there is no available online app for screening that is used in clinical practice. Therefore, a multidomain developmental screening tool is urgently needed [21,22].

In this study, we investigated the feasibility of screening toddlers (1- to 3-year olds) using the MCAT combined with MuSiC for toddlers, including (i) comparisons with MCAT and nonadaptive testing (NAT; responding to all items) in efficiency and precision using a Monte Carlo simulation method, (ii) determining cutoff points for a variety of ages and stages using a parent-completed child monitoring system, and (iii) developing an online MCAT app for mobile phones to efficiently collect data and discriminate developmental delays for preschoolers.

Methods

Study Data: Item Difficulty and Person Measures

After retrieving 75 item parameters from the MuSiC literature item bank [7] for 1- to 3-year-old children, we simulated 1000 person measures from a normal standard distribution to compare the efficiency and precision of MCAT and NAT in five domains: cognitive skills, language skills, gross motor skills, fine motor skills, and social skills (see Multimedia Appendix 1).

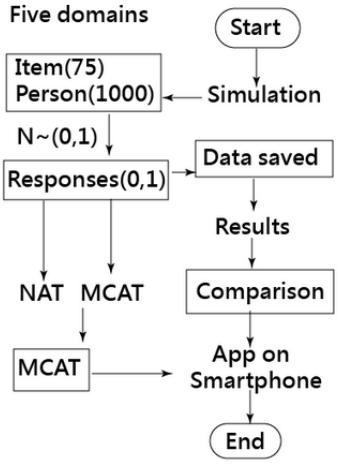
Based on the maximum reported range of the released item difficulties from –7.35 to 8.03 [7], person measure true scores were set in the range of –8 to 8 logits (log odds). Applying the study's cutoff points (mean –7.366, cognitive skills –4.85, language skills –7.44, gross motor skills –9.95, fine motor skills –6.15, and social skills –8.44) in logits for the 137 participants (2-year-old children) [7], the highest skill level was found to be in the cognitive domain and the lowest was in the gross motor domain. The lower the score, the greater the developmental delay. Finally, we used Rasch [23] ConQuest software for calibrating item difficulties for these five domains in the tools.

As the reliability of a scale (ie, Cronbach alpha) increases, so does the person-number of ranges that can be confidently distinguished [24-27]. Measures with a reliability of 0.67 will vary within two groups, those of 0.80 will vary within three groups, and those of 0.90 will vary within four groups [24].

Simulating Person Response to Items Across Domains

When the person abilities and item difficulties are known, as described above, the responses can be obtained in a rectangle 1000 × 75 matrix form that contains the five domains using a Rasch simulation computer process [28]. Therefore, the first study aim of comparing the efficiency and precision of MCAT and NAT can be assessed using a Monte Carlo simulation method (Figure 1 and Multimedia Appendix 2).

Figure 1. Study flowchart.



Design of the App

Algorithm Using Rasch Analysis for Considering Item Difficulties

In classical test theory, the summation score (or the linear transformed score such as a T score) is often used as the latent trait estimation (ability=success rate) under the condition that all item difficulties are equal (ie, have a common weight). The item response theory (IRT)-based Rasch model [23] was developed to deal with the real-world scenario that not all item difficulties are equal.

All person measures and item difficulties were compared using a common scale unit in logit. The person (n) probability of answering a specific item (i) is denoted by the formula: $\text{Prob}_{ni}=\exp(\text{ability}_n–\text{difficulty}_i)/(1+\exp[\text{ability}_n–\text{difficulty}_i])$. If all item difficulties are known, all possible likelihood values can be obtained using the formula IIp_{ni} (ie, multiplying all probabilities across items) and using a range of possible abilities from –8 to 8 logits. This is the principle of CAT using the two known conditions (ie, item difficulties and person responses to items) to estimate the person measure. All person measures and item difficulties are on an interval continuum [29]. Two other requirements are that items should be unidimensional and locally independent when CAT is applied; otherwise, the estimation will not be precise.

Cutoff Points Used for Multidimensional Screening in Child Development

To determine the overall global level of developmental delay, we first computed the number of the strata based on subscale reliability, and then referred to the Rasch threshold difficulty guideline [30] to optimize an appropriate distance between two thresholds in the range of 1.4-5.0 logits for all separated groups with an equal sample size.

As suggested by Maslach et al [31,32], an equal sample size in each stratum was applied to determine the cutoff points. Accordingly, a threshold at zero logits is suggested for two strata; –0.7 and 0.7 {1.4 logit difference with probabilities at 0.33 and 0.67=1–exp(–0.7)/(1+exp[–0.7])} for three strata; –1.1, 0.0, and 1.1 {1.1 logit difference with probabilities at 0.25, 0.50, and 0.75=1–exp (–1.1)/(1+exp[–1.1])} for four strata; and –1.4, –0.4, 0.4, and 1.4 {1.0 logit difference with probabilities at 0.20, 0.40, 0.60, and 0.80=1–(–1.4)/(1+exp[–1.4])} for five strata. Therefore, the second study aim of determining cutoff points is possible.

Multidimensional Computer Adaptive Testing Used on a Developmental Screening Tool

The multidimensional random coefficients multinomial logit model (MRCMLM) has been proposed to capture the complexity of modern assessments [33,34]. The merging of MRCMLM and CAT, or other multidimensional IRT models and CAT, is called multidimensional computerized adaptive testing (MCAT) [35]. We can consider using MCAT to simultaneously estimate person measures for an inventory consisting of multiple subscales such as the developmental screening tool developed in this study [7]. We programmed an online MCAT using maximum-likelihood estimation with the Newton-Raphson iteration method to administer the 5-domain developmental screening tool.

We applied MCAT stop rules as described previously [36], such as when the person reliability for each domain reaches a specific level; for example, $0.80=[1\text{SEM}_{pi}^2]=10.44^2]$, where SEM_{pi}=person standard error of measurement on item $i=1/\text{variance}_{pi}=1/\text{information}_{pi}$, and the last three average consecutive person estimation changes are <0.05 in residual difference between the two stages in the CAT process after the minimal necessarily completed number of items on each domain is 3. The final graphical representation is shown with items in domain order on a mobile phone. Therefore, the third study aim for online MCAT development is also possible (see the video in Multimedia Appendix 2).

Data Analysis and Website Design

ConQuest Rasch software [37] was used to calculate parameters on the five subscales of response datasets. The variance-covariance and correlation matrices in relation to the five domains were extracted from tables in ConQuest (see Multimedia Appendix 3). Independent *t* tests were used to compare the efficiency and precision of NAT and MCAT. Significance was set at $P<.05$ (two-tailed).

Availability of Data and Materials

This research is based on a simulation study. All codes and data can be obtained from the Multimedia Appendix files of this study.

Results

Analyses of Domains and Items

Figure 2 shows the dispersed person measures and item difficulties, demonstrating that the different means of the five domains are significantly located upward and downward on the left side of the dispersion. Correlation coefficients were highly consistent among the five domains in person measures (Table 1). All person reliabilities showed a correlation coefficient >.8, indicating three person strata separated in this sample [24].

Figure 2. Multidimensional analysis of dispersions of persons (first 5 columns) and items (last column) across domains.

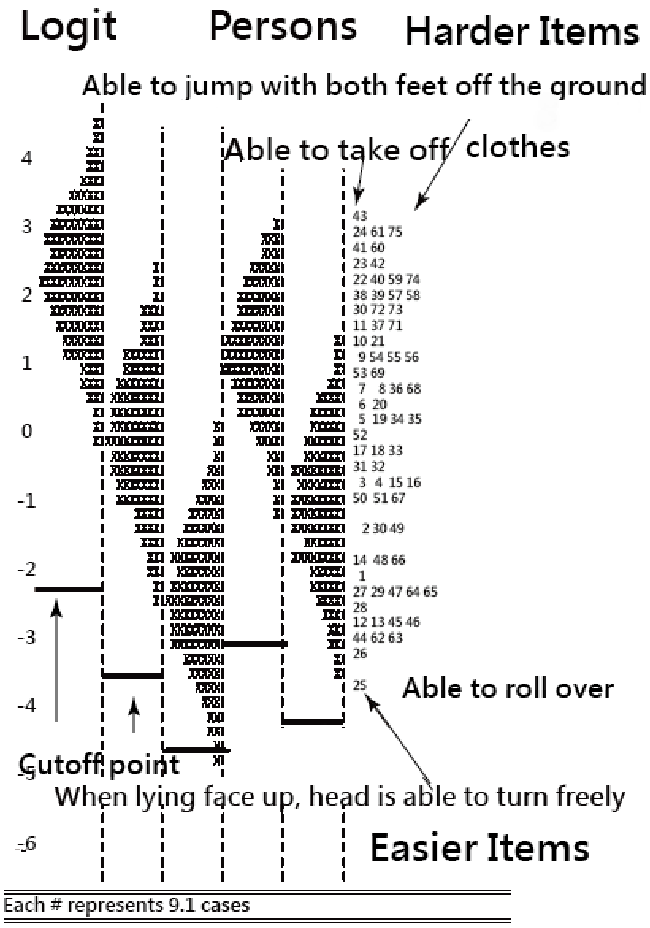


Table 1. Variance-covariance matrix (plus correlation matrix and reliability) for the five domains.[a]

Category	Cognitive	Language	Gross motor	Fine motor	Social
Domain skill					
Cognitive		0.95	0.95	0.85	0.98
Language	0.93		1.05	0.96	1.07
Gross motor	0.93	0.94		0.96	1.09
Fine motor	0.91	0.93	0.94		0.99
Social	0.92	0.92	0.94	0.93	
Variance	0.94	0.12	1.11	0.94	1.21
Reliability	0.84	0.85	0.86	0.86	0.85

[a] The bottom left diagonal shows correlation coefficients; the right top diagonal shows covariance.

Comparison of Efficiency and Precision Between Nonadaptive Testing and Multidimensional Computer Adaptive Testing

Significantly (*P*<.001) fewer items were answered on MCAT than on NAT without compromising its precision (*P*=.22). The efficiency of MCAT was a 46.67% (=(75-40)/75) savings in item length. The average means of items used across domains in MCAT were 6, 6, 10, 10, and 8 for cognitive, language, gross motor, fine motor, and social domains, respectively. There were significant differences in item length across domains between NAT and MCAT (Table 2).

Table 2. Comparisons of item length and skill ability on domains between nonadaptive testing (NAT) and computerized adaptive testing (CAT).

Category	Cognitive	Language	Gross motor	Fine motor	Social	*P* value
Item length						
NAT	11	13	19	18	14	
CAT	6	6	10	10	8	.01
Skill ability						
NAT	0.088	0.15	0.065	0.021	0.032	
CAT	0.086	0.067	0.023	0.023	0.033	.07

Cutoff Points Used for Multidimensional Screening in Child Development

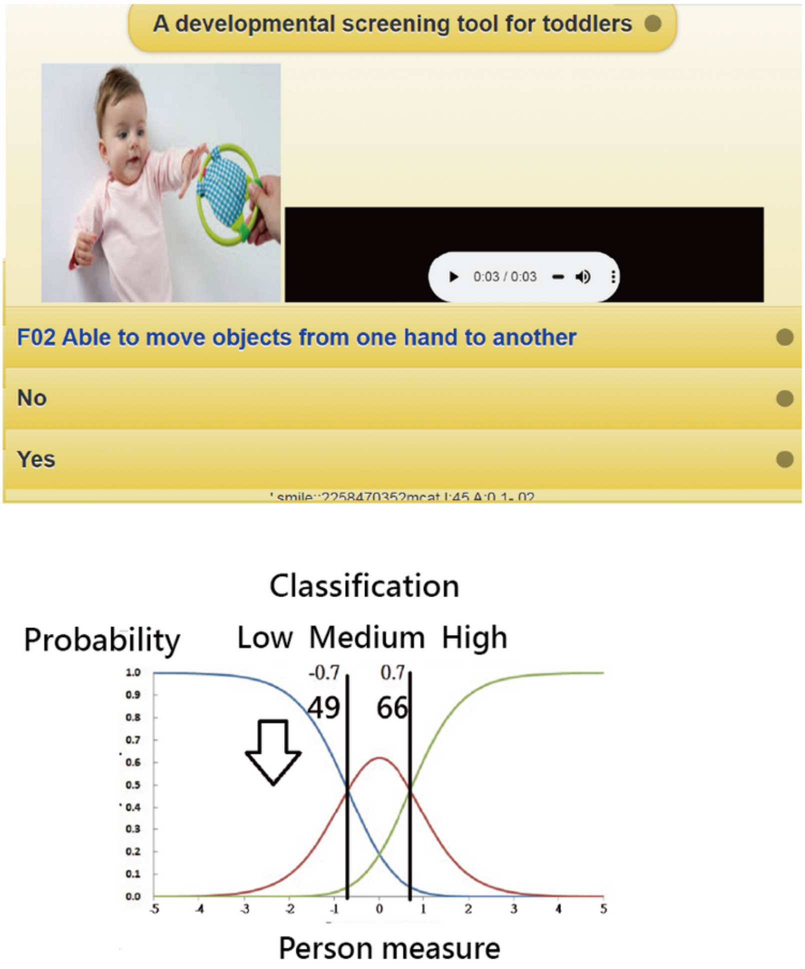
The person strata could be separated into three subgroups. The global cutoff points were determined at –0.7 and 0.7 logits using the criterion of averaging all domain logit scores. Each stratum had an equal accumulated probability of 0.33. The original domain cutoff points for 24-month-old children are shown in Figure 2.

Online Multidimensional Computer Adaptive Testing Assessment

Scanning a Quick Response (QR) code (Figure 3) or downloading the app will cause the MuSiC developmental delay questionnaire to appear on the mobile phone. We developed an MCAT mobile survey procedure to demonstrate our newly designed MuSiC application in action. The assessment used audio and video to process each child item-by-item (Figure 3, top left). Person domain scores can be estimated using MCAT (Figure 3).

In the MCAT process, adaptive item selection is based on maximizing the determinant of the provisional information matrix across unanswered items. The measurement of standard error for each subscale decreased when the number of items increased (Figure 3). The result with person measures across all domains instantly displays on the mobile phone (Figure 3). The global cutoff points shown in Figure 3 can serve as a guide to roughly check the level of developmental delay for the child at a low, medium, or high location. The detailed cutoff point for a specific age can be determined using Figure 2 to assess whether a follow-up stage that requires a re-examination of development delay is reached or to refer to the indicator for which any specific item should be passed but failed for the age.

Figure 3. The online process of MCAT on a mobile phone.



A developmental screening tool for toddlers

F02 Able to move objects from one hand to another

No

Yes

Discussion

Principal Findings

We verified that (1) the number of answered items is significantly lower (*P*=.01) on MCAT than on NAT without compromising its precision (*P*=.07), (2) the global cutoff points should be set to –0.7 and 0.7 logits to separate persons into equal size groups (*P*=.33 each) (cutoff points for 24-month-olds are shown in Figure 2), and (3) an available-for-download online MCAT app for parents is suitable for mobile phones.

Contribution to Existing Research

We verified that CAT [38,39] (or MCAT [34-36]) is more efficient than NAT, which is consistent with the literature. We also confirmed that, without compromising its measurement precision, MCAT-based MuSiC requires significantly fewer questions to measure developmental delay for children compared with NAT. MCAT is more efficient than NAT, especially in cases of high correlation among measures and more dimensions [33-35]. However, this is the first online MCAT app reported to date.

Twenty-one pieces of Ages & Stages Questionnaires (ASQ-3)—a parent-completed child monitoring system) [20]—were developed to be used for children aged 2, 4, 6, 8, 9, 10, 12, 14, 16, 18, 20, 22, 24, 27, 30, 33, 36, 42, 48, 54, and 60 months old. Thus, we should develop 21 item pools (eg, 21 tests) and domains for each age by mimicking the use of MCAT in this study to screen for developmental delays. If the child's age is known at the start of the screening, MCAT can estimate the person measure and show the cutoff points in a diagram (Figure 3) along with a judgment (pass or fail) according to specified items for the age as previously described for methods used in Taiwan [15-17].

If at least one developmental delay is found in one of the domains, the child should be sent to a hospital for a medical examination because MCAT covers multiple domains with tailored items for an individual child, which is expected to increase assessment precision. MCAT considers item difficulties and correlations between domains. In contrast, the ASQ-3 contains only six items in each domain, which reduces the instrument's reliability because of the short items and ignored item weights. This sacrifices assessment precision because of a large amount of measurement error.

Implications for Change

In 2001, the AAP recommended that all children undergo standardized developmental screening as part of their well-child care [8] and hoped for all children to have access to a standardized, quick, simple, valid, and reliable developmental screening tool [8], along with the rapid development of computer technologies, such as an app for identifying children at risk for developmental problems.

There has been no discussion on methods for determining the cutoff points for CAT (or MCAT) because not all items are endorsed, making it impossible to obtain summation scores in practice. Here, two types of MCAT cutoff points are demonstrated: (1) global cutoff points (set at –0.7 and 0.7) to separate the sample into three equally sized groups (Figure 3), and (2) item-by-item cutoff points (Figure 2) that show whether there is any developmental delay by identifying specific items that the child failed to pass for their age.

Strengths of This Study

In the MCAT, we included several useful indicators that work well with a Rasch model and CAT. First, the greater the number of difficult items correctly answered by a person, the higher their performance level will be, because the adjustment depends on the residual of the response (ie, observed score – expectation) using the Newton-Raphson iteration method. Second, the outfit mean square error ([Σ^2 -score]/L=(Σ [residual/standard deviation]^2)/L, where L=item length) is a macroaberrant behavior indicator that detects whether a person responds with a reasonable behavior pattern to the items [34]. Third, a z-score (residual/standard deviation) is used as a microaberrant response indicator that detects whether the item response is in an acceptable range (ie, $|Z|>2.0$ [30]) in line with the person’s provisional skill level. All of these indicators, which benefit the interpretation of responses, are rarely seen in classical test theory.

We used ConQuest to estimate the parameters, which is reported to accurately estimate both item and person parameters in multidimensional Rasch models [32,34,37]. The process can be recommended for future studies on the parameter estimation of MCAT.

Limitations and Future Studies

This study has some limitations. First, the study data were retrieved from published papers [7]. If any parameter was incorrectly embedded, the MCAT would be problematic in practice. Therefore, the MCAT module should be reexamined by many future studies. Second, we determined any cutoff points for age groups in this study. The cutoff point criteria were determined on a theoretically logical basis of an interval latent trait continuum in a logit unit. That is, all abilities within a domain were incrementally increased by the number of logits appropriate for each particular age increase. Future studies are recommended for cutoff point determination across ages in domains for the ASQ-3 or to refer to the indicator for any specific item that should be passed but failed for the age. Third, Figure 2 indicates that some gaps should be filled with missing items, and that more difficult and easier items should be added to the top and bottom areas. The MCAT items were merely extracted from three screening tools commonly used in Taiwan [15-17]. To improve the MuSiC item bank, more appropriate items used in other developmental delay screening tools such as the ASQ-3 should be considered [18]. Fourth, Yes/No items were used in the study. For a more accurate estimate, Yes/Sometimes/Not Yet items, which are used in the ASQ-3, should be investigated in future studies. Finally, the MuSiC item pool was originally used for 1- to 3-year-old children. Future studies are recommended to expand the item pool to include a wider age range in practice.

Conclusions

Although the MCAT had significantly fewer items than the NAT, the precision of MCAT was not compromised. The online MCAT with a mobile phone facilitates screening for developmental delays in toddlers.

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Authors' Contributions

CF developed the study concept and design. TC and JC analyzed and interpreted the data. CF drafted the manuscript, and all authors provided critical revisions for important intellectual content. The study was supervised by WC. All authors have read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Data in MS Excel format.
[XLSX File (Microsoft Excel File), 24 KB - pediatrics_v3i1e14632_app1.xlsx]

Multimedia Appendix 2
Link to online assessment for the MCAT video.
[DOCX File , 13 KB - pediatrics_v3i1e14632_app2.docx]

Multimedia Appendix 3
Link to ConQuest.

[DOCX File , 13 KB - pediatrics_v3i1e14632_app3.docx]

References

1. Kurtz-Nelson E, McIntyre LL. Optimism and positive and negative feelings in parents of young children with developmental delay. J Intellect Disabil Res 2017 Jul;61(7):719-725 [FREE Full text] [doi: 10.1111/jir.12378] [Medline: 28444813]
2. Tsao R, Moy E, Velay J, Carvalho N, Tardif C. Handwriting in Children and Adults With Down Syndrome: Developmental Delay or Specific Features? Am J Intellect Dev Disabil 2017 Jul;122(4):342-353. [doi: 10.1352/1944-7558-122.4.342] [Medline: 28654414]
3. Srour M, Mazer B, Shevell MI. Analysis of clinical features predicting etiologic yield in the assessment of global developmental delay. Pediatrics 2006 Jul;118(1):139-145. [doi: 10.1542/peds.2005-2702] [Medline: 16818559]
4. Valla L, Wentzel-Larsen T, Hofoss D, Slinning K. Prevalence of suspected developmental delays in early infancy: results from a regional population-based longitudinal study. BMC Pediatr 2015 Dec 17;15:215 [FREE Full text] [doi: 10.1186/s12887-015-0528-z] [Medline: 26678149]
5. Simpson GA, Colpe L, Greenspan S. Measuring functional developmental delay in infants and young children: prevalence rates from the NHIS-D. Paediatr Perinat Epidemiol 2003 Jan;17(1):68-80. [doi: 10.1046/j.1365-3016.2003.00459.x] [Medline: 12562474]
6. Kuo HT, Muo C, Chang Y, Lin CK. Change in prevalence status for children with developmental delay in Taiwan: a nationwide population-based retrospective study. Neuropsychiatr Dis Treat 2015;11:1541-1547 [FREE Full text] [doi: 10.2147/NDT.S84088] [Medline: 26203248]
7. Hwang A, Chou Y, Hsieh C, Hsieh W, Liao H, Wong AM. A developmental screening tool for toddlers with multiple domains based on Rasch analysis. J Formos Med Assoc 2015 Jan;114(1):23-34 [FREE Full text] [doi: 10.1016/j.jfma.2014.07.001] [Medline: 25127503]
8. Committee on Children with Disabilities. Developmental surveillance and screening of infants and young children. Pediatrics 2001 Jul;108(1):192-196. [doi: 10.1542/peds.108.1.192] [Medline: 11433077]
9. Radecki L, Sand-Loud N, O'Connor KG, Sharp S, Olson LM. Trends in the use of standardized tools for developmental screening in early childhood: 2002-2009. Pediatrics 2011 Jul;128(1):14-19. [doi: 10.1542/peds.2010-2180] [Medline: 21708798]
10. Frankenburg WK. Developmental surveillance and screening of infants and young children. Pediatrics 2002 Jan;109(1):144-145. [doi: 10.1542/peds.109.1.144] [Medline: 11773555]
11. Dobos AE, Dworkin PH, Bernstein BA. Pediatricians' approaches to developmental problems: has the gap been narrowed? J Dev Behav Pediatr 1994 Feb;15(1):34-38. [doi: 10.1097/00004703-199402000-00006] [Medline: 7515076]
12. Sand N, Silverstein M, Glascoe FP, Gupta VB, Tonniges TP, O'Connor KG. Pediatricians' reported practices regarding developmental screening: do guidelines work? Do they help? Pediatrics 2005 Jul;116(1):174-179. [doi: 10.1542/peds.2004-1809] [Medline: 15995049]
13. Rydz D, Srour M, Oskoui M, Marget N, Shiller M, Birnbaum R, et al. Screening for developmental delay in the setting of a community pediatric clinic: a prospective assessment of parent-report questionnaires. Pediatrics 2006 Oct;118(4):e1178-e1186. [doi: 10.1542/peds.2006-0466] [Medline: 17015506]
14. Chang C, DiPace J, Hong S. Improving Developmental Screening in a Resident Group Continuity Clinic Practice. Acad Pediatr 2011 Jul;11(4):e10. [doi: 10.1016/j.acap.2011.05.021]
15. Liao HF, Cheng LY, Hsieh WS, Yang MC. Selecting a cutoff point for a developmental screening test based on overall diagnostic indices and total expected utilities of professional preferences. J Formos Med Assoc 2010 Mar;109(3):209-218 [FREE Full text] [doi: 10.1016/S0929-6646(10)60044-7] [Medline: 20434029]
16. Liao H, Cheng L, Hsieh W, Yang M. Selecting a cutoff point for a developmental screening test based on overall diagnostic indices and total expected utilities of professional preferences. J Formos Med Assoc 2010 Mar;109(3):209-218 [FREE Full text] [doi: 10.1016/S0929-6646(10)60044-7] [Medline: 20434029]
17. Xie H, Clifford J, Squires J, Chen CY, Bian X, Yu Q. Adapting and validating a developmental assessment for chinese infants and toddlers: The ages & stages questionnaires: Inventory. Infant Behav Dev 2017 Nov;49:281-295. [doi: 10.1016/j.infbeh.2017.09.004] [Medline: 29078066]
18. Liao H, Cheng L, Hsieh W, Yang M, Tsou K, Tsai K. The reliability and validity of the Developmental Items of Child Health Pamphlet (DICHP). Formosan J Med 2008;12:502e12 In Chinese, English abstract.
19. Squires J, Bricker D. Ages & Stages Questionnaires®, Third Edition (ASQ®-3): A Parent-completed Child Monitoring System. Baltimore, MD: Brookes Publishing; 2009.
20. Chang C, DiPace J, Hong S. Improving Developmental Screening in a Resident Group Continuity Clinic Practice. Acad Pediatr 2011 Jul;11(4):e10. [doi: 10.1016/j.acap.2011.05.021]
21. Liao HF, Cheng LY, Hsieh WS, Yang MC. Selecting a Cutoff Point for a Developmental Screening Test Based on Overall Diagnostic Indices and Total Expected Utilities of Professional Preferences. J Formos Med Assoc 2010 Mar;109(3):209-218 [FREE Full text] [doi: 10.1016/S0929-6646(10)60044-7] [Medline: 20434029]
22. Rasch G. Probabilistic models for some intelligence and attainment tests. Chicago, IL: MESA Press; 1993.

23. Wu M, Adams R, Wilson M. Acer ConQuest: Generalised Item Response Modelling Software Manual. Melbourne, Australia: ACER Press; 1998.
24. Wright B, Masters G. Number of person or item strata. Rasch Meas Trans 2002;16(3):888.
25. Wright B. Reliability and separation. Rasch Meas Trans 1996;9(4):472.
26. Fisher WJ. The cash value of reliability. Rasch Meas Trans 2008;22(1):1160-1163.
27. Linacre J. How to Simulate Rasch Data. Rasch Meas Trans 2007;21(3):1125.
28. Wang W. Recent Developments in Rasch Measurement. Hong Kong: The Hong Kong Institute of Education Press; 2010.
29. Linacre JM. Optimizing rating scale category effectiveness. J Appl Meas 2002;3(1):85-106. [Medline: 11997586]
30. Maslach C, Schaufeli WB, Leiter MP. Job burnout. Annu Rev Psychol 2001 Feb;52(1):397-422. [doi: 10.1146/annurev.psych.52.1.397] [Medline: 11148311]
31. Ma S, Wang H, Chien T. A new technique to measure online bullying: online computerized adaptive testing. Ann Gen Psychiatry 2017;16:26 [FREE Full text] [doi: 10.1186/s12991-017-0149-z] [Medline: 28680455]
32. Adams RJ, Wilson M, Wang W. The Multidimensional Random Coefficients Multinomial Logit Model. Appl Psychol Meas 2016 Jul 27;21(1):1-23. [doi: 10.1177/0146621697211001]
33. Wang W, Chen P. Implementation and Measurement Efficiency of Multidimensional Computerized Adaptive Testing. Appl Psychol Meas 2016 Jul 26;28(5):295-316 Not indexed in PUBMED [FREE Full text] [doi: 10.1177/0146621604265938]
34. Segall DO. Multidimensional adaptive testing. Psychometrika 1996 Jun;61(2):331-354. [doi: 10.1007/bf02294343]
35. Lee Y, Lin K, Chien T. Application of a multidimensional computerized adaptive test for a Clinical Dementia Rating Scale through computer-aided techniques. Ann Gen Psychiatry 2019 May 17;18(1):5 [FREE Full text] [doi: 10.1186/s12991-019-0228-4] [Medline: 31131014]
36. Djaja N, Janda M, Olsen CM, Whiteman DC, Chien T. Estimating Skin Cancer Risk: Evaluating Mobile Computer-Adaptive Testing. J Med Internet Res 2016 Jan 22;18(1):e22 [FREE Full text] [doi: 10.2196/jmir.4736] [Medline: 26800642]
37. Fisher WJ. Reliability, separation, strata statistics. Rasch Meas Trans 1994;6(3):238.
38. Chien T, Lin W. Improving Inpatient Surveys: Web-Based Computer Adaptive Testing Accessed via Mobile Phone QR Codes. JMIR Med Inform 2016 Mar 02;4(1):e8 [FREE Full text] [doi: 10.2196/medinform.4313] [Medline: 26935793]
39. Smith E. Detecting and evaluating the impact of multidimensionality using item fit statistics and principal component analysis of residuals. J Appl Meas 2002;3(2):205-231. [Medline: 12011501]

Abbreviations

AAP: American Academy of Pediatrics
ASQ-3: Ages & Stages Questionnaires
CAT: computer adaptive testing
IRT: item response theory
MCAT: multidimensional computer adaptive testing
MuSiC: Multidimensional Screening in Child Development
MRCMLM: multidimensional random coefficient multinomial logit model
NAT: nonadaptive testing
QR: Quick Response

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Original Paper

The Sign 4 Little Talkers Intervention to Improve Listening, Understanding, Speaking, and Behavior in Hearing Preschool Children: Outcome Evaluation

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Abstract

Background: Gaining age-appropriate proficiency in speech and language in the early years is crucial to later life chances; however, a significant proportion of children fail to meet the expected standards in these early years outcomes when they start school. Factors influencing the development of language and communication include low income, gender, and having English as an additional language (EAL).

Objective: This study aimed to determine whether the Sign 4 Little Talkers (S4LT) program improves key developmental outcomes in hearing preschool children. S4LT was developed to address gaps in the attainment of vocabulary and communication skills in preschool children, identified through routine monitoring of outcomes in early years. Signs were adapted and incorporated into storybooks to improve vocabulary, communication, and behavior in hearing children.

Methods: An evaluation of S4LT was conducted to measure key outcomes pre- and postintervention in 8 early years settings in Luton, United Kingdom. A total of 118 preschool children were tested in 4 early years outcomes domains—listening, speaking, understanding, and managing feelings and behavior—as well as Leuven well-being scales and the number of key words understood and spoken.

Results: Statistically significant results were found for all measures tested: words spoken ($P<.001$) and understood ($P<.001$), speaking ($P<.001$), managing feelings and behavior ($P<.001$), understanding ($P<.001$), listening and attention ($P<.001$), and well-being ($P<.001$). Approximately two-thirds of the children made expected or good progress, often progressing multiple steps in educational attainment after being assessed as developmentally behind at baseline.

Conclusions: The findings reported here suggest that S4LT may help children to catch up with their peers at a crucial stage in development and become *school ready* by improving their command of language and communication as well as learning social skills. Our analysis also highlights specific groups of children who are not responding as well as expected, namely boys with EAL, and who require additional, tailored support.

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KEYWORDS

sign language; early years; intervention; disadvantage

Introduction

Background

As the importance of speech and language ability in later educational outcomes and life chances has been acknowledged, systematic research has tried to evaluate the effectiveness of interventions or programs to improve educational attainment in these areas. A UK Department of Education review of interventions for children who need support with speech, language, and communication found a *sound emerging evidence base* for them [1]. A Cochrane review of the effectiveness of speech and language interventions for children with speech and language delay or disorders described an overall positive effect [2]. Carneiro and Heckman [3] argued that the early development of cognitive and noncognitive skills is key to determining children's chances of success and that early interventions are much more likely to be beneficial than those targeted at older age groups: "The evidence points to a high return to early interventions and a low return to remedial of compensatory interventions later in the lifecycle" [3].

The UK government has been committed to expanding preschool education in recent years. Currently, all children aged 3 to 4 years in England are entitled to free nursery education or childcare with an approved childcare provider. Children receive 15 hours of free nursery education or childcare from their third birthday, with some parents eligible for 30 hours if employed or getting parental leave (with each parent earning at least the national minimum wage for 16 hours per week). Two-year-old children in England are also entitled to 15 hours of free nursery education with a *Funded 2* childcare place if their parents are in receipt of benefits, if they are looked after by the local council or by guardians, if they have a current statement of special educational needs or are on disability living allowance [4].

Factors Influencing Development in the Early Years

Low Income

Different social environments support language acquisition to varying degrees, depending on the availability of the opportunity for communication to facilitate language acquisition. It has been found that lower-income parents gesture less frequently, with their children starting school with smaller vocabularies than children of a higher socioeconomic status (SES). This is particularly significant as vocabulary is viewed as a key predictor of educational attainment [5]. Children from professional families were found to speak nearly 300 more words per hour when compared with families in receipt of benefits, resulting in a *30-million word gap* [6]. Similarly, children who are surrounded by receptive parents, teachers, and siblings who listen, interact, and respond to facial expressions develop speech at a faster rate [7]. Exposure to high volumes of language enhances learning [8], and current vocabulary makes children more receptive to new learning [9]. Environments rich in cognitive, emotional, and social interactions, where children are exposed to general knowledge, can help children advance quicker [10].

A UK government report highlights the importance of parental behavior [11]. The children of parents who have some form of qualification, who read to their children, and who are interested in their schooling are likely to do better: "…not reading to young children is serving as a proxy for a lack of interest in children's education, the dominant variable" [11]. The report uses data from the 1970 British birth cohort and concludes that children who perform well academically who are as young as 5 years of age are more likely to escape poverty. Further analysis of the cohort data found that scores at 22 months predicted educational qualifications at 26 years, and this was related to SES. Children of educated or wealthy parents were able to catch up if they had low scores as young children, in contrast with children of lower SES parents who were extremely unlikely to catch up if they had lower scores [12].

Focusing on the shorter term, lower-income children were found to lag behind their higher-income counterparts in vocabulary by 16 months when they start school. The gaps found in language are much larger than the gaps in other cognitive skills [13], and children from the poorest fifth of UK families are nearly 1 year behind their middle-income peers in vocabulary tests at age 5 years when starting school [14]. Children of lower SES and with English as an additional language (EAL) are less skilled in English oral language compared with children of higher SES, English-speaking homes, which then affects academic achievement. The challenges faced by children with EAL are explored further in the following subsection.

English as an Additional Language

A study assessing UK primary school children over a 3-year period reported that children learning English had lower levels of vocabulary and comprehension, which is attributed to a lack of fluency when starting school [15]. A later study confirmed these findings, reporting that EAL learners have difficulty understanding written and spoken texts, and have significantly lower levels of vocabulary [16]. Similarly, whereas children with EAL often have good reading skills, limited vocabulary constrains the comprehension of spoken and written texts and therefore support is recommended to develop vocabulary in early years settings [17]. This is in addition to the need to develop appropriate background knowledge in children with EAL to facilitate text comprehension [18]. Comparing samples of bilingual and monolingual speaking children on measures of vocabulary and grammar, monolingual children were significantly more advanced in vocabulary and grammar, but comparable in terms of total vocabulary size [19].

Gender

In the late 1980s, a meta-analysis of gender differences in verbal ability reported that differences no longer exist, with females scoring only slightly better than males [20]. However, later work showed that symbolic gestures develop alongside children's early words, that girls tended to rely more heavily on such gestures than boys, and that structured parent-child interaction is important in developing these gestures and is positively related to verbal vocabulary development [21]. Nevertheless, concern has increased over girls outperforming boys educationally. However, the evidence appears to be more nuanced for school-aged children. For example, a large-scale longitudinal study found that girls and boys outperform each other depending on the learning domains investigated. Similarly, an international study investigating sex differences in the Program for International Student Assessment achievement and national measures of gender equality found inconsistencies across assessments. However, in terms of overall achievement across reading, mathematics, and science literacy, girls outperformed boys in 70% of the countries under study. Gender differences become most pronounced in higher education, where male participation has dropped substantially as female participation has increased. This has been reported both in the United Kingdom and worldwide [22].

Emotional Literacy

Socioemotional development is increasingly acknowledged as important for future life opportunities. *Effective mastery* of social and emotional skills supports the attainment of key life outcomes such as *good health and social well-being, educational attainment and employment, and the avoidance of behavioral and social difficulties* [23]. This is in the context of increasing concern over children's mental health and well-being [24]. Gesturing has been proposed as a *therapeutic communication tool* to help children express emotions and construct an understanding of their own internal states [25].

Goodman et al [26] linked social, emotional, and cognitive skills recorded at 10 years of age from the British Cohort Study of those born in 1970 with experiences at 42 years of age. Therefore, developing a good range of cognitive, social, and emotional skills in childhood was viewed as important for success in adult life, including encouraging good emotional well-being, self-regulation, and a sense of self-efficacy. Moreover, psychological problems experienced in childhood affect the ability to work in adulthood, earning power, marital stability, and intergenerational and within-generation social mobility [27]. In terms of ensuring school readiness, it is argued that developing preschool children's socioemotional competence and language skills help them to adjust to junior school. This is particularly important for at-risk children as a way of ensuring school readiness [28].

Evidence of the Effectiveness of Sign Language or Gesturing in Children

Recent guidance from the Education Endowment Foundation recommends the prioritization of the development of communication and language and embedding opportunities to develop self-regulation [29]. The use of sign language to encourage speech and vocabulary range in hearing children has been investigated in recent years, suggesting that gesturing is a precursor to speech [30], and in the relationship between motor skills and language development [31]. A multisensory learning approach using visual aids, hearing, speaking, and signing helped preschool children retain more words and phonetic sounds [32]. Cook and Goldin-Meadow [33] found that gesturing during teaching and encouraging children to mirror them increased engagement and interaction with learning. Daniels [34] found that young hearing children significantly increased their vocabularies when teachers used sign language when compared with conventionally taught children and that such positive effects were maintained throughout the following school year [34]. Similar significant gains in vocabulary were reported when hearing children were taught to incorporate American Sign Language [35]. Elsewhere, gesturing at 18 months was found to predict vocabulary at 42 months, and gesture and speech combinations at 18 months predicted the degree of sentence complexity at 42 months [36]. Brain scanning research has found that symbolic gesturing, signs, and words activate the same brain areas, suggesting that word learning is enhanced with activity such as gesturing conveying meaning, facilitating word learning [37,38].

The Sign 4 Little Talkers Intervention

Sign 4 Little Talkers (S4LT) was developed to address gaps in the attainment of vocabulary and communication skills in preschool children, which were identified through routine monitoring of early years outcomes (EYOs) by Luton Borough Council, United Kingdom. The town faces additional challenges due to higher than average levels of deprivation, a transient population, and multiple languages being spoken. The S4LT intervention consists of 5 books, *Feelings*, *The Lost Teddy*, *I want that!*, *Can I go to the park?*, and *It is too noisy* [39], which depict 2 characters, Zak and Zoe. Zak and Zoe are also dolls that are used during story sessions to engage children. A DVD and poster are also available for early years settings to train practitioners to use S4LT stories and signing.

Signs are adapted from British Sign Language to increase vocabulary in hearing children. The S4LT books are designed to improve communication in preschool children, express their emotions, and start regulating their own behavior. Stories depict different situations, and the emotions that children might feel, accompanied by signs, for example, "Zoe is excited. Why is she excited? Because she‘s on the roundabout!" By reading the stories, parents and carers are engaged in promoting positive behavior such as sharing, turn taking, using linking words to form longer and more complex sentences as well as those needed in social interactions such as *please* and *thank you*. Parents and carers are encouraged to talk to children about how useful it is to use hand gestures when telling a story to help them remember vocabulary and to encourage children to say and sign words with them.

We investigated the effectiveness of the S4LT intervention for preschool children [40]. S4LT is one of many Sign 4 programs developed to improve various aspects of child development. An evaluation of another of these, Sign 4 Big Feelings, designed to support children with challenging behavior was also conducted [41]. This is part of a wider evaluation of services for children aged under 5 years in Luton, United Kingdom [42-45]. Underlying the S4LT intervention is the hypothesis that the adoption of sign language by hearing children accelerates proficiency in speech, language acquisition, and well-being, thereby improving outcomes in these developmental areas at a better-than-expected rate. An analysis of pre- and post-S4LT outcome data collected from Luton early years settings aims to answer the following research question: Does the S4LT intervention improve language, communication, and well-being outcomes in preschool children?

Methods

Ethics Approval and Consent to Participate

This study was approved by the University of Bedfordshire Research Ethics Committee (UREC104) on April 10, 2017. Written consent was obtained from the parents.

Availability of Data and Materials

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

Implementation

The S4LT intervention was introduced into 8 early years settings (nursery schools, preschools, or kindergartens) in Luton. These settings were chosen because they reported lower than expected progress in the attainment of communication and language skills as monitored by the Early Years Foundation stage outcome data (EYOs) routinely collected and inputted into Luton Borough Council's tracking system. This targeted strategy was adopted to ensure that children with the greatest level of need could benefit from the intervention. Children attending these early years settings do not do well when compared with both the Luton and UK national average in communication, language, and managing feelings and behavior as measured by the Early Years Foundation stage profile. This statutory framework sets standards for the development and care of children aged below 5 years in the United Kingdom to ensure effective learning and development and ensure that they are ready to start school.

Principals or managers in the 8 settings signed a memorandum of understanding, setting out expectations regarding the implementation of S4LT. A training session was organized at each of the 8 settings for staff to familiarize themselves with the books, learn the signs, and practice with each other. The intervention was to be incorporated into daily routines such as story times, giving children the opportunity to learn the Sign 4 stories and sign language gradually on a daily basis. Staff in each early years setting were asked to identify 10 children who were assessed as below expected levels of development and therefore judged to be most in need of targeted help to catch up with their peers. The chosen children received additional support with extra story sessions, and their parents were invited to an S4LT session with their children to learn the stories and signs. They were given a set of 2 S4LT books and dolls to use with their children at home. Data were collected from 10 children per setting before the introduction of S4LT and again after 2 terms, starting autumn 2016 and ending spring 2017 (approximately 6 months).

Outcome Measures

Early Years Outcome Developmental Bandings

Nursery staff in Luton use EYO developmental bands to monitor children on a termly basis. Children are placed in age bands according to their level of development (ie, 22-36 months, 30-50 months). Children are placed in a specific age band, and each band is subdivided into c=low, b=secure, and a=high, until they reach the early learning goal (ELG), which is the expected level of learning and development for children at the end of the reception year at school (Table 1). Assessment is made in a number of different areas of learning, but for the purposes of this study, we were interested in 4 particular domains: listening, understanding, speaking, and managing feelings and behavior. For example, a child may be rated in the 22- to 36-month band at *high*, indicating they are in the upper end of educational attainment in that particular age band. The banding may not reflect chronological age as it depends on individual progress. Therefore, a child aged 28 months may be put into the 30- to 50-month banding if they are above typical levels of development for their age and conversely in a lower band than their age if they are below typical levels. Children are expected to progress to 1 developmental stage per term, for example, 30-50c (low) to 30-50b (secure). As data collection pre- and postintervention was over 2 terms, children would be expected to progress 2 bands on average.

Table 1. Early years outcomes up to early learning goals.

Developmental stage	EYOs[a] to ELGs[b]
1	8-20c
2	8-20b
3	8-20a
4	16-26c
5	16-26b
6	16-26a
7	22-36c
8	22-36b
9	22-36a
10	30-50c
11	30-50b
12	30-50a
13	40-60c
14	40-60b
15	40-60a
16	ELG1
17	ELG2
18	ELG3

[a] EYOs: early years outcomes.

[b] ELGs: early learning goals.

Leuven Well-Being Scales

To explore hypothesized links between low levels of well-being, involvement, and compromised development [46,47], well-being was measured. To ascertain if children's well-being improved after the intervention period, the Leuven well-being scale was employed [48] and is used by early years professionals in Luton.

Number of Words Understood and Spoken

The number of words understood and spoken from 42 keywords featured in the S4LT story books were recorded pre- and postintervention (happy, sad, angry, frustrated, disappointed, frightened, worried, excited, upset, tired, hungry, sorry, please, thank you, calm down, sit down, well done, gentle, wait, stop, share, kind, your turn, listen, why, because, first, next, finally, so, what, who, quiet, loud, where, hiding, dangerous, safe, crying, secret, shouting, proud). The demographic information collected included gender, child's age in months, EAL, and if the child had a funded nursery place (Funded 2), which was also used as an indicator of deprivation.

Results

Summary of the Data Set: Participants

Data from 119 children were collected (Table 2), with more boys (65/119, 54.6%) than girls (44/119, 37.0%). Just under 48% of children were in the 2- to 3-year age band and 41.2% (49/119) were in the 3- to 4-year age band. Some of the data were marked *unknown* where forms were incomplete but contained sufficient data to be included. Some measures had totals of less than 119 children where data were missing. Just over one-third of the children had EAL, and over 70.0% had a funded early years childcare place (Funded 2).

A total of 118 EYO assessments in 4 domains were completed (listening, understanding, speaking, and managing feelings and behavior); 108 assessments of keywords understood and spoken pre- and postintervention, and 46 Leuven well-being scales pre- and postintervention (Table 3) These measures are described under the previous outcomes section. Baseline data were collected in September 2016, and follow-up data were collected 6 months later in March 2017. Descriptive statistics, a paired samples two-tailed *t* test, and correlations were completed.

Table 2. Preschool children by age, gender, English as an additional language, and Funded 2 status.

Children	Values, n (%)
Gender	
Male	65 (54.6)
Female	44 (37.0)
Unknown	10 (8.4)
EAL[a]	
Yes	40 (33.6)
No	78 (65.5)
Unknown	1 (0.8)
Age (years)	
1-2	3 (2.5)
2-3	57 (47.9)
3-4	49 (41.2)
Unknown	10 (8.4)
Funded 2	
Yes	72 (60.5)
No	37 (31.1)
Unknown	10 (8.4)

[a] EAL: English as an additional language.

Table 3. Summary of the Sign 4 Little Talkers data set.

Variables	n	EYO[a] progress (range)	Value, mean (SD)
Listening_Progress_Made	118	−2.00 to 6.00	2.3051 (1.51634)
Understanding_Prog_Made	118	−1.00 to 7.00	2.4661 (1.58347)
Speaking_Progress_Made	118	0 to6.00	2.4492 (1.50553)
Feelings_Progress_Made	118	−2.00 to 6.00	2.5508 (1.54476)
Words Autumn1_Understanding	108	0 to 16.00	6.3796 (4.04118)
Words Autumn1_Speaking	108	0 to 16.00	4.1852 (3.92725)
Words Spring2_Understanding	108	3.00 to 16.00	11.3704 (3.58760)
Words Spring2_Speaking	108	0 to 16.00	9.6296 (4.47964)
Leuven wellbeing_Autumn1	46	1.00 to 5.00	2.8913 (1.07968)
Leuven wellbeing_Spring2	46	2.00 to 5.00	4.0217 (.71458)
EYO Aut1_Listening	118	0 to 14.00	7.7203 (2.94939)
EYO Aut1_Understanding	118	0 to 14.00	7.2797 (2.97536)
EYO Aut1_Speaking	118	0 to 14.00	6.5678 (2.87779)
EYO Aut1_Feeling	118	0 to 13.00	6.9153 (2.78757)
EYO Spr2_Listening	118	0 to 15.00	10.0254 (2.80860)
EYO Spr2_Understanding	118	0 to 15.00	9.7373 (2.88061)
EYO Spr2_Speaking	118	0 to 15.00	9.0169 (2.94387)
EYO Spr2_Feeling	118	0 to 14.00	9.4661 (2.90794)

[a] EYO: early years outcome.

Paired Sample t Test

A paired sample *t* test was conducted to ascertain any statistically significant difference in mean scores before and after the introduction of the S4LT intervention. Statistically significant differences in mean scores were found for each of the 7 pre- and postpairs tested (Table 4). The mean of keywords understood in the spring term (mean 11.37, SD 3.59) was significantly higher than that of the autumn term (mean 6.38, SD 4.04; t_{107}=16.44; *P*<.001; Cohen *d*=1.58). The mean of keywords spoken was significantly higher in the spring term (mean 9.63, SD 4.48) than that of the previous autumn term (mean 4.18, SD 3.93; t_{107}=15.21; *P*<.001; Cohen *d*=1.47). The mean Leuven well-being scale in the spring term (mean 4.02, SD 0.71) was significantly higher than that of the autumn term (mean 2.89, SD 1.08; t_{45}=10.24; *P*<.001; Cohen *d*=1.53). The mean of EYO listening and attention were significantly higher in the spring term (mean 10.02, SD 2.81) than that of the autumn term (mean 7.72, SD 2.95; t_{117}=16.51; *P*<.001; Cohen *d*=1.52). The mean of EYO understanding in the spring term (mean 9.74, SD 2.88) was significantly higher than that of the autumn term (mean 7.28, SD 2.97; t_{117}=16.92; *P*<.001, Cohen *d*=1.50). The mean of EYO speaking in the spring term (mean 9.02, SD 2.94) was significantly higher than that of the autumn term (mean 6.57, SD 2.88; t_{117}=17.67; *P*<.001; Cohen *d*=1.62). The mean of EYO managing feelings and behavior was significantly higher in the spring term (mean 9.47, SD 2.91) than that of the autumn term (mean 6.91, SD 2.79; t_{117}=17.94; *P*<.001; Cohen *d*=1.65). All 7 tested pairs had large effect sizes, indicating large statistically significant differences.

Table 4. Paired sample t test: words understood and spoken, well-being, and early years outcomes.

Number and pairs		Paired differences			*t* test (*df*)	Significance (two-tailed)
		Mean (SD)	SE	95% CI		
Pair 1	Words Aut1 Understand—Words Spr2 Under	−4.99 (3.15)	0.30	−5.59 to −4.39	−16.44 (107)	0
Pair 2	Words Aut1 Say—Words Spr2 Say	−5.44 (3.72)	0.36	−6.15 to −4.73	−15.21 (107)	0
Pair 3	Leuven Wellbeing Aut1—Leuven Well Spr2	−1.13 (.75)	0.11	−1.35 to −0.91	−10.24 (45)	0
Pair 4	EYO[a] Aut1 Listening—EYO Spr2 Listening	−2.31 (1.52)	0.14	−2.58 to −2.03	−16.51 (117)	0
Pair 5	EYO Aut1 Understanding—EYO Spr2 Under	−2.46 (1.58)	0.15	−2.75 to −2.17	−16.92 (117)	0
Pair 6	EYO Aut1 Speaking—EYO Spr2 Speaking	−2.45 (1.51)	0.14	−2.72 to −2.17	−17.67 (117)	0
Pair 7	EYO Aut1 Feelings—EYO Spr2 Feelings	−2.55 (1.55)	0.14	−2.83 to −2.27	−17.94 (117)	0

[a] EYO: early years outcome.

Correlations

A correlation analysis was run with children’s age, the 4 EYO domains, Leuven well-being scales, and words understood and spoken (Table 5). There was a positive, statistically significant relationship between age and the 4 EYO domains: listening and attention (Pearson correlation coefficient r_{109}=0.49; *P*<.001); understanding (r_{109}=0.52; *P*<.001); speaking (r_{109}=0.48; *P*<.001); managing feelings and behavior (r_{109}=0.59; *P*<.001); and words spoken (r_{108}=0.20; *P*<.03). No relationship was found between age and the Leuven well-being scales and words understood.

A positive, statistically significant relationship was found between each of the EYO domains. For example, listening and understanding (r_{118}=0.94; *P*<.001) and between speaking and managing feelings and behavior (r_{118}=0.87; *P*<.001). A positive, statistically significant relationship was also found between the Leuven well-being scale and words understood (r_{46}=0.39; *P*<.007) and spoken (r_{46}=0.39; *P*<.008).

Table 5. Pearson correlations: words understood and spoken, well-being, and early years outcomes.

Variables	Age	EYO[a] Spr2 List&Att	EYO Spr2 Under	EYO Spr2 Speak	EYO Spr2 Feel	Leuven Spr2	Words Spr2 Under	Words Spr2 Say
Pearson correlation, *r*	1.00	0.49	0.52	0.48	0.59	−0.08	0.16	0.20
Significance (two-tailed)	N/A[b]	0.00	0.00	0.00	0.00	0.60	0.09	0.03
Number of participants, n	109	109	109	109	109	46	108	108
EYO spring (second term) listening and attention								
Pearson correlation, *r*	N/A	1.00	0.94	0.89	0.91	−0.26	0.03	0.07
Significance (two-tailed)	N/A	N/A	0.00	0.00	0.00	0.08	0.78	0.45
Number of participants, N	N/A	118	118	118	118	46	108	108
EYO spring (second term) understanding								
Pearson correlation, *r*	N/A	N/A	1.00	0.92	0.92	−0.24	0.04	0.05
Significance (two-tailed)	N/A	N/A	N/A	0.00	0.00	0.11	0.66	0.60
Number of participants, N	N/A	N/A	118	118	118	46	108	108
EYO spring (second term) speaking								
Pearson correlation, *r*	N/A	N/A	N/A	1.00	0.87	−0.27	0.04	0.05
Significance (two-tailed)	N/A	N/A	N/A	N/A	0.00	0.07	0.66	0.58
Number of participants, N	N/A	N/A	N/A	118	118	46	108	108
EYO spring (second term) feelings and behavior								
Pearson correlation, *r*	N/A	N/A	N/A	N/A	1.00	−0.24	0.09	0.11
Significance (two-tailed)	N/A	N/A	N/A	N/A	N/A	0.11	0.37	0.26
Number of participants, N	N/A	N/A	N/A	N/A	118	46	108	108
Leuven well-being spring (second term)								
Pearson correlation, *r*	N/A	N/A	N/A	N/A	N/A	1.00	0.39	0.39
Significance (two-tailed)	N/A	N/A	N/A	N/A	N/A	N/A	0.01	0.01
Number of participants, n	N/A	N/A	N/A	N/A	N/A	46	46	46
Words spring (second term) understood								
Pearson correlation, *r*	N/A	N/A	N/A	N/A	N/A	N/A	1.00	0.66
Significance (two-tailed)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	0.00
Number of participants, n	N/A	N/A	N/A	N/A	N/A	N/A	108	108
Words spring (second term) spoken								
Pearson correlation, *r*	N/A	N/A	N/A	N/A	N/A	N/A	N/A	1.00
Significance (two-tailed)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Number of participants, n	N/A	N/A	N/A	N/A	N/A	N/A	N/A	108

[a]EYO: early years outcome.

[b]N/A: not applicable.

Progress of Early Years Outcomes by Stage

Control data collected from the same academic year showed the average progress of children in Luton over 2 terms, with 1 or 2 steps made in each domain under study (Table 6). Children are typically expected to progress 1 step per term and therefore fell short of the expected progress in listening and attention and speaking over the 2 terms reported here. Table 7 shows the progress made by children in the study sample in each EYO domain. Approximately two-third of children made expected (2 stages over 2 terms) or good progress in listening (67%), understanding (71%), and speaking (69.5%). Nearly four-fifth (79%) made expected or good progress in managing feelings and behavior.

In terms of listening, children with EAL made less progress than English speakers; boys made less progress than girls (Table 8). Boys with a Funded 2 childcare place made significantly more progress than nonfunded boys; nonfunded girls made slightly more progress than those with funded places (Table 9). With understanding, boys with EAL made the least progress. Girls made more progress than boys overall; children with EAL made less progress than their peers did (Table 8). Children in Funded 2 childcare places made better-than-expected progress (more than 2 levels) and outperformed nonfunded children in terms of understanding; overall, boys made less progress (Table 9).

In terms of managing feelings and behavior, boys made less progress than girls, with children with EAL doing less well overall (Table 8). However, boys in Funded 2 childcare places progressed more than their nonfunded peers, whereas nonfunded girls progressed slightly more than funded girls (Table 9). In the final EYO area, speaking, girls progressed more than boys, with children with EAL behind their English-speaking peers (Table 8). Children in Funded 2 childcare places made more progress in speaking than nonfunded children (Table 9). The Leuven well-being scales pre- and postintervention show a shift up the scale. The majority of children were assessed as moderate in the autumn term, shifting to *high* in the spring term, with girls proportionately moving further up the scale than boys (Table 10).

Table 6. Control data: average steps progress of children over 2 school terms.

EYO[a] domain	Autumn term 1				Spring term 2				Steps progress
	Total number of pupils, N	Below expected progress, n	At expected progress, n	Above expected progress, n	Total number of pupils, N	Below, n	At, n	Above, n	
Listening and attention	413	34	45	20	498	26	38	36	1
Understanding	413	41	41	18	498	36	34	30	2
Speaking	404	47	40	14	498	43	30	26	1
Managing feelings and behavior	394	40	48	12	498	38	38	25	2

[a]EYO: early years outcome.

Table 7. Progress made by children in each early years outcome domain.

EYO[a] domain	EYO stages progressed									
	2− stages	1− stage	0 stages	1+ stage	2+ stages (expected progress)	3+ stages	4+ stages	5+ stages	6+ stages	7+ stages
Listening	2	N/A[b]	11	28	25	32	12	4	3	N/A
Understanding	N/A	1	12	20	23	34	16	5	3	2
Managing feelings and behavior	1	1	7	15	37	28	13	11	4	N/A
Speaking	N/A	N/A	10	26	23	35	11	7	5	N/A

[a]EYO: early years outcome.

[b]N/A: not applicable.

Table 8. Progress made by children with and without English as an additional language in each early years outcome domain.

EYO[a] domain	English as an additional language			
	Male		Female	
	Yes	No	Yes	No
Listening	1.5	2.5	2.0	3.0
Understanding	1.5	2.8	2.5	2.9
Managing feelings and behavior	1.8	2.5	2.4	3.0
Speaking	1.7	2.5	2.2	2.8

[a] EYO: early years outcome.

Table 9. Progress made by children with and without a Funded 2 childcare place in each early years outcome domain.

EYO[a] domain	Funded 2 place			
	Male		Female	
	Yes	No	Yes	No
Listening	2.5	1.6	2.5	2.8
Understanding	2.5	2.0	2.7	2.6
Managing feelings	2.4	1.9	2.7	3.0
Speaking	2.5	2.0	2.8	2.2

[a] EYO: early years outcome.

Table 10. Well-being of children in autumn and spring terms as assessed by the Leuven scale.

Leuven term	Scale					Values, mean (SD)
	Extremely low	Low	Moderate	High	Extremely high	
Autumn						
Male	N/A[a]	5	14	3	3	3.16 (0.89)
Female	5	5	6	4	1	2.57 (1.20)
Spring						
Male	N/A	N/A	4	15	6	4.12 (0.66)
Female	N/A	1	4	12	4	3.90 (0.76)

[a] N/A: not applicable.

Discussion

Principal Findings

Statistically significant differences in mean scores were found in each of the pairs tested pre- and postintervention: words understood and spoken, Leuven well-being scales, and the 4 EYO domains. The majority of children made expected progress or better in terms of EYO stages (67% listening, 71% understanding, 69.5% speaking, and 79% managing feelings and behavior), with many progressing multiple steps. The mean progress in each domain was between 2.3 and 2.5 steps (Table 3) and therefore better than that reported in the control data (Table 6), particularly in relation to listening and attention and speaking, where an average of 1 step progress was made. Children monitored as part of the intervention were chosen because they were identified as making less-than-expected progress, and it could be argued that they were even further behind as they were identified as most in need of help by early years professionals working with them on a daily basis. This makes the multiple *steps* of progress made by the majority of children in the S4LT intervention even more notable.

The correlation analysis found a positive, statistically significant relationship between age and the 4 EYO domains, suggesting that as age increases, so does the degree of educational attainment. A statistically significant relationship was also found between each of the 4 EYOs, suggesting that progression in one area is related to progression in the others, which, in terms of understanding, listening, managing feelings and behavior, and speaking, would make sense given the interdependence between them as children gain core skills. This finding was confirmed by early years professionals who routinely observe and therefore would expect children to make progress across all domains after an initial advance in one developmental area as they are inextricably linked. The positive, statistically significant relationship between well-being and words understood and spoken suggests that the ability to communicate and be understood enhances well-being in the children under study. Well-being as measured by the Leuven scale appeared to improve markedly, although caution is advised due to the smaller subgroup of children who were measured.

Although the majority of children made better-than-expected progress, of note is a sizeable minority who made less-than-expected progress or who regressed (33% listening, 30.5% speaking, 29% understanding, and 21% managing feelings and behavior). Possible explanations put forward by early years staff based at the study sites suggest that this may be because of undiagnosed learning difficulty, health issues such as hearing problems, or illness resulting in frequent absences, severe behavioral problems, difficulties at home, and/or an unstable home environment.

Limitations

A relatively small sample size was collected overall, with the Leuven well-being scale data being particularly limited. This was because not all early years practitioners in Luton were trained to use this particular scale to assess well-being. At the 2-term duration, the intervention period was viewed as quite brief, and this was remarked on by some early years professionals. Timings were decided by the Sign 4 team and the University of Bedfordshire as part of an agreed timeline to report on results in a defined period. Future work would benefit from longer time frames and a longitudinal approach, which would be possible given the type of data collected by Luton Borough Council over time.

In terms of steps taken during EYO progression, caution is advised for children who made multiple steps of progress (smaller numbers moved up to 5-7 stages). However, practitioners working in these settings view it as possible for children to change quite drastically with the right help, support, and encouragement. A forthcoming process study of S4LT, with an analysis of interviews with parents, staff, and stakeholders, will examine lay accounts of the intervention and perceptions of progress made. Regarding fidelity of delivery, the same signing trainer visited all the settings, working with staff, parents, and children. The degree to which settings adopted S4LT and the motivation of the staff to sign would most likely vary. However, inspection of the data did not show much variability between the settings. The assessment of children in terms of EYOs is subject to monitoring by Luton Borough Council. Staff are trained regularly and are moderated to reduce inconsistencies in assessment as much as possible.

This study is concerned with progress measured in terms of steps of EYO developmental bands rather than final results; therefore, these children may still be behind their peers developmentally despite making considerable progress. Nevertheless, the children were selected because they were below the expected levels of development, and within this context, the progress made by the majority is notable. An exception was boys with EAL who made the least progress, suggesting that they require additional, intensive, and tailored support to catch up with their peers and reduce inequalities in educational attainment as much as possible.

Previous Research and Theory

Children with EAL have been found to have lower levels of vocabulary and comprehension [15,16], potentially putting them at a disadvantage both in the short and long term. The data presented here show that children with EAL made less progress than their English-speaking peers, and boys with EAL made less progress than girls with EAL. Significantly, girls with EAL are making expected progress (2 stages) in each domain after the intervention, whereas boys with EAL are yet to reach this milestone. Nevertheless, they may have made considerable progress given their ability at a given time, and they may catch up more over a longer intervention period.

Although gender differences in educational attainment become apparent as children progress through secondary school and are most pronounced in the university years [22], monitoring of EYOs shows that girls continue to perform better than boys in all early years key areas (76.5% of girls reached the expected levels in all ELGs versus 61.8% of boys) [49]. Our data show that girls outperform boys to varying degrees depending on the EYO domain; however, certain groups of boys are making expected or good progress in some areas. Of note are the boys in Funded 2 childcare places, who outperformed nonfunded boys in listening, understanding, and managing feelings and behavior, and were close to the progress made overall by the girls.

We know that children from lower-income families are at a disadvantage in terms of vocabulary and that the command of vocabulary is a key predictor of educational attainment [5]. The word gap, when compared with professional parents, is particularly stark [6]. Of course, factors such as EAL, gender, and deprivation are not mutually exclusive and children in this study will fall into multiple categories, such as having EAL and low income; therefore, potential risk factors may intersect and further hamper development.

Recent UK data show that over a quarter (28%) of 4- and 5-year-old children lack early communication skills [49]. Arguably, the children participating in the evaluation of S4LT reflect the 28% who are making less-than-expected progress and who may be given the opportunity to make significant advances toward expected progress when such targeted support is given. We acknowledge that there is emerging evidence showing the benefit of interventions for children in need of support with speech, language, and communication [1]. Recent guidance on preparing children for literacy recommends prioritizing the development of communication and language, emphasizing the vital role that adults play in helping children to extend their vocabulary as well as instilling self-regulation [29].

Conclusions

The findings from this evaluation suggest that S4LT is a tangible, effective approach to help children to catch up with their peers at a crucial stage in development and help them to become school ready by improving their command of language and communication as well as learning social skills. Our analysis also highlights specific groups of children who are not responding as well as expected, namely boys with EAL, and who require additional, tailored support.

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Authors' Contributions

RD led the evaluation design, data collection, analysis, and writing of the manuscript. GR was the principal investigator and adviser and contributed to writing the manuscript. Both authors have read and approved the manuscript.

Conflicts of Interest

None declared.

References

1. Law J, Lee W, Roulstone S, Wren Y, Zeng B, Lindsay G. Digital Education Resource Archive (DERA). 2010. "What Works': Interventions for Children and Young People With Speech, Language and Communication Needs URL: http://dera.ioe.ac.uk/id/eprint/16323 [accessed 2020-05-05]
2. Law J, Garrett Z, Nye C. Speech and language therapy interventions for children with primary speech and language delay or disorder. Cochrane Database Syst Rev 2003(3):CD004110. [doi: 10.1002/14651858.CD004110] [Medline: 12918003]
3. Carneiro PM, Heckman JJ. (SSRN) Papers. 2003. Human Capital Policy URL: https://ssrn.com/abstract=434544 [accessed 2020-04-03]
4. Government of UK. Childcare You Can Get Help Paying for URL: https://www.gov.uk/help-with-childcare-costs/free-childcare-2-year-olds-benefits [accessed 2020-04-03]
5. Hoff E. How social contexts support and shape language development. Dev Rev 2006 Mar;26(1):55-88. [doi: 10.1016/j.dr.2005.11.002]
6. Hart B, Risley T. Meaningful Differences in the Everyday Experience of Young American Children. Maryland, USA: Brookes Publishing; 1995.
7. Huttenlocher J, Vasilyeva M, Cymerman E, Levine S. Language input and child syntax. Cogn Psychol 2002 Nov;45(3):337-374. [doi: 10.1016/S0010-0285(02)00500-5]
8. Nelson KE, Camarata SM, Welsh J, Butkovsky L, Camarata M. Effects of imitative and conversational recasting treatment on the acquisition of grammar in children with specific language impairment and younger language-normal children. J Speech Hear Res 1996 Aug;39(4):850-859. [doi: 10.1044/jshr.3904.850] [Medline: 8844564]
9. Clark EV. The Lexicon in Acquisition. Volume 65. Cambridge, USA: Cambridge University Press; 1995.
10. Carr L, Johnston J. Morphological cues to verb meaning. Appl Psycholinguist 2002 Jul 11;22(4):601-618. [doi: 10.1017/s0142716401004064]
11. Blanden J. 'Bucking the Trend': What Enables Those who are Disadvantaged in Childhood to Succeed Later in Life?. London, UK: Department of Work and Pensions; 2006.
12. Feinstein L. Inequality in the early cognitive development of British children in the 1970 cohort. Economica 2003 Feb;70(277):73-97. [doi: 10.1111/1468-0335.t01-1-00272]
13. Waldfogel J, Washbrook EV. Explore Bristol Research. 2010. Low Income and Early Cognitive Development in the UK: A Report for the Sutton Trust URL: https://research-information.bris.ac.uk/en/publications/low-income-and-early-cognitive-development-in-the-uk(5e2b25b5-9ec8-4aaf-8ee7-fbe3a51b0d6e)/export.html [accessed 2020-05-05]
14. Washbrook E, Waldfogel J. Social Care Online: Standard Search. 2010. Cognitive Gaps in the Early Years: a Summary of Findings From the Report 'low Income and Early Cognitive Development in the UK' URL: https://www.scie-socialcareonline.org.uk/cognitive-gaps-in-the-early-years-a-summary-of-findings-from-the-report-low-income-and-early-cognitive-development-in-the-uk/r/a11G00000017wWsIAI [accessed 2020-05-05]
15. Hutchinson JM, Whiteley HE, Smith CD, Connors L. The developmental progression of comprehension-related skills in children learning EAL. J Res Read 2003 Feb;26(1):19-32. [doi: 10.1111/1467-9817.261003]
16. Burgoyne K, Kelly JM, Whiteley HE, Spooner A. The comprehension skills of children learning english as an additional language. Br J Educ Psychol 2009 Dec;79(Pt 4):735-747. [doi: 10.1348/000709909X422530] [Medline: 19288977]
17. Burgoyne K, Whiteley HE, Hutchinson JM. The development of comprehension and reading-related skills in children learning english as an additional language and their monolingual, English-speaking peers. Br J Educ Psychol 2011 Jun;81(Pt 2):344-354. [doi: 10.1348/000709910X504122] [Medline: 21542823]

18. Burgoyne K, Whiteley HE, Hutchinson JM. The role of background knowledge in text comprehension for children learning English as an additional language. J Res Read 2011 May 17;36(2):132-148. [doi: 10.1111/j.1467-9817.2011.01493.x]
19. Hoff E, Core C, Place S, Rumiche R, Señor M, Parra M. Dual language exposure and early bilingual development. J Child Lang 2012 Jan;39(1):1-27 [FREE Full text] [doi: 10.1017/S0305000910000759] [Medline: 21418730]
20. Hyde JS, Linn MC. Gender differences in verbal ability: a meta-analysis. Psychol Bull 1988;104(1):53-69. [doi: 10.1037/0033-2909.104.1.53]
21. Acredolo L, Goodwyn S. Symbolic gesturing in normal infants. Child Dev 1988 Apr;59(2):450-466. [doi: 10.2307/1130324] [Medline: 2452052]
22. Hillman N, Robinson N. HEPI: Higher Education Policy Institute. 2016. Boys to Men: The Underachievement Of Young Men in Higher Education – And How To Start Tackling It URL: https://www.hepi.ac.uk/wp-content/uploads/2016/05/Boys-to-Men.pdf [accessed 2020-05-05]
23. Clarke AM, Morreale S, Field CA, Hussein Y, Barry MM. Assets: Government of UK Developer Documentation. 2015. What Works in Enhancing Social and Emotional Skills Development During Childhood and Adolescence?: A Review of the Evidence on the Effectiveness of School-based And Out-of-school Programmes in the UK URL: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/411492/What_works_in_enhancing_social_and_emotional_skills_development_during_childhood_and_adolescence.pdf [accessed 2020-05-05]
24. Mental Health Foundation. URL: https://www.mentalhealth.org.uk/ [accessed 2020-05-05]
25. Vallotton C. Signs of emotion: what can preverbal children 'say' about internal states? Infant Ment Health J 2008 May 13;29(3):234-258 [FREE Full text] [doi: 10.1002/imhj.20175] [Medline: 19750136]
26. Goodman A, Joshi H, Nasim B, Tyler C. Early Intervention Foundation. 2015. Social and Emotional Skills in Childhood and Their Long-term Effects on Adult Life URL: https://www.eif.org.uk/report/social-and-emotional-skills-in-childhood-and-their-long-term-effects-on-adult-life [accessed 2020-05-05]
27. Goodman A, Joyce R, Smith JP. The long shadow cast by childhood physical and mental problems on adult life. Proc Natl Acad Sci U S A 2011 Apr 12;108(15):6032-6037 [FREE Full text] [doi: 10.1073/pnas.1016970108] [Medline: 21444801]
28. Nix RL, Bierman KL, Domitrovich CE, Gill S. Promoting children's social-emotional skills in preschool can enhance academic and behavioral functioning in kindergarten: findings from head start REDI. Early Educ Dev 2013;24(7):1000 [FREE Full text] [doi: 10.1080/10409289.2013.825565] [Medline: 24311939]
29. Education Endowment Foundation. Digital Education Resource Archive (DERA). 2018. Preparing for Literacy: Improving Communication, Language and Literacy in the Early Years URL: https://dera.ioe.ac.uk//31819/ [accessed 2020-05-05]
30. Vigliocco G, Perniss P, Vinson D. Language as a multimodal phenomenon: implications for language learning, processing and evolution. Philos Trans R Soc Lond B Biol Sci 2014 Sep 19;369(1651):20130292 [FREE Full text] [doi: 10.1098/rstb.2013.0292] [Medline: 25092660]
31. Iverson JM. Developing language in a developing body: the relationship between motor development and language development. J Child Lang 2010 Mar;37(2):229-261 [FREE Full text] [doi: 10.1017/S0305000909990432] [Medline: 20096145]
32. Felzer L. A multisensory reading program that really works. Teach Change 1998;5(2):169-183 [FREE Full text]
33. Cook SW, Goldin-Meadow S. The role of gesture in learning: do children use their hands to change their minds? J Cogn Dev 2006 Apr;7(2):211-232. [doi: 10.1207/s15327647jcd0702_4]
34. Daniels M. ERIC. 1995. Seeing language: the effect of sign language on vocabulary development in young hearing children URL: https://eric.ed.gov/?id=ED392103 [accessed 2020-05-05]
35. Daniels M. Happy hands: the effect of ASL on hearing children's literacy. Read Res Instr 2004 Sep;44(1):86-100. [doi: 10.1080/19388070409558422]
36. Rowe ML, Goldin-Meadow S. Early gesture selectively predicts later language learning. Dev Sci 2009 Jan;12(1):182-187 [FREE Full text] [doi: 10.1111/j.1467-7687.2008.00764.x] [Medline: 19120426]
37. Kelly SD, McDevitt T, Esch M. Brief training with co-speech gesture lends a hand to word learning in a foreign language. Lang Cognitive Proc 2009 Feb;24(2):313-334. [doi: 10.1080/01690960802365567]
38. Xu J, Gannon PJ, Emmorey K, Smith JF, Braun AR. Symbolic gestures and spoken language are processed by a common neural system. Proc Natl Acad Sci U S A 2009 Dec 8;106(49):20664-20669 [FREE Full text] [doi: 10.1073/pnas.0909197106] [Medline: 19923436]
39. Sign 4 Learning. 2014. URL: http://www.sign4learning.co.uk/ [accessed 2020-05-05]
40. Davidson R, Randhawa G. ISRCTN Registry. 2018. Improving Speech, Language and Communication in Pre-school Children: Implementation and Effectiveness of the Sign 4 Programme, Luton, UK URL: http://www.isrctn.com/ISRCTN42025531 [accessed 2020-04-03]
41. Davidson R, Randhawa G. Bridging the gap with sign language? Evaluation of the sign 4 big feelings programme for pre-school children. under review 2020 under review.
42. Davidson R, Randhawa G. ISRCTN Registry. 2018. Steps to Evaluation: How to Set Up an Evaluation With External Organisations URL: http://www.isrctn.com/ISRCTN26468622 [accessed 2020-04-03]

43. Davidson R, Randhawa G, Cash S. Identification of complex health interventions suitable for evaluation: development and validation of the 8-step scoping framework. JMIR Res Protoc 2019 Mar 5;8(3):e10075 [FREE Full text] [doi: 10.2196/10075] [Medline: 30835240]
44. Davidson R, Randhwa G. ISRCTN Registry. 2018. Reducing Obesity in Pre-school Children: Implementation and Effectiveness of the HENRY Programme, Luton, UK URL: http://www.isrctn.com/ISRCTN62454430 [accessed 2020-04-03]
45. Davidson R, Randhwa G. ISRCTN Registry. 2018. Reduction and Prevention of Aggression and Behavioural Problems in Disadvantaged Pre-School Children: Implementation and Effectiveness of the Incredible Years Programme, Luton, UK URL: http://www.isrctn.com/ISRCTN14311503 [accessed 2020-04-03]
46. Durand M. The OECD better life initiative: and the measurement of well-being. Rev Income Wealth 2014 Nov 25;61(1):4-17. [doi: 10.1111/roiw.12156]
47. Park N. The role of subjective well-being in positive youth development. Ann Am Acad Pol Soc Sci 2016 Sep 8;591(1):25-39. [doi: 10.1177/0002716203260078]
48. Laevers F. Kind en Gezin. 2005. Well-Being and Involvement in Care Settings. A Process-oriented Self-Evaluation Instrument (SIC's) URL: https://www.kindengezin.be/img/sics-ziko-manual.pdf [accessed 2020-05-05]
49. Government of UK. 2017. Early Years Foundation Stage Profile Results: 2017 to 2018 URL: https://www.gov.uk/government/statistics/early-years-foundation-stage-profile-results-2017-to-2018 [accessed 2020-05-05]

Abbreviations

EAL: English as an additional language
ELG: early learning goal
EYO: early years outcome
S4LT: Sign 4 Little Talkers
SES: socioeconomic status

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