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## Contents

### Original Papers

|   |    |
|---|----|
| 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 ( <a href="#">e13552</a> )<br>Christine Chambers, Justine Dol, Jennifer Parker, Line Caes, Kathryn Birnie, Anna Taddio, Marsha Campbell-Yeo, Scott Halperin, Jennifer Langille. .... | 3  |
| Hidden Communities of Practice in Social Media Groups: Mixed Methods Study ( <a href="#">e14355</a> )<br>Kara Skelton, Retta Evans, Jenna LaChenaye. ....   | 14 |
| Web-Based Technology to Improve Disease Knowledge Among Adolescents With Sickle Cell Disease: Pilot Study ( <a href="#">e15093</a> )<br>Anjelica Saulsberry, Jason Hodges, Audrey Cole, Jerlym Porter, Jane Hankins. ....   | 26 |
| Quality of Pregnancy Dating and Obstetric Interventions During Labor: Retrospective Database Analysis ( <a href="#">e14109</a> )<br>Zilma Reis, Juliano Gaspar, Gabriela Vitral, Vitor Abrantes, Ingrid de-Souza, Maria Moreira, Regina Lopes Pessoa Aguiar. ....   | 35 |
| A Web-Based Intervention for Youth With Physical Disabilities: Comparing the Role of Mentors in 12- and 4-Week Formats ( <a href="#">e15813</a> )<br>Sally Lindsay, Elaine Cagliostro. ....   | 44 |
| College Student Problematic Internet Use and Digital Communication Medium Used With Parents: Cross-Sectional Study ( <a href="#">e17165</a> )<br>Bradley Kerr, Jon D’Angelo, Ali Diaz-Caballero, Megan Moreno. ....   | 56 |
| Association of Social Media Use and High-Risk Behaviors in Adolescents: Cross-Sectional Study ( <a href="#">e18043</a> )<br>Teresa Vente, Mary Daley, Elizabeth Killmeyer, Laura Grubb. ....  | 63 |
| Perspectives of Nurses and Doulas on the Use of Information and Communication Technology in Intercultural Pediatric Care: Qualitative Pilot Study ( <a href="#">e16545</a> )<br>Nataliya Berbyuk Lindström, Rocio Rodríguez Pozo. ....  | 73 |
| Families’ Degree of Satisfaction With Pediatric Telehomecare: Interventional Prospective Pilot Study in Catalonia ( <a href="#">e17517</a> )<br>Francesc López Seguí, Astrid Battle Boada, Juan García García, Ana López Ulldemolins, Ane Achotegui del Arco, Cristina Adroher Mas, Francesc García Cuyàs. ....   | 82 |
| Using Digital Media to Empower Adolescents in Smoking Prevention: Mixed Methods Study ( <a href="#">e13031</a> )<br>Eunhee Park, Yu-Ping Chang. ....  | 90 |

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|   |     |
|---|-----|
| Using Social Media and Technology to Communicate in Pediatric HIV Research: Qualitative Study With Young Adults Living With or Exposed to Perinatal HIV ( <a href="#">e20712</a> )  |     |
| Claire Berman, Deborah Kacanek, Mindy Nichamin, Dominique Wilson, Mariam Davtyan, Liz Salomon, Kunjal Patel, Megan Reznick, Katherine Tassiopoulos, Sonia Lee, Jose Bauermeister, Mary Paul, Theresa Aldape, George Seage III. .... | 99  |
| An App for Identifying Children at Risk for Developmental Problems Using Multidimensional Computerized Adaptive Testing: Development and Usability Study ( <a href="#">e14632</a> )   |     |
| Chen-Fang Hsu, Tsair-Wei Chien, Julie Chow, Yu-Tsen Yeh, Willy Chou. ....   | 118 |
| The Sign 4 Little Talkers Intervention to Improve Listening, Understanding, Speaking, and Behavior in Hearing Preschool Children: Outcome Evaluation ( <a href="#">e15348</a> )   |     |
| Rosemary Davidson, Gurch Randhawa. ....   | 128 |

## Viewpoint

|  |     |
|--|-----|
| Digital Approaches to Remote Pediatric Health Care Delivery During the COVID-19 Pandemic: Existing Evidence and a Call for Further Research ( <a href="#">e20049</a> ) |     |
| Sherif Badawy, Ana Radovic. ....   | 109 |

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.

**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].

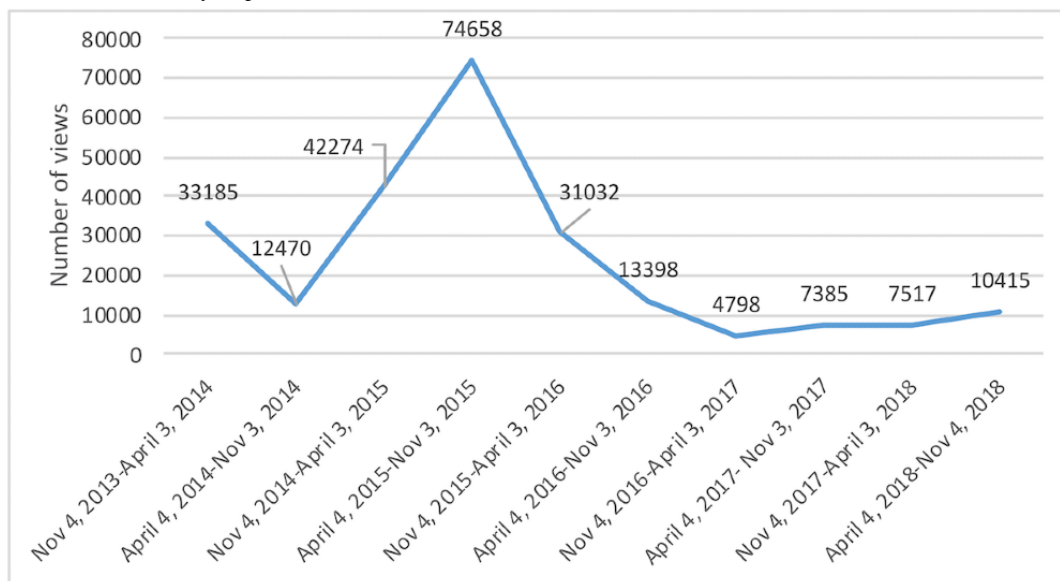
## Results

### 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 phrases 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 <sup>a</sup> (n=278), n (%) |
|---|------------------------|----------------------------------|
| <b>Children<sup>b</sup></b>                 |                        |                                  |
| Baby (newborn to 12 months)                 | 22 (9.2)               | — <sup>c</sup>                   |
| 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)               | —                                |
| <b>HCP occupation</b>                       |                        |                                  |
| 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)                        |
| <b>Location<sup>d</sup></b>                 |                        |                                  |
| Canada                                      | 118 (72.4)             | 128 (46.0)                       |
| The United States                           | 34 (20.9)              | 124 (44.6)                       |
| Other                                       | 11 (6.7)               | 26 (9.4)                         |
| <b>Age<sup>d</sup> (years)</b>              |                        |                                  |
| 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)                         |
| <b>Sex<sup>d</sup></b>                      |                        |                                  |
| Woman                                       | 142 (87.1)             | 240 (86.3)                       |
| Man   | 17 (10.4)              | 33 (11.9)                        |

<sup>a</sup>HCP: health care professional.

<sup>b</sup>Parents could select more than 1 age group.

<sup>c</sup>Not applicable/no response.

<sup>d</sup>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) <sup>a</sup> |
|---|----------------------------------|
| <b>Parents (n=163)</b>  |                                  |
| 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)                      |
| <b>Health care professionals (n=278)</b>                      |                                  |
| 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)                      |

<sup>a</sup>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            |
|---|-------------|---------------|---------------|--------------------|
| <b>Parents (n=163)</b>                  |             |               |               |                    |
| Deep breathing or bubbles               | 25 (14.7)   | 89 (54.6)     | 39.9          | <.001 <sup>a</sup> |
| Distraction                             | 108 (66.3)  | 126 (77.6)    | 11.3          | .04                |
| Topical anesthetic cream                | 31 (19.0)   | 102 (62.6)    | 43.6          | <.001 <sup>a</sup> |
| <b>Health care professionals (n=78)</b> |             |               |               |                    |
| Deep breathing or bubbles               | 165 (59.4)  | 242 (87.1)    | 27.7          | <.001 <sup>a</sup> |
| Distraction                             | 230 (82.7)  | 245 (88.1)    | 5.4           | <.05 <sup>a</sup>  |
| Topical anesthetic cream                | 171 (61.5)  | 213 (76.6)    | 15.1          | <.001 <sup>a</sup> |

<sup>a</sup>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\*](#)]

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## 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 led 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 woman'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).

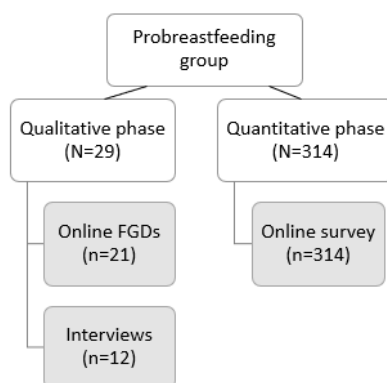
### Setting and Sample

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 mid-sized 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 <sup>a</sup> 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                    |

<sup>a</sup>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.

|  |
|--|
| <p>Problem solving</p> <ul style="list-style-type: none"><li>• “Any tips for a very sore and cracking nipple situation? It hurts so bad to latch”</li></ul> <p>Requests for information</p> <ul style="list-style-type: none"><li>• “When baby is on solid foods 3x a day, how much breast milk should he be getting?”</li></ul> <p>Seeking experience</p> <ul style="list-style-type: none"><li>• “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?”</li></ul> <p>Reusing assets</p> <ul style="list-style-type: none"><li>• “We love the MommyMeds app from the Infant Risk Center- download it!”</li></ul> <p>Coordination and synergy</p> <ul style="list-style-type: none"><li>• “We will be teaming up with Babywearing International of for a baby wearing meet-up!!!”</li></ul> <p>Mapping knowledge and identifying gaps</p> <ul style="list-style-type: none"><li>• “I know occasionally we have mamas post they are stranded without their pump or certain parts. What if we had ‘pumping stations’ around town?”</li></ul> |
|--|

## 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) |
| <b>Race, n (%)</b>  |               |
| African American  | 4 (1.3)       |
| American Indian or Alaskan Native                         | 2 (0.6)       |
| White   | 300 (95.5)    |
| Other   | 8 (2.5)       |
| <b>Marital status, n (%)</b>                              |               |
| Single, never married                                     | 7 (2.2)       |
| Married   | 284 (90.4)    |
| In a monogamous relationship                              | 23 (7.3)      |
| <b>Education, n (%)</b>                                   |               |
| 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)      |
| <b>Working status, n (%)</b>                              |               |
| 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)    |
| <b>Interaction with social media group, n (%)</b>         |               |
| 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 assess 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 (%) <sup>a</sup> | 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 <sup>b</sup> |
| 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/advice 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)      |

<sup>a</sup>n is reported as the number of women who agreed or strongly agreed with the statement.

<sup>b</sup>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**

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## 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  $\geq 3$  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

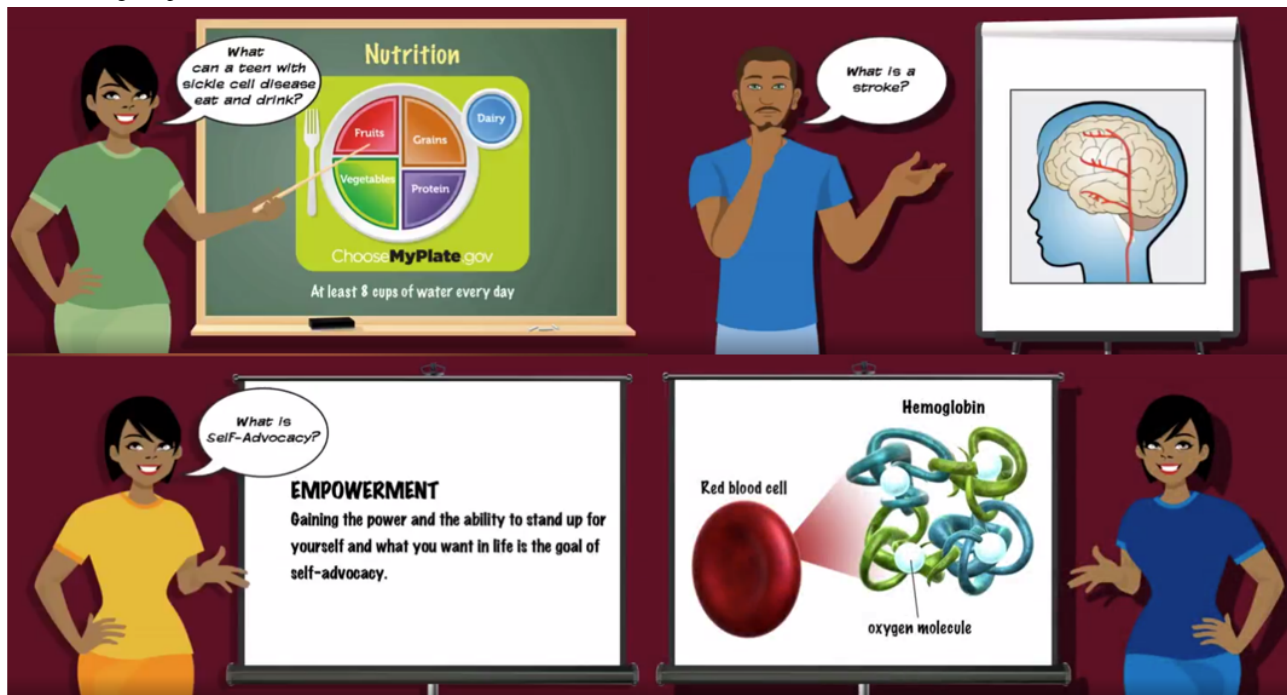
### Participant Selection

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 HbS $\beta$ <sup>0</sup> 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  |
|--|-------------|
| <b>Sex, n (%)</b>  |             |
| Male   | 33 (62)     |
| Female   | 20 (38)     |
| <b>Genotype, n (%)</b>   |             |
| HbSS/ HbS $\beta^0$ thalassemia                                    | 35 (66)     |
| HbSC/HbS $\beta^+$ thalassemia                                     | 18 (34)     |
| Race (African American), n (%)                                     | 53 (100)    |
| Ethnicity (non-Hispanic), n (%)                                    | 53 (100)    |
| <b>Sickle Cell Transition E-Learning Program modules completed</b> |             |
| Mean (SD)  | 2.79 (1.08) |
| Median (range)   | 3.00 (1-6)  |
| <b>Grouping of modules completed, n (%)</b>                        |             |
| 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 ( $P=.945$ ).

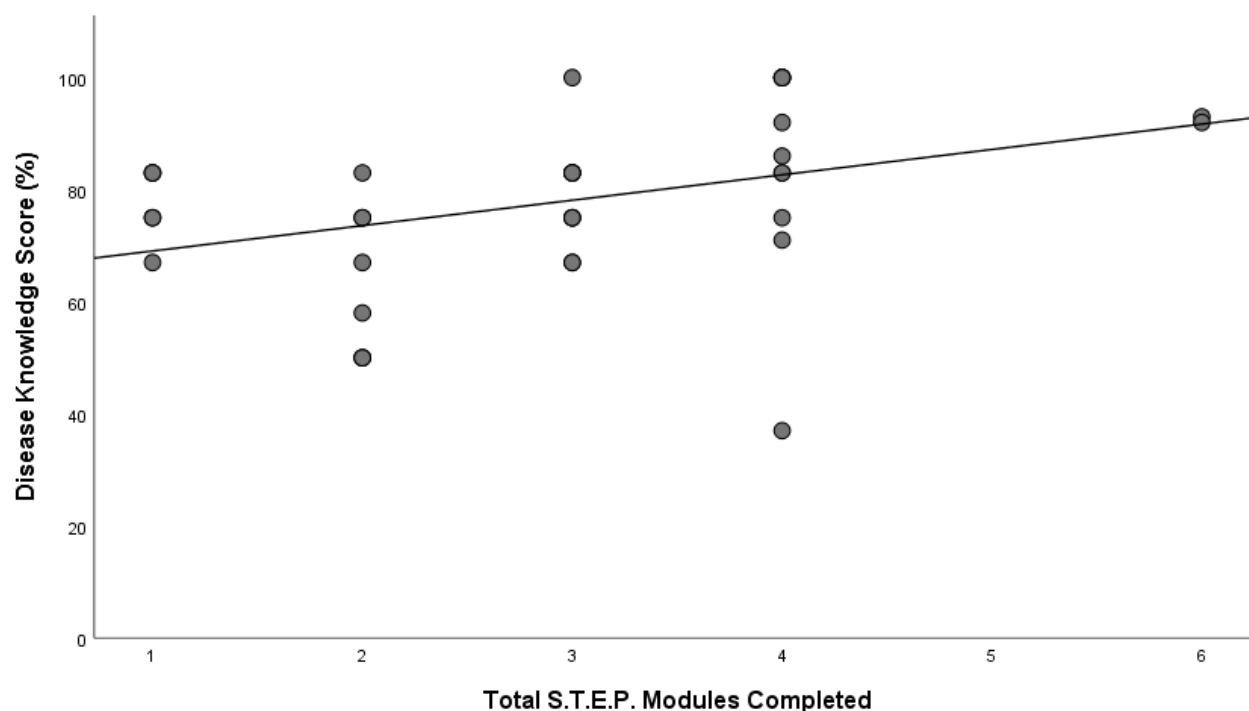
The median disease knowledge score was significantly higher among participants who completed  $\geq 3$  STEP modules (82.7 [SD 14.68]) compared with those who completed  $\leq 2$  modules (69.57 [SD 12.82];  $U=149.0$ ;  $P=.007$ ). Furthermore, a positive correlation ( $r=0.502$ ) was found between 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        |
|--|---------------|
| <b>Age at first STEP<sup>a</sup> module (years)</b>  |               |
| Mean (SD)  | 14.07 (1.27)  |
| Median (range)   | 14.19 (12-15) |
| <b>Disease knowledge score</b>   |               |
| STEP participants with score, n  | 37            |
| Mean (SD)  | 77.53 (14.69) |
| Median (range)   | 79 (37-100)   |
| <b>Age at disease knowledge score (years)</b>  |               |
| Mean (SD)  | 16.0 (0.263)  |
| Median (range)   | 16 (15-17)    |
| <b>Self-management confidence score</b>  |               |
| STEP participants with score, n  | 39            |
| Mean (SD)  | 8.05 (1.58)   |
| Median (range)   | 8 (5-10)      |
| <b>Age at self-management confidence score (years)</b>   |               |
| Mean (SD)  | 15.18 (0.756) |
| Median (range)   | 15 (13-17)    |
| <b>Time between administration of disease knowledge and self-management assessments (months)</b> |               |
| Mean (SD)  | 11.5 (7.34)   |
| Median (range)   | 12 (5-38)     |

<sup>a</sup>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](#) ]

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## 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  $\pm 5$  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  $\geq 20$  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  $\geq 20$  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  $\pm 5$  to 7 days [1]. Despite a  $\pm 10$ -day margin of error, GA determined by ultrasound assessments  $\geq 14$  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.

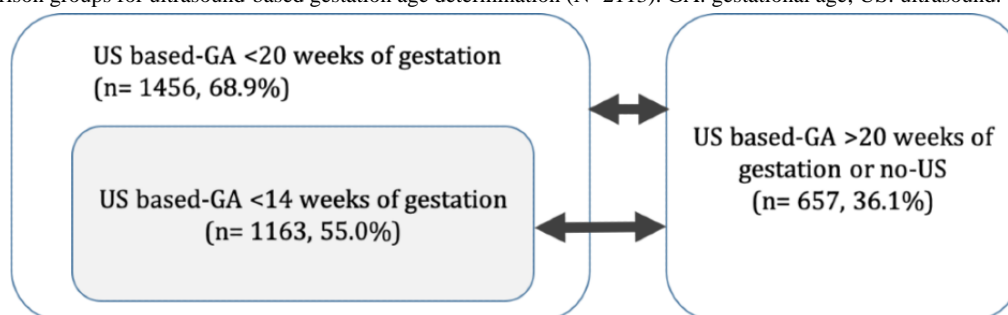
**Methods****Study Design**

This hospital-based cohort study retrospectively evaluated the quality of pregnancy dating and obstetric information in a computerized medical database, SIS Mater, 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  $\geq 20$  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.

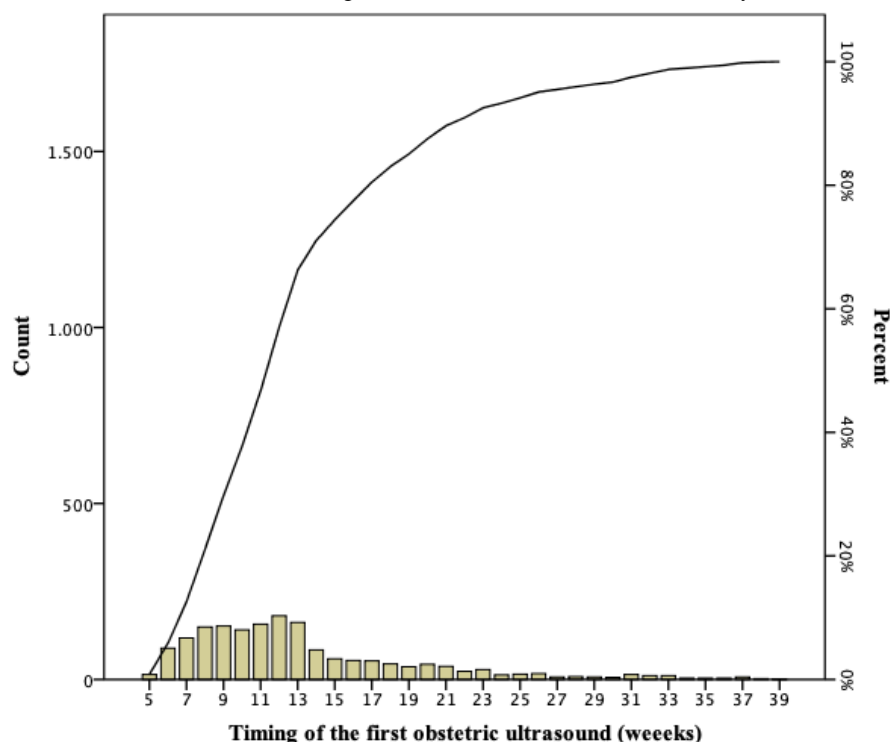
### Statistics

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 <sup>a</sup> , 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 <sup>b</sup> , n/N (%)                    | 219/2030 (10.79)       | 9.5-12.2      |
| NICU <sup>c</sup> admissions, n/N (%)                            | 382/2030 (18.82)       | 17.1-20.4     |
| NICU admissions <sup>d</sup> , n/N (%)                           | 271/1885 (14.38)       | 13.3-16.3     |
| Fetal or newborn mortality <sup>e</sup> , n/N (%)                | 136/2113 (6.44)        | 5.4-7.6       |
| Fetal or newborn mortality <sup>d,e</sup> , n/N (%)              | 71/1885 (3.77)         | 2.9-4.7       |

<sup>a</sup>Undetermined sex: 8 (0.4%).

<sup>b</sup>Received at least one step of neonatal resuscitation [13].

<sup>c</sup>NICU: neonatal intensive care unit.

<sup>d</sup>Excluding major malformations.

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

<sup>a</sup>PD: pregnancy dating.

<sup>b</sup>US: ultrasound.

<sup>c</sup>Ultrasound done  $\geq 20$  weeks of gestation or not done at all.

<sup>d</sup>Comparison between ultrasound dating <14 weeks and suboptimal dating.

<sup>e</sup>Comparison between ultrasound dating <20 weeks and suboptimal dating.

<sup>f</sup>Chi-square test used.

<sup>g</sup>ICU: intensive care unit.

<sup>h</sup>Mann-Whitney test used.

<sup>i</sup>At least one step of neonatal resuscitation [14].

<sup>j</sup>Excluding major malformations.

<sup>k</sup>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 <sup>a</sup> with US <sup>b</sup> <14 weeks (N=1163), n (%) | PD with US<20 weeks (N=1456), n (%) | Suboptimal PD <sup>c</sup> (N=657), n (%) | <14 weeks vs suboptimal dating, OR <sup>d</sup> (95% CI) | <i>P</i> value <sup>e</sup> | <20 weeks vs suboptimal dating, OR (95% CI) | <i>P</i> value <sup>e</sup> |
|-------------------------------------|--|-------------------------------------|---|--|-----------------------------|---|-----------------------------|
| 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                         |

<sup>a</sup>PD: pregnancy dating.

<sup>b</sup>US: ultrasound.

<sup>c</sup>Ultrasound done  $\geq 20$  weeks of gestation or not done at all.

<sup>d</sup>OR: odds ratio.

<sup>e</sup>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](#) ]

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**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)     |
| <b>Sex, n (%)</b>                             |                |                |               |
| Male  | 4 (44)         | 6 (40)         | 2 (67)        |
| Female  | 5 (56)         | 9 (60)         | 1 (33)        |
| <b>Disability type, n (%)</b>                 |                |                |               |
| 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)        |
| <b>Group, n (%)</b>                           |                |                |               |
| 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) | <i>t</i> test (df) | <i>P</i> 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.

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## 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](#) ]

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## 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.

**Table 1.** Participant demographics.

| Characteristic          | Value, n (%) |
|-------------------------|--------------|
| <b>Gender</b>           |              |
| Female                  | 90 (59.6)    |
| Male                    | 61 (40.4)    |
| <b>University</b>       |              |
| Midwestern              | 94 (62.3)    |
| Northwestern            | 57 (37.7)    |
| <b>Race/ethnicity</b>   |              |
| 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)      |

### **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.

## 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.

**Table 2.** Predictors of risk of problematic internet use.

| Characteristics                        | B      | SE B  | $\beta$ | <i>t</i> value | <i>P</i> 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

## 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.

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.

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## 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      |
|-------------------------------------|------------|
| <b>Gender, n (%)</b>                |            |
| Male                                | 58 (32.4)  |
| Female                              | 120 (67.0) |
| Other                               | 1 (0.6)    |
| Age in years, mean (SD)             | 16.8 (2.2) |
| <b>Grade level, n (%)</b>           |            |
| 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)  |
| <b>Average grades, n (%)</b>        |            |
| Mostly As                           | 46 (25.7)  |
| Mostly Bs                           | 90 (50.3)  |
| Mostly Cs                           | 25 (14.0)  |
| Mostly Ds                           | 0 (0)      |
| Missing                             | 18 (10.0)  |
| <b>Race/ethnicity, n (%)</b>        |            |
| 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)    |
| <b>Being bullied, n (%)</b>         |            |
| Yes                                 | 74 (41.3)  |
| No                                  | 103 (57.5) |
| Missing                             | 2 (1.1)    |
| <b>Parent marital status, n (%)</b> |            |
| 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 (%) |
|--------------------------|--------------|
| <b>Self-harm subtype</b> |              |
| Cutting                  | 17 (77)      |
| Burning                  | 3 (14)       |
| Scratching               | 10 (46)      |
| Hitting                  | 14 (64)      |
| Skin picking             | 7 (32)       |
| Other                    | 0 (0)        |
| <b>Frequency</b>         |              |
| 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 (%) |
|-------------------------|--------------|
| <b>Sexting subtype</b>  |              |
| 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)       |
| <b>Recipient</b>        |              |
| Classmates              | 11 (22)      |
| Boyfriend/girlfriend    | 34 (69)      |
| Other friends/neighbors | 10 (20)      |
| Online friends          | 4 (8)        |
| <b>Reason</b>           |              |
| 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) |
|---|------------------------|
| <b>Any social media use</b>                         |                        |
| 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)       |
| <b>Use of 4 or more social media applications</b>   |                        |
| 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)       |
| <b>&gt;5 hours of social media use per day</b>      |                        |
| 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.

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## 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 δούλα, 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

**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

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.

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](http://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](http://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.

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## Conflicts of Interest

None declared.

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## 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) |
|--|---------------|
| <b>Gender, n (%)</b>                     |               |
| Total                                    | 95 (100)      |
| Boy                                      | 53 (56)       |
| Girl                                     | 42 (44)       |
| Age (years), mean (SD)                   | 4.22 (4.57)   |
| <b>Source of referral, n (%)</b>         |               |
| Total                                    | 95 (100)      |
| Hospitalization                          | 85 (89)       |
| Outpatient visits                        | 8 (8)         |
| Emergencies                              | 2 (2)         |
| <b>Medical field, n (%)</b>              |               |
| 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) |
| <b>Main caregiver, n (%)</b>             |               |
| Total                                    | 95 (100)      |
| Mother                                   | 54 (57)       |
| Mother and father                        | 35 (37)       |
| Father                                   | 5 (5)         |
| Other                                    | 1 (1)         |
| <b>Type of intravenous line, n (%)</b>   |               |
| Total                                    | 48 (100)      |
| Peripheral route                         | 44 (92)       |
| Peripherally inserted central catheter   | 2 (4)         |
| Broviac                                  | 1 (2)         |
| Midline                                  | 1 (2)         |
| <b>Schedule of administration, n (%)</b> |               |
| 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 (%) |
|--|----------------------------|
| <b>How many days passed since your child was discharged from hospital until their first visit home?</b>                                      |                            |
| Total  | 64 (100)                   |
| Between 1 and 3 days   | 15 (23)                    |
| Less than 1 day  | 49 (77)                    |
| <b>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?</b>             |                            |
| Total  | 65 (100)                   |
| Yes  | 30 (46)                    |
| No   | 35 (54)                    |
| <b>If so, was the problem resolved quickly?</b>  |                            |
| Total  | 33 (100)                   |
| Yes  | 30 (91)                    |
| No   | 3 (9)                      |
| <b>Do you think that the pediatrician and the nurses worked in a coordinated way?</b>  |                            |
| Total  | 65 (100)                   |
| Yes  | 65 (100)                   |
| No   | 0 (0)                      |
| <b>Do you think that the staff spent enough time with your child and family during their home visits?</b>                                    |                            |
| Total  | 65 (100)                   |
| Yes  | 65 (100)                   |
| No   | 0 (0)                      |
| <b>How would you rate the way in which the staff has taken care of your child and family?</b>  |                            |
| Total  | 65 (100)                   |
| Excellent  | 60 (92)                    |
| Very good  | 5 (8)                      |
| <b>How would you rate the information provided to you by the home-hospitalization team during the home-based care?</b>                       |                            |
| Total  | 65 (100)                   |
| Excellent  | 54 (83)                    |
| Very good  | 11 (17)                    |
| <b>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?</b> |                            |
| Total  | 65 (100)                   |
| As expected  | 49 (75)                    |
| Less than expected   | 14 (22)                    |
| More than expected   | 2 (3)                      |
| <b>Would you have preferred conventional hospitalization instead of your child being at home?</b>  |                            |
| Total  | 65 (100)                   |
| Yes  | 2 (3)                      |
| No   | 61 (94)                    |
| I don't know   | 2 (3)                      |
| <b>If necessary, would you like your child to be taken care of by the home-based care team again?</b>  |                            |
| 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) |
|--|---------------|
| <b>How would you rate the software's accessibility? n (%)</b>  |               |
| Total  | 58 (100)      |
| Easy   | 47 (81)       |
| Neither easy nor difficult   | 3 (5)         |
| I did not access the program   | 8 (14)        |
| <b>Have you been able to easily take the vitals that you have been asked to take? n (%)</b>                                      |               |
| 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 <sup>a</sup> (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)   |

<sup>a</sup>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](#)]

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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  |
|----------------------------------|----------------------------------|-----------------------------------|---------|---|
| <b>Intrapersonal domain</b>      | — <sup>a</sup>                   | —                                 | —       | <ul style="list-style-type: none"> <li>• “Smoking makes your teeth get yellow.”</li> <li>• “I learned that smoking is bad for you.”</li> <li>• “I just learned that smoking is bad and it could hurt your lungs and could affect your voice.”</li> <li>• “Now I can actually tell people not to smoke.”</li> <li>• “I can help other people not to smoke.”</li> <li>• “I know not to smoke and to actually tell people not to smoke and stuff.”</li> <li>• “I liked that I got to talk to [my friend] for her not to smoke just like in the video.”</li> </ul>  |
| 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     | —   |
| <b>Interactional domain</b>      | —                                | —                                 | —       | <ul style="list-style-type: none"> <li>• “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.”</li> <li>• “We’re making videos that helps people to stop smoking.”</li> <li>• “I want to help and try to help any way I can though this program.”</li> </ul>   |
| Advocacy                         | 4.27 (2.91)                      | 5.17 (2.92)                       | .01     | —   |
| Assertiveness                    | 10.55 (1.50)                     | 13.60 (1.92)                      | .01     | —   |
| <b>Behavioral domain</b>         | —                                | —                                 | —       | <ul style="list-style-type: none"> <li>• “This program has influenced me not to smoke.”</li> <li>• “I am going to share this video to my friends and family, and some people who smoke.”</li> <li>• “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.”</li> <li>• “...everybody in the world. I want to put this up on the YouTube.”</li> <li>• “I like to do other videos too [about] substance use or drugs.”</li> <li>• “I do community service with my school.”</li> </ul> |
| Smoking intention                | 12.91 (3.42)                     | 14.70 (0.69)                      | .02     | —   |

<sup>a</sup>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.

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## Conflicts of Interest

None declared.

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Multimedia Appendix 1

Supplementary tables.

[DOCX File, 16 KB - [pediatrics\\_v3i1e13031\\_app1.docx](#) ]

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## 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 (%)   |
|----------------------------------|---------|
| <b>Gender</b>                    |         |
| Male                             | 14 (35) |
| Female                           | 26 (65) |
| Transgender                      | 0 (0)   |
| <b>Age (years)</b>               |         |
| 18 to 21                         | 35 (87) |
| 22 to 24                         | 5 (13)  |
| <b>Race</b>                      |         |
| 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) |
| <b>HIV status</b>                |         |
| PHIV <sup>a</sup>                | 33 (83) |
| PHEU <sup>b</sup>                | 7 (17)  |

<sup>a</sup>PHIV: perinatal HIV.

<sup>b</sup>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 <sup>a</sup> | 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) |

<sup>a</sup>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 <sup>a</sup> | Never   |
| <b>Texting</b>                            |                  |                |           |                      |         |
| Use in personal life <sup>b</sup>         | 26 (65)          | 4 (10)         | 0 (0)     | 5 (13)               | 5 (13)  |
| Preferred use with the study <sup>c</sup> | 9 (23)           | 9 (23)         | 1 (3)     | 1 (3)                | 20 (51) |
| <b>Email</b>                              |                  |                |           |                      |         |
| 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) |
| <b>Facebook</b>                           |                  |                |           |                      |         |
| 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) |
| <b>Twitter</b>                            |                  |                |           |                      |         |
| 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) |
| <b>Telephone call</b>                     |                  |                |           |                      |         |
| 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) |

<sup>a</sup>Any use: use is indicated but the frequency is not specified.

<sup>b</sup>Survey question: “How often do you and your friends use the following to communicate with each other?”

<sup>c</sup>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.

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## 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.

**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 (JITAs). 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 is 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](#)]

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## 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](#)).

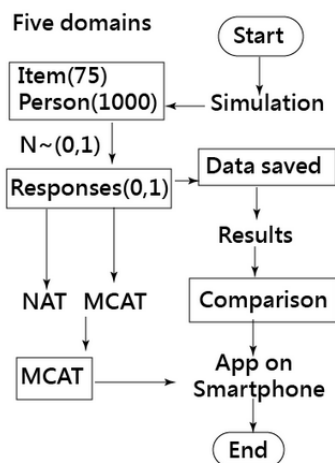
Based on the maximum reported range of the released item difficulties from  $-7.35$  to  $8.03$  [7], person measure true scores were set in the range of  $-8$  to  $8$  logits (log odds). Applying the study's cutoff points (mean  $-7.366$ , cognitive skills  $-4.85$ , language skills  $-7.44$ , gross 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  $1000 \times 75$  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:  $Prob_{ni} = \exp(\text{ability}_n - \text{difficulty}_i) / (1 + \exp[\text{ability}_n - \text{difficulty}_i])$ . If all item difficulties are known, all possible likelihood values can be obtained using the formula  $\prod p_{ni}$  (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,  $0.80 = [1SEM_{pi}^2] = 10.44^2$ , 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.

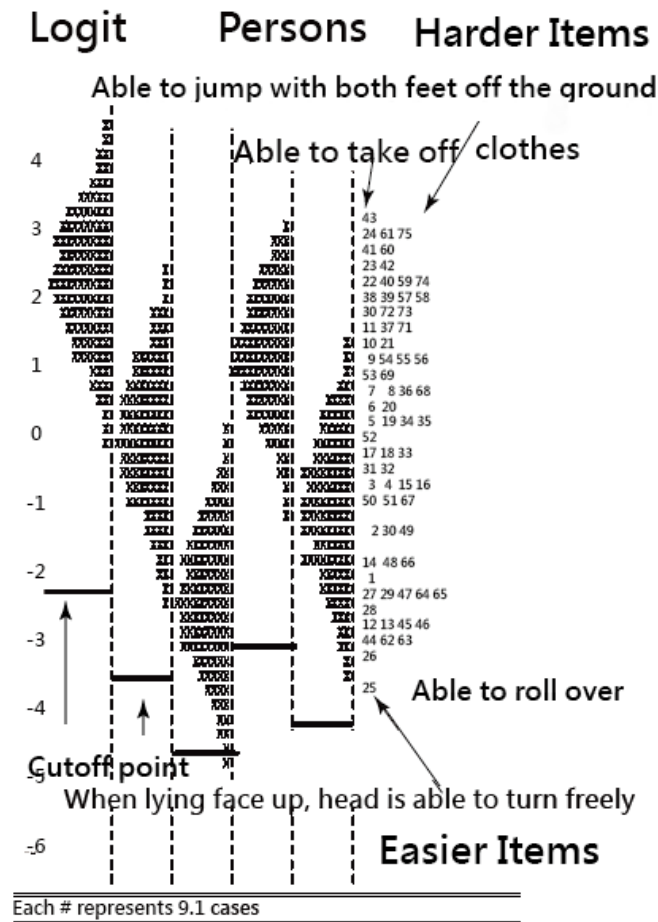


Table 1. Variance-covariance matrix (plus correlation matrix and reliability) for the five domains.<sup>a</sup>

| Category            | Cognitive | Language | Gross motor | Fine motor | Social |
|---------------------|-----------|----------|-------------|------------|--------|
| <b>Domain skill</b> |           |          |             |            |        |
| 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   |

<sup>a</sup>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 | <i>P</i> value |
|----------------------|-----------|----------|-------------|------------|--------|----------------|
| <b>Item length</b>   |           |          |             |            |        |                |
| NAT                  | 11        | 13       | 19          | 18         | 14     |                |
| CAT                  | 6         | 6        | 10          | 10         | 8      | .01            |
| <b>Skill ability</b> |           |          |             |            |        |                |
| 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

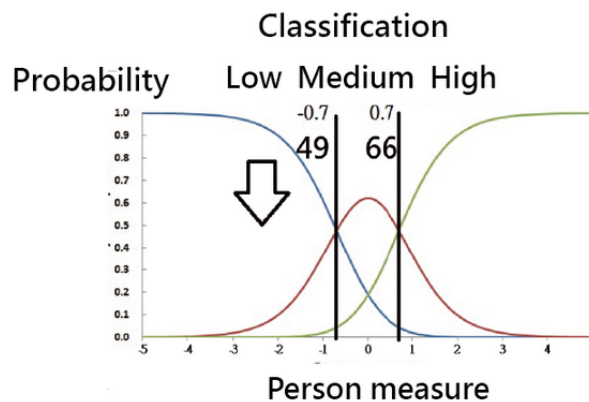
Scanning a Quick Response (QR) code (Figure 3) or downloading the app will cause the MuSiC developmental delay questionnaire to appear on the mobile phone. We developed an MCAT mobile survey procedure to demonstrate our newly designed MuSiC application in action. The assessment used

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 developmental 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.



## 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 ( $(\sum^2 \text{-score})/L=(\sum [\text{residual}/\text{standard deviation}]^2)/L$ , 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.

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### Conflicts of Interest

None declared.

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#### Multimedia Appendix 1

Data in MS Excel format.

[\[XLSX File \(Microsoft Excel File\), 24 KB - pediatrics\\_v3i1e14632\\_app1.xlsx \]](#)

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#### Multimedia Appendix 2

Link to online assessment for the MCAT video.

[\[DOCX File , 13 KB - pediatrics\\_v3i1e14632\\_app2.docx \]](#)

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#### Multimedia Appendix 3

Link to ConQuest.

[DOCX File , 13 KB - [pediatrics\\_v3i1e14632\\_app3.docx](#) ]

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## 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 or 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 <sup>a</sup> to ELGs <sup>b</sup> |
|---------------------|--|
| 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                                   |

<sup>a</sup>EYOs: early years outcomes.

<sup>b</sup>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 (%) |
|------------------------|---------------|
| <b>Gender</b>          |               |
| Male                   | 65 (54.6)     |
| Female                 | 44 (37.0)     |
| Unknown                | 10 (8.4)      |
| <b>EAL<sup>a</sup></b> |               |
| Yes                    | 40 (33.6)     |
| No                     | 78 (65.5)     |
| Unknown                | 1 (0.8)       |
| <b>Age (years)</b>     |               |
| 1-2                    | 3 (2.5)       |
| 2-3                    | 57 (47.9)     |
| 3-4                    | 49 (41.2)     |
| Unknown                | 10 (8.4)      |
| <b>Funded 2</b>        |               |
| Yes                    | 72 (60.5)     |
| No                     | 37 (31.1)     |
| Unknown                | 10 (8.4)      |

<sup>a</sup>EAL: English as an additional language.

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

| Variables                   | n   | EYO <sup>a</sup> 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 to 6.00                         | 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)  |

<sup>a</sup>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 |      |                | <i>t</i> test ( <i>df</i> ) | 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 <sup>a</sup> 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                         |

<sup>a</sup>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 <sup>a</sup> Spr2 List&Att | EYO Spr2 Under | EYO Spr2 Speak | EYO Spr2 Feel | Leuven Spr2 | Words Spr2 Under | Words Spr2 Say |
|---|------------------|--------------------------------|----------------|----------------|---------------|-------------|------------------|----------------|
| Pearson correlation, <i>r</i>                           | 1.00             | 0.49                           | 0.52           | 0.48           | 0.59          | -0.08       | 0.16             | 0.20           |
| Significance (two-tailed)                               | N/A <sup>b</sup> | 0.00                           | 0.00           | 0.00           | 0.00          | 0.60        | 0.09             | 0.03           |
| Number of participants, <i>n</i>                        | 109              | 109                            | 109            | 109            | 109           | 46          | 108              | 108            |
| <b>EYO spring (second term) listening and attention</b> |                  |                                |                |                |               |             |                  |                |
| Pearson correlation, <i>r</i>                           | 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, <i>N</i>                        | N/A              | 118                            | 118            | 118            | 118           | 46          | 108              | 108            |
| <b>EYO spring (second term) understanding</b>           |                  |                                |                |                |               |             |                  |                |
| Pearson correlation, <i>r</i>                           | 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, <i>N</i>                        | N/A              | N/A                            | 118            | 118            | 118           | 46          | 108              | 108            |
| <b>EYO spring (second term) speaking</b>                |                  |                                |                |                |               |             |                  |                |
| Pearson correlation, <i>r</i>                           | 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, <i>N</i>                        | N/A              | N/A                            | N/A            | 118            | 118           | 46          | 108              | 108            |
| <b>EYO spring (second term) feelings and behavior</b>   |                  |                                |                |                |               |             |                  |                |
| Pearson correlation, <i>r</i>                           | 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, <i>N</i>                        | N/A              | N/A                            | N/A            | N/A            | 118           | 46          | 108              | 108            |
| <b>Leuven well-being spring (second term)</b>           |                  |                                |                |                |               |             |                  |                |
| Pearson correlation, <i>r</i>                           | 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, <i>n</i>                        | N/A              | N/A                            | N/A            | N/A            | N/A           | 46          | 46               | 46             |
| <b>Words spring (second term) understood</b>            |                  |                                |                |                |               |             |                  |                |
| Pearson correlation, <i>r</i>                           | 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, <i>n</i>                        | N/A              | N/A                            | N/A            | N/A            | N/A           | N/A         | 108              | 108            |
| <b>Words spring (second term) spoken</b>                |                  |                                |                |                |               |             |                  |                |
| Pearson correlation, <i>r</i>                           | 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, <i>n</i>                        | N/A              | N/A                            | N/A            | N/A            | N/A           | N/A         | N/A              | 108            |

<sup>a</sup>EYO: early years outcome.

<sup>b</sup>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 <sup>a</sup> 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              |

<sup>a</sup>EYO: early years outcome.

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

| EYO <sup>a</sup> 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 <sup>b</sup> | 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       |

<sup>a</sup>EYO: early years outcome.

<sup>b</sup>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 <sup>a</sup> 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 |

<sup>a</sup>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 <sup>a</sup> 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 |

<sup>a</sup>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 |
| <b>Autumn</b> |                  |                   |     |          |      |                |
| Male          | N/A <sup>a</sup> | 5                 | 14  | 3        | 3    | 3.16 (0.89)    |
| Female        | 5                | 5                 | 6   | 4        | 1    | 2.57 (1.20)    |
| <b>Spring</b> |                  |                   |     |          |      |                |
| Male          | N/A              | N/A               | 4   | 15       | 6    | 4.12 (0.66)    |
| Female        | N/A              | 1                 | 4   | 12       | 4    | 3.90 (0.76)    |

<sup>a</sup>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.

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## 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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