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Original Paper

Feasibility and Acceptability of a Culturally Tailored Website to Increase Fruit and Vegetable Intake and Physical Activity Levels in African American Mother-Child Dyads: Observational Study

Alicia Chung¹, EdD, MPH; Barbara Wallace², PhD; Monica Stanton-Koko³, EdD, MPH; Azizi Seixas¹, PhD; Girardin Jean-Louis¹, PhD

¹New York University School of Medicine, New York, NY, United States

²Teachers College, Columbia University, New York, NY, United States

³Mercy College, Dobbs Ferry, NY, United States

Corresponding Author:

Alicia Chung, EdD, MPH

New York University School of Medicine

180 Madison Avenue

New York, NY, 10016

United States

Phone: 1 646 501 2608

Email: alicia.chung@nyumc.org

Abstract

Background: African American youth (aged 8-14 years) do not adhere to national dietary and physical activity guidelines. Nonadherence to these recommendations contributes to disproportionate rates of obesity compared with their white counterparts. Culturally tailored electronic health (eHealth) solutions are needed to communicate nutrition and physical activity messages that resonate with this target population.

Objective: This study aimed to identify the impact of exposure to a website hosting culturally tailored cartoons to inspire fruit and vegetable uptake and physical activity levels in African American mother-child dyads.

Methods: Statistical analysis included paired sample *t* tests to evaluate knowledge gains, self-efficacy, and readiness to change. Adapted items from Prochaska's Stages of Change toward the following 4 behaviors were assessed with pre- and posttest surveys: (1) fruit and vegetable selection on my plate, (2) meal preparation, (3) fruit and vegetable selection outside of home, and (4) physical activity. Open-ended comments on videos from mother-child dyads were used to determine user acceptance. Observations of repeated responses during content analysis informed coding and development of key themes.

Results: A final sample size of 93 mother-child dyads completed the study. Mothers reported significant improvement from precontemplation or contemplation stages to preparation or action stages for (1) fruit and vegetable selection on her plate ($P=.03$), (2) meal preparation for her family ($P=.01$), (3) fruit and vegetable selection outside the home ($P<.001$), and (4) physical activity ($P<.001$). Significant improvements were found in knowledge, stage of change, and self-efficacy for the 4 target behaviors of interest ($P<.001$). Children's open-ended commentary reported vicarious learning and positive character identification with brown-skinned cartoons exhibiting healthful food and exercise behaviors. Mothers commented on the lack of accessible produce in their neighborhoods not depicted in the cartoon videos.

Conclusions: Culturally adapted cartoons that incorporate tailored preferences by African American families, such as race or demography, may help increase adherence to target health behaviors when developing eHealth behavior solutions.

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KEYWORDS

childhood obesity; eHealth; social justice

Introduction

Background

Compared with their white counterparts (14%), African American (22%) children and adolescents are disproportionately affected by childhood obesity [1]. Poor adherence to the US Dietary Guidelines and physical activity recommendations has been consistently found to be major risk factors for obesity among minority youth, particularly among adolescents aged 12 to 19 years [2-5]. In a nationally representative sample of children and adolescents, black adolescents were the least likely to adhere to daily dietary targets of 5 or more servings of fruits and vegetables and more than 1 hour of physical activity. Nearly none (3%) of the children adhered to dietary fruit and vegetable targets, whereas 71% met physical activity goals [5]. Given the low adherence to dietary guidelines compared with physical activity, this study focused on 3 of the 4 target behaviors around healthy eating behaviors in African American youth.

Nonadherence to dietary recommendations can be attributed to a lack of tailored interventions that address the contextual, structural, and family environments that influence food choices. Inclusion of the family, especially the mother who generally makes food purchasing decisions for the family, serve as a crucial area to intervene to address food choice (proximally) and obesity (distally). Customized framing of dietary messages for mother and child aims to tailor messages that match the receivers' race, culture, ethnicity, demography, socioeconomics, or other preferences [6]. Tailored messages aim to ensure they are well received and accepted by the end user.

Programs that address multiple levels of the socioecological model have led to the successful engagement of minority communities [7]. This framework can be accounted for the personalization of tailored messaging to black mothers and their children. The levels of the socioecological model include intrapersonal (knowledge, attitudes, and beliefs), interpersonal (family and friends), environmental (physical structures in urban design), community (neighborhood access and safety), and policy levels (federal programs that affect food price, access, and quality). At the environmental level, structural factors such as limited access to healthy foods in one's neighborhood (ie, food deserts for healthy foods or food swamps of fast-food chains) presents the need for novel yet sustainable solutions to increase healthier food choice (proximal outcomes) and in turn reduce the high prevalence of obesity among African American adolescents (distal outcomes) [8]. At the interpersonal level, family influence plays an instrumental role in food choices and eating behaviors. Intrapersonal factors are influenced by education as well as messaging in one's surrounding environment. Thus, family-based interventions targeting both mother and child are needed to influence multiple levels of the family structure to reinforce messaging of key health behaviors.

Healthy People 2020 health communication and health information technology objectives aim to increase the proportion of social marketing in health promotion and health literacy communications available through media technology [9]. Nearly 75% of African American adults own a mobile phone device [10], serving as an opportune channel for disseminating health

messages. Culturally tailored dietary education provided via digital media to mothers can effect wholesale change in a family's eating habits and food choice [11]. Tailored digital solutions may lead to the adoption of obesity prevention behaviors in African American children and parents [12,13].

Objective

We argue that to optimize uptake and adherence to culturally tailored electronic health (eHealth) nutrition and physical activity messaging interventions among black youth, it is critical to embed family-based food preferences and their contextual landscape that may spur self-referential thinking that resonates with the viewer. Incorporating these preferences is crucial to ensure receptiveness and behavior change [14]. Prior websites and gaming interventions have increased 100% fruit juice intake, vegetable consumption, and physical activity patterns and reduced body weight in African American youth [15-17]. Behavioral interventions targeting the African American mother and child as a family unit have not yet been explored.

This study aimed to assess the feasibility and acceptability of a culturally tailored website hosting cartoons to increase willingness to increase fruit and vegetable selection and physical activity among African American mother-child dyads.

Methods

Procedures

This study employed an observational study design. The Web-based trial began with the website storyboard, an outline of the digital story elements in a website [18]. Cartoons were created using the GoAnimate platform. Character dialogue in the scripts, developed and edited by health educators and mothers, ensure preferences of website content. Storytelling narrative via cartoon storyboards may be effective for influencing diet and physical activity change in minority youth [15-17]. Culturally appropriate cartoons, where health behaviors are modeled in a virtual representation of the viewer's self, employ role modeling constructs from Bandura's Social Cognitive Theory, which has led to successful behavior change in at-risk populations [19]. This theory served as the theoretical underpinning of this study and evidence-based approach for adherence of the target behaviors.

Final videos were uploaded from GoAnimate to YouTube and then onto the intervention website. The study setting was a website portal that included an embedded link to the study survey. Subjects were able to move freely from the study survey to the new website portal (for exploring the website and watching the 9 videos) and back to the survey to answer final questions.

Website

The website portal included an open-access website with dietary information and pictures following the US Department of Agriculture's MyPlate guideline introduced under the former First Lady, Michelle Obama. Moreover, 2-min cartoon videos on the following 4 target behaviors were included: (1) food choices for their plate, (2) meal preparation, (3) food choices when outside of the home, and (4) physical activity. Cartoons

were depicted in the grocery store, school, home, and playground (see [Multimedia Appendix 1](#) for a screenshot of one of the cartoons). Storylines were told from the mother's, child's, and teacher's perspective. Scripts were developed by health educators and finalized by the principal investigator.

Participants

Eligibility criteria included being female, aged 25 years or older, having at least a high school education, being the mother of a child between the ages of 8 to 14 years, and identified as African American. One child per mother was permitted. Participants were recruited via Web-based social media such as Facebook, electronic mail distribution lists, and Web-based Mommy blogger groups. The sampling frame included African American mothers with children in the United States. Flyers were posted at faith-based organizations and community centers throughout the New York City area. Participants were compensated with an opportunity to win a US \$300 prize, US \$200 prize, or US \$100 Amazon gift card lottery prize. All study activities were approved by the Teachers College Institutional Review Board in 2012. Data collection was conducted from January to April 2013.

Measures

Research measures and instruments included an open electronic survey questionnaire via Qualtrics. The internal consistency of survey items for mothers' global stage of change, knowledge, self-efficacy, and evaluation of website for the 4 behaviors before and after watching the 9 2-min cartoon-like videos was .951 (Cronbach alpha), and .898 (Cronbach alpha), respectively. Items were not randomized or alternated. Study participants created an alphanumeric unique identifier when beginning the pre- and posttest surveys. The survey was displayed on 10 screen pages, with 10 items displayed per page. Adaptive questioning was used with conditional response options for certain demographic and personal health background questions to reduce the number of questions asked, preserving only relevant question items. Respondents were able to review responses with a back button and review survey completion progress with a status bar. Nonresponse options were included, and all survey quantitative items were set to force-response settings. Qualitative feedback was obtained from open field response options.

Mothers viewed the website and watched the cartoons with their child. Quantitative questions asked self-assessed knowledge, self-efficacy, and stage of change in executing the target behaviors. Mothers reported their child's rating of the videos for motivating their personal behavior change with open-ended question responses. The purposive sample completed the survey on a voluntary and confidential basis (ie, indicating having read the informed consent for parents, including an electronic assent form for minors, as well as electronic participants' rights) as anonymous participants. The study measure required approximately 45 to 55 min for successful completion, including 15 to 20 min to complete pre- and posttest surveys. Data storage location, time length, and name of the primary investigator were clearly visible on the study eligibility, informed consent, and study website.

Statistical Analysis

Descriptive statistics of mothers' income, age, education, marital status, child age, gender, school enrollment, and self-reported health status for herself and her child was reported. A mixed-methods analysis was conducted. Statistical analysis included paired sample *t* tests, independent *t* tests, and backward stepwise regression to evaluate knowledge gains and self-efficacy. Pretest and posttest questions, adapted from Prochaska's Stages of Change Theory, aimed to determine how likely participants may be ready to perform and adhere to the following 4 target behaviors after viewing the website: (1) fruit and vegetable selection on my plate, (2) meal preparation, (3) fruit and vegetable selection outside of home, and (4) physical activity. Backward stepwise regression analysis was conducted to determine the best predictor of a high score for the website. Incomplete data were dropped from the final dataset.

Open-Ended Feedback on Mothers' and Childs' Preferences for Video Improvements

Open-ended feedback captured comments on video quality and recommendations for improvement. Participants were asked to rate website and video quality based on aesthetics, literacy level, content, and recommendations for improvement. Mothers recorded their child's feedback on the videos and preferences for improvement. Finally, observations of repeated responses during content analysis informed coding and development of key themes. Thematic categories were developed based on commonalities in responses by mother and child, corresponding to their respective questions. Debriefing questions, categories, emergent themes, and direct quotes were used to develop tables in the Results section.

Results

Participant Description

A total of 641 African American mothers older than 25 years with children between the ages of 8 and 14 years began the Web-based study. The final sample included 93 mother-child dyads, indicating a 14.5% (93/641) response rate for those dyads that met the study criteria and successfully completed the study questionnaires (N=93). In this study, successful completion was defined by at least 100% completion of the survey responses. Internet protocol addresses were checked to identify potential duplicate entries. Of the 93 mother and child dyads that completed the study, 65% (60/93) were single mothers and reported an annual income between US \$20,000 and US \$60,000. Mothers were on average aged 38 years. Of the 93 children, 54% (50/93) were female and aged 10 years on average. A total of 69% (64/93) of children attended public school. After watching the study videos, a significant portion of the sample moved from their baseline readiness to change status to preparation, action, or maintenance stage for the target health behaviors. Qualitative questions assessed website acceptance and user preferences for improvement.

Statistical Analysis

A total of 15 paired sample *t* tests indicated significant improvement across 13 areas at the Bonferroni adjustment significance (0.05/15; $P < .001$; see [Table 1](#)). In the backward

stepwise regressions, predictor variables that reported nonsignificant outcomes were removed from the model in a stepwise manner until a model with all significant predictors at $P < .05$ was obtained. Mothers who reported their children to be both overweight ($\beta = .109$; $P < .001$) and underweight ($\beta = .881$; $P = .02$) were predictors for higher overall ratings of the website. In addition, mothers with a lower educational level ($\beta = -.13$; $P = .05$) or currently enrolled in school ($\beta = .589$; $P < .001$), serving as a proxy for family socioeconomic status level, were at the significance level for being a predictor for a high global rating of the cartoons.

The results of [Table 1](#) indicate significant improvements in mothers' level of knowledge, self-efficacy, and global stage of change scores for each of the 4 target behaviors ($P < .001$) reported. Average stage of change results was scored on a 1 to 5 scale, corresponding to precontemplation, contemplation, preparation, action, and maintenance. Mothers reported significant improvement from precontemplation or contemplation to preparation or action for eating outside of the home and physical activity.

Children's Feedback and Preferences for Video Improvements

Mothers' recordings of children's feedback were quantified based on thematic categories to children's open-ended responses. Participants were allowed to skip questions. Of the 93 children, 64% (60/93) positively viewed the cartoons and would recommend them. A total of 33% (30/93) children reported they learned about eating fruits and vegetables at home and away from home. In addition, 15% (14/93) found the videos on exercising educational, 9% (8/93) learned about cooking at home with mom, and 7% (7/93) wanted more examples on food choice selection. Overall, 10% (9/93) found the content boring, and 35% (33 of 93) thought the animation could be improved. Direct quotes from participants were categorized based on emergent themes (see [Table 2](#)).

Moreover, 64 out of 80 (80%) children reported that they would recommend the videos to other mothers and their children. Completion of open-ended questions was not required, and the respective n values are reflected as such. Children's reasons for not recommending the videos are listed in [Table 3](#).

Table 1. Paired sample *t* tests stage of change, knowledge, and self-efficacy for mothers' pre- and postevaluation of the electronic health cartoon videos (N=93). Bonferroni adjustment significance (0.05/15; $P=.003$). All *P* values above .003 are considered nonsignificant and only those below .003 are considered statistically significant.

Paired sample <i>t</i> tests stage of change, knowledge, and self-efficacy for mothers	Stages of change, mean (SD)	<i>t</i> test	
		<i>t</i> value (<i>df</i>)	<i>P</i> value
Pair 1^a			
Prevideos	3.59 (1.25)	-2.15 (92)	.03
Postvideos	3.74 (1.97)	-2.15 (92)	.03
Pair 2^b			
Prevideos	4.22 (0.82)	-7.99 (92)	<.001
Postvideos	5.08 (1.22)	-7.99 (92)	<.001
Pair 3^c			
Prevideos	4.39 (1.22)	-10.17 (92)	<.001
Postvideos	5.38 (.77)	-10.17 (92)	<.001
Pair 4^d			
Prevideos	3.65 (1.28)	-2.643 (92)	.01
Postvideos	3.85 (1.10)	-2.643 (92)	.01
Pair 5^e			
Prevideos	4.37 (.11)	-8.16 (92)	<.001
Postvideos	5.18 (.79)	-8.16 (92)	<.001
Pair 6^f			
Prevideos	4.43 (1.25)	-9.31 (92)	<.001
Postvideos	5.35 (.78)	-9.31 (92)	<.001
Pair 7^g			
Prevideos	3.00 (1.47)	-5.82 (92)	<.001
Postvideos	3.48 (1.07)	-5.82 (92)	<.001
Pair 8^h			
Prevideos	3.94 (1.40)	-9.36 (92)	<.001
Postvideos	5.06 (.79)	-9.36 (92)	<.001
Pair 9ⁱ			
Prevideos	4.13 (.80)	-9.73 (92)	<.001
Postvideos	5.20 (1.30)	-9.73 (92)	<.001
Pair 10^j			
Prevideos	3.34 (1.30)	-5.69 (92)	<.001
Postvideos	3.70 (1.03)	-5.69 (92)	<.001
Pair 11^k			
Prevideos	4.52 (1.28)	-6.66 (92)	<.001
Postvideos	5.23 (.84)	-6.66 (92)	<.001
Pair 12^l			
Prevideos	4.38 (1.29)	-8.07 (92)	<.001
Postvideos	5.24 (.79)	-8.07 (92)	<.001
Pair 13^m			

Paired sample <i>t</i> tests stage of change, knowledge, and self-efficacy for mothers	Stages of change, mean (SD)	<i>t</i> test	
		<i>t</i> value (<i>df</i>)	<i>P</i> value
Prevideos	3.40 (1.10)	-6.02 (92)	<.001
Postvideos	3.69 (.93)	-6.02 (92)	<.001
Pair 14ⁿ			
Prevideos	4.23 (1.01)	-9.56 (92)	<.001
Postvideos	5.32 (.65)	-9.56 (92)	<.001
Pair 15^o			
Prevideos	4.33 (1.13)	-10.556 (92)	<.001
Postvideos	5.30 (.66)	-10.556 (92)	<.001

^aPair 1: Mother's stage of change for fruits and vegetables selection on her plate.

^bPair 2: Mother's knowledge for fruits and vegetables selection on her plate.

^cPair 3: Mother's self-efficacy for fruit and vegetable selection on her plate.

^dPair 4: Mother's stage of change for selecting more fruits and vegetables when preparing family meals.

^ePair 5: Mother's knowledge for selecting more fruits and vegetables when preparing meals.

^fPair 6: Mother's self-efficacy for selecting more fruits and vegetables when preparing family meals.

^gPair 7: Mother's stage of change for selecting more fruits and vegetables outside of the home.

^hPair 8: Mother's level of knowledge for selecting more fruits and vegetables outside of the home.

ⁱPair 9: Mother's self-efficacy for selecting more fruits and vegetables outside of the home.

^jPair 10: Mother's stage of change for engaging in physical activity.

^kPair 11: Mother's level of knowledge for engaging in physical activity.

^lPair 12: Mother's self-efficacy for engaging in physical activity.

^mPair 13: Global stage of change score.

ⁿPair 14: Global knowledge score.

^oPair 15: Global self-efficacy score.

Table 2. Children's reasons for recommending cartoon videos.

Emergent themes	Direct quotes
Dietary knowledge gains	"They're funny and help you learn more about what to eat if you want to eat healthy and stay healthy."
Dietary knowledge gains	"Because people need to eat better and I think that this is a good way to help people see that it is good to eat fruit and veggies."
Vicarious learning via character identification	"The people are brown skinned like me."
Vicarious learning via character identification	"Because they are cartoons and kids can relate to them and it might get the point across about healthy eating."
Vicarious learning via character identification	"Because some of my friends are fat and they have big bellies."
Influential for both mother and child	"Because some moms do not want their children to have diabetes."

Table 3. Children's reasons for not recommending videos.

Emergent themes	Direct quotes
Vicarious learning via an urban environment	"Maybe if the videos talked about why neighborhoods don't have certain foods. We live in Queens and can go to Fairway, Stop n Shop and Trader Joe's and even Whole Foods. My friends who live in the school's neighborhood can't."
Vicarious learning via an urban environment	"Just make it more compatible to an urban child's experience in day to day life situations."
Vicarious learning via character identification	"Better cartoon people and talk about how we kids may overeat when being bullied."
Animation quality and graphic design	"Add arms, legs, and necks to the characters, make the voices match the characters, find different ways to show excitement."

Mothers' Feedback and Preferences for Video Improvements

Mothers' responses were analyzed for emergent themes, and direct quotes are provided—as shown in [Table 4](#). Of the 93 mothers, 68 (73%) found the cartoons to be a good educational resource worth recommending to their peers, thereby diffusing the innovation. Moreover, 37% (34/93) mothers stated the

cartoons were educational about eating at home, eating away from home, and cooking with their child. Furthermore, 23% (21/93) mothers said they learned about exercising. A total of 26% (24/93) women commented that the website could have been improved with better graphics and animation. Finally, 16% (15/93) mothers commented that more activities should be included to make the website longer.

Table 4. Mothers' reasons for recommending the website.

Emergent themes	Selected direct quotes
Dialogue via mother and child	"Helps start conversation about nutrition and exercise with children."
Dialogue via mother and child	"Because watching these videos with my child caused an instant change in my families' eating habit, but also more importantly in some way created an instant bond that we didn't know we lacked! We'll be preparing meals together more frequently and sharing lots of other parent/child activities!"
Dietary knowledge gains	"The website is very informative, I think there is a lot of information to be found on this website on creating healthy choices."
Diffusion of innovation	"I would recommend it because I believe there are many moms that may not know the various food groups and how to provide proper nutrition."

Discussion

Principal Findings

Our findings indicate that culturally adapted nutrition and physical activity messages can inspire African American mother-child dyads' readiness to adhere to national dietary and physical activity guidelines. This study aligns with previous research indicating that digital cartoon animation storytelling motivated mothers and children toward dietary and physical activity improvements [15-17,19-21]. Our eHealth intervention extends beyond prior interventions targeting only children and adolescents by incorporating the mother, thereby influencing the larger family unit. Our study was effective in increasing knowledge and self-efficacy in both mother and child. Both mother and child moved across the Stage of Change continuum from not thinking about or considering diet and physical activity improvements (precontemplation or preparation) to considering and carrying out diet and physical activity improvements (preparation or action or maintenance). Given that African American participation in eHealth interventions is low [22], culturally adapted animation may have helped with participation rates.

Mothers' Preferences for Culturally Tailored Animation

Our findings reinforce the importance of including mothers in Web-based behavior change interventions because they typically influence the food choice decisions for their families [23,24]. Children's food preferences into adolescence may be shaped by the foods they are exposed to early in life [25], which may be predisposed by mothers' own food preferences. Parental role modeling of food intake has also been shown to influence children's engagement in physical activity and food choices [26-28], which are adjunctive strategies in obesity prevention and management. Dwyer et al found a positive correlation between parent-adolescent dyad autonomous motivation and fruit and vegetable intake [29]. Similarly, Vepsäläinen et al

reported that mother-child dietary patterns were stronger than father-child dietary patterns as a significant predictor for the child's food intake [30]. Targeting the family environment is crucial in inducing adherence to healthy dietary patterns among children and their families [31].

Comparisons With Prior Work

Prior interventions involving African American parent-child dyads related to healthy eating and physical activity were found in within-person interventions. The FIT Families trial in Michigan conducted from 2011 to 2013 [32] examined satisfaction and content acceptance of a 6-month family-based weight loss intervention. Semi-structured interviews with 136 African American adolescents (median age: 14 years) and caregivers of which 89.7% (122/136) were mothers reported that program components (parent involvement and weight loss counseling) and content (cognitive behavioral skills training, motivational interviewing, and contingency management) were helpful and acceptable. Identified areas of improvement included a need for more engaging skills-based learning, inclusion of exercise sessions, and the need for personalized tailoring to meet adolescent and caregiver interest. Parenting support, active learning, and individualized personalization were positive attributes of the intervention. Personalized tailoring of educational content was consistent feedback among our participants, reinforcing the significance of incorporating features that address interests and issues germane to the target population.

Berry et al evaluated the efficacy of a 5-year cluster-randomized controlled trial in North Carolina on diet and exercise education with coping skills training in elementary school children and their parents [33]. A total of 63.5% (117/184) of participant families were African American, 54.8% (101/184) of whom were mothers. The intervention included an hour of nutrition and exercise coping skills training and 45 min of exercise once a week for 12 weeks. Researchers aimed to examine changes in adiposity, weight, health behaviors, and self-efficacy in children and parents (n=184) in an 18-month program.

Intervention group parents reported positive correlations between parent and child waist circumference ($r=.409$; $P<.001$), triceps ($r=.332$; $P<.001$), and subscapular ($r=.292$; $P<.001$) skinfolds compared with controls but failed to find significant correlations in nutrition and exercise self-efficacy and knowledge or change in children's and parents' body mass index. Changes in parent-child body weight could be attributed to the consistent physical activity component. Our study effectively increased knowledge and self-confidence to carry out diet and behavior change but does not measure any actual changes in body weight or actual food intake, indicating that an in-person component may help lead to participant weight loss.

Mothers' open-ended responses regarding video improvements included the preference for the cartoons to better depict food desserts. African American neighborhoods experience the highest rates of unhealthy food environments compared with whites and proportionally the highest rates of obesity and diabetes [34,35]. Character dialogue and backgrounds that illustrate limited access to healthy foods in their neighborhood environment would better reflect the experience of mothers when making food purchasing decisions and proffer possible solutions to overcome this challenge.

Children's Preferences for Culturally Tailored Animation

Cartoons are an effective tool for improving children's adherence to specific health behaviors [36]. Culturally tailored cartoons allowed for positive character identification and vicarious learning for African American children. Open-ended comments from children stating that they liked the videos "because they have brown skin like me," reflects a positive connection and identification with the characters viewed.

Vicarious learning through brown-skinned characters allows for positive reinforcement of healthful behaviors that is particularly important for African American children to be exposed to and identify with. Viewing brown-skinned cartoon characters is important for instilling self-esteem in children as part of their socioemotional development [37,38]. Evidence suggests children least prefer the color black with a positive happy emotion [39]. Instilling self-confidence in African American youth through vicarious learning could increase self-efficacy toward consuming a more healthful diet.

Limitations

Stages of Change pre- and posttest surveys assessed readiness toward the target behaviors but not actual consumption. Furthermore, child responses may have reflected the mother's interpretation as mothers served as a proxy respondent for their children. The study did not include other caregivers, such as

grandmothers, who may also make food purchasing decisions and cook meals in the home. The study design assumes target participants have internet access. Moreover, 13% of African Americans do not use the internet [40]. Health literacy [41], internet self-efficacy [42], and parental consent form literacy [43] may have been enrollment barriers. Technological limitations hampered recommending the videos to others. Internet privacy is also a concern, given the degree of mistrust in the black community with the health care system [44].

Low sample size may have affected statistical power during study analysis. Response, social desirability, and selection bias may have been introduced. Methodological improvements could have addressed survey measures that were based on an adapted survey tool. Survey items should be validated for future use. External validity of this study may only apply to the target population.

Future Directions

Future research should evaluate the role of culturally tailoring as a mediator to influence behavioral outcomes. Explaining how cultural adaptations influence outcomes is critical to understanding their significance [45] and identifying preferable mechanisms for reaching this hard-to-reach population. Animation and content features preferred by this population could be important for future research.

Animation design improvements are needed in the next steps, especially for improving computerized cartoon voices that were a prominent concern in children's feedback. Privacy concerns and internet access may be areas to address when developing eHealth solutions targeting the African American community [10]. Future study design improvements could include interactive methods to increase engagement, such as photo uploads of before and after pictures of meals consumed and regularly updated website content.

Conclusions

This study demonstrated that culturally adapted cartoons may be an effective educational tool to inspire healthy behaviors in African American mother-child dyads. Future directions should incorporate key findings from this study for animation design to better reflect the preferences by the target population. Food justice issues commonly experienced in African American communities should be depicted graphically and reflected in character dialogue. Technological advances in mobile apps could draw upon these findings to develop solutions with preferred features by this target population to address their health needs. Self-monitoring tools with goal-setting attributes that have reported successful behavior change may also be considered, including the mother for collective participation and objective measurement.

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Authors' Contributions

AC and BW conceived the study concept and design. MS-K conducted the qualitative analysis. AS contributed to the Introduction and Discussion. GJ-L contributed to editing the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshot of mother and children meal planning in grocery store.

[[PDF File \(Adobe PDF File\), 570KB - pediatrics_v2i1e12501_app1.pdf](#)]

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Abbreviations

eHealth: electronic health

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Original Paper

Online Information About Periviable Birth: Quality Assessment

Adriane F Haragan¹, MD; Carly A Zuwiala², MD; Katherine P Himes³, MD, MS

¹Department of Obstetrics and Gynecology, Kalispell Regional Healthcare, Kalispell, MT, United States

²Department of Obstetrics and Gynecology, Magee-Womens Hospital, University of Pittsburgh, Pittsburgh, PA, United States

³Department of Obstetrics, Gynecology and Reproductive Sciences, Magee-Womens Research Institute, University of Pittsburgh, Pittsburgh, PA, United States

Corresponding Author:

Katherine P Himes, MD, MS

Department of Obstetrics, Gynecology and Reproductive Sciences

Magee-Womens Research Institute

University of Pittsburgh

300 Halket Street

Pittsburgh, PA, 15228

United States

Phone: 1 412 973 2249

Email: himekp@upmc.edu

Abstract

Background: Over 20,000 parents in the United States face the challenge of participating in decisions about whether to use life support for their infants born on the cusp of viability every year. Clinicians must help families grasp complex medical information about their baby's immediate prognosis as well as the risk for significant long-term morbidity. Patients faced with this decision want supplemental information and frequently seek medical information on the Internet. Empirical evidence about the quality of websites is lacking.

Objective: We sought to evaluate the quality of online information available about periviable birth and treatment options for infants born at the cusp of viability.

Methods: We read a counseling script to 20 pregnant participants that included information typically provided by perinatal and neonatal providers when periviable birth is imminent. The women were then asked to list terms they would use to search the Internet if they wanted additional information. Using these search terms, two reviewers evaluated the content of websites obtained via a Google search. We used two metrics to assess the quality of websites. The first was the DISCERN instrument, a validated questionnaire designed to assess the quality of patient-targeted health information for treatment choices. The second metric was the Essential Content Tool (ECT), a tool designed to address key components of counseling around periviable birth as outlined by professional organizations. DISCERN scores were classified as *low quality* if scores were 2, *fair quality* if scores were 3, and *high quality* if scores were 4 or higher. Scores of 6 or higher on the ECT were considered high quality. Interreviewer agreement was assessed by calculated kappa statistic.

Results: A total of 97 websites were reviewed. Over half (57/97, 59%) were for-profit sites, news stories, or personal blogs; 28% (27/97) were government or medical sites; and 13% (13/97) were nonprofit or advocacy sites. The majority of sites scored poorly in DISCERN questions designed to assess the reliability of information presented as well as data regarding treatment choices. Only 7% (7/97) of the websites were *high quality* as defined by the DISCERN tool. The majority of sites did not address the essential content defined by the ECT. Importantly, only 18% of websites (17/97) indicated that there are often a number of reasonable approaches to newborn care when faced with periviable birth. Agreement was strong, with kappa ranging from .72 to .91.

Conclusions: Most information about periviable birth found on the Internet using common search strategies is of low quality. News stories highlighting positive outcomes are disproportionately represented. Few websites discuss comfort care or how treatment decisions impact quality of life.

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KEYWORDS

periviable birth; patient education; patient counseling; Internet resources

Introduction

While the rate of survival with or without neurodevelopmental impairment for infants born between 22 and 25 weeks has improved over time, there is considerable uncertainty regarding short- and long-term prognosis for infants born during the periviable period [1-8]. Periviable birth, defined as delivery occurring from 20 0/7 weeks to 25 6/7 weeks, complicates roughly 20,000 deliveries annually in the United States. Survival with neonatal interventions ranges from roughly 10% at 22 weeks gestation to over 60% at 25 completed weeks [1]. The risk of long-term neurodevelopmental impairment remains high for all periviable infants who survive [1-5]. Women and families must navigate this uncertainty to make time-sensitive and value-laden decisions regarding obstetrical interventions for fetal benefit and neonatal care when periviable birth is imminent. Women facing periviable birth have expressed a desire for supplemental information after provider counseling [9-13].

Increasingly, patients are turning to the Internet for supplemental health information. Survey estimates suggest that over half of people in the United States search the Internet for health information [14]. While data specific to periviable birth are limited, studies of other preference-sensitive decisions suggest that both patients and providers support provision of supplemental information that presents the pros and cons of all reasonable treatment options. Health care providers remain skeptical about the value of the Internet as a source of unbiased supplemental information [11,15].

The usefulness of the Internet as a source of supplemental health information depends on the quality of information easily available to patients. There are now a number of validated assessment checklists—the DISCERN tool, Journal of American Medical Association Benchmarks, and Health On the Net Foundation Principles—to determine the quality of online information [16-18]. The aim of this study was to evaluate data regarding the quality of online information about periviable birth.

Methods

Defining Internet Search Terms

We recruited pregnant women at gestation of 37 weeks or more from the Magee-Womens Hospital, Pittsburgh, PA, outpatient obstetrical clinics to participate in this study during June 2016. Women were excluded if they had experienced a prior preterm birth or had experienced threatened preterm labor during their current pregnancy. We approached all women meeting inclusion criteria. Following informed consent, women were read a script describing a hypothetical situation in which they were faced with a preterm birth at 23-weeks' gestation. The script included information on short- and long-term outcomes, risks and benefits of obstetrical interventions for neonatal benefit, as well as care options for the neonate after delivery. The script was developed by input from members of the division of Maternal Fetal Medicine and Newborn Medicine at the University of Pittsburgh Medical Center, Pittsburgh, PA. Participants were then given a written survey asking them to identify the search engine they used most frequently and how often they searched for health

information online. They were then asked to list four search terms they would use to seek out additional information about periviable birth. They were also asked whether they would prefer to learn about (1) statistics regarding survival and outcomes for periviable neonates, (2) narrative descriptions about women who delivered in the periviable period and the outcomes for their neonates, or (3) both. Women were recruited until we reached saturation in themes of search terms. We did not recruit partners of pregnant women as they were not readily present at the clinical venues where we recruited participants.

Website Identification

Using the four most common search terms provided, two reviewers (AFH and CAZ) independently evaluated the informational content of websites found via a Google search. Additional websites listed by participants were WebMD and Wikipedia. Sites were excluded if they were non-English or if registration was required for access. Eligible websites were then independently reviewed on the same date. The first three pages of websites using the top four search terms were included in the evaluation, as marketing data demonstrate that only 1.6% of users click on links from the third page of results or beyond [19].

Analysis of Website Quality

Websites were classified into six main categories: (1) government, (2) scientific resources, (3) nonprofit and advocacy organizations, (4) news and media reports, (5) for-profit organizations, and (6) personal commentary (eg, personal blogs). Two metrics were used to evaluate the quality and content of the websites. The first was the DISCERN instrument, a validated questionnaire designed to assess the quality of patient-targeted health information for treatment choices [20]. We elected to use this tool because it is tailored to evaluate how well websites prepare patients and providers to engage in a shared decision-making process, the approach recommended to help families make decisions about neonatal care after periviable birth. Questions included in the DISCERN instrument fall into three main sections. Section 1 (Questions 1-8) addresses the reliability of the site and whether it can be trusted as a source of information about treatment choices. These questions address the sources of information used to compile the site, the website's ability to provide accurate and impartial information, and areas of uncertainty regarding treatment choices. Section 2 (Questions 9-15) focuses on specific details of the information about treatment choices. These questions examine the risks and benefits of each treatment choice and how well the site supports shared decision making. Section 3 (Question 16) is a subjective assessment by the reviewer of the overall quality of the website. Each question on the DISCERN tool is scored on a scale of 1 (low quality/not addressed) to 5 (high quality/fully addressed). We considered scores of 4-5 to be *high quality*, 3 to be *fair quality*, and 1-2 to be *poor quality* sources of information.

The DISCERN tool can be used for any health-related content area and, thus, is not specific to periviable birth. Therefore, a second metric was developed—the Essential Content Tool (ECT)—to address whether websites covered information defined as critical for decision making around periviable birth. This tool was developed in two phases. First, we extracted 21

key components of periviable counseling as outlined by both the American College of Obstetrics and Gynecology and the American Academy of Pediatrics statements about periviable birth [21,22]. Content validity was evaluated by querying four physician members of the divisions of Maternal Fetal Medicine and Newborn Medicine to identify the minimum number of constructs necessary to provide families with essential information about periviable birth decision making. This process identified 10 essential topics pertinent to periviable birth. These included information about short- and long-term neonatal morbidity and mortality at different gestational ages as well as obstetrical interventions for neonatal benefit and options for neonatal care. We also assessed whether information was presented in a preference-sensitive manner: there is no right or wrong decision. All 10 domains are outlined in [Multimedia Appendix 1](#). Thus, the ECT contains a total of 10 content questions that were scored dichotomously (present or not present). A website was considered of *good quality* if it addressed at least six of the content domains and *high quality* if it addressed at least eight of the content domains.

Statistical Analysis

Descriptive statistics were calculated to characterize participants and summarize results of the DISCERN tool and the ECT. Interreviewer agreement was assessed by a calculated kappa statistic and descriptive statistics were performed. This study was approved by the University of Pittsburgh's Institutional Review Board.

Results

Patient Population and Search Terms

A total of 20 women were recruited for the first stage of the study. The median age of our patient population at the time of enrollment was 28 years (interquartile range [IQR] 25-30), 35% (7/20) had Medicaid insurance, 65% (13/20) had private insurance, and 50% (10/20) of the women were black. A total of 90% (18/20) of women had graduated high school. The median gestational age was 38.0 weeks (IQR 37.6-38.6) and 40% (8/20) were nulliparous. Of those surveyed, 85% (17/20) chose Google as their preferred search engine and 75% (15/20) reported they used the Internet to search for health information *often or all the time*.

Patients were asked to provide four search terms they would use to search for supplemental information online regarding periviable birth. Overall, participants recorded a total of 54 search terms. The four most common search terms elicited were (1) preterm birth, (2) birth at 23 weeks, (3) long-term effects of preterm birth, and (4) chances of survival at 23 weeks. These four responses or minor variations of these responses (ie, long-term complications of preterm birth) accounted for 83% (45/54) of total search terms provided by participants. Other search terms recorded by participants included the following:

recurrence risk of preterm birth, prevention of preterm birth, resources available for people with preterm infants, and care decisions made by families facing periviable birth. Patients overwhelmingly desired both statistical information about survival and prognosis as well as patient narratives about their experiences with periviable birth, with 90% of women indicating they wanted both types of information.

Website Characteristics

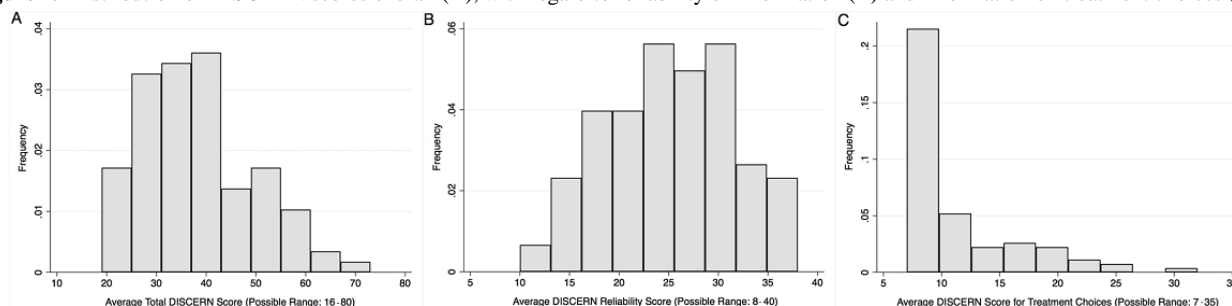
After exclusion criteria were applied, 97 unique websites were reviewed out of a total of 120 possible websites (80.8%). Of those queried, 59% (57/97) were for-profit sites, news stories, or personal blogs; 28% (27/97) were government, hospital or research institution, or medical journal sites; and 13% (13/97) were nonprofit or advocacy sites. Most websites were from the United States (75/97, 77%), followed by the United Kingdom (17/97, 18%), Australia (3/97, 3%), and New Zealand (2/97, 2%).

Quality of Website Content: The DISCERN Tool

The DISCERN tool evaluates the reliability of website information as well as the quality of information about treatment choices. The reviewers defined "treatment" as neonatal interventions with the goal of sustaining the life of the neonate. Therefore, when the DISCERN tool asks if the website "addresses what would happen if no treatment was used or if there are alternatives to treatment," we interpreted this as the website referring to the option of comfort care and subsequent neonatal death.

Overall, websites scored poorly. A website could score a total of 80 points on 16 questions, 40 points on questions addressing the reliability of information (Questions 1-8), and 35 points on the questions addressing treatment choices (Questions 9-15). High scores indicate *high quality*. The distribution of scores is shown in [Figure 1](#). While website quality was poor overall (see [Figure 1A](#)) with a median overall score of 36 (IQR 30-44), websites fell markedly short at discussing treatment options (see [Figure 1C](#)). The median score for the questions addressing treatment choices was 8 (IQR 7-13).

As indicated above (see [Figure 1C](#)), information on treatment choices was poor and this was particularly notable for questions addressing support for shared decision making. Only 10% (10/97) of the websites scored highly (4 or 5) on the question of whether it was clear there was more than one reasonable treatment choice or medical approach. A total of 68% of websites (66/97) scored poorly (<2) in acknowledging uncertainty around the best treatment options. Importantly, 16% (16/97) had evidence of strong bias indicating a completely unbalanced view of options available to patients experiencing a periviable birth. The bias was uniformly in favor of presenting the option of a trial of resuscitation and not presenting comfort care as an option.

Figure 1. Distribution of DISCERN scores overall (A), with regard to reliability of information (B) and information on treatment choices (C).

Website Content Using the Essential Content Tool

The ECT provides a more granular assessment of the quality of information as it pertains to periviable birth. Consistent with the findings using the DISCERN tool, most websites lacked the essential content necessary for periviable decision making as defined by the ECT. Only 38 of the 97 sites (39%) reviewed morbidity and mortality statistics by gestational age, and these were often not reflective of the current literature [1]. Roughly a quarter (27/97, 28%) reviewed obstetrical interventions for neonatal benefit, such as administration of betamethasone or magnesium for neuroprotection. Interestingly, the content area most commonly addressed by the queried websites (59/97, 61%) was the potential long-term outcomes for periviable neonates (eg, cognitive impairment, cerebral palsy, deafness, blindness, feeding difficulties, and oxygen requirement). Consistent with our findings from the DISCERN tool, only 18% (17/97) of websites presented a full range of care options for periviable infants, including comfort care. Few websites (10/97, 10%) characterized decision making around periviable birth as preference-sensitive, indicating that there is often no clear right or wrong choice in deciding to pursue life-sustaining interventions versus comfort care for the neonate. The complete distribution of scores for ECT are included in [Multimedia Appendix 1](#).

Overall Website Quality

The overall quality of website content was measured using the last question on the DISCERN tool and by the presence of six

out of 10 essential domains as defined by the ECT. Only 7% (7/97) of the websites were thought to represent high-quality websites by both reviewers using the last question on the DISCERN tool, and 2% (2/97) were considered high quality according to the ECT. A total of 20% (19/97) of the websites were of good quality according to the ECT. Notably, over half (5/9, 56%) of the high-quality websites were found by our reviewers on page 2 or 3 of the search results. Additionally, 74% (14/19) of good-quality websites were from academic sources, governmental sources, or nonprofit organizations. Only 2 out of 19 (11%) of the good-quality websites according to the ECT were from a for-profit site. To illustrate high- and low-quality websites, we provided quotes demonstrative of the websites' messages. We found that many websites, particularly news stories and personal blogs, focused on sensational stories that do not always represent the more likely outcomes (see [Table 1](#)).

Interviewer agreement was substantial with kappa ranging from .72 to .90 for the ECT questions and from .36 to .71 for the individual DISCERN questions. The stronger agreement within the ECT can be explained by the binary nature of the questions, while the DISCERN questions are answered using a 1-5 scale. When using a weighted kappa statistic to account for the degree of disagreement within the DISCERN questions, agreement was strong, with kappa ranging from .66 to .91 for the individual DISCERN questions.

Table 1. Content from high- and low-quality websites.

Characteristics by DISCERN tool	Representative quotes
High-quality website	
Address both survival and long-term disabilities	<p>“For babies born at 23 or 24 weeks, the chance of survival if they receive intensive treatment is about 50:50. If the baby survives, they may have one or more of the problems described in this website...About 1 in 4 or 1 in 5 children who survive have very serious problems affecting their movement or learning or both that mean they will need lifelong help and support for everyday activities.” [23]</p> <p>“The success of improved survival in very premature infants has raised some serious ethical issues. It is now possible to save more, smaller, and earlier babies. The difficult question is whether this is always in the best interest of the baby...Decisions pertaining to these sensitive issues are influenced by a number of factors, not least by parental views.” [24]</p>
Address patients’ values	<p>“Parents have difficult decisions to make at this time and your views and values are very important.” [23]</p> <p>“For some families, the worst thing that could happen is that their baby dies. For them, intensive treatment is the right choice as this gives the baby the best chance of surviving. For other families, the worst thing that could happen is that the baby has to go through intensive treatment and then survives with a serious disability. They worry about the effect on the child and on the rest of their family. For those families, comfort care may be the right choice. This option has the lowest chance of the baby surviving with a serious disability.” [25]</p>
Encourage shared decision making	<p>“If you don’t know what would be best for your family and for your baby, you may find it helpful to talk to other members of your family. If there is time, you could speak to different medical specialists about your situation, eg, obstetricians and paediatricians.” [23]</p> <p>“Your doctors will talk with you about your situation and try to understand what is important for you and your family. There is no right or wrong answer.” [25]</p>
Low-quality website	
Sensational news stories	<p>“With his chances of survival being between 15-30 percent, sweet Haiden has beat the odds...Within hours Emily gave birth to her 1.5-pound baby boy—14 hours away from the nearest hospital...Emily credits her boy’s strong lungs, a makeshift incubator and her cruise’s early arrival into a Puerto Rico dock. ‘The doctors really tell us that he’s a miracle baby,’ Emily stated. ‘It’s a miracle he’s here.’”</p> <p>“‘They didn’t think she was going to be alive, but I knew she was. Because I just knew it,’ ...She remembered the dream she had the night before going into labor. In it, she said God told her he would take care of her daughter, but she had to have ‘faith...’”</p>
Biased testimonials	<p>“...studies show that depending on medical care, at 22 weeks—the age that Planned Parenthood is killing viable babies—preemies can survive with care. So, Trevor Frolek came into the world at 23 weeks. At the time of his birth, he weighed in at 1 pound, 6 ounces, and like many of the babies born alive in ‘botched’ abortions would do if given the chance, Trevor fought to stay alive. And stay alive he did. Trevor survived, and after spending the first year of his life in Fargo, North Dakota’s Essential Health neonatal intensive care unit, weighing a healthy 20 pounds, he went home.”</p> <p>“She was fully human, just smaller than we had ever seen before in our lives. Four months later, Ava Joy came home with us as a completely healthy baby with a minor case of reflux.”</p>
Statements with unclear sources of information	<p>“A prematurity prevention program has been developed and implemented at the Pope Paul VI Institute for the last 25 years...This entire protocol cannot be properly discussed in a website such as this, however, it can be stated emphatically that the prematurity rate can be decreased with the use of this protocol...For the entire group, the comparison group had a preterm birth rate of 12.0 percent and the Pope Paul VI Institute group protocol only had a 7.0 percent prematurity rate and in that group, only 1.3 percent were at < to 33.9 weeks of gestation. This is three times less than the comparison group.”</p>

Discussion

Principal Findings

The American College of Obstetricians and Gynecologists, the Society for Maternal Fetal Medicine, and the American Academy of Pediatrics all emphasize the need for shared decision making regarding interventions for infants born during the periviable period [21,22]. Given patients frequently access the Internet for supplemental health information when faced with medical decision making, we sought to provide data regarding the quality of online information as it pertains to periviable delivery [11,12]. Our work revealed that the overwhelming majority of websites do not address content considered essential for patient education about the difficult

decisions surrounding periviable birth. Less than 20% of websites addressed comfort care as a treatment option in periviable neonates and, if mentioned, it was often a single sentence. Furthermore, only 10% of websites acknowledged that there is more than one reasonable approach to care—a frame that is critical to supporting shared decision making. Additionally, over 15% of websites were found to have strong bias in favor of neonatal resuscitation, potentially further eroding high preference-based decision making.

Roughly one in 10 websites were considered *high quality* by the DISCERN tool. The websites receiving the highest scores were nonprofit sites and government sites (eg, Wikipedia and the Australian Perinatal Practice Guidelines). Of concern, the highest-quality websites were often difficult to find within our

search, often listed on the second or third page of the results. Prior research has shown that 91% of Internet users do not go beyond the first page of search results [15]. The websites that Google ranks on the first page of their search results for any given search term are those considered the most relevant using a complex algorithm, which is constantly updated and revised. Therefore, it can be difficult to move high-quality sites to the front of the search results without search engine optimization consultants [26].

Prior studies have investigated the quality of online information for other preference-sensitive decisions, including treatment for localized breast cancer and treatment options for prostate cancer [27,28]. Consistent with our results, these studies concluded that although many websites address these topics, very few provide essential information necessary to actively participate in decision making related to treatment options. These studies suggest that there is a potential for the Internet to provide valuable information for patients, but it is up to their health care providers to identify high-quality websites to guide their patients.

Our study has several important strengths. First, ours is the first investigation to specifically investigate the quality of online information as it pertains to periviable birth. Additionally, the search terms we used were defined by patients and thus likely reflect the usual search strategies employed by the general population. Furthermore, we used two metrics to evaluate the individual websites—both a validated tool to assess the quality of information for preference-sensitive decisions as well as a content tool that specifically assessed information related to periviable birth. This approach allowed for a multidimensional evaluation of the websites that addressed both content-specific as well as big-picture concepts that support high-quality shared decision making. Finally, interviewer agreement was found to be strong after our analysis.

Our study also has several important limitations. First, the Internet search terms used in our study were generated by pregnant women at term, rather than women facing imminent periviable birth. This approach was taken after extensive deliberation with the study team and review board. We weighed the risk of the added stress and anxiety that participating in this study would cause a woman facing periviable birth versus the minimal added benefit that would come from asking the intended population to generate the search terms for our study. At the conclusion of our discussions, we felt a hypothetical approach with term women would generate realistic and useful search terms and opted for this approach. Second, we attempted to recreate how the patients would search the Internet for additional information regarding treatment options and outcomes surrounding a periviable birth and thus only one search engine

was used, which may limit the generalizability of our findings. This search engine, however, was overwhelmingly picked as the search engine of choice by our sample population and still provided a large amount of pilot data. Third, the review of the websites was completed on personal computers, as opposed to mobile phones, which are often the modality used by patients. Over two-thirds of Americans now own a mobile phone, and 62% of mobile phone owners use their mobile phone to get information about a health care condition [14]. In light of this, it is possible that the search engine may have organized websites differently, and the websites themselves may be navigated differently for mobile phone users. We used a validated questionnaire specifically designed to assess the quality of patient-targeted health information for treatment choices. There are other elements of website design that could meaningfully impact the user experience and patient education that we did not assess. These include ease of readability and use of illustrative graphics. Neither the ECT nor the DISCERN tool include patient perspectives in what they would define as a high-quality website, and we acknowledge that patients may desire different content within websites than physicians. We did not take into account the idea that parents have different values and the role of incorporating their values into decision making regarding periviable delivery, but these are important areas of future research. Finally, we did not consider the Internet self-efficacy or health literacy of our population. These are important areas for future investigation.

Although not the major focus of our study, 90% of our survey population indicated that in addition to high-quality information about prognosis and treatment for periviable neonates, they also wanted to learn about other patients' experiences with periviable birth and periviable decision making. This suggests that there is a patient desire for the inclusion of narratives in the educational component of preference-sensitive counseling and that providing these narratives in a balanced fashion may be important. It also speaks to potential gaps in counseling by health care providers. Understanding these gaps is an important research effort of our group as well as others [12]. We hope that the information generated by this pilot study will lead to a larger, comprehensive review of online resources available to patients facing a periviable birth.

Conclusions

Moving forward, the creation of an evidence-based Internet resource that addresses both short- and long-term neonatal outcomes, patients' values, the importance of shared decision making, and the option for comfort care should be developed to help parents make treatment decisions when facing a periviable delivery.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

The 10 essential topics pertinent to periviable birth.

[[PPTX File, 2MB - pediatrics_v2i1e12524_app1.pptx](#)]

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Abbreviations

ECT: Essential Content Tool

IQR: interquartile range

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Original Paper

Gamifying Breastfeeding for Fathers: Process Evaluation of the Milk Man Mobile App

Becky White¹, BSc (HlthPr), GradCert, PhD; Roslyn C Giglia², BAppSci, GradDipDiet, MPH, PhD; James A White³, BSocSc, GradDip, PhD; Satvinder Dhaliwal¹, BSc (Hons), MSc, PhD; Sharyn K Burns^{1,4}, BEd, DipTch (HPE), GradDipHlthProm, MPH, PhD; Jane A Scott^{1,4}, BAppSc, GradDipDiet, MPH, PhD

¹School of Public Health, Curtin University, Perth, Australia

²Telethon Kids Institute, University of Western Australia, Perth, Australia

³Reach Health Promotion Innovations, Perth, Australia

⁴Collaboration for Evidence, Research and Impact in Public Health, Curtin University, Perth, Australia

Corresponding Author:

Jane A Scott, BAppSc, GradDipDiet, MPH, PhD

School of Public Health

Curtin University

GPO Box U1987

Bentley

Perth, 6845

Australia

Phone: 61 8 9266 9050

Fax: 61 8 9266 2958

Email: jane.scott@curtin.edu.au

Abstract

Background: Mobile technology offers unique opportunities to reach people with health promotion interventions. Breastfeeding is an important public health issue, and fathers are a key support. Milk Man is a father-focused breastfeeding app that sought to engage fathers with information and conversation about breastfeeding, with the goal to impact positively on breastfeeding duration.

Objective: The study aimed to describe the process evaluation of the Milk Man app that was trialed in the Parent Infant Feeding Initiative randomized controlled trial.

Methods: The app used an information library, gamification, push notifications, and social connectivity via a Web-based conversation forum, which included polls and conversation starters, to engage fathers with breastfeeding information. Fathers had access to the app from approximately 32 weeks of gestation to 6 months postpartum. Process evaluation data were collected from a self-completed questionnaire administered via a Web-based link sent to participants at 6 weeks postpartum, and app analytics data were collected directly from the app. Quantitative data from both sources and qualitative responses to open-ended questions were used to triangulate findings to investigate patterns of usage and the effectiveness of each app engagement strategy to motivate and engage users.

Results: A total of 80.3% (586/730) of participants, who were randomized to receive the app, downloaded Milk Man. Push notifications and interest in what other fathers had posted in the forum were the 2 main motivators to app use. Fathers used the app most while their partners were still pregnant and in the weeks immediately after the birth of their baby. Perspectives on the gamification strategy were varied. However, at 6 weeks postpartum, approximately one-third of fathers still using the app said that the gamification elements were encouraging the app use. The ease of use of the app and the design were important elements that were rated positively. The conversation forum emerged as the hub of app activity; all but 1 of the most accessed library articles and external organization links had been prompted as part of a conversation starter. Fathers posted comments in the conversation forum 1126 times (average of 2.21 per user) and voted in polls 3096 times (average of 6 per user).

Conclusions: These results demonstrate that the Milk Man app was an acceptable source of breastfeeding information and support that fathers and fathers-to-be are prepared to use throughout the perinatal period. The app showed encouraging results with facilitating conversation between partners. The conversation forum was clearly central to the success of the app, and fathers provided suggestions for improvement. Gamification results were varied, yet it was a key motivator for some users. These results

provide valuable insight into the acceptability of the engagement strategies, including motivations for use and user perspectives on the app.

Trial Registration: Australian New Zealand Clinical Trials Registry ACTRN12614000605695; <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12614000605695>

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KEYWORDS

mHealth; app; breastfeeding; fathers; gamification; socially connected; push notifications

Introduction

Breastfeeding

Breastfeeding is a key public health issue with well-evidenced health benefits for both infants and mothers [1,2]. For infants, short-term benefits include protection from gastrointestinal and respiratory tract infections, otitis media, and sudden infant death syndrome [3-5], and long-term benefits include a lower risk of obesity and type 2 diabetes [6]. For mothers, benefits include a reduction in the risk of ovarian and breast cancer, diabetes, and hypertension [2,7]. The World Health Organization recommends exclusive breastfeeding for the first 6 months of life, with breastfeeding to continue thereafter with the introduction of complementary foods [8]. Despite near-universal initiation of breastfeeding among Australian women [9], the latest available data (2014-2015) from the National Health Survey indicate that only one-quarter (24.7%) of infants are exclusively breastfed to at least 6 months [10], and less than 6 out of every 10 infants receive any breast milk at the age of 6 months [9]. These statistics have remained relatively stagnant for the last two decades or so [11], and new and innovative ways of increasing the duration and exclusivity of breastfeeding are urgently needed to ensure that most Australian children (and their mothers) receive maximum and continued benefits of breastfeeding.

Social Support and Breastfeeding

Although there are many complex factors that can impact on breastfeeding [12,13], social support is one of the most crucial [14]. In Western societies in particular, there is convincing evidence that fathers are a key source of breastfeeding support and influence decisions regarding both the initiation [15,16] and duration [17,18] of breastfeeding and contribute to maternal breastfeeding confidence [19,20]. Due to the value of this support, much research has been conducted to define what contributes to positive paternal support, and how health professionals can better support fathers [21-23]. Previous empirical and qualitative studies tell us that fathers want the following: more education to feel more empowered about their role in breastfeeding, increased social support, and help to overcome specific barriers (including public breastfeeding and perceived bonding postponement) [22-25].

However, while they are encouraged to, and often do, attend antenatal classes with their partners, these classes are generally directed at the mother, and men feel left out or feel that their role and their information and support needs are not a priority [26]. Furthermore, work commitments may limit a man's involvement in their partner's pregnancy care and the number

of antenatal classes and appointments that they can attend [27]. Information and support, therefore, needs to be targeted toward men in a way that is appropriate and readily accessible [27].

Mobile Technology and Health Promotion

Electronic and mobile technology offers public health researchers unique opportunities to reach people with health information and tailored interventions with a wide reach and at a low cost. Parents have traditionally accessed the internet for information on pregnancy and early parenting [28,29], but newer digital media information sources, such as apps and social media platforms, are increasingly being used [28,30]. Men are seeking information about parenting and infant care (including breastfeeding), supporting and improving their relationship with their partner, and managing stress [29]. They are accustomed to ready and immediate access to information using digital technologies and want better access to information than that offered by health professionals [28]. Mobile technology can provide the user with accessible information despite geographical distance or time constraints, and the immediacy of this technology provides users with information when it is most needed [28]. Peer support can be provided through app-based and Web-based forums and can assist the transition to fatherhood by providing fathers with the opportunity to share information and experiences, mutual support, and the recognition that they are not alone with their problems [31,32].

Although digital technologies, including mobile apps, targeted at mothers have been used successfully to improve breastfeeding outcomes [33], there were no digital technology-based breastfeeding interventions specifically targeting fathers at the time this research was conceived. Smartphone ownership is almost universal (89%) among Australian adults across men and women [34]. The Milk Man app was conceived as a novel way of delivering targeted breastfeeding information to fathers in a readily accessible format. Little was known about how fathers would receive and use such an app. There is a growing consensus that the concept of engagement in digital health interventions encompasses a range of metrics including both usage and reported experience [35]. This paper adds to the evidence by describing the process evaluation of the Milk Man app, investigating which of the app engagement strategies were effective in motivating and engaging users in app use by using a combination of data from the app analytics framework as well as self-report data from a questionnaire.

Methods

The Milk Man App

Milk Man was a mobile app designed to provide fathers with information and support about breastfeeding and was developed to be trialed in the Parent Infant Feeding Initiative (PIFI), a 4-armed factorial randomized controlled trial (RCT; ACTRN12614000605695) [36]. The PIFI study aimed to examine the impact on breastfeeding duration of 2 separate father-focused breastfeeding interventions (a male-facilitated, father-focused, antenatal breastfeeding class and the Milk Man app) both in isolation and in combination, compared with a control group that received usual care.

The app's design and development have been described previously [37]; in brief, Milk Man was developed based on a best practice approach [38] that involved development by a multidisciplinary team, in consultation with new and expecting fathers and was based on the social cognitive theory [39]. A range of sophisticated engagement strategies, designed to encourage fathers to start and continue using the app, were employed. The app contained a comprehensive evidence-based information library presented in a colloquial and light-hearted manner. The library included information about a wide variety of breastfeeding-related topics and broader parenting topics, posted by the research team, that were designed to encourage fathers to read the information in the library. A list of the library headers has been included in [Multimedia Appendix 1](#).

Fathers were placed into a group with others at a similar perinatal stage to facilitate relevant conversations. The conversation also used polls comprising multiple-choice questions, where users could choose an answer and view the aggregated responses of other users. Biweekly push notifications were used to alert the fathers to new content being added to this conversation and to remind them to check-in. The notifications were sent around lunchtime, and it read as follows: *there's a new conversation starting*. Users could swipe the notification to be taken directly to the new content in the conversation. The conversation forum was monitored by researchers throughout

the study [31]. The app's engagement strategy was underpinned by gamification. Gamification elements, such as points, badges, and leaderboards, were integrated into the app, and fathers received virtual rewards in the form of points for completing the actions the researchers wanted to encourage, such as reading articles and commenting on forum posts. A 2-tiered leaderboard system was introduced whereby participants could see their position on the leaderboard, both within their own group and within the whole cohort. [Figure 1](#) shows the introductory onboarding screens shown to users when they first opened the Milk Man app, explaining the various components of the app, including the library, conversation, points, badges, and leaderboards.

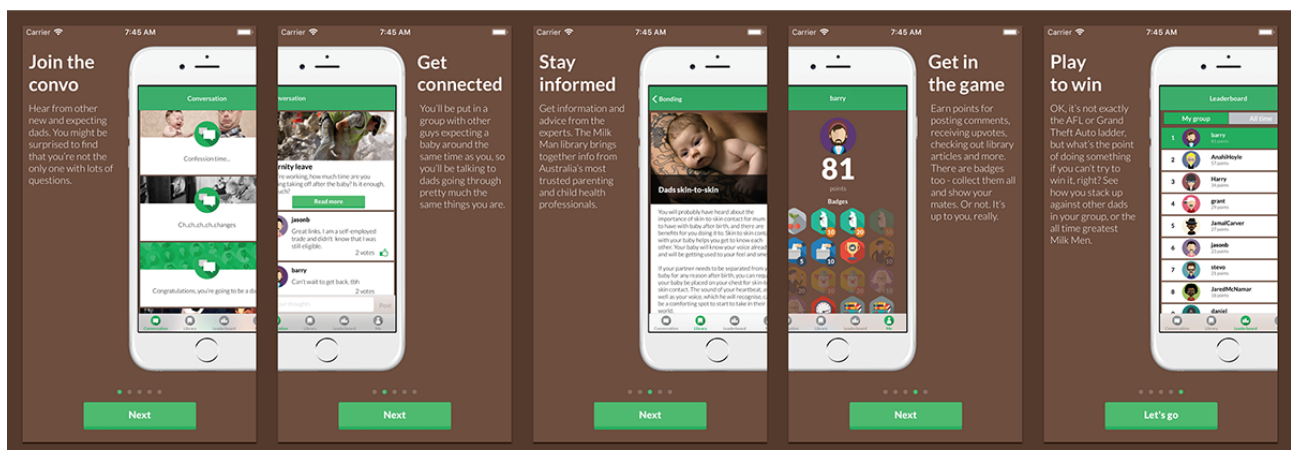
Participants

Participants were recruited directly by members of the research team from hospital-based antenatal classes in metropolitan Perth, Western Australia, between August 2015 and December 2016. Couples were eligible to participate if they owned a compatible smartphone (iOS or Android), lived in Western Australia, had internet access, spoke English, and if both parents intended to coparent their child. Signed informed consent was obtained face to face from both fathers and mothers at the time of recruitment. The study was approved by the Curtin University Human Research Ethics Committee (HR 82/2014; May 14, 2014).

Study Design

Fathers randomized into either of the 2 intervention groups that had access to the Milk Man app were provided with instructions on how to access the app. There was no prescribed usage; participants were asked to use the app as they would use any other app. Fathers had access to Milk Man from when they signed up for the study (at an average of 32.5 gestational weeks) to 26 weeks postpartum. Questionnaire data were collected at recruitment and at 6 and 26 weeks postpartum. Preliminary analysis of the data revealed that app usage was the highest in the first 6 weeks and declined thereafter and that little new information was obtained from the 26 weeks questionnaire. Hence, this study reports results to 6 weeks postpartum.

Figure 1. Milk Man onboarding screenshots.



Process evaluation describes the implementation of an intervention and seeks to understand how the study functioned and how participants reacted [40]. A comprehensive evaluation plan was developed for the study that has been described previously [41]. On the basis of a framework developed by O'Grady et al [42], the evaluation plan outlined evaluation indicators over 5 distinct focus areas: *people*, *content*, *technology*, *computer-mediated technology*, and *health system integration*. The results of the process evaluation are presented according to these 5 areas of focus that are briefly defined below:

- **People:** Fathers' perspectives on the app including intentions and motivators for use and satisfaction with the app.
- **Content:** The library content built into the app and the dynamic user-generated content in the conversation forum. User' perspectives on the key engagement strategies are also included in this section including gamification and push notifications.
- **Technology:** This refers to describing and monitoring the software that was created to run the app, including tracking how participants used the app and the response of the software to operating system updates for the duration of the trial.
- **Computer-mediated technology:** This refers to the interaction of the users and the app interface and whether this supported community interaction. It includes examining how easy it was for participants to locate information and the usability of the app and the user perspectives on the app in general.
- **Health system integration:** The impact the app had on the participants' use of other services. These were measured through app-originated visits to external service provider's websites.

Quantitative evaluation data were collected from 2 different sources, a custom-built app analytics framework and a Web-based questionnaire, the link to which was sent to fathers via an email at 6 weeks postpartum. The analytic framework was embedded in the Milk Man app, and it recorded user actions performed in the app over time. These actions included app opens, the article reads, and engagement in the gamification and conversation forum. The framework allowed for more fine-grained analysis and data matching as compared with other commercially available frameworks and was integral to the ongoing monitoring of the robust process evaluation indicators.

The questionnaire sought the fathers' perspectives of the Milk Man app. The questions were specific for this study and were guided by the key items that have been identified as important in app quality—engagement, functionality, aesthetics, information, and personal opinion [43]. Most questions required respondents to indicate on a 5-point Likert scale the degree to which they agreed or disagreed with a statement related to the usability and acceptability of the app, with some additional questions presented as an open text response or a multiple-choice question. To reduce participant burden, none of the questions in the questionnaire were compulsory to answer, and the denominators presented in this paper show the actual number of respondents to each individual question. Qualitative responses to open-ended questions are used as quotes to illustrate the sentiments of app users. The questions asked about the Milk Man app are included as [Multimedia Appendix 2](#).

Results

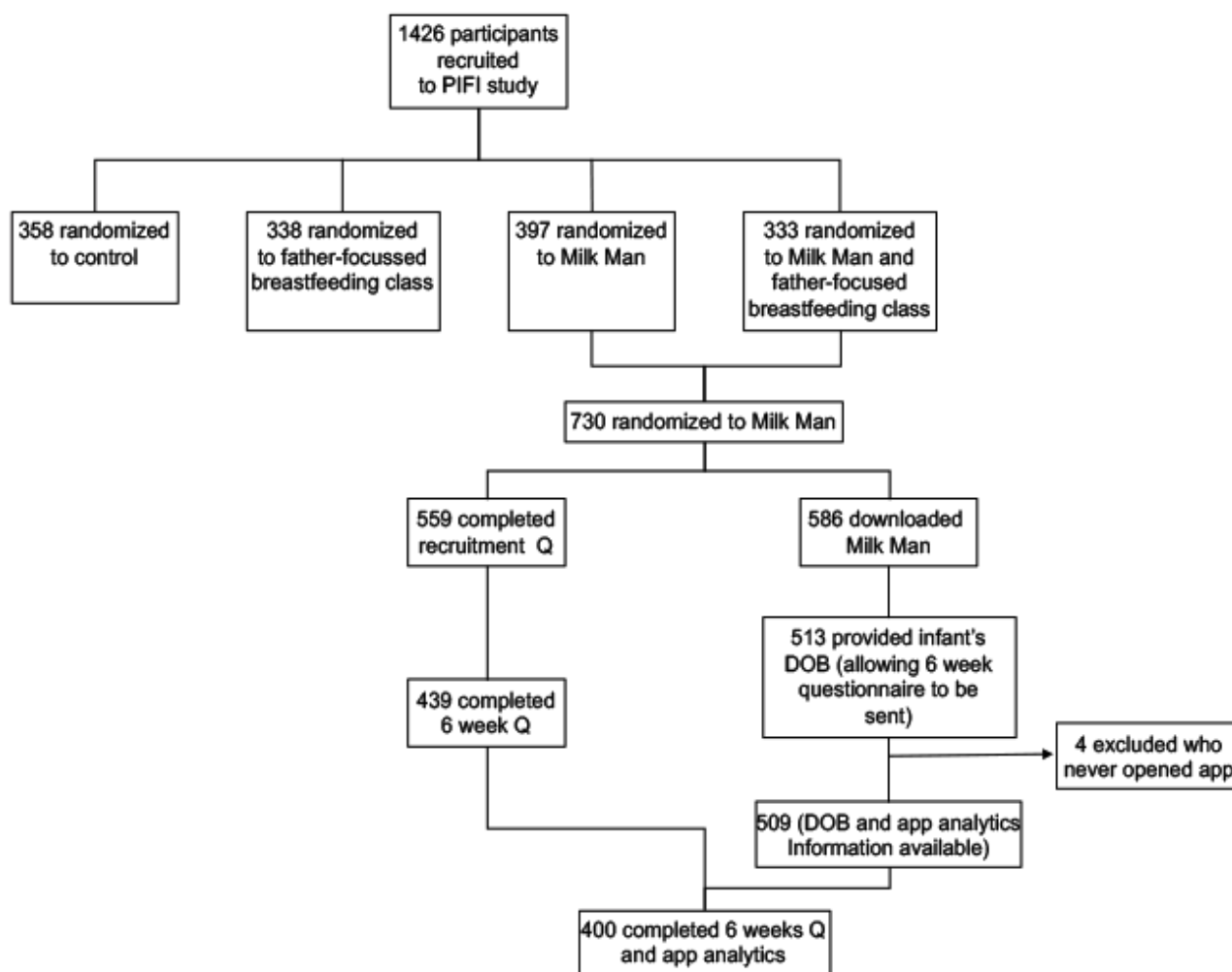
Participant Characteristics

A total of 1426 couples were recruited to the RCT, with 51.19% (730/1426) of couples being assigned to an intervention group with access to Milk Man. Of these, 80.3% (586/730) of the fathers downloaded the Milk Man app, providing app analytics data. The fathers were asked to provide the date of birth of their baby, and this was needed to enable the 6-week questionnaire to be sent out and for mapping of the analytics over time. A total of 76.6% (559/730) and 60.1% (439/730) of the fathers completed the baseline and the 6-week questionnaires, respectively. [Figure 2](#) shows the participant flow in the study.

A summary of baseline demographics for those with access to Milk Man is presented in [Table 1](#). The median age of fathers (33.0 years) was similar to that of Australian fathers of newborn children (33.3 years) [44]. Most of the PIFI cohort (66.2%) were born in Australia, which also mirrors the general population (67%) [45]. However, they were more highly educated than the general population as only 25.4% of Australian men aged between 20 and 39 years have completed a Bachelor's degree or higher [46].

Process Evaluation Indicators

For clarity of reporting, throughout the Results section, participants are referred to as *respondents* when data derived from the questionnaires completed at 6 weeks are reported, and as *users* when data collected from the app analytics framework are reported.

Figure 2. Participant flowchart. PIFI: Parent Infant Feeding Initiative; DOB: date of birth; Q: Questionnaire.**Table 1.** App group participant demographic characteristics.

Characteristic	Parent Infant Feeding Initiative, n (%)
Age (years; n=559)	
<30	97 (17.3)
30-34	249 (44.5)
35+	213 (38.1)
Education (n=550)	
High school or trade certificate	201 (36.5)
Undergraduate university education or higher	349 (63.5)
Country of birth (n=551)	
Australia/New Zealand	365 (66.2)
United Kingdom/Eire	69 (12.5)
Africa/Middle East	39 (7.1)
Asia	39 (7.1)
Other	39 (7.1)

People

The majority of fathers responding to the 6-week questionnaire (367/390, 94.1%) indicated that they had downloaded the Milk Man app. The most common reasons given by respondents for not downloading the app were either *too busy* or *just not gotten around to it*. Motivators for using the Milk Man app are described in Figure 3. Push notifications were the highest reported motivating factor (n=164). This was followed by liking seeing what other dads had written (n=129) and the need to find information (n=109).

Overall, respondents' perspectives on the app were positive. In total, 247 of 296 responders (83.4%) agreed that the app was easy to use, and 231 of 296 responders (78.0%) said the visual design was appealing. Two-thirds of respondents would recommend the app to other fathers (199/296), and 59.0% of respondents agreed that it was interesting or fun to use (170/288). In terms of actual breastfeeding support, 54.6% of respondents (161/295) agreed that the app had made them more aware of how they could help with breastfeeding, and a similar proportion of respondents (160/296, 54.0%) indicated that the app had led to discussions with their partner.

Content

Information Library

App analytics data showed the range of library articles viewed by users was 0 to 79 (mean 11.46 per participant, SD 13.7). All

except 1 of the most frequently accessed articles were linked to via a conversation topic. Many of the library articles contained links to external sources including websites and YouTube videos. Users followed unique links to external sites (not including multiple visits to the same link over time) between 0 and 43 times. The average number of unique links followed per person was 3 (SD 5.3). The top 10 most followed links were all associated with topics in the conversation forum, either by a direct link from the topic or from a library article the topic linked to.

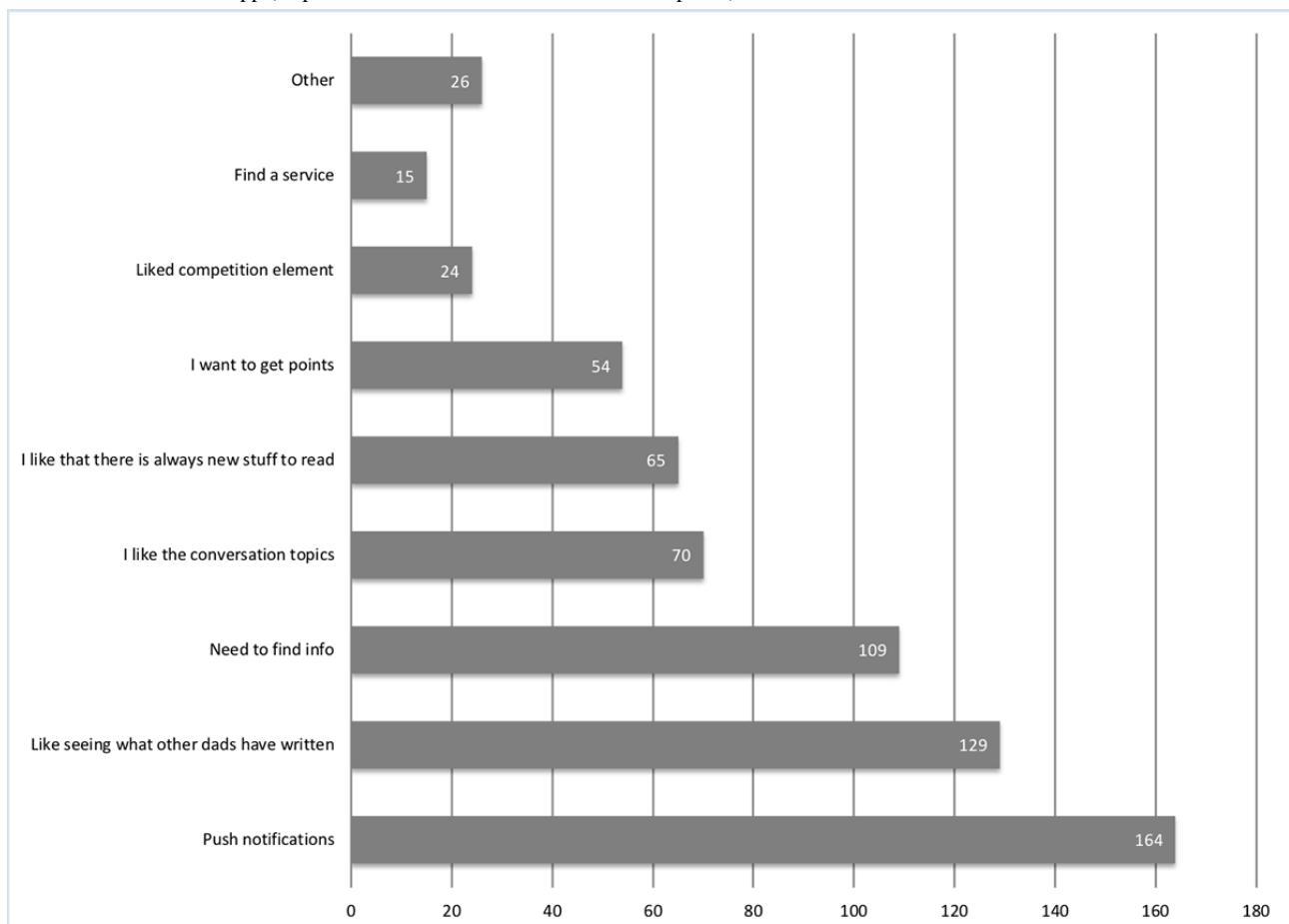
Overall, responses to the 6-week questionnaire, regarding perspectives on the library, were positive and demonstrated value to respondents. Two-thirds of respondents reported that they found the information easy to find (201/297, 67.7%) and that the links were appropriate and useful (194/296, 65.5%). The following comments from the 6-week questionnaire reinforce these results:

The information was useful and especially links to other websites and organisation[s].

It's helpful to have information at your fingertips.

Informative, fun and covers different areas of breastfeeding.

Figure 3. Motivators to use app (respondents could choose more than one response).



A total of 72.3% of respondents (214/296) said that they learned new information from the library, whereas 78.4% of respondents (233/297) trusted the information. However, only 23.6% of respondents (70/296) reported using the app when they needed to find information, and 57.6% of respondents (171/297) agreed that the library contained enough information. The following comments were received from the fathers in the 6-week questionnaire:

Maybe more content in the LIBRARY that doesn't necessarily focus as much on breastfeeding but on other newborn baby facts/issues/problems/events.

It's actually very good like it is. More contents would be good though.

Conversation

The total number of comments posted in the conversation forum by users was 1126. The number of comments made by each participant ranged from 0 to 57 with an average of 2.21 (SD 5.246). The fathers used the conversation to offer and seek social support, to source connection and information, and to share experiences. Users voted on polls 3096 times.

The fathers were asked their perspectives on the conversation section of the app. The responses to each of the questions in the 6-week questionnaire are displayed in Table 2. Overall, 63.0% of respondents (186/295) agreed (choosing to agree or strongly agree) that it was good to hear from other dads; however, only 29.9% (89/297) agreed that they found the conversation engaging. In addition, 37.1% of respondents (110/296) reportedly returned to the conversation after first viewing the topic to see if there were any new comments in the thread.

Respondents to the 6-week questionnaire were also asked about the impact the app had on generating conversations. A total of 54.1% (160/296) said that the information in the app had led to conversations with their partner, and 52.5% (156/297) said that the conversation forum itself had prompted discussions. These results were more pronounced for those who used the app for a longer period. Of those respondents who had stopped using Milk Man before 6 weeks postpartum, 38.3% (54/141) said that the conversation forum had prompted a discussion with their partner, compared with 65.4% (102/156) who were still using it at 6-weeks postpartum. Similarly, only 34.3% (48/140) of respondents not using the app at 6 weeks postpartum said that the information in the app had prompted a discussion, compared

with 71.8% (112/156) who were still using the app. Respondents also provided comments indicating that the app was raising new information:

[Good for] generating discussion for something not normally considered.

[I liked] Different topics provided that fathers may not have thought to discuss or read up on.

Due to the way fathers were grouped depending on when their baby was due, the sizes of some of the conversation groups were quite small (group numbers ranged from 16 to 47), and the small numbers in some groups impacted the level of conversation. Several of the fathers noted that having an active researcher participating in the conversation could be of benefit:

It's pretty quiet in there, hardly any interaction to comments. Need to get someone in there to reply to comments, get things going a bit in there.

The community is either not big enough or I am limited to only being exposed to what my own group posts. I find most of the time the conversation sections are empty. I post something and rarely does anyone else respond. I am 11th in the leaderboard and feel I have barely contributed. The people above me I have basically never seen post so maybe they used it a while ago and have since stopped?

Other suggestions for increasing collaboration included incorporating threaded replies and increasing the number of polls. A total of 4 fathers suggested incorporating a face-to-face aspect would be beneficial as well:

I think the app would work better if you had met the other dads a few times.

A real-world meetup would be nice as well - over a couple of beers.

The conversation was also one of the most commonly cited aspects that the fathers liked about the app. Some fathers reported that the conversation had helped them feel less alone and had created a sense of community. Others reported enjoying the polls, talking to others, and the humor:

Hearing from other dads; the community feel.

Helpful tips from other blokes who are in the same position.

It's a reminder that I'm not alone!

Table 2. User perspectives on the conversation.

User perspectives on Milk Man Conversation Forum	Agree or strongly agree, n (%)	Neither agree nor disagree, n (%)	Disagree or strongly disagree, n (%)
I find the conversation engaging (n=297)	89 (29.9)	125 (42.1)	83 (27.9)
It was good hearing from other dads (n=295)	186 (63.0)	84 (28.5)	25 (8.5)
I sometimes returned to the conversation to see if there were any new comments (n=296)	110 (37.2)	88 (29.7)	98 (33.1)
I trusted the information in the conversation (n=297)	89 (29.9)	170 (57.2)	38 (12.8)
I have acted on advice that I have read in the conversation (n=297)	57 (19.2)	149 (50.1)	91 (30.6)

Push Notifications

The most common thing that motivated the responders to the 6-week questionnaire to use the app was receiving the biweekly push notifications. This is reinforced by app analytics data on the usage of the app showing consistent spikes in activity on the days new content was added to the conversation and the push notifications were sent out. The usage over a 1-month period is displayed in Figure 4, demonstrating consistent spikes in activity on the days push notifications were sent out. This usage was typical of what was observed throughout the study. The average number of times that users swiped into the app from the push notifications was 2.5, and this indicated that although the swipe function was not highly used, the push notifications were a trigger for app use.

Gamification

Users earned points for their level of participation with the different components of the app. The number of points achieved by users ranged from 0 to 153 with an average of 22.24 per user (SD 25.6). Badges were another feature of the gamification strategy and were earned for completing certain actions. The most commonly achieved badges were as follows: voting on 5 polls (n=231), reading 10 articles (n=195), posting their first comment (n=187), opening the app 5 weeks in a row (n=184), and voting on 10 polls (n=155).

For those who were still using the app at 6-weeks postpartum, approximately one-third of respondents said that the gamification elements were encouraging that use. This included earning points (64/156, 41.0%), earning badges (54/156, 34.6%), and their position on the leaderboard (43/154, 27.9%). Those who had stopped using the app before completing the 6-week questionnaire were significantly less likely to agree that any of the gamification functions encouraged their use ($P<.001$).

There was a diverse range in respondents' opinions on the gamification. Some fathers reported enjoying the gamification elements and said that aspects of it actively encouraged their continued use of the app, with some reporting that it was their main motivator:

Have you seen my points? I'm totally kicking ass.

[I liked] the competition aspect.

Others, however, did not like it and some respondents reported that it discouraged their use of the app. The following comments were posted in response to the open-ended questions asking what respondents liked about the app, and what could improve it:

Make it a little easier to earn points and badges, at least initially, to motivate use.

Review the points system as having points for people liking your comments etc creates scenarios of people making comments for the sake of it to get points.

Change out the leaderboard style for one where people earn status credentials, where people's credentials are listed next to their name on posts. E.g. such as how's it is done with reviewers in Amazon. Personally I do not want to be listed on a leaderboard on this kind of app; it didn't encourage me to use the app.

Technology

The app was built for the iOS and Android platforms and included a customized app analytics framework that tracked how and when individual fathers were using the app over time. Figure 5 shows the aggregated total number of unique days the app was opened each week, ranging from 10 weeks before birth, to 6 weeks after the birth of their baby. The graph shows that the highest usage of the app by fathers was in the week their baby was born.

Figure 4. App usage over a 1-month period.

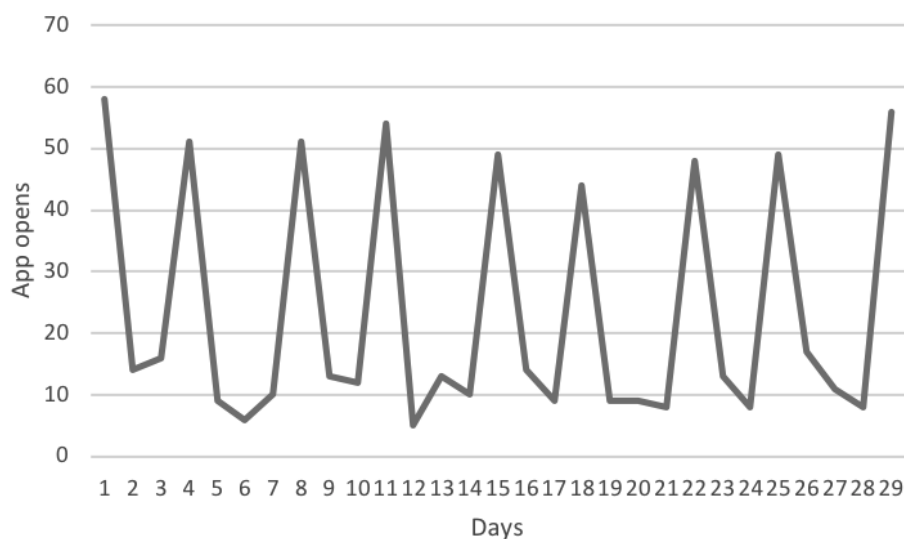
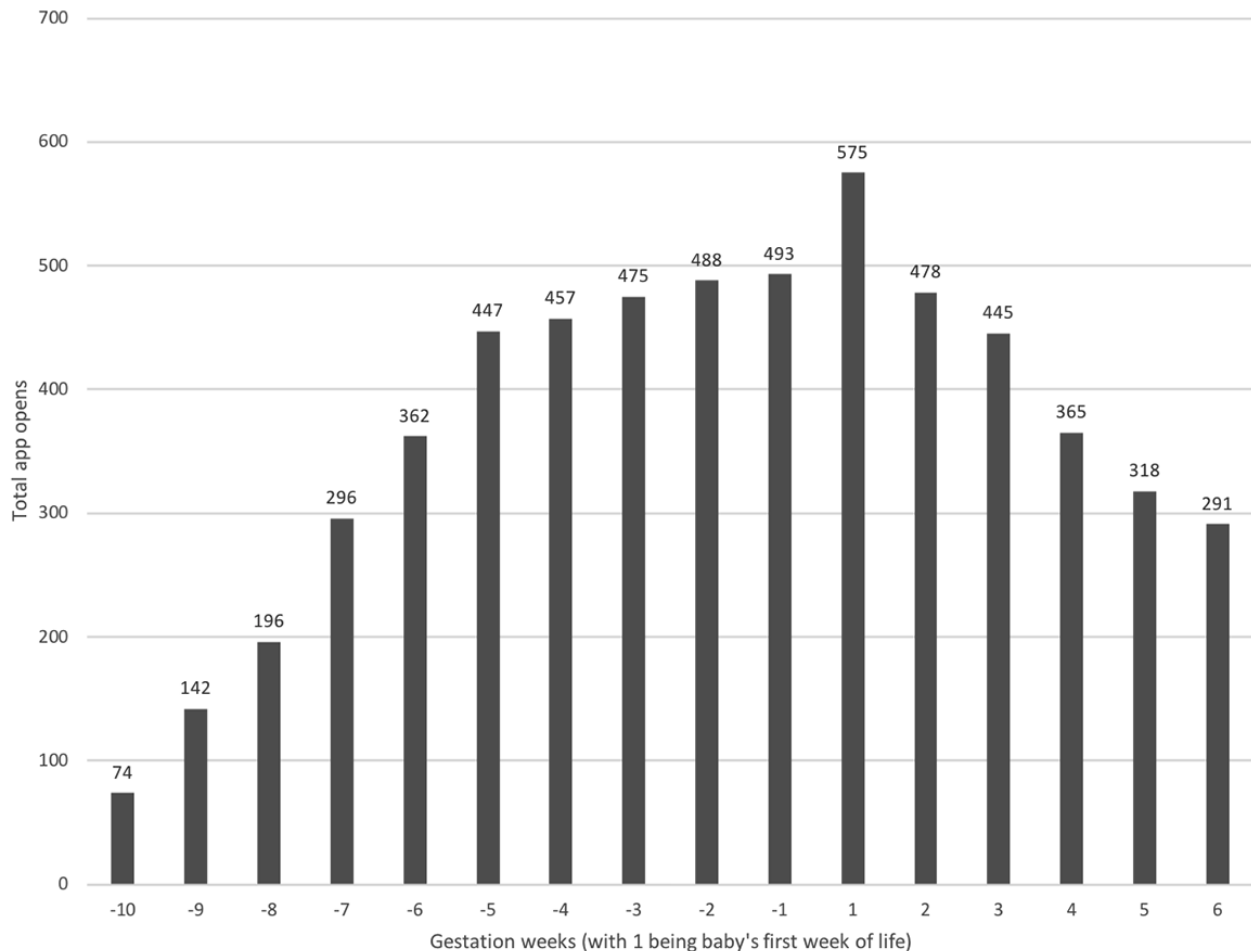


Figure 5. Unique days app was opened over time.

During the implementation of the study (24 months), there were 4 operating system updates (2 iOS and 2 Android), and the app required updating a total of 4 times. A detailed log was kept of each technological event that happened over the trial period and the impact it had on the app intervention and app users. There were 2 major technological events that had an impact on the app during the intervention. The first was the retiring of the Parse service that was hosting the backend of the app, resulting in the need to migrate the backend to another hosting service midtrial. The second was the identification of a bug that prevented some users from viewing the conversation. Close monitoring of the analytics framework during and after these events demonstrated minimal impact on participants' use of the app and on the trial.

Computer-Mediated Technology

Findability, usability, and functionality are important concepts in information technology. Over two-thirds of respondents (199/297, 67.0%) agreed or strongly agreed that the information was easy to find within the app. A total of 83.4% (247/296) of respondents said that they found the app easy to use, and 78.0% (231/296) agreed that the visual design was appealing.

These findings were reinforced by qualitative data from the questionnaires. When asked what they liked about the app, comments about both the design and the ease of use were common. Of the 139 open-ended responses received, 23 specifically referenced the app design in a positive manner, and

31 said they liked how easy the app was to use. Comments about the design of the app covered specific features such as the graphics, the visual design, the general layout, and how well it worked:

Well designed and very engaging.

I have no interest in the points thing but I thought it was good stuff, well done. I thought the app was really well put together.

Easy to use right on your smart phone to check regularly.

In considering the collaboration of the community, when examining responses to open-ended questions asking the fathers what they liked about Milk Man, many respondents (38/139, 27.3%) made specific suggestions for improving the conversation that would better support interaction and collaboration. The most common suggestion was for the fathers to be able to start their own conversation topics, as this was not available during the trial, and fathers could only comment on researcher-generated content:

Also, changing the format of the CONVERSATION aspect to maybe allow users to create their own conversation and polls on particular topics that they might be seeking guidance or support on.

A chat section where we can start conversations or ask questions and answer each other's questions. At

the moment we can only talk about what Milk Man posts.

Health System Integration

Health system integration represents the larger system in which the intervention is being implemented. This was measured at the process evaluation level by examining how the app facilitated access to other services. Users used the app to access the websites of other health organizations a total of 912 times. This includes government and nongovernment health organizations. The 2 most common websites visited were the Raising Children Network (329) and the Australian Breastfeeding Association (264).

Discussion

Principal Findings

The findings described in this study demonstrate both the usage and user perspectives of the Milk Man mobile app. One of the strengths of this study is that app usage was not prescribed. The fathers were asked to use the app as they would use it in real life rather than, for example, being asked to spend a certain number of hours using it each week. This resulted in a wide variance in usage patterns, which is likely to reflect a real-life situation. The process evaluation provided 7 key insights:

- The Milk Man app intervention is an acceptable approach, and the weeks immediately around the time of their baby's birth may be a key time to reach fathers with information.
- The conversation forum emerged as the hub of app activity; however, there are ways it could be strengthened.
- Push notifications were an effective way of encouraging engagement.
- The library was well received and trusted, but the fathers wanted additional and more comprehensive information.
- Gamification can be a powerful motivator for usage for some members of this target group.
- The app showed encouraging results in facilitating conversations between partners.
- Working in partnership with the app developer throughout the trial was beneficial.

Acceptable Approach

The data show that the Milk Man app intervention was an acceptable approach and one that the fathers were prepared to engage with and received value from. User perspectives confirmed this, with high percentages of fathers agreeing that the app was easy to use, the visual design was appealing, and that they would recommend the app to other fathers. The usage data suggested that the weeks immediately before and after the birth of their baby may be a key time to reach fathers with information. Milk Man is the first breastfeeding app targeted to fathers, and the research on using digital interventions to reach new fathers is in its infancy. This finding of acceptability is important as other studies have demonstrated that while fathers are important in providing breastfeeding support to their partners, they can sometimes feel that antenatal education is not targeted to them [25,47,48].

The Conversation Forum Was Central

There was little in the literature to suggest how fathers would use a breastfeeding conversation forum; however, the forum emerged as the focal point of the app. When asked what motivated them to use the app, *liking seeing what other dads have written* was the second highest motivator. Almost all the most read library articles and external links followed from the app originated from links within the conversation forum. Our team has previously reported how fathers have used the app to seek and offer social support [31]. This finding is consistent with that of other researchers who have reported that fathers use parenting forums to find emotional support [28], with parenting websites being particularly helpful in supporting men's transition to fathering [49].

Whereas the conversation was clearly important, some of the overall perspectives on its value were relatively low. Although 63% of respondents said it was good hearing from other dads, only 30% found the conversation engaging, and only 30% trusted the information in the forum. There are real opportunities to explore further how this forum could best work on a population level, and participants had some suggestions for how to improve it.

The main suggestion was the ability for fathers to start their own conversation topics. Several fathers also suggested that having an active researcher participating in the conversation could be beneficial. Electronic coaching has been demonstrated as a promising approach to healthy lifestyle interventions [50], yet little is known about how this would impact a father-focused perinatal intervention. Having an active peer-facilitator embedded in the app may help to start conversations, to answer respondents, and increase opportunities for conversations and support. A higher percentage of fathers commented in the Milk Man conversation forum as compared with what has been observed in other studies [31]. Trialing the app on a population level will increase the number of fathers in each group and potentially impact the level and quality of conversation.

Push Notifications

The push notifications proved to be an effective way of encouraging engagement with a mobile app and the analytics data show that there was increased app activity on the days that new content was added to the app and the push notifications were sent out. This was reinforced by fathers stating that the push notifications were the highest factor motivating their use of the app. Push notifications have been associated with increased engagement in other studies [51], including with a workplace health promotion intervention reporting users being more likely to engage with the app in the 24 hours after a notification was sent [52]. There is a balance to be struck as too many push notifications may be annoying and cause people to turn them off, and too few may cause people to lose connection with the intervention. The Milk Man app sent 2 notifications each week, however, more may be acceptable, particularly in the weeks immediately before and after the birth of the baby when usage was at the highest. More research is needed to understand the optimal schedule.

Library

The use of the information in the library section was strongly associated with the conversation forum. Articles and websites that contained links from the conversation were more likely to be highly accessed. The app was useful as a gateway to other organizations. The top 2 external websites visited were national peak bodies (Raising Children Network and the Australian Breastfeeding Association) that are sources of credible and reliable information.

Fathers (79%) trusted the information in the library section, yet only 25% reported coming to the app when they needed to source information. The library contained information on topics broader than breastfeeding, including sleep, crying, fatherhood, and mental health among others. Despite this, there was a strong push for more diverse and greater quantity of content in the library. Repositioning the app to be both a breastfeeding *and* early parenting app may help with this. Recent research with new and expecting parents in Canada has highlighted the need for breastfeeding information to be provided in a broad context. [53] This needs assessment for an infant feeding website found that fathers most wanted information on the benefits of breastfeeding, identifying babies' cues, how fathers can be involved and help their partners with breastfeeding, and what to expect in the early days.

Gamification

Use of the gamification strategy was mixed in this study. Some fathers embraced it and it was their main motivator for using the app, whereas others reported that it had an adverse impact. There were differences in how people perceived gamification, with participants who were still using the app at 6-weeks postpartum being significantly more likely to report that the gamification functions were encouraging use, than those who stopped before 6 weeks. Other researchers have found that gamification can positively impact aspects of engagement [54], and more research is needed to better understand this dynamic in the context of Milk Man.

This study has shown that gamification can be a powerful motivator with this target group; however, care needs to be taken to better understand how its inclusion may impact those who reported not enjoying it, and the app should include the option of being fully functional without participation in the gamification.

Conversation Between Parents

A key intent of the app was to increase parental self-efficacy by encouraging communication between parents. This, along with increasing understanding and knowledge about breastfeeding, was important in giving parents the tools to work together. Throughout the app, the content regularly suggested that fathers *check-in* with their partners about different issues. Over half of the fathers overall said that the information in the app had led to a discussion with their partner. This was more apparent for those participants who were still using the app at 6 weeks postpartum. Aiming to keep people engaged with the app for a longer period may increase the level of discussion between partners.

The findings from this study showed promising results in terms of fathers discussing or showing their partner something from the app. Research from a text messaging-based study for fathers has also found that targeted content delivered in a mobile intervention can encourage conversation between parents [55]. These are important findings as parents who work together to prepare for challenges and changes in the perinatal period fare better in terms of mental health outcomes compared with those who do not [56].

Partnership With App Developer

Many researchers have recommended bringing app developers onboard early in the ideation process and involving them in the project planning and implementation [38,57,58]. Our project benefited significantly from implementing this recommendation, and the app developer was engaged at the design and ideation phase of the study and remained a team member throughout. In addition, the app developer contributed heavily to the app's design and usability, both of which were key factors with many participants.

Trialing an app over a 24-month period is a long time, and there were several technological events identified over this time period, including software bugs and operating system updates. The customized analytics framework embedded in the app allowed for fine-grained monitoring of per-user use and early detection of technical issues. The issues that were identified could be addressed quickly and smoothly with minimal disruption to participants and the project implementation. Other studies have reported difficulties working with app developers or with technological challenges impacting the study implementation [59-61]. By engaging app developers as part of the research team and having them be, in part, responsible for monitoring the implementation throughout the trial, technological challenges are more likely to be identified earlier and addressed promptly.

Recommendations

This paper adds significant understanding of on how to effectively use a mobile app to reach fathers with information during the perinatal period and has resulted in the following recommendations for future research:

- In developing mobile apps for fathers, considered engagement is key. Incorporating regular push notifications that are carefully timed and linked to new content can be an effective way of encouraging engagement with a mobile app.
- Incorporating user consultation throughout the app development process and working in partnership with app developers are important steps.
- The weeks immediately around the birth of their child are likely to be a key time when fathers are receptive to new information, and more information and support should be targeted toward fathers at this important time.
- Gamification can be a powerful motivator with this target group; however, care needs to be taken to understand how its inclusion may impact those who do not enjoy it, and apps should be fully functional without participating in the gamification.

- The Milk Man app should be released publicly in Australia to enable research into the impact and the engagement of fathers on a national level.
- To standardize and ensure best practice in app development, public health researchers should consider broad process evaluation plans. Researchers should plan ways to closely monitor the robustness of the technology over time to ensure any impact on the intervention is identified and addressed quickly.

Strengths and Limitations

A strength of this study is the triangulation of robust and objective app usage data collected from the custom-built app analytics framework, with more subjective quantitative data collected from users via a Web-based questionnaire. The combination of both types of quantitative data was integral in understanding user involvement in the study and how that impacted on process evaluation indicators. The comprehensive approach to reporting on process evaluation provides a framework that can be adapted by other researchers. A notable limitation of this study was that not all participants completed the 6-week questionnaire, which resulted in a gap in understanding of their motivation to use the app. Having brief incidental assessments delivered through the app directly could have been one way of mitigating this loss.

A further limitation relates to the generalizability of the findings as all participants were from metropolitan Perth and were more highly educated than the general population, which may have biased the results. In addition, participants were recruited directly from antenatal classes. As these classes are recommended by care providers, but not mandated, this may have introduced a bias in that participants may already be more engaged with childbirth and breastfeeding than other members of the target group. Further research needs to be undertaken to understand the acceptability and impact of this method with people living outside of the Perth area, with Aboriginal and

Torres Strait Islander parents, culturally and linguistically diverse parents, and with other specific populations.

Conclusions

Although this paper does not report on the effectiveness of the Milk Man mobile app in relation to breastfeeding outcomes, it does provide useful insights into the effectiveness of the innovative strategies that were incorporated in the app to encourage fathers to use the app. As this was the first breastfeeding app for fathers, little was known about how participants would interact with the app, and these comprehensive results will help guide future work in this area and with this target group. There are many different aspects that can affect the implementation of health promotion interventions using a mobile app. Having a process evaluation framework that is comprehensive and specifically focused on areas that include the robustness of the technology and interaction between users and the app interface, will provide an overall picture of usability and acceptability. This was significantly aided by the custom-built analytics framework embedded in the app. Reporting process evaluation indicators against a broad evaluation framework as described here will help researchers better understand and interpret app intervention studies.

Current research in this field highlights that fathers are important in breastfeeding, that they want to help support their partners, and that they need additional information and support. This study demonstrates that fathers are prepared to seek that information and support through a carefully designed mobile app. It was hypothesized that increasing paternal support for breastfeeding may have a positive impact on breastfeeding outcomes. This paper describes the way in which fathers used the Milk Man app; the next stage is to examine the impact of this on behavior change and breastfeeding outcomes. The strategies described here show encouraging results in engaging fathers and the learnings and recommendations from this research will inform the continued development of Milk Man to better support families.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Milk Man library headers.

[\[DOCX File, 18KB - pediatrics_v2i1e12157_app1.docx \]](#)

Multimedia Appendix 2

Questionnaire (Milk Man questions at 6 weeks postpartum).

[\[DOCX File, 21KB - pediatrics_v2i1e12157_app2.docx \]](#)

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Abbreviations

PIFI: Parent Infant Feeding Initiative

RCT: randomized controlled trial

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Original Paper

Advancing Optimal Development in Children: Examining the Construct Validity of a Parent Reflective Functioning Questionnaire

Monica De Roo¹, MC; Gina Wong¹, RPsych, PhD; Gwen R Rempel², RN, PhD; Shawn N Fraser², PhD

¹Graduate Centre for Applied Psychology, Faculty of Health Disciplines, Athabasca University, Athabasca, AB, Canada

²Centre for Nursing and Health Studies, Faculty of Health Disciplines, Athabasca University, Athabasca, AB, Canada

Corresponding Author:

Shawn N Fraser, PhD

Centre for Nursing and Health Studies

Faculty of Health Disciplines

Athabasca University

1 University Drive

Athabasca, AB, T9S 3A3

Canada

Phone: 1 7804300590

Email: shawnf@athabascau.ca

Abstract

Background: Parental reflective functioning (PRF) is the capacity parents have to understand their own mental states and those of their children, as well as the influence of those mental states on behavior. Parents with greater capacity for PRF are more likely to foster secure attachment with their children. The Parental Development Interview is a gold standard measure of PRF but is hampered by cost, training, and length of administration. The 18-item Parent Reflective Functioning Questionnaire (PRFQ-18) is a simpler option developed to capture 3 types of PRF: (1) prementalizing, (2) parent's certainty, and (3) interest and curiosity surrounding a child's mental state.

Objective: The aim of this study was to examine the factor structure and select psychometric properties of the PRFQ in a sample of Canadian parents.

Methods: We examined the factor structure and discriminant and construct validity of the PRFQ-18 among 306 parents (males=120 and females=186) across Canada; the age range of children was 0 to 12 years. Parents also completed Web-based measures of perceived stress, parental coping, parenting competence, and social support.

Results: A confirmatory factor analysis confirmed the hypothesized 3-factor structure of the PRFQ-18 providing evidence that the PRFQ-18 may be a useful and practical measure of PRF in Canadian adults and showed minor revisions may improve the suitability of the PRFQ-18 for assessing PRF.

Conclusions: These results add support for the construct validity of the PRFQ-18.

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KEYWORDS

mentalization; parent reflective functioning; questionnaire design; parenting

Introduction

Background

Decades of research unequivocally demonstrate that reflective processes enhance parental insight and sensitivity toward children's emotions [1-5]. Reflective functioning (RF), first introduced by Fonagy et al in 1991, describes an individual's cognitive capacity to recognize and interpret one's own mental state as well as the mental state of others to identify and comprehend the meaning behind behavior [2,6]. In the literature,

RF is akin to mentalizing, which is a fundamental and intrinsic human capacity to regulate affect and attune to interpersonal relationships [7]. Similarly, maternal mind-mindedness is described as a mother's ability to recognize her child as a separate agent with independent thoughts, experiences, and emotions [8], and parental insightfulness is defined as a parent's representation of their child's intentions and mental states [3].

Rather than a natural ability, RF is believed to develop through the internal organization of an individual's understanding of one's own and other's feelings and behaviors through

experiences, social and emotional information, meaning making [2,6], and interactions with primary caregivers [2,6,9]. In addition, social interactions, family structure, family size, parenting quality [9], and environmental responses [10] influence the development of RF. The development of the RF neurological function is noteworthy as it provides individuals with the ability to predict behavior, distinguish between manifestation and reality, and enhance interpersonal communications, self-organization [6], and impulse control and affect regulation [9]. Understanding the development of RF is crucial, given the relationship between how a parent chooses to respond to their child's needs, which affects the child's attachment status [2,4,11] as well as the child's development and capacity to mentalize [1], and circumscribes the health of the parent-child relationship overall [5,12].

Parental reflective functioning (PRF) pertains to a parent's proclivity to understand and comprehend mental states influencing their child's behavior [13], playing a crucial role in how parents respond to their child's needs and feelings [4,14] and behaviors [6]. PRF is a core cognitive capacity that connects parents to their child's emotions and also to their own early attachment experiences in an integrated way to see their parents' experience as distinct from their own and to provide a secure base for their own children [1,6,7].

PRF is described as an attachment-related concept [15], wherein parental ability to interpret a child's mental state and the parents' responsiveness, or lack thereof, act as a conduit that establishes the attachment status of children. In other words, a child's attachment status is emblematic of the parent's capacity for PRF. The interrelationships between attachment and (1) child psychopathology; (2) inflammation and health; (3) neurobiology; (4) empathy, compassion, and altruism; and (5) school readiness have been substantiated [16]. In addition, the quality of attachment to a parent has been shown to be predictive of numerous developmental outcomes in children such as general well-being, self-esteem, social competence with peers, problem-solving abilities, academic success, behavioral outcomes, and resilience [17-21].

Parents with high RF who possess clear mentalizing abilities have a positive influence on the biological, interpersonal, cognitive, and emotional experiences of the child [1]. They understand their own mental states and those of their children, as well as the influence of those mental states on behavior [1]. In addition, those with high RF are better able to perceive themselves as parents and their relationships with their child, therefore seeking out social support [22] and enhancing parental coping abilities [23].

Initial purposes of PRF measures were to directly measure maternal representations of their child [24] and the PRF functions that influence the intergenerational transmission of attachment [1,4]. The application of PRF measures has expanded to different contexts such as drug use disorders [25], mothers with childhood maltreatment [26,27], infant distress [28], and parenting programs [12,29-33].

The gold standard narrative-based RF measure assessing parental representations of their relationship with their child is the Parent Development Interview (PDI) [24]. The interview takes

approximately 2 hours to administer and is audio recorded for transcribing. The original 45-item PDI scoring process involved a trained coder who utilized narrative data to evaluate RF across 4 factors: (1) awareness of the nature of mental states, (2) the ability to tease out underlying behavior of mental states, (3) identifying developmental aspects of mental states, and (4) the mental states in relation to the interviewer [24]. The PDI has been revised to a 40-item and 29-item measure to assess parent RF relative to their own child, their parents, and self (personal communication, A. Slade, January 2016). Trained coders rate each item on a Likert scale from -1 to 9 to produce an RF score [24]. A limitation in terms of application and use of the PDI is that the training and coding requirements for the PDI are time consuming and expensive. Clinicians and researchers may experience these prohibitive factors, making the PDI unattractive and unrealistic.

As an alternative to the narrative-based PDI, the Parent Reflective Functioning Questionnaire (PRFQ-18) is an 18-item self-report measure [13] which examines 3 domains of PRF: (1) prementalizing modes (PM), designed to capture a parent's inability to hold the child's mental state in mind; (b) interest and curiosity in mental states (IC), intended to capture the level of interest in parents thinking about their child's mental states; and (c) certainty about mental states (CMS), measuring a parent's acknowledgment that their thoughts about their child's mental states are accurate [13]. The main advantage of the PRFQ-18 is that it is a brief screening tool of RF designed to meet the growing demand of measures to assess the effectiveness of interventions to improve parent-child attachment and PRF [13].

The PRFQ-18 is an open source questionnaire available [34]. There is no training requirement; the questionnaire takes about 10 min to complete and the scoring syntax is downloadable. The questionnaire can be completed on paper or Web-based and is available in 10 languages. Parents rate each subscale item on a Likert scale from 1 (*strongly disagree*) to 7 (*strongly agree*). The preliminary studies 1 and 2 [13] have provided evidence supporting the validity and reliability of the PRFQ-18 for measuring PRF.

In Study 1, PRF was examined in mothers with children aged 0 to 36 months [13]. Construct validity of the PRFQ-18 was supported with a confirmatory factor analysis (CFA) of a 3-factor model with a good fit ($\chi^2_{123}=217.73$; $P<.001$; $\chi^2/df=1.77$; root mean square error of approximation [RMSEA]=.05; CI 0.04 to 0.06; comparative fit index [CFI]=.91; non-normed fit index [NNFI]=.91). Internal consistencies were good for PM (.70), IC (.82), and CMS (.75), and discriminant validity was identified in negative correlations between the PRFQ-18 factors and demographic features. As expected, PM was positively correlated to attachment avoidance, attachment anxiety, and symptomatic distress, whereas IC and CMS were not.

In Study 2, opposing results in the correlations between IC and CMS were found [13], revealing factorial variance across mothers and fathers. In contrast to Study 1, correlations between PRFQ-18 factors and demographic features were nonexistent

or moderately related to the subscales; no relationships were found between fathers PM, attachment, and symptomatic distress, indicating differences in factor loading among mothers and fathers. On the contrary, Study 2 identified similar correlations between parenting stress and mothers and fathers. Parenting stress had negative correlations with IC and CMS but positive correlations with PM on all subscales including parental competence. Furthermore, in Study 3, the PRFQ-18 was utilized with the Strange Situation Procedure (SSP) [35]. Preliminary studies found correlations between PM and IC and the SSP [13], supporting the notion that a parent's ability to hold their child's mental state is related to attachment security. Given that RF has previously been found to significantly correlate with infant attachment [2], Study 3 strongly supports the validity of the PRFQ-18 as an indicator of PRF.

These studies from the originators of the PRFQ-18 provide some initial information on the psychometric properties of the PRFQ-18, but further research is warranted to offer an independent examination of the construct validity of the PRFQ-18. The purpose of this study was to examine the construct validity of the PRFQ-18 in a diverse sample of Canadian parents.

Hypotheses

On the basis of results of existing studies of the PRFQ-18 and existing conceptualizations for PRF, we tested 6 hypotheses:

1. A CFA will support a 3-factor structure in the PRFQ-18, illustrating 3 distinct characteristics of RF (PM, IC, and CMS).
2. Small-to-moderate correlations will exist between the 3 PRFQ-18 subscales.
3. PM will negatively correlate with parental competence; IC and CMS will positively correlate with parental competence.
4. PM will positively correlate with parenting stress; IC and CMS will negatively correlate with parenting stress.
5. PM will negatively correlate with social support; IC and CMS will positively correlate with social support.
6. PM will negatively correlate with parental coping; IC and CMS will positively correlate with parental coping.
7. The PRFQ-18 will demonstrate measurement invariance between men and women.

Methods

Ethical Approval

Ethical approval for this study was obtained through our university's Research Ethics Board. Subjects were then randomly contacted through SurveyMonkey's *Survey Audience* to participate in a study of *Experiences in Parenting*. The survey panel members were randomly selected, contacted, and screened by SurveyMonkey, and the authors had no role in the recruitment and selection process other than defining the inclusion criteria for SurveyMonkey. Eligible participants were parents of at least 1 child living in the home aged 12 years or under. After screening for eligibility, parents completed the Web-based PRFQ-18, 4 additional measures, and the demographic data form, 52 questions excluding demographic data questions. Only 1 parent from each household provided study data.

Measures

Parent Reflective Functioning Questionnaire

The PRFQ-18 [13] is an 18-item self-report measure for parents with children aged 0 to 5. It measures PRF across 3 domains: (1) PM (items 1, 4, 7, 10, 13, and 16), (2) IC (items 3, 6, 9, 12, 15, and 18), and (3) CMS (items 2, 5, 8, 11, 14, and 17). Parents are required to rate each subscale item on a Likert scale from 1 (*strongly disagree*) to 7 (*strongly agree*). The questionnaire is available from the authors.

Parenting Sense of Competence Scale

The Parenting Sense of Competence Scale (PSOC) is a 17-item self-report measure for assessing parents' sense of confidence and satisfaction with their parenting [36]. Owing to poor factor loading for item 17 (.40), the PSOC was revised to a 16-item measure to assess parent sense of competence across 2 factors: (1) satisfaction and (2) efficacy and had good internal consistency for the total score (.79), satisfaction (.75), and efficacy (.76) [36]. Internal consistencies were reported .80 for both efficacy and satisfaction in mothers and .77 for efficacy and .80 for satisfaction in fathers [37]. Parents are required to rate each subscale item on a Likert scale from 1 (*strongly disagree*) to 6 (*strongly agree*). Higher scores indicate greater parenting self-confidence. For our sample, satisfaction internal consistency estimates were $\alpha=.89$ and $\omega=.92$ and efficacy estimates were $\alpha=.86$ and $\omega=.90$.

Perceived Stress Scale

The Perceived Stress Scale (PSS) [38] is originally a self-reported 14-item measure to examine the degree to which individuals view situations as stressful. The original PSS had good reliability in 3 preliminary samples (.84, .85, and .86) and in 2 test-retest samples (.85 and .55). The PSS was later revised to a simple 4-item (items 2, 6, 7, and 14) scale with an alpha reliability coefficient of .60, identifying it to be an adequate brief measure of perceptions of stress [39]. The PSS requires individuals to rate 4 items on a Likert scale from 0 (*never*) to 4 (*very often*). For our sample, internal consistency estimates were .68 for alpha and .85 for omega.

Medical Outcome Study Social Support Survey

The Medical Outcome Study Social Support Survey (MOS-SSS) [40] 12-item measure has 4 social support domains (tangible support, emotional information support, affectionate support, and positive interaction) [40]. The MOS-SSS has exhibited excellent reliability (.94) and good internal consistency for tangible support (.87), emotional information support (.91), affectionate support (.88), and positive interaction (.92) [40]. The MOS-SSS requires individuals to rate each subscale item on a Likert scale from 1 (*none of the time*) to 5 (*all of the time*). For our sample, internal consistency for the subscales ranged from $\alpha=.91$ to .93 and from $\omega=.94$ to .98.

Parent Coping Scale

The Parent Coping Scale (PCS) [41] is a single item scale to assess parent's perception of their own ability to cope with parenting. A preliminary study of the PCS found strong intraclass correlation coefficients (.93) and concurrent criterion validity (.54) with the Parenting Self-Agency Measure [42].

The PCS requires parents to respond to a single question (“How are you coping with being a parent these days?”) on a response scale ranging from 1 (*I feel I am not coping at all these days*) to 5 (*I always feel I am coping really well—things never or hardly ever get on top of me*).

Data Analysis

Data were exported into IBM SPSS 23 for analysis. The data analysis was conducted in 3 stages. First, data were screened for outliers and missing data. Outliers were defined as unusually influential data or data with unusual or extreme values. For example, responses outside of possible ranges were considered unusual. Given the nature of the constrained response options (eg, Web-based Likert scales), we did not notice any unusual values. We also examined partial regression plots and did not notice any outliers. Screening for influential multivariate outliers was examined with Mahalanobis d-squared in IBM AMOS [43], and we noted no distinct values indicating influential outliers. Missing data were not imputed, given the small rates of missing data. Second, the hypothesized factor structure of the PRFQ-18 was tested using a CFA in IBM AMOS 23 graphics [43] and R 3.3.2 [44]. The CFA was conducted in the usual iterative fashion [45], that is, we tested the initial hypothesized factor structure as indicated in preliminary studies [13] followed by changes to the model based on model fit, nonsignificance of path coefficients, and/or substantive suggestions offered by modification indices. Model fit was determined by consulting multiple fit indices, consistent with suggested practice (eg, [46,47]). We consulted chi-square as a global fit index. Whereas this is not a particularly useful indicator of the fit of a given model owing to its sensitivity to sample size, for example (eg, as noted by Kelloway [48]), it can be useful in terms of model comparison [47]. Thus, a change in the chi-square value was used to test the improvement of a given model over a previous model. Other fit indices included the CFI, normed fit index

(NFI), NNFI, and RMSEA. Akaike’s information criterion (AIC) was used as another indicator of comparative fit, where a lower AIC indicated a relatively better model fit. As noted, identifying precise cutoffs for model fit is probably unrealistic, given the behavior of fit statistics under varying conditions [20,49], as is shown by others [46]. Thus, we interpreted fit by consulting multiple indices and used a cutoff based upon *adequate fit*. Specifically, a fit of $\leq .08$ was deemed adequate for the RMSEA and Standardized Root Mean Square Residual, and a fit of $\geq .90$ was deemed adequate for the CFI, NFI, and NNFI [49]. Measurement invariance among men and women was tested using standard procedures [50], for example, using IBM AMOS 24 [43]. As we were only interested in testing whether or not the proposed CFA model held good for men and women, we tested configural, metric scale, and residual forms of invariance [49]. Finally, the relationships between the PRFQ-18 subscales and the subscales of the MOS-SSS, PSOC, PSS, and PCS data were investigated using bivariate correlations in IBM SPSS Statistics 23. RStudio (using R 3.3.2) was used to calculate ordinal alpha and omega forms of scale reliability [51] and to test for structural invariance.

Results

Sample Description

A total of 344 Canadian adult parents (aged 20 to 60 years) with at least 1 child between the age of 0 and 12 years were randomly sampled through SurveyMonkey’s *Survey Audience*. After screening for eligibility, 317 participants completed the PRFQ-18 and 306 participants (120 male and 186 female) completed all study measures. Participant demographics of our diverse sample are reported in Table 1. Of the 306 participants who completed all study measures, most parents had 1 (n=106) or 2 (n=132) children in the home with 68 parents having more than 2 children in the home.

Table 1. Demographics of the sample population.

Variable	Males (n=120), n (%)	Females (n=186), n (%)	Total (n=306), N (%)
Age (years)			
20-29	15 (12.5)	33 (17.7)	48 (15.7)
30-39	60 (50.0)	91 (48.9)	151 (49.3)
40-49	36 (30.0)	55 (29.6)	91 (29.7)
50-60	9 (7.5)	7 (3.8)	16 (5.2)
Age of child(ren) in household (years)			
0-3	36 (30.0)	83 (44.6)	119 (38.9)
4-6	52 (43.3)	64 (34.4)	116 (37.9)
7-9	49 (40.8)	64 (34.4)	113 (36.9)
10-12	37 (30.8)	65 (34.9)	102 (33.3)
13 and older	23 (19.2)	45 (24.2)	68 (22.2)
Children in household			
Biological	118 (38.6)	184 (60.1)	302 (98.7)
Step	37 (12.1)	52 (17.0)	89 (29.1)
Foster	32 (10.5)	51 (16.7)	83 (27.1)
Adopted	32 (10.5)	51 (16.7)	83 (27.1)
Education			
Less than high school degree	4 (3.3)	6 (3.2)	10 (3.2)
High school degree or equivalent	20 (16.7)	26 (14.0)	46 (15.0)
Some college but no degree	11 (9.2)	29 (15.6)	40 (13.1)
Technical degree or diploma	26 (21.7)	44 (23.7)	70 (22.9)
Bachelor's degree	44 (36.7)	59 (31.7)	103 (33.7)
Graduate degree	15 (12.5)	22 (11.8)	37 (12.1)
Household income (Can \$)			
0-24,999	6 (5.0)	14 (7.5)	20 (6.5)
25,000-74,999	47 (39.1)	75 (40.4)	122 (39.9)
75,000-124,999	44 (36.7)	62 (33.3)	106 (49.0)
125,000-199,999	18 (15.1)	20 (10.8)	38 (20.3)
200,000 and above	2 (1.7)	1 (.5)	3 (1.0)
Prefer not to answer	3 (2.5)	14 (7.5)	17 (5.56)
Relationship status			
Married	90 (75.0)	131 (70.4)	221 (72.2)
Widowed	1 (0.8)	1 (0.5)	2 (1.0)
Divorced	7 (5.8)	6 (3.2)	13 (4.2)
Separated	3 (2.5)	10 (5.4)	13 (4.2)
Common law	12 (10.0)	21 (11.3)	33 (10.8)
Single, never married	6 (5.0)	16 (8.6)	22 (7.2)
Open relationship	1 (0.8)	1 (0.5)	2 (1.0)
Residence (province)			
Western Canada	32 (26.7)	71 (38.2)	103 (33.6)
Eastern Canada	86 (71.1)	115 (61.9)	201 (65.7)
Race/ethnicity			

Variable	Males (n=120), n (%)	Females (n=186), n (%)	Total (n=306), N (%)
Asian and/or Pacific Islander	17 (14.0)	34 (18.2)	50 (14.7)
African	2 (1.7)	0 (0.0)	2 (0.6)
Black	1 (0.8)	1 (0.5)	2 (0.6)
Canadian	8 (6.7)	14 (7.5)	22 (5.8)
Caucasian	80 (66.7)	117 (62.9)	198 (58.2)
European	3 (2.5)	1 (0.5)	4 (1.2)
First Nations	0 (0.0)	4 (2.2)	4 (1.2)
Latin	1 (0.8)	2 (1.1)	3 (0.9)
Middle Eastern	2 (1.6)	2 (1.0)	4 (1.2)
Mixed	3 (2.5)	3 (1.6)	7 (2.0)
Prefer not to say	3 (2.5)	9 (4.8)	12 (3.5)

Parent Reflective Functioning Questionnaire-18 Factor Structure

Factor structure analysis of the PRFQ-18 resulted in examining 4 different CFA models (see Table 2) utilizing 317 participants. The initial CFA model testing of the hypothesized 3-factor structure of the PRFQ-18 (PM, CMS, and IC) resulted in a reasonably poor model fit, as shown in Table 2. Results of the initial CFA indicated that Item 11 was not significantly ($P=.10$) contributing to the PRFQ-18 measure. To decipher whether or not the model fit could improve with the removal of Item 11, a second CFA was conducted. Results in Model 2 found improvements in the model fit in terms of the fit statistics reported in Table 2, and the chi-square difference test showed that the change in the chi-square value from Model 1 to 2 was significant (chi-square difference=138, $P<.001$). However, Model 2 showed a low standardized regression weight for Item 18 (.27). To attempt enhancing the model fit even further, Item 18 was removed in Model 3. After testing Model 3, results identified a more respectable model fit (see Table 2, chi-square difference test=.210 $P<.001$) and modification indices suggested a better model fit by adding a covariance between error terms 6 and 9. Adding a correlated error term between the errors for

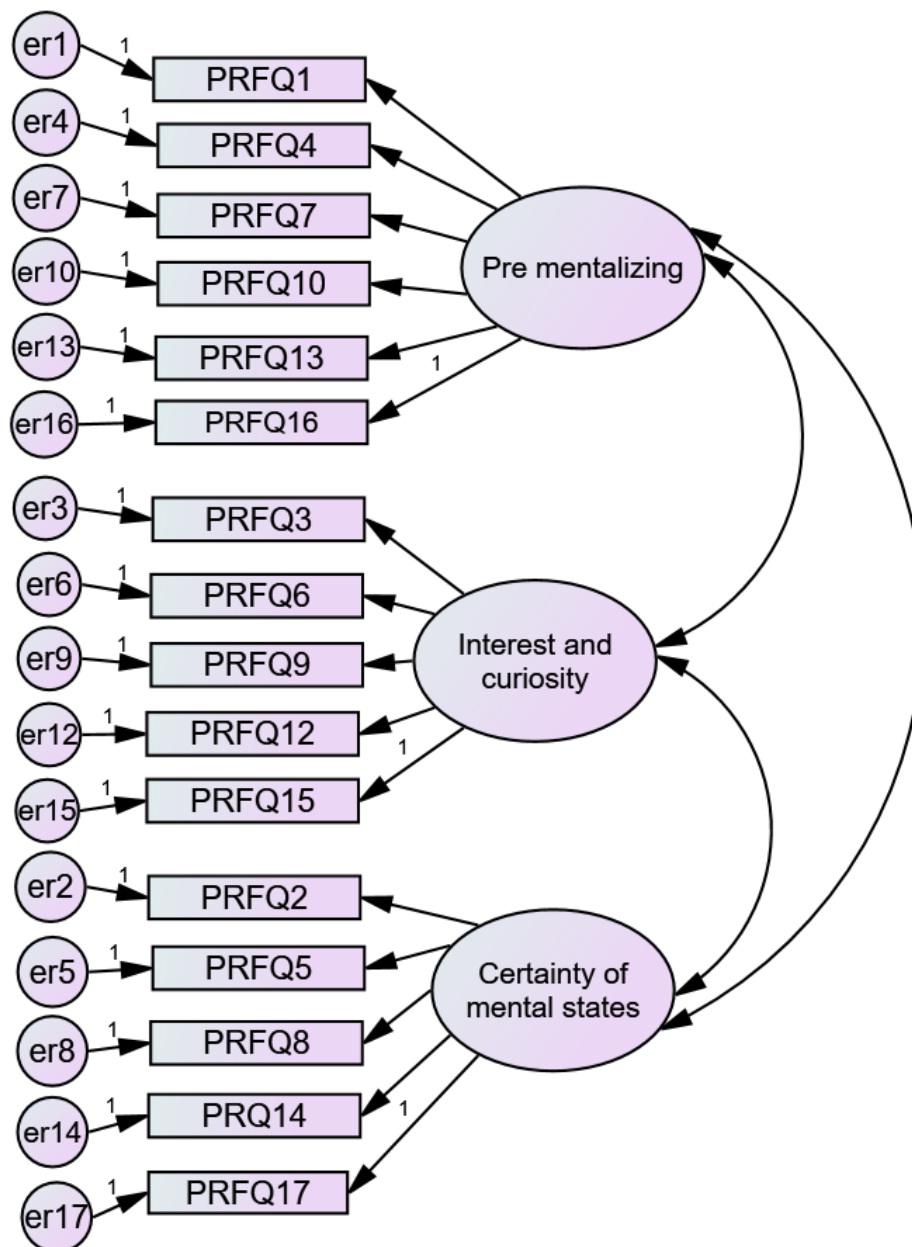
items 6 and 9 further improved the model fit as seen in Table 2 (Model 4, chi-square difference test=52; $P<.001$). Model 4 resulted in a negative correlation between PM and IC (-.26) and positive correlations between CMS and IC (.36) and between CMS and PM (.37), suggesting that the PRFQ-18 measures 3 relatively independent characteristics of PRF (see Figure 1). On the basis of this model, internal consistencies for the PM, IC, and CMS subscales were $\alpha=.91$, .88, and .88, and $\omega=.91$, .92, and .95, respectively.

A test of measurement variance showed strong support for invariance between men and women. The test for configural invariance showed that the same factor model applied for both men and women ($\chi^2_{200}=435.60$; $P<.001$; RMSEA=.062; 90% CI 0.054 to .070; CFI=.91; AIC=579.56). Measurement/metric invariance was also supported as seen in a change in chi-square, $\chi^2_{13}=8.42$, $P=.82$, and a small change in CFI of .001. Compared with the measurement invariance, structural invariance and then residual invariance showed a change in CFI of less than .001 each. These results show strong support for invariance between men and women suggesting the tool functions similarly among men and women.

Table 2. Fit statistics for confirmatory factor analysis models.

Model	Chi-square (df)	Chi-square/df	Root mean square error of approximation (90% CI)	Comparative fit index	Normed fit index	Non-normed fit index (Tucker Lewis Index)	Akaike Information Criterion	Standardized Root Mean Square Residual
Model 1 ^a	703 (132)	5.33	0.117 (0.109-0.126)	.81	.78	.78	781	.144
Model 2	565 (116)	4.87	0.111 (0.102-0.120)	.84	.81	.82	639	.137
Model 3	355 (101)	3.52	0.089 (0.079-0.099)	.91	.87	.89	425	.081
Model 4	303 (100)	3.03	0.80 (0.070-0.091)	.92	.89	.91	375	.077

^aInitial model contains all 18 items: Model 2 has Item 11 removed, Model 3 has Items 11 and 18 removed, and Model 4 adds a correlated error term to Model 3.

Figure 1. The Parent Reflective Functioning Questionnaire (PRFQ) model without items 11 and 18.

Intercorrelations Among Measures

Following the CFA, we proceeded to examine the intercorrelations among study variables with the revised version of the PRFQ that does not include items 11 and 18. Complete data for these analyses were available for 306 participants.

Relationships With Parenting Sense of Competence

Similar to preliminary findings [13], the PSOC demonstrated a range of correlation results across the PRFQ-18 subscales (see [Multimedia Appendix 1](#)). Negative correlations were found between PM and satisfaction ($r_{\text{males}}=-.65$; $r_{\text{females}}=-.50$) and efficacy for females ($r_{\text{females}}=-.14$). This suggests that parents with an inability to hold their child's mental state also have a lower sense of satisfaction with their parenting and a lower sense of efficacy for mothers. As expected, the IC subscale was positively correlated with efficacy ($r_{\text{males}}=.44$; $r_{\text{females}}=.28$) but

not with satisfaction. These results indicate that parents with relatively higher levels of interest and curiosity in their child's mental state also have relatively higher levels of satisfaction as a parent and perceptions of parental competence. Finally, the CMS subscale had positive correlations with both satisfaction in men ($r_{\text{males}}=.21$) and efficacy for both men and women ($r_{\text{males}}=.43$; $r_{\text{females}}=.32$). This shows that parents who are more certain of their child's mental states report more efficacy for the parenting role. Furthermore, for fathers, more certainty around mental states was associated with more satisfaction around being a parent.

Relationships With Stress

Consistent with preliminary findings [13], both the IC ($r_{\text{males}}=-.17$; $r_{\text{females}}=-.09$) and CMS ($r_{\text{males}}=-.16$; $r_{\text{females}}=-.13$) subscales were negatively correlated with stress, but these were not significant. On the contrary, PM was positively correlated

with stress ($r_{\text{males}}=.30$; $r_{\text{females}}=.27$), that is, those reporting higher levels of stress had a relatively higher inability to hold their child's mental state, as expected.

Relationships With Social Support

As expected, correlation results from the MOS-SSS subscales varied across the PRFQ-18 subscales. The PM subscale was negatively correlated to tangible support ($r_{\text{males}}=-.27$; $r_{\text{females}}=-.13$), emotional information support ($r_{\text{males}}=-.21$; $r_{\text{females}}=-.24$), affectionate support ($r_{\text{males}}=-.24$; $r_{\text{females}}=-.28$), and positive interaction ($r_{\text{males}}=-.23$; $r_{\text{females}}=-.23$) subscales. That is, those reporting less social support tended to report higher levels of prementalization. The IC subscale was positively correlated to tangible support ($r_{\text{males}}=.27$; $r_{\text{females}}=.17$), emotional information support ($r_{\text{males}}=.19$; $r_{\text{females}}=.19$), affectionate support ($r_{\text{males}}=.28$; $r_{\text{females}}=.22$), and positive interaction ($r_{\text{males}}=.22$; $r_{\text{females}}=.19$) subscales. Thus, those with relatively more social support reported higher levels of interest and curiosity in their child's state of mind. Finally, the CMS subscale also had positive but nonsignificant correlations with social support subscales.

Relationships With Parental Coping

In line with our hypothesis, the PCS had positive correlations with IC ($r_{\text{males}}=.37$) and CMS ($r_{\text{males}}=.33$; $r_{\text{females}}=.14$) and negative correlations among PM ($r_{\text{males}}=-.21$; $r_{\text{females}}=-.28$; see [Multimedia Appendix 1](#)). In other words, those with a relatively high ability to cope with parenting also display better levels of mentalization than those with a relatively lower ability to cope.

Relationships Between Mothers and Fathers

Interestingly, key findings identified a variety of commonalities between mothers and fathers. Both mothers and fathers had negative correlations among PM ($r_{\text{males}}=-.65$; $r_{\text{females}}=-.50$) and satisfaction. In addition, both mothers and fathers had positive correlations between both IC ($r_{\text{males}}=.44$; $r_{\text{females}}=.28$) and CMS ($r_{\text{males}}=.43$; $r_{\text{females}}=.32$) with efficacy. On the contrary, mothers had negative correlations ($r_{\text{females}}=-.27$) and fathers had nonsignificant correlations between PM and efficacy. In correspondence to preliminary findings [13], we found positive correlations among PM ($r_{\text{males}}=.30$; $r_{\text{females}}=.27$) and parental stress for both mothers and fathers [13], that is, a higher perceived stressful situation was associated with low mentalization in parents. In addition, both mothers and fathers had negative correlations between PM and social support subtypes. The exception was tangible support which was not related to prementalization in women. Overall, parents with more social support tended to have higher levels of RF. Finally, results showed negative correlations within PM and parental coping but only positive links with IC in fathers. Overall, these findings suggest that parents with high RF capabilities are better able to cope with parenting but that the type of RF related to coping might vary between mothers and fathers.

Discussion

Overview

The PRFQ is a brief self-report instrument designed to assess parent RF capacities [13]. Support for the validity of the PRFQ-18 has been presented previously in mothers and fathers [13]. To date, we have been unable to find any independent studies examining the factor structure and testing the discriminant and construct validity of the PRFQ-18. This study intended to further test the factor structure by means of a CFA and to expand the discriminant and construct validity of the PRFQ-18 by exploring relationships between this measure and the MOS-SSS, PCOS, PCS, and the PSS in a Canadian sample ($n=306$) of parents of children aged 0 to 12 years.

Results of this study extend and replicate earlier findings of the PRFQ-18 factor structure. Specifically, the CFA supported a 3-factor structure capturing key characteristics of RF: (1) prementalizing, (2) interest and curiosity, and (3) certainty of mental states. In addition, our results suggest items 11 and 18 may not be contributing to the measurement of PRFQ-18. Interestingly, items 11 and 18 are negatively worded and when removed, improved the PRFQ-18 model fit changes from poor to acceptable, as indicated in the fit measures. This may not be surprising as a mix of negative and positively worded items has the potential to cause problems as positively and negatively worded items may not be measuring the same underlying trait [52]. Taking this into consideration, it seems the removal of items 11 and 18 may be appropriate when using the PRFQ-18 in the future. Weak loadings for items 11 and 18 were also reported in preliminary studies [13]. However, given the early state of the PRFQ-18, 2 items in the PRFQ-18 were removed [13]. Our results suggest that it may be prudent to conduct further research examining the model fit of the 16-item measure reported here.

Validity Evidence

In terms of predictive and discriminant validity, the PRFQ-18 subscales were correlated with the MOS-SSS, PCOS, PCS, and PSS subscales in the expected directions, that is, the PRFQ-18 subscales were generally found to correlate with perceived social support, parental competence, and parent's perceptions of coping abilities and stressful situations in the right direction. Furthermore, the intercorrelations among PRFQ-18 subscales were low-to-moderately correlated, supporting a relative distinction among these subtypes adding support to the notion of 3 separate PRF concepts.

In terms of the PRFQ-18 construct validity support, prementalizing had negative correlations with coping, efficacy, and forms of social support. This result is similar to findings that individuals capable of perceiving themselves as parents and their relationships with their child will seek out social support [22]. In addition, PM was seen to have a positive relationship with satisfaction and perceived stress. These results are comparable to findings that identify parents with low RF as being unable to imagine the type of support they would need and if it would be available [23].

Theoretical Explanations

Interestingly, our results identified IC as positively correlated with parental coping, emotional information support, affectionate support, positive interaction, tangible support, and efficacy. These outcomes match findings that suggest parents with greater levels of parenting coping abilities and an awareness of stress display higher levels of RF, influencing how they feel about their parenting capabilities [23]. On the contrary, IC was negatively correlated to perceived stress and satisfaction, that is, a parent's awareness and curiosity of a child's mental state is relatively low among those reporting higher levels of stress and dissatisfaction with their parenting. These results are consistent with research and theory arguing that stress can impair one's mentalization [53]. This consistency adds construct validity support to the PRFQ measure.

Furthermore, CMS was positively correlated with satisfaction, efficacy, social support types, and coping. These results confirm that a parent's perception that their thoughts about their child's mental states are accurate contributes to their feelings of satisfaction, parental competence, and ability to manage and cope with parenting. In contrast, CMS was found to have nonsignificant negative associations with perceptions of stress. This suggests that stress may have less of an impact on this form of RF. This result requires further study, as it may speak to how specific forms of RF operate under different circumstances. In sum, our results show that PRFQ subscales are generally related to other social cognitive variables as one would expect based on the literature, adding support for the construct validity of the measure. Although the PRFQ-18 is a fairly new measure within the field of psychology [54], our results are consistent with those reported in preliminary studies [13].

Finally, we identified both similarities and differences among mothers and fathers in terms of PRFQ correlates. In general, both mothers and fathers with high RF had lower levels of parental stress and more social support, satisfaction, efficacy, and better coping. However, some differences in terms of how RF operates in terms of coping and competence among men and women were noted here. Specifically, men who reported good coping with parenting reported more interest and curiosity in their child's mental state, more certainty around understanding their child's mental state, and better mentalization. Another notable difference was the relationship between parental efficacy and PM. Women with more parental efficacy had lower levels of PM and, thus, better mentalization. In contrast, PM was unrelated to a father's efficacy. For women, good coping was

primarily related to better mentalization, as seen in lower PM scores. However, for fathers, satisfaction with parenting was strongly negatively correlated with PM, showing that fathers with a great deal of satisfaction with being a parent also have a better ability to mentalize.

Limitations and Future Directions

Advantages of self-report measures include time efficiency, cost-effectiveness, and ease of administration. Self-report measures are reported to be valid measures in examining cognitive constructs, emotions, and moods [55]. However, one issue concerning self-report measures is the level of insight required from an individual [55]. Other cautions against self-report measures include potential inaccuracy in participants' answers and various response styles influencing results [56]. To further support the validity of the PRFQ-18 and to allay concerns about the PRFQ-18 being a self-report measure, future research should consider including a gold standard measure such as the PDI to compare these results observed here to uncover if the PRFQ-18 can offer insights similar to the current gold standard measures. In addition, this research would provide more evidence as to the reliability and validity of the PRFQ-18.

A limitation of this study is the reliance on a preexisting survey panel. Whereas this method allows for easy access to a wide cross-section of Canadians, the survey panel may differ in unknown and important ways from a true random sample of Canadians. If future research could replicate these findings in a random sample of Canadians recruited through other means, we would have increased confidence in the findings in this study.

Ideally, an independent sample should be used as a follow-up to our CFA to determine the extent to which PRFQ-18 subscales are related to theoretically meaningful constructs. However, a follow-up study should attempt to replicate our findings to see if the removal of items 11 and 18 is supported in other samples. Considering the preliminary studies had similar findings to this study [13], we would expect this result to hold. In this study of parents with children aged 0 to 12 years, we found evidence supporting the construct validity of a revised PRFQ; however, it is possible that the PRFQ might perform differently between younger and older children [13]. This is a question for future research to examine in an independent sample. Finally, variances among mothers and fathers suggest further exploration between mothers, fathers, RF, and cognitive variables is needed. That is, our results suggest that RF subtypes may be differentially influenced by the social and psychological parenting context.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary of intercorrelations, means and stand deviations for scores on the Parent Reflective Functioning Questionnaire -18, Medical Outcome Study Social Support Survey, Parenting Sense of Competence Scale, Perceived Stress Scale, Parent Coping Scale in males and females.

[[PDF File \(Adobe PDF File\), 94KB - pediatrics_v21e11561_app1.pdf](#)]

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Abbreviations

CFA: confirmatory factor analysis
CFI: comparative fit index
CMS: certainty about mental states
IC: interest and curiosity in mental states
MOS-SSS: Medical Outcome Study Social Support Survey
NFI: normed fit index
NNFI: non-normed fit index
PCS: Parent Coping Scale
PDI: Parent Development Interview
PM: prementalizing modes
PRF: parental reflective functioning
PRFQ: Parent Reflective Functioning Questionnaire
PSOC: Parenting Sense of Competence Scale
PSS: Perceived Stress Scale
RF: reflective functioning
RMSEA: root mean square error of approximation
SSP: Strange Situation Procedure

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Original Paper

Use of Physical Activity Monitoring Devices by Families in Rural Communities: Qualitative Approach

Iryna Sharaievska¹, PhD; Rebecca A Battista², PhD; Jennifer Zwetsloot², PhD

¹Department of Recreation Management and Physical Education, Appalachian State University, Boone, NC, United States

²Department of Health and Exercise Science, Appalachian State University, Boone, NC, United States

Corresponding Author:

Iryna Sharaievska, PhD

Department of Recreation Management and Physical Education

Appalachian State University

111 Rivers Str, ASU Box 32181

Boone, NC, 28608

United States

Phone: 1 8282626327

Email: sharaievska@appstate.edu

Abstract

Background: Several studies support the impact of information communication technology–based interventions to promote physical activity among youth. However, little is known on how technology can be used by the entire family to encourage healthy behavior. Previous studies showed that children and youth rely and are dependent upon the decisions and values of their caregivers when it comes to having a healthy lifestyle. Thus, the exploration of behavior and attitudes of the entire family is needed.

Objective: The study aimed to explore (1) perceptions of how the use of physical activity tracking devices (Fitbit Zip) by families in rural communities influence their patterns of participation in physical activity, (2) how attitudes toward physical activity change as a result of using physical activity tracking devices as a family, and (3) what factors influence participation in physical activity among families in rural communities.

Methods: A total of 11 families with 1 to 3 children of different ages (7-13 years) took part in semistructured group interviews following 2 weeks of using physical activity tracking devices (Fitbit Zip) as a family. The participants were asked to discuss their experience using the Fitbit Zip as a family, the motivation to be physically active, the changes in their pattern of participation in those activities, the level of engagement by different family members, and the factors that affected their participation. All interviews were voice-recorded with the participants' permission and later transcribed verbatim using pseudonyms. To analyze the data, the principal investigator (IS) used open, axial, and selective coding techniques.

Results: A total of 3 themes and several subthemes appeared from the data. The families in rural communities reported no or minimal changes in physical activities as a result of using physical activity tracking devices (Fitbit Zip) because of a lack of interest or an already active lifestyle. However, the attitude toward physical activity was altered. The family members reported an increased awareness of their activity level, introduced more conversations about active and healthy lifestyles, and changed their view of physical activity to a more positive one. The participants described the changes they were able to make and the constraining factors that stopped them from making further changes in their lifestyle.

Conclusions: Technology might serve as a facilitator to participation in physical activity among families. Technology can motivate the change in attitude toward active recreation. As long-term changes in lifestyle require internal motivation, the change in the attitude might have a more long-lasting impact than the change in the immediate behavior. More longitudinal studies are needed to further explore long-term change in both behavior and attitude toward physical activity. Additional exploration of constraints to participation in physical activity among families is also an important area of exploration.

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KEYWORDS

motion sensors; physical activity; family; rural community

Introduction

Background

Increasing physical activity among adults and children has been a primary goal of many disciplines, government initiatives, and nonprofit organizations, including Let's Move! Active Schools, NFL Play 60, Presidential Youth Fitness Program, Reviving Baseball in Inner Cities, and others [1,2]. Unfortunately, only 1 in 5 adults [3] and only 22% of children aged 6 to 19 years meet the physical activity guidelines [4]. There are multiple factors that may negatively influence adults' participation in physical activities, including advanced age, low income, lack of time, low motivation, rural residency, perception of the effort needed for exercise, excessive weight or obesity, perception of poor health, and physical disability [5]. Among children and adolescents, parental support and belief in one's ability to be active (self-efficacy), as well as walkability of the community and access to recreational spaces, were named as influential factors in physical activity participation [5,6].

Use of Technology in Promoting Health

Contemporary technology is often seen as one of the significant constraints to participation in physical activity [7]. Technology addiction was connected to decreased exposure to the outdoors and, as a result, decrease in physical activity [7,8]. However, more and more often technology is being used to improve one's health. For example, a study claimed that mental health information and self-help tools could be successfully delivered via the internet to rural communities where limited access to health providers and the culture of self-reliance may prevent residents from receiving needed help [9]. Moreover, multiple studies supported the effectiveness of using activity trackers and online support to improve overall health behaviors including physical activity. For example, older adults in rural communities indicated a tracking device was *easy to use* [10], whereas overweight adults showed benefits from using a virtual coach [11]. Another example of how online education programs could be used to modify health-related behaviors was in the area of sex education [12,13]. The results showed increased knowledge and improved use of healthier practices among sexually active youth [12,13]. Finally, a systematic review suggested that smartphones can be a viable tool in promoting physical activity [14], whereas a comprehensive review reported internet-based physical activity interventions can also be successful [15]. Thus, technology may in fact play an important role in changing health-related behaviors.

In the area of changing behaviors related to diet and physical activity, technology has also been shown to be a successful tool [16-19]. For example, in a study exploring diet and physical activity smartphone apps, users found these apps effective in promoting healthy eating and exercising [16]. The study participants believed the apps affected their actions, health consciousness, and self-education about nutrition and physical activity [16]. Similarly, in a study focused on the use of Fitbit trackers among female breast cancer survivors, the participants increased their physical activity, which was associated with their frequency of looking at their own data on the tracker [17]. Thus, the tracker may have been a source of motivation to alter

their physical activity. There has been recent interest in using the internet and mobile phone technology to deliver automated physical activity programs to motivate adults to be more physically active [14,15,18,19]. As a result of several strategies, including the distribution of possible solutions to perceived constraints, detailing a weekly exercise plan, sharing the results with others, and providing feedback on their level of physical activity, the participants of these programs significantly increased their level of physical activity and lost a higher percent of body fat than the control group. Among an adult population with chronic obstructive pulmonary disease, it was revealed that an electronic health app was stimulating and that reaching daily physical activity goals was rewarding [19]. In addition, older adults living with chronic illness found wearable activity trackers (including Fitbit) were useful and acceptable, although participants stated they may need support with setting up the device and interpreting the data [20]. Finally, wearable activity trackers have also been used in weight loss interventions; however, the results have been mixed [21,22]. Nonetheless, tracking devices were shown to improve total step counts and percent body fat in first year medical students [23]. Although many of these interventions involve populations with various health issues (eg, overweight, obesity, and chronic illness), the tracking devices were somewhat successful in promoting physical activity. This suggests that activity tracking devices were overall a beneficial factor in behavioral change and thus could be useful in promoting physical activity among adults and youth.

Use of Technology in Promoting Health Among Youth

The impact of SMS (short message service) text message-based interventions to promote physical activity among youth was also supported by multiple studies discussed in a review of the previous literature [24]. Out of 13 studies reviewed [24], 7 interventions resulted in improvement for physical activity, and 6 interventions resulted in improvement in sedentary behavior among youth aged 10 to 19 years. Moreover, technology-based interventions that used global positioning systems (GPS devices) as an activity (eg, geocaching and treasure hunting) were also described as more enjoyable and intrinsically motivating to youth compared with walking without technology (eg, GPS device) [25,26]. In fact, the youth had similar physical activity levels (eg, light physical activity) over the same distance (1 mile loop) in performing the required activity with the GPS device (eg, geocaching) compared with walking [27]. In other words, technology alone may be utilized to increase physical activity participation among youth. In fact, in a recent systematic review, it was suggested that physical activity trackers may be useful in promoting physical activity among this population [28]. Despite studies suggesting benefits of using technology to improve physical activity in adults with chronic disease and encourage healthy lifestyles among youth, little is known on how technology can be used by the entire family (eg, adults and youth) to promote healthy behavior that can be sustained over a long period of time.

Families and Physical Activity

Previous studies showed that children and youth rely and are dependent upon the decisions and values of their caregivers

when it comes to physical activities [6]. Studies showed that parents' engagement in physical activity is an important predictor of children's engagement in physical activity, both during childhood and in the later years in life [29,30]. Moreover, parents' support and encouragement can help a child to develop physical competence and self-worth, crucial factors in long-term engagement in physical activity among children [5,31]. Although there are multiple factors that prevent families from being more active, including time and money, family structure, environment, geographical location, and others [5,6,30,32], technology could be used to lower the impact of some of these constraints by offering tips for time management or providing recommendations for physical activities that do not cost money and could be enjoyed by the entire family. This could be particularly important in rural communities where the opportunities for organized physical activities are limited. Considering that contemporary children spend more than 7 hours a day in front of a screen [33], an activity tracking device was selected as a primary factor for this study as it could be appealing to the youth interested in technology and could serve as a facilitator to participation in physical activity among families. Previous literature regarding families and physical activity was either focused on the parents' perceptions of the benefits of and barriers to physical activity among their children [34] or revealed that the children were not very active with their parents [35]. However, a recent systematic review suggested that family-based interventions can be an effective way to improve physical activity participation among families [36]. It was suggested that the best way to improve physical activity within the family unit was to focus on family relationships and experiences (spending time together, being active as a family) rather than the benefits of being active [36].

As a result, this study focused on the families' experience with physically active recreation and their use of activity-tracking devices. Although this study used a stand-alone physical activity tracking device (ie, Fitbit Zip), contemporary smartphones provide access to apps with similar functions (step count, distance walked, connection with others, etc), which could be used as a substitute for an activity tracking device (ie, Fitbit Zip). Thus, the objectives of this study were to explore (1) the perception of how the use of a physical activity tracking device (ie, Fitbit Zip) by families in rural communities influences their participation in physical activity, (2) how the use of a physical activity tracking device (ie, Fitbit Zip) by families in rural communities influences their attitude toward physical activity, and (3) what factors influence the participation in physical activity among families in rural communities.

Methods

Study Design

The study was conducted during 2014 in a small town in rural Appalachia. The study comprised 2 stages. During the first stage, 22 families with at least one child at home aged between 7 and 13 years took part in a 2-week long intervention study measuring the effect of a physical activity tracking device (Fitbit Zip) on physical activity participation in families. During those 2 weeks, each family member was asked to wear a Fitbit Zip

as well as record the types of physical activities and the length of their participation in those activities into a journal. The data from the first stage of the study (eg, step counts and total physical activity levels) were presented at regional conferences and are in submission for publication. For the second stage of the study, families were asked to take part in family group interviews to reflect on their experiences using physical activity tracking devices. This paper is focused on the second qualitative part of the study and presents the results of these 11 interviews. The study protocol was approved by the university's institutional review board. Both parents and children signed an informed consent.

Method of Data Collection

Semistructured group interviews were conducted with each family separately in the principal investigator's (IS) office within a 2-week period after the first stage of the study was completed. The interviews lasted between 30 min to an hour. The participants were asked to discuss their experience using the Fitbit Zip as a family, the motivation to be physically active, the changes in their pattern of participation in those activities, the level of engagement by different family members, and the factors influencing their participation. All interviews were voice-recorded with the participants' permission and later transcribed verbatim by the principal investigator and a research assistant using pseudonyms.

Data Analysis

Data analysis had begun as soon as several of the initial interviews were recorded and continued until the point of data saturation was reached [37]. The principal investigator used open, axial, and selective coding techniques to analyze the data [38]. This approach was selected to allow the data to speak for themselves, to *discover* and label variables and their interrelationships. After several initial interviews were conducted, the principal investigator read through the data to create labels emerging from the data. Among some of the codes that emerged during the open coding stage were "walk instead of bus, park farther, already active, and feeling accountable." During the axial coding stage, the principal investigator identified relationships among labels emerging during the open coding stage. The codes that lacked in depth or richness were eliminated or combined to create a more general code. For example, several codes that were focused on specific activities—"walking a dog, doing things around a house, etc"—were combined into 1 category—"doing more of what they were already doing or small, everyday changes." During the selective coding stage, the principal investigator identified core themes—perception of changes in behavior, changes in attitude, and factors influencing participation—around which the final data analysis was structured [38]. The trustworthiness of the study was enhanced by ensuring credibility, originality, resonance, and usefulness [37]. To ensure credibility, the principal investigator familiarized herself with the literature in the subject area before data analysis, stayed conscious of the depth and range of the data, as well as made sure there were strong and direct links between the gathered data and the conclusions. The principal investigator reviewed the data, codes, and themes with another qualitative researcher (BM) to ensure

their logical consistency. The principal investigator also evaluated the data on the novelty and usefulness by comparing the results of the study with previous research to ensure the study provides a new insight into the phenomena. In addition, the resonance was evaluated by ensuring fullness of categories and maintaining openness toward possible meanings of data to ensure the coconstruction of new knowledge [37].

Results

Study Participants

A total of 11 families took part in this study. Among these families, 3 families had a father involved in the study, whereas the rest of the participants comprised mothers and their children. The families had between 1 and 3 children of different ages, with at least one child aged between 7 and 13 years. All the families self-reported as being of white background (which is a typical characteristic of the general population in rural Appalachia), and 66% of the parents had at least a Bachelor's degree.

Several themes appeared from the data: families perceived no or minimal changes in physical activity as a result of using Fitbit Zip as a family and provided a description of small changes in their everyday activities; families discussed changes in their attitude toward physical activity as a result of using Fitbit Zip as a family; and families described factors that influenced their participation in physical activity.

Perception of Changes in Physical Activity

No Changes in Physical Activity

The majority of the participants in this study reported no change in physical activity as a result of Fitbit Zip use because of their rather active lifestyle before their participation in the study or because of a lack of interest toward adopting a more active lifestyle. These findings were supported by the step count data from the first stage of the study discussed in a separate manuscript. A total of 65% (13/20) of the families who took part in the first stage of the study either did not change or decreased their daily step counts over a 2-week period, whereas 35% (7/20) increased their daily step counts.

The mother from family 6 explained:

We were already pretty active so I don't know. [...] We get outside a fair amount, we go biking and running and stuff throughout the week outside.

Another mother (family 3) stated:

I am [...] on routines already so I don't think I found myself looking at it.

The father from family 10 had a similar reflection:

I have a regimen and did my normal thing, I exercise 30 mins a day 5 or 6 days a week.

There was also a group of families who reported no change because of a lack of interest from the parents. For example, a boy aged 12 years (family 11) had no specific reason for why his level of physical activity did not increase. However,

following his mother's response about her busy schedule and lack of interest, he stated:

Well not much was different for me. It was kind of just daily stuff and that's kind of how it was. [...] Nothing really changed, it's just kind of how life is.

Although some participants lacked interest in increasing their level of physical activity, those who wanted to be more active experienced a number of constraints that stopped them from being more active.

Small Changes in Physically Active Recreation

There were several families who reported introducing small changes into their everyday life as a result of Fitbit Zip use. As the father from family 1 explained, he was more motivated when he could visualize his inactivity:

Yeah, it [FitBit Zip™] gave me more incentive to go do the activity because you're looking and seeing you only have 5000 steps, I need 5000 more to go. I need to figure out something more to do today to increase my steps.

Small everyday changes mentioned by the participants included walking instead of taking a bus, parking farther away, and walking around house, etc. For example, the mother from family 6 described:

It didn't make me exercise on a day, like if I just felt tired and felt like I wasn't going to exercise that day, it didn't make me plan an exercise activity, but it did make me maybe just walk around a little more and run in place while I'm making dinner.

Several families stated that although they did not introduce any new activities, they increased their level of participation in the activities in which they were already involved. Going on a longer hike or walk, practicing dancing or gymnastics more often, and other activities were listed by the participants. The mother from family 5 shared her thoughts:

I don't think we did anything new just more often. We didn't do anything longer just more daily than a few days a week. We tried to fit more in during the week. [...] Just having a goal.

A girl from family 4 had a similar reflection:

I'm a dancer and I'm about to start pointe after Christmas. So I would put on my pointe shoes after I had on my pajamas and practice in the living room so I could gain a couple more steps.

Factors Influencing Participation in Physical Activity

Despite some participants lacking an interest in increasing their participation in physical activity, more participants reported an interest in living a more active lifestyle. However, many of them also experienced a number of constraints that stopped them from being more physically active. These constraints included a lack of energy, time, money, and companionship; the constraints also included environmental constraints (weather, lack of sidewalks), interest in other nonactive recreational activities, and distraction by technology.

Several participants stated that using Fitbit Zip allowed them to monitor their activities, have a healthy competition among family members, and encourage each other to be more physically active. However, despite all the benefits, many participants claimed that constraints to participation in physical activities were more significant. Among the most commonly reported constraints by both parents and children were lack of time and a busy schedule. For example, a girl from family 1 stated:

We don't get recess anymore so we don't really have a choice; and we have more homework and stuff so it is hard to do stuff when we are doing homework.

A boy from family 3, when asked what stopped him from being more active, shared a similar experience:

School, 6 and a half hours, no going outside.

The mother from family 5 summarized her daughter's experiences:

She has a lot of stuff going on. She is in a play and has rehearsal 3 times a week and swimming twice a week. Just having to be somewhere. Schedule.

Environmental constraints, including weather and lack of sidewalks, were also mentioned by the participants. The mother from family 3 explained:

I miss sidewalks since moving up here, you can't just go out and do in a safe way. I definitely have to coordinate with what they are doing. I think just scheduling makes it difficult to work it in or you have to get really creative.

Several participants reported distraction by technology as one of the constraints to physical activity participation among children. For example, the father from family 1 stated "Instagram" when asked about constraining factors, whereas his son confessed, "I'm glued to the Wii." Thus, although technology such as Fitbit Zip may encourage and motivate slight changes in physical activity participation among families, there are multiple factors that may be more powerful constraints when it comes to leading a more active lifestyle.

Change in the Attitude Toward Physical Activity

Increased Awareness and Accountability

The majority of participants in this study reported a change in their attitude toward physical activity. They reported becoming more aware of what it takes to have an active lifestyle, they reported increased conversations in the family about health and physical activities, and they also reported a change in their view of physical activity to a more positive one. For example, many participants were surprised by how active or inactive their everyday activities were. The mother from family 6 explained:

It made you a little more aware maybe when you thought you got enough exercise but maybe you didn't quite. [...] I think it did make me more aware and how even just doing some little things, like we live near the [grocery store] and how walking to the [grocery store] could add, little bit more walking home from school, how that can give you some more steps.

In many cases, this increased level of awareness motivated study participants to be more active during their recreational and everyday activities. The mother from family 3 described her son's increase in motivation as a result of using Fitbit Zip:

I think more awareness. He [son] was extra aware and made more of an effort like "oh I need to feed the FitBit Zip™" so he was making an extra effort. I could see that when he actually could see it, he was taking extra time to find ways, so yeah I noticed that behavior about him.

Similarly, the mother from family 5 shared her own increase in motivation to be more physically active as a result of Fitbit Zip use:

I would try to be more active because before I would think 3 days a week was good. But thinking about the 10,000 each day made me want to do more.

More Conversations About Active Recreation

In addition to an increased awareness, the Fitbit Zip use provoked more conversations about an active lifestyle and health in general among family members. As the father from family 10 described:

In the evening at least we talked about the steps and what they were doing and what they did for PE and things like that.

His daughter added:

At dinner we would usually look at our fitbits and all say how many steps we did.

Comparing the number of steps among different family members allowed families to be more intentional in planning physical activity:

They were constantly looking and seeing how many steps they had and what they were going to do.
[Mother, family 1]

Moreover, families enjoyed the friendly competition with each other and celebrated the achievement of the winning family member, which further initiated conversations about active recreation. The mother from family 3 explained:

I think it was cool that we were thinking about it and checking on each other. [...] I think we kind of talked about it and looked at it, maybe twice a day or so. [...] It is kind of interesting because he [son] is ultra-competitive with it [...], and it was kind of neat to celebrate with him and be like how did you get that many? What did you do today to get there? So I think for me as a parent it was fun to see him have this accomplishment and know that there were many days that he had more than I had.

Physical Activity as a Benefit

Finally, the participants reported that after using the physical activity tracking device as a family, their view of physical activity was changed to a more positive one. As a result of the participation in the study, many participants changed their perception of physical activity from inconvenient and

burdensome to beneficial. For example, walking the dog, parking farther away, and getting something from another room were now the activities that family members did not mind doing. For example, a mother from one of the least active families stated:

I had a better attitude about being more physical, like instead of being annoyed I had to park further away, I would be like that's ok. This is good for me.

A father described how he was using the Fitbit Zip to motivate his children to walk the dog together. The son from family 10 described how being active was no longer perceived as a burden by him and his sibling but rather as an opportunity to earn more steps:

One night someone was like "will you go get such and such for me" and no one would get off the couch, [...] and when she said that or anyone said that to me, I would be like "I'll do it." I got up and got up straight to do it.

Discussion

Principal Findings

Overall, the major finding from this study suggests a physical activity tracking device may not immediately impact total physical activity but may provide an awareness of total physical activity participation among families. The awareness or perception regarding how active or inactive they are as individuals or as a family may eventually lead to actions to become more active despite some commonly discussed constraints.

The findings in this study highlight several important issues related to increasing the level of physical activity among children previously discussed in the literature. First, adults play a crucial role when it comes to the health and active lifestyle of the entire family [31]. As our data suggested, parents who were interested in increasing physically active recreation encouraged their children's participation, introduced discussions about experiences, and celebrated their children's achievements. Unfortunately, many of them also reported multiple constraints that prevented the family's participation in physical activity, including a lack of energy, time, money, companionship; the constraints also included environmental constraints (weather, lack of sidewalks), interest in other nonactive recreational activities, and distraction by technology. Second, to increase participation in physical activity among children, it is important to make it fun yet still be challenging [31]. Our participants reflected on the enjoyment from the experience of using Fitbit Zip and friendly competition among family members. Thanks to the evening discussions about the step counts every family member obtained during the day, many children were excited to compete with their siblings and parents and, as a result, found the process of being active to be fun. Finally, as previous studies described that the sense of mastery and self-efficacy often encourages children's engagement in physical activities [31,39], physical activity tracking devices could be used to enhance those emotions among youth. For example, having a set goal and being able to observe (on the activity tracking device) how one's actions can allow the individual to achieve that goal might

develop a sense of mastery and self-efficacy among youth. Goal setting and reinforcement were among the suggested ways to increase family-based physical activity discussed in a recent meta-analysis review [36]. The perception of a great effort needed for exercise was mentioned in previous research as one of the constraints for physical activity among adults [5]. The users of activity tracking devices in this study mentioned how the small changes in their everyday routine and increased participation in activities they already enjoyed allowed the participants to increase their step count in an easy way with little or no preparation. Thus, the use of the activity tracking device could assist in changing the perception of physical activity from physical activity requiring great effort to it being simpler and more manageable.

The important message from this study is the relationships between technology and physically active recreation. Although technology is often viewed as a constraint to physical activity [7], it might also be used as a facilitator [39]. Moreover, as the results of this study suggest, a physical activity tracking device can motivate the change in attitude toward active recreation. As intrinsic motivation is often viewed as an important part of long-term change in behavior [40], the change in attitude and perception of physical activity and a healthy lifestyle overall might have a valuable impact on the future of physical activity among families.

Limitations

Although the study brings attention to some important areas in the research on physically active recreation, it also has several limitations. First, because of the self-selection process, a majority of the participants who agreed to participate in the study were already predominantly active and healthy residents of the community. Second, the engagement of families with physical activity tracking devices (Fitbit Zip) was rather short (2 weeks), and the novelty and excitement from this experience might decrease with time [41]. In future studies, we recommend to allow participants a longer period of engagement, as well as to ensure that the interviews are conducted soon after participation as well as several months after the experience ends. Third, the data were analyzed by only 1 of the authors. To address this limitation, the authors reviewed the data, codes, and themes with other qualitative researchers to ensure their logical consistency. Despite these limitations, the study provided a novel perspective on family units and their use of technology to modify health-related behavior such as physical activity. In addition, the study used a qualitative approach to gauge a deep understanding of the perception of the experience with technology and physical activity as a family.

Conclusions

Family-based physical activity interventions may be an effective way to improve the physical activity for both adults and children. Our results suggest that introducing simple everyday activities into family routines may encourage parents and their children to increase their overall physical activity level. Moreover, it may lead to a changed perception of physical activities from difficult and time-consuming to easy and enjoyable. Our results also suggest that facilitating the engagement of the entire family with a physical activity intervention may encourage more

discussions about active recreation and the ways to achieve it. Such discussions, healthy competition, and celebrations of achievements among family members may further promote a healthy and active lifestyle among the family as a unit. Finally, the use of activity tracking devices by families can allow both parents and children to be aware of the levels of physical activities among family members in their family unit, as well as observe what activities and strategies can be the most helpful in achieving their goals for physical activities.

There are several implications for future research in this area. Due to an increased presence of technology in the lives of families, we suggest more studies focused on the use of technology to promote physical activities among children and families are needed. More specifically, further studies should explore whether the latest technology can be used as a successful facilitator for physical activities among families. Family is a

complex system, and a change in one area of life of the family (eg, employment of parents) may lead to changes in other areas of life (eg, use of technology or physical activity participation). Moreover, families may have various structures and go through various stages in life, as well as represent individuals of diverse backgrounds. A more thorough understanding of the barriers of those with diverse backgrounds may assist in developing more effective family-based physical activity interventions. It is also important to utilize different methods to evaluate the family's physical activity. For example, measuring the total physical activity of each family member and comparing the perception that families have regarding their personal and children's physical activity may be a critical component. Thus, it is important to continue both qualitative and quantitative exploration of this area of study to produce theoretical foundation and empirical results that could further inform the work of practitioners working with families.

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Conflicts of Interest

None declared.

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Abbreviations

GPS: global positioning system

SMS: short message service

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Original Paper

A Personalized eHealth Transition Concept for Adolescents With Inflammatory Bowel Disease: Design of Intervention

Katrine Carlsen¹, MD, PhD; Mette Hald¹, MSc; Marla C Dubinsky², MD; Laurie Keefer³, PhD (Psych); Vibeke Wewer¹, MD, PhD

¹Department of Pediatrics, Hvidovre University Hospital, Hvidovre, Denmark

²Division of Pediatric Gastroenterology and Hepatology, Susan and Leonard Feinstein IBD Center, Icahn School of Medicine at Mount Sinai Hospital, New York, NY, United States

³Division of Gastroenterology, Susan and Leonard Feinstein IBD Center, Icahn School of Medicine at Mount Sinai Hospital, New York, NY, United States

Corresponding Author:

Katrine Carlsen, MD, PhD
Department of Pediatrics
Hvidovre University Hospital
Kettegaards alle 30
Hvidovre, 2650
Denmark
Phone: 45 26180513
Email: katrinec@gmail.com

Abstract

Background: Transfer from pediatric to adult care is a crucial period for adolescents with inflammatory bowel disease (IBD).

Objective: Our aim was to develop a personalized transition-transfer concept including relevant tools in an established eHealth (electronic health) program.

Methods: Required transition skills and validated patient-reported outcome measures (PROMs) were identified via bibliographic search and clinical experience and were implemented into an existing eHealth program.

Results: The following skills were identified: disease knowledge, social life, disease management, and making well-informed, health-related decisions. The PROMs included the following: self-efficacy (the IBD Self-Efficacy Scale—Adolescents), resilience (the 10-item Connor-Davidson Resilience Scale), response to stress (the Child Self-Report Responses to Stress—IBD), and self-management and health care transition skills (the Self-Management and Transition to Adulthood with Treatment questionnaire). Starting at age 14, the patient will be offered a 1-hour annual transition consultation with an IBD-specialized nurse. The consultation will be based on the results of the PROMs and will focus on the patient's difficulties. Patients will complete the PROMs on the eHealth program at home, allowing nurses and patients to prepare for the meeting. Symptom scores and medication will be filled out on the eHealth program to support disease self-management. The consultation will be a topic-centered dialogue with practical exercises. During routine outpatient visits with the provider, parents will be left out of half of the consultation when the patient is 16 years old; at 17 years old, the parents will not be present. At the transfer consultation, the pediatric provider, the adult gastroenterologist, the pediatric nurse, the patient, and the parents will be present to ensure a proper transfer.

Conclusions: We have conducted a personalized eHealth transition concept consisting of basic elements that measure, train, and monitor the patients' transition readiness. The concept can be implemented and adjusted to local conditions.

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KEYWORDS

inflammatory bowel disease; adolescents; transition; transfer; adult care

Introduction

The incidence of inflammatory bowel disease (IBD)—primarily represented by the diagnoses ulcerative colitis and Crohn's

disease—is increasing among children and adolescents [1-6]. Consequently, in the coming years there will be a larger burden on adult IBD care settings to manage the complex needs of patients transferred from pediatric IBD departments [7-9].

Ensuring that the patients and parents are prepared for the transfer, specifically the *physical handover* of patients from one setting to another, as well as receiving the patients after the transfer, is a challenge for both the pediatric and adult gastroenterological staff [10]. One of the most costly periods for IBD care is in the first year after transfer, from pediatric to adult care; the costs during this period are largely preventable, driven by unplanned hospitalizations, relapse, and nonattendance at scheduled appointments [7-9].

Different approaches have been used over time to improve the transfer process. These approaches have included structured discharge summaries provided on behalf of the pediatric department for the convenience of the adult department and/or joint consultations. Consultations include the patient, the parents, the nurse, and the adult and pediatric provider focused on facilitating the referral between providers in a *warm* handoff [11]. This approach is insufficient. Studies in adolescents and young adults with other chronic illnesses suggest that in order to improve disease outcomes and reduce health care costs, care must include (1) coordination provided over time, (2) communication between the patient and at least one member of the care team, and (3) skills-based training [12]. Transition care is an extended period of patient empowerment that equips adolescents (10-19 years old) [13] with the skills and knowledge necessary to manage their own health and well-being as they move from pediatric to adult-centered services. This is a more comprehensive approach to addressing the needs of adolescents and young adults with IBD. The process requires a coordinated, team-based shifting of responsibilities of disease self-management from the parent to the patient [14]. Less is known about how to best leverage technology to drive delivery of personalized skills training to a transitioning patient prior to entering adult-centered care [15].

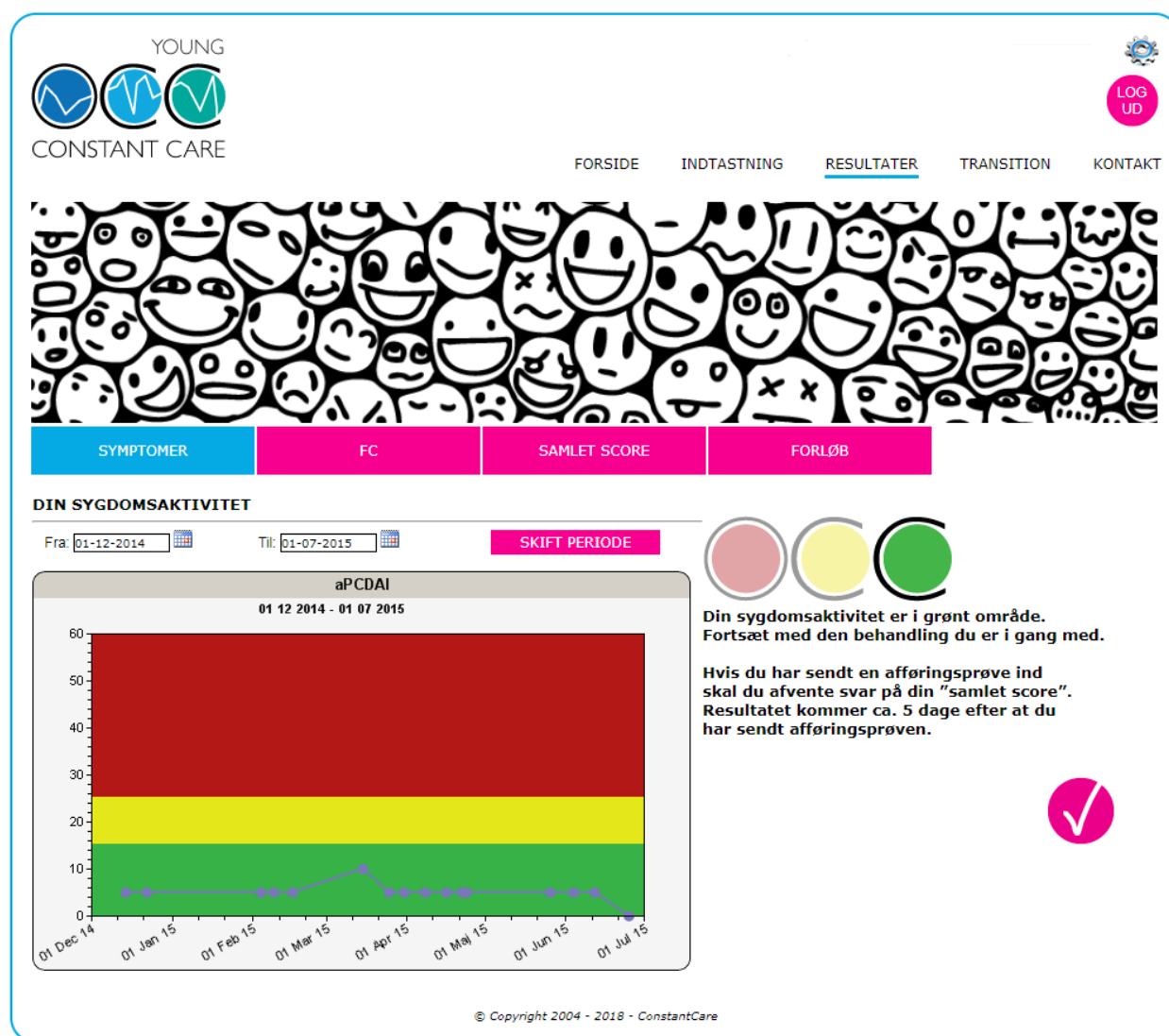
We have previously demonstrated and published that the use of the interactive eHealth (electronic health) solution Young Constant Care [16], designed for adolescents (10-17 years old)

with IBD, is usable in this age group [17,18]. An essential element of eHealth is the use of patient-reported outcome measures (PROMs) registered in real time due to the Internet connection, which allows timely relevant monitoring and personalized treatment to the individual patient. Specifically, patients register symptoms through the Pediatric Ulcerative Colitis Activity Index or abbreviated Pediatric Crohn's Disease Activity Index [19,20] and their type of medication. The symptom score is presented for the patient as a curve with traffic light zones (ie, green, yellow, and red colors) to indicate whether the disease activity is mild, moderate, or severe (see Figure 1). The traffic light acts as feedback to the patient on his or her symptoms and a guide to the patient to interpret how severe the disease activity is at a given time. Registration of medication helps the patient to remember and be aware of his or her own treatment progress. On an administration page only seen by the IBD team, all patients are listed and the staff can access the scores from the patients. Participants using our eHealth program were empowered and educated to be responsible for reporting symptoms themselves instead of relying on their parents [17].

The disease activity is tracked over time and the traffic light color code is used to visualize disease activity based on symptom index. On the right-hand side of the screenshot in Figure 1, the patients are provided with a guideline regarding the disease activity.

Based on our previous results involving adolescent patients in self-managing their disease through eHealth, it was natural to extend this program beyond reporting of IBD symptoms to include assessment and remediation of other critical self-management skills. We wished to personalize patients' transition preparedness by involving patients actively in their own transition process. Specifically, our aim was to develop a transition-transfer concept that included incorporation of validated measures of transition preparedness in the established eHealth program.

Figure 1. Screenshots from the website Young Constant Care (Danish) [16]. The disease activity is tracked over time; the traffic light color code is used to visualize disease activity based on symptom index. Patients are provided with a guideline regarding the disease activity (right-hand side of screenshot).



Methods

Development of the Transition Concept

The structure of the transition concept was developed in cooperation and agreed upon by two pediatric IBD centers to improve the ability of adapting the concept, regardless of cultural diversions. One center was located in Europe—Department of Pediatrics, Hvidovre University Hospital, Hvidovre, Denmark—and one was located in North America—Division of Pediatric Gastroenterology and Hepatology, Susan and Leonard Feinstein IBD Center, New York, United States.

Identification of Transition Skills

Identification of needed transition and transfer skills and expectations was based on a bibliographic search and clinical experience. The bibliographic search was performed without a date restriction in June 2016 on the online database PubMed. Medical Library Subject Heading (MeSH) terms and keywords were created by combinations of “inflammatory bowel disease”

with the subjects “transition to adult care,” “education,” and “skills” using “AND.” Relevance was determined by screening titles, abstracts, or full-text publications. Reference lists of relevant articles were screened for further potentially relevant studies. A total of 125 publications were returned using the initial search and 28 were excluded based on their abstracts or full text. After retrieving duplications, 40 original publications remained. The types of publications were as follows: randomized clinical trial (n=1); intervention trials (n=3); investigations of the patients’ transition readiness (n=13); investigations of providers’ transition experience and opinions (n=6); reviews of the literature (n=8); and transition recommendations (ie, needs and concerns) (n=9). Domains were extracted and transformed to a *transition readiness checklist* for the pediatric provider and a *transfer readiness checklist* for the adult provider to assess the patient’s transition and transfer progress, respectively (see [Multimedia Appendices 1 and 2](#)).

Patient-Reported Outcome Measures

The US Food and Drug Administration defines patient-reported outcomes as any report of the status of a patient’s health

condition that comes directly from the patient, without interpretation by a provider or anyone else [21]. In this context, PROMs [22] are questionnaires that evaluate the patient's self-reported capability and performance of transition readiness; these were identified in this study. The requirements of the PROMs were that they needed to be previously validated and usable in international settings; the questionnaires also had to be of an accepted length (ie, maximum 20 items). Furthermore, the total number of questionnaires were limited in order to ensure the quality of the answers. The agreement of included PROMs was performed by a consensus group (ie, consultants, physicians, psychologists, and nurses). PROMs existing in nonnative languages were translated by the cross-cultural adaptation translation method (ie, forward translation, backward translation, and cognitive testing) after agreement and approval with the developers of the PROMs [23]. Selected PROMs were implemented within the existing eHealth program Young Constant Care [16].

Approval

Young Constant Care [16] meets the requirements of the EU General Data Protection Regulation (May 2018) and is hosted on a server owned by the Capital Region, Denmark. Approval from the Danish Ethical Committee and Data Protection Agency will be obtained before enrollment of patients.

Results

Four Components of the Transition Concept

Component 1: Preparation of the Annual Consultation (eHealth and Face-to-Face)

The transition concept offers the patient an annual 1-hour transition consultation with a pediatric IBD-specialized nurse. The purpose of the transition consultation is to improve transition skills and to discuss individual difficulties. Patients will complete the questionnaire on the eHealth webpage Young Constant Care [16], to which the patients are provided access in advance through a personal double log-in—personal password and a code sent to the patient's phone. The webpage is designed to work on mobile phones, tablets, and laptops. Completing the PROMs prior to the consultation allows patients to be prepared for the topics around which the consultation should be centered. It also allows the nurse to prepare the consultation based on the patient's answers to the selected PROMs addressing the patient's abilities and difficulties (ie, the patient's score). The PROMs are presented below in the *Specific Contents of the Transition Concept: Transition Skills and Patient-Reported Outcome Measures* section. The actual topic of each consultation will be defined in collaboration between the patient and the nurse at the beginning of each consultation, leading to an individualized topic-centered dialogue with practical exercises (see Table 1).

The eHealth transition concept also provides the patient with mind-body techniques of progressive muscle relaxation,

relaxation imagery, and deep breathing exercises to cope with pain and fatigue, which are often present despite relevant treatment [24]. If the patient presents substantial psychological difficulties, the patient can be referred to a psychologist. Nurses are supervised in regular 6-month intervals by a health psychologist, allowing the nurses to evaluate and reflect on the themes of the conversations in the transition consultation and to discuss the challenges encountered during the sessions. The disease knowledge is not systematically evaluated by tests, but is discussed during the regular conversation and consultation with the nurse and the provider.

Component 2: Regular Consultations With the Provider (Face-to-Face)

Aiming to prepare and train the patient in disease management, the patient will register his or her symptoms at home prior to the consultation with the provider, interpret his or her disease activity, and record current medications in the eHealth program Young Constant Care [16]. Starting at age 14, the consultation with the provider in the outpatient clinic will change from being oriented toward the parents to being primarily oriented toward the patient. Once the patient is 16 years old, parents will only take part in half of the consultation; when the patient is 17 years old, the parents will no longer participate. This may be a challenge for both the patient, parent, and pediatrician and the rationale for this step should be addressed at the previous consultation.

Component 3: Transfer Consultation (Face-to-Face)

At a joint consultation when the patient is 18 years old, the pediatric provider, the adult gastroenterologist, the pediatric nurse, the patient, and the patient's parents will participate. At the joint consultation, the adult gastroenterologist will explain the structure and the approach of the adult department and, going forward, how the consultations will be conducted. Afterward, the adult gastroenterologist will receive a summary of the disease history in the medical journal and the patient will receive a status letter.

Component 4: Evaluation

Progression in PROMs will be evaluated by comparing the repetitive scores from the patients. The patient's answers to the questionnaires will be stored in the eHealth program. The patient will complete the Self-Management and Transition to Adulthood with Treatment (STARx) questionnaire at the time of transfer. The pediatric provider will assess the patient annually using the *transition readiness checklist* (see Multimedia Appendix 1) and the gastroenterologist will assess the patient at transfer using the *transfer readiness checklist* (see Multimedia Appendix 2). The triple assessment results in a comprehensive evaluation, which is needed, as transition readiness is multidimensional and is biased by the assessor. The transition consultations with IBD nurses will be documented systematically in the patient's medical record. The flowchart of the concept is presented in Figure 2.

Table 1. Exercises to improve the patient's transition skills.

Topics	Exercises (requests and items to address by the IBD ^a -specialized nurse) ^b
IBD knowledge	<p>Explain the disease for me.</p> <p>Mark on a drawing of the intestinal system where your disease is located.</p> <p>Review your onset of diagnosis, treatment history, and surgeries.</p> <p>Explain what symptoms you should be aware of.</p> <p>Explain what to do during a relapse.</p> <p>Where can you gather additional information about the disease?</p> <p>Information from the nurse: significance of alcohol and drugs on the disease.</p> <p>Information from the nurse: IBD in relation to sex, contraception, fertility, and pregnancy.</p>
Management of contact with the hospital	<p>Explain how to contact the hospital and how to make a new appointment in the outpatient clinic.</p> <p>Prepare a list of topics you can reference prior to your outpatient visits.</p> <p>Make a list of phone numbers and contact information for the hospital.</p>
Medication	<p>Explain what medication your treatment consists of (ie, type, dose, and when to take the medication).</p> <p>Explain how to renew prescriptions.</p> <p>Are you aware of how to travel with your medication?</p> <p>Are you aware of what travel documentation you need?</p>
Medical adherence	<p>Identification of the obstacles to good adherence (ie, forgetful, self-conscious, uncomfortable, and belief by patient that "it doesn't work anyway").</p> <p>Solution to improve adherence (ie, use of alarm, pill box, and goals).</p>
Worries	<p>Conversation concerning what is difficult in relation to the disease.</p> <p>Define beforehand who you would like to inform about the disease.</p> <p>Prepare sentences about the disease to be used in new relationships and among acquaintances.</p> <p>Conversation regarding feeling different from peers.</p> <p>Conversation regarding how the family manages the disease.</p> <p>Challenges related to absence from school and work.</p>
Network: family and friends	<p>Are you aware of whom you can rely on if or when the disease progresses?</p> <p>Write the names of the persons that you can place in your "inner circle" and "peripheral circle" of relationships.</p>
Stress, pain, and fatigue	<p>Relaxation exercise and visualization</p> <p>Breathing exercise</p> <p>Mindfulness</p>

^aIBD: inflammatory bowel disease.

^bThe exercises are performed in cooperation with the IBD-specialized nurse. Selected topics depend on the patient's difficulties, which are partially determined from the patient's responses to the patient-reported outcome measures (PROMs).

Specific Contents of the Transition Concept: Transition Skills and Patient-Reported Outcome Measures

Overview

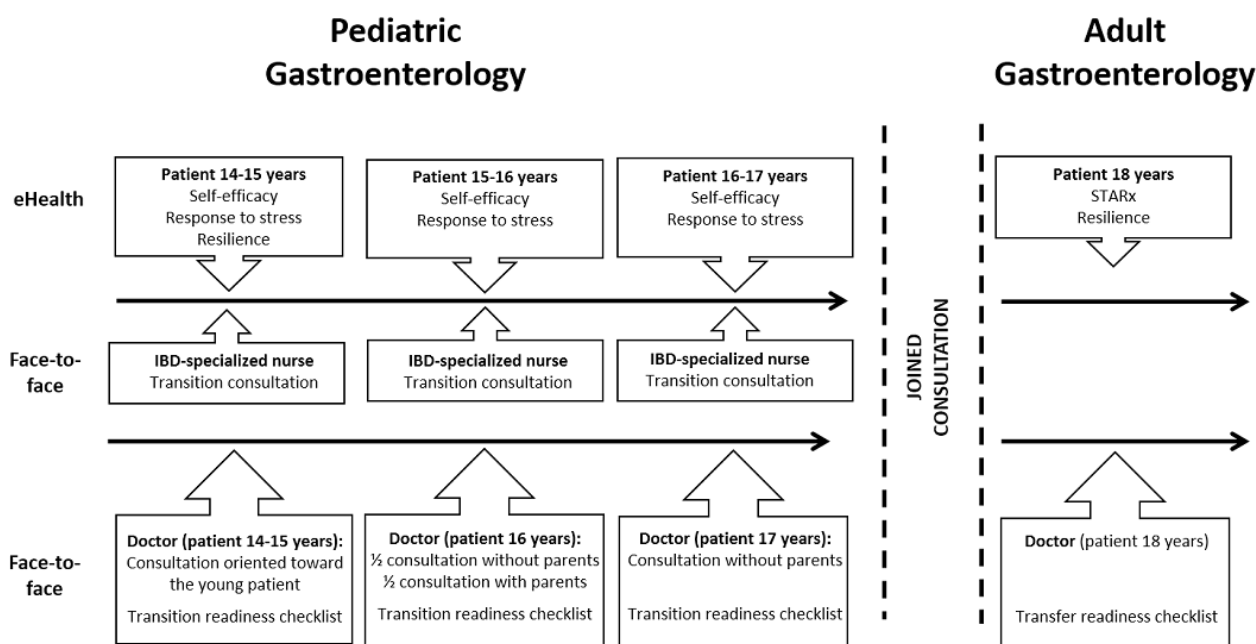
Based on the bibliographic search and discussion among the consensus group, the following skills were found to be important for adolescents to achieve in the transition phase [25]:

1. Disease knowledge (eg, regarding the diagnosis, medication, adherence, hospital procedures, and symptoms).
2. Disease self-management (eg, independently report to the provider, recognize and react on a flare, refill of prescriptions, and coping with the disease).

3. Management of social challenges (eg, social challenges related to the disease, who to rely on, and missed school and work because of the disease).
4. Taking part in health-related decisions in cooperation with the provider.

Therefore, the existing eHealth program Young Constant Care [16] was expanded with an implementation of four selected PROMs that evaluated the patient's self-reported capability and performance of transition readiness: disease knowledge, disease self-management, management of social challenges, and taking part in health-related decisions.

Figure 2. Flowchart of the transition-transfer concept. IBD: inflammatory bowel disease; STARx: Self-Management and Transition to Adulthood with Treatment.



Self-Efficacy: The Inflammatory Bowel Disease Self-Efficacy Scale—Adolescents

The construct of self-efficacy describes a person's perception of his or her own ability to manage skills required to master new challenges and has proven to be related to their level of self-management [26]. The disease-specific, self-reported, IBD Self-Efficacy Scale—Adolescents [26,27] questionnaire has been developed in cooperation with adolescents with IBD and covers skills related to the challenges of living with IBD between the ages of 12 and 25 years old. During prior work investigating transition readiness, we found self-efficacy to be a predictor [28]. The questionnaire is centered on confidence in various self-management tasks: managing medical care, managing everyday life with IBD, managing feelings, and managing the future with IBD. Answers are given on a 5-point Likert scale and a higher score represents increased self-efficacy (range 13-65) [26,27].

Resilience: The 10-Item Connor-Davidson Resilience Scale

Resilience refers to a person's capability to restore good functioning after exposure to stress or trauma; for instance, how well a person "bounces back" after a diagnosis of IBD [29,30]. The results of adaptation to a given exposure can either improve, neutralize, or overload functioning of a person leading to different levels of dysfunction. The 10-item Connor-Davidson Resilience Scale [29] is a validated measure of the resilience construct [29]; in previous work, we have found this measure to be a good predictor of transition readiness [28]. The topics of the questionnaire are centered on how to adapt and handle changes and the capability to achieve goals despite obstacles. Answers are given on a 5-point Likert scale, ranging from 0 (*not true at all*) to 4 (*true nearly all the time*), and a higher score represents increased resilience (range 0-40) [29,30].

Response to Stress: The Child Self-Report Responses to Stress—Inflammatory Bowel Disease

The impact of a stressor on an individual is mitigated by his or her coping mechanisms. The Child Self-Report Responses to Stress—IBD questionnaire [31,32] was developed specifically for children and adolescents with IBD and covers topics that the patients may find stressful or difficult to deal with. The items cover coping and stress responses related to control engagement (eg, problem solving and positive thinking), disengagement coping (eg, avoidance), involuntary engagement (eg, physiological arousal), and involuntary disengagement (eg, emotional numbing). This questionnaire consists of 10 items; answers are given on a 4-point Likert scale (ie, *none*, *a little*, *some*, or *a lot*) [31]. The score is calculated using a scoring system delivered by the developer.

Self-Management and Health Care Transition Skills: The Self-Management and Transition to Adulthood With Treatment Questionnaire

The STARx [33] is a generic self-reported questionnaire that measures self-management and health care transition skills in adolescents with a chronic disease who are in current treatment [34]. The items are divided into the following factors: medication management, provider communication, engagement during appointments, disease knowledge, adult health responsibilities, and resource utilization. Answers are given on a 5-point Likert scale and a higher score represents an increased transition readiness.

Discussion

Principal Findings

We have developed a personalized transition concept including relevant and concrete measures involving the patient, provider, and nurse. Transition elements (ie, PROMs and exercises) are

implemented in an existing eHealth program. The current transition concept is presented by specific transition skills that are needed; exercises on how to improve the patient's skills by identification of difficulties via PROMs can be adapted to other sites. The adaptation can be implemented with and without access to an eHealth tool, as the concept can be managed nondigitally (ie, use of paper) as well. The concept has been made ready for testing in clinical practice.

Skills and habits learned during the years of adolescence to manage their own disease and social challenges related to the disease form the basis of the patients' behavior in adulthood [35]. Transition readiness is one of the factors affected by the patients' coping strategies and how they adapt to new circumstances and cultural differences. Therefore, there is a need to approach the transition phase in a holistic and individual manner and to provide patients with appropriate coping strategies that can support them later in life.

A few intervention studies have investigated the impact of a different approach to improve transfer readiness, of which joint consultations were an essential part [36-39]. In a study by Cole et al [36], disease outcomes were evaluated retrospectively according to joint consultations (ie, pediatric provider, adult gastroenterologist, and nurse), which were offered to the patient beginning at the age of 15. At the joint consultation, disease-specific education and information were provided to the patients and parents. In a study by Yerushalmy-Feler et al [38], patients were offered three appointments during a 6-month period in a transition clinic offering joint consultation at the age of 17. The three appointments focused on (1) introduction to the transition (2), improvement of IBD knowledge and self-management, and (3) summation and short-term and long-term planning. Both studies reported improvements in outcome—disease activity and self-efficacy, respectively—after participation in the transition clinic. Yerushalmy-Feler et al [38] evaluated patients' self-efficacy using the IBD-Yourself questionnaire [40] at baseline and at the end of the intervention; however, no monitoring of transition readiness progress was implemented, neither by the providers nor the patient. Cole et al [36] monitored transition readiness using nonvalidated tools by the provider but did not involve PROMs. In our opinion, it is essential to regularly monitor the transition process for both the patient and provider, in order to optimize the process and individualize the effort.

Providing the right support can be a difficult task as it is complex to measure patients' transition readiness. Different questionnaires, such as the Transition Readiness Assessment Questionnaire [41] and the STARx questionnaire, have been used widely; however, no gold standard exists. Therefore, it seems that an appropriate solution is to involve both the pediatric assessment (ie, *Transition readiness checklist*) and the adult provider's assessment (ie, *Transfer readiness checklist*), as well as the patient's view (ie, STARx) on the situation to ensure a comprehensive evaluation of the patient's transition readiness, thereby gaining a measure of the transition concept's effectiveness.

Systematic Approach

The regular consultations with the provider are often busy, with limited time per consultation, which emphasizes the need for an incorporated systematic approach to ensure a proper individual transition and transfer process for all patients. However, the concept needs to embrace individualities and the ideal number of pretransfer consultations should be flexible depending on the patient's needs. The use of PROMs can help focus resources on the patients who need it most; however, access to a multidisciplinary team of providers and an economic surplus are needed.

Advantages of Technology

Using an Internet-based tool to collect questionnaires has advantages. This is true for both for the patient, who can prepare for the consultation at home, and for the providers, since results from the PROMs, which are available beforehand, can be implemented in the consultation. Information and exercises can easily be accessed through an Internet platform. The eHealth program is future oriented and intended to be managed by the adolescent who must report symptoms and medication changes in the program as part of building his or her involvement in their own disease management. This facilitates and promotes the competencies and management skills of the patient, enabling him or her to gradually take full responsibility for the management of their disease and allowing the parents to step back. The challenge is to establish an eHealth system and to ensure that the system is in accordance with standards that cybersecurity officials request.

Perspectives

Our transition concept focuses on the patient, IBD nurse, and provider. However, two components could receive further attention. First, more attention should be paid to the parents and the need for information about how best to promote independence in their adolescent child and how to gradually relinquish responsibility and let go [42]. Second, a posttransfer adaptation environment should be provided in the adult gastroenterological department, acknowledging that the patients may not be completely ready for transfer at age 18 [10]. This is especially relevant in countries with public health services, where postponing transfer is not a possibility for economic reasons [15].

Strengths and Limitations

This transition concept was developed by an interdisciplinary team involving two IBD centers. The strength of the concept is the inclusion of both the provider's and the patient's evaluation of the transition process, acknowledging the strength of implementing and using PROMs. All self-reported components in the concept are validated and translated from English to Danish through a systematic translation process involving cognitive tests by the target group (ie, adolescent patients). However, a limitation is that we did not involve patients and parents in the selection of the PROMs. The involvement of the user (ie, the patient) in the design phase has been shown to be important and to improve the usability of the concept. Patients will be invited to evaluate the concept after use and, based on their evaluation, changes can be implemented.

Despite the transition and transfer checklists being based on existing knowledge of selected topics that dominate the literature, they are limited by a lack of validation. The effectiveness of the concept will be evaluated after implementation in the clinic. The search strategy of the literature to identify transition skills was limited by the use of only one database, and that search was not validated by multiple reviewers.

Conclusions

In conclusion, we have developed a personalized transition concept consisting of basic core elements, which can be implemented and adjusted to local conditions. The concept involves transition consultations with an IBD-specialized nurse and ongoing evaluation from both the patient and provider. The transition concept is designed to run for a long period of time

for each patient—3 years—to ensure proper preparedness before transfer.

The transition concept will be evaluated at the Department of Pediatrics, Hvidovre University Hospital, Hvidovre, Denmark, in an interventional case-control study (ie, patients enrolled in the transition concept intervention group versus patients without transition preparedness). We hypothesize that the intervention group will achieve a higher transition and transfer readiness score than the control group at the time of transfer as assessed by PROMs and observer-reported outcomes. We also hypothesize that the intervention group will show improved disease management and disease course the first year following transfer. Participants will include IBD patients, 14-18 years old: an intervention group, 14-16 years old, and a control group, 17-18 years old, naïve to the transition concept. All patients will be followed until the age of 19.

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Authors' Contributions

All authors made substantial contributions to the concept and design of the study. The article was drafted by KC and was revised critically by MH, MCD, LK, and VW for important intellectual content. All authors approved the final version.

Conflicts of Interest

KC received a research grant from Merck Sharp & Dohme Corporation, Denmark, and Tillotts Pharma. MH is a speaker for AbbVie and Tillotts Pharma. MCD is a consultant for Janssen, Takeda, Abbvie, Pfizer, and Celgene. LK received a research grant from Abbvie and Pfizer and is a consultant for Pfizer. VW received a research grant from Merck Sharp & Dohme Corporation, Denmark, and Tillotts Pharma.

Multimedia Appendix 1

Transition readiness checklist for the pediatric provider.

[\[PDF File \(Adobe PDF File\), 207KB - pediatrics_v2i1e12258_app1.pdf\]](#)

Multimedia Appendix 2

Transfer readiness checklist for the gastroenterological provider in adult care.

[\[PDF File \(Adobe PDF File\), 217KB - pediatrics_v2i1e12258_app2.pdf\]](#)

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Abbreviations

eHealth: electronic health

IBD: inflammatory bowel disease

MeSH: Medical Library Subject Heading

PROM: patient-reported outcome measure

STARx: Self-Management and Transition to Adulthood with Treatment

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Original Paper

Qualitative and Quantitative Evaluation of the Make Safe Happen App: Mobile Technology–Based Safety Behavior Change Intervention for Parents

Kristin J Roberts¹, MS, MPH; Rebecca J McAdams¹, MA, MPH; Orië V Kristel², PhD; Alison M Szymanski², PhD; Lara B McKenzie^{1,3,4}, PhD, MA, FAAHB

¹Center for Injury Research and Policy, The Research Institute, Nationwide Children's Hospital, Columbus, OH, United States

²Illuminology, Columbus, OH, United States

³Department of Pediatrics, College of Medicine, The Ohio State University, Columbus, OH, United States

⁴Division of Epidemiology, College of Public Health, The Ohio State University, Columbus, OH, United States

Corresponding Author:

Kristin J Roberts, MS, MPH

Center for Injury Research and Policy

The Research Institute

Nationwide Children's Hospital

Research Building III, 5th Floor

700 Children's Drive

Columbus, OH, 43205

United States

Phone: 1 614 355 5858

Email: kristin.roberts@nationwidechildrens.org

Abstract

Background: Nearly half of the unintentional injuries in children happen in and around the home; many of these injuries are preventable. Providing parents and caregivers with proper injury prevention information that is easily accessible may help them make their homes safer for children.

Objective: The aim of this study was to evaluate parental injury prevention awareness and home safety behaviors, motivations for and challenges to taking injury prevention and safety actions for parents as well as user experience following the use of the Make Safe Happen mobile app.

Methods: A total of 40 parents with children aged 0-12 years living in Columbus, Ohio, participated in 1 of 5 focus group discussions following the completion of (1) a pretest survey, (2) use of the Make Safe Happen app, and (3) a posttest survey.

Results: Following the use of the Make Safe Happen app, parents reported a significant increase in injury prevention awareness and completed 45% more home *safety behaviors* in and around their homes. Nearly all of the parents felt the app provided them with the information needed to make their home safer for their children; the great majority of parents intended to make such changes in the future.

Conclusions: The combination of qualitative and quantitative data collection allowed for rich data capture and provided a deeper understanding of parents' safety knowledge, behaviors, app use, and decision making regarding child injury prevention in and around the home. The Make Safe Happen app provides the information and motivation parents and caregivers need to help them take steps to prevent child injuries that may occur in and around their homes.

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KEYWORDS

smartphone; mobile phone; mobile app; parents; focus groups; technology

Introduction

Injury Prevention

Unintentional injuries, such as injuries caused by burns, falls, drowning, poisoning, and motor vehicles, are the leading cause of death among children aged 1 to 19 years [1], resulting in over 9000 deaths and more than 9 million emergency department visits annually [2]. Approximately one-half of unintentional injuries in children occur in and around the home [3]. Fortunately, parents can reduce the risk of these injuries by removing hazards from their home, consistently practicing safe behavior (eg, storing medicines and household cleaners in locked cabinets), and by properly installing and regularly using safety products such as smoke alarms, carbon monoxide detectors, stair gates, cabinet locks and latches, and television (TV) and furniture anchors [4,5].

Parents and caregivers play a critical role in the prevention of home injuries, yet barriers include locating credible injury prevention information and identifying home hazards [6] as well as obtaining and properly installing safety devices in the home [7,8]. Successful preventive strategies rely on parental education and behavior change as well as environmental modifications [8-10]. Previous research suggests that the delivery of injury prevention information should coincide with the appropriate ages and developmental stages of the child to be most effective [11]. Offering home safety information on multiple topics in conjunction with the ability to easily acquire recommended safety devices may provide more efficient, wide-reaching means to reduce these potential barriers and encourage parental behavior change.

Mobile technologies, specifically apps (on mobile phones) provide a means to deliver efficient and cost-effective health information. It is estimated that nearly 80% of Americans own a mobile phone [12], and adults spend nearly 2 hours each day using mobile apps on these devices [13]. Although mobile technologies have been associated with behavior change in the areas of public health [14,15], few have been created to prevent unintentional injuries and even fewer have been systematically and rigorously evaluated [16-19]. Thus, there is a need for evaluating the effectiveness of a wide-reaching injury prevention mobile app.

The Make Safe Happen App

The Make Safe Happen app was created to help parents and caregivers with young children (aged 0 through 12 years) make their homes safer by helping them to identify injury hazards in and around their home. The app was developed by the safety experts in the Center for Injury Research and Policy at Nationwide Children's Hospital in partnership with Nationwide and allows users to tailor safety information by their child's age and by features of their home. The authors sought to examine if and how parents would use an injury prevention mobile app (the Make Safe Happen app) to learn how to take safety actions in their home and adopt behaviors that could prevent unintentional injuries [20].

We conducted a series of *enhanced focus groups* to explore the following themes: (1) injury prevention awareness and home

safety behaviors, (2) Make Safe Happen app user experience, and (3) motivation for taking injury prevention or safety actions and challenges to accomplishing home safety as perceived by parents with children aged 12 years and younger. Understanding how parents and caregivers used the *Make Safe Happen* app was thought to have important implications for confirming the efficacy of a potentially broad-reaching injury-prevention, behavior change intervention.

Methods

Study Design

We conducted 5 focus groups with parents of children aged 0 through 12 years in Columbus, Ohio, to explore attitudes and actions around home safety as well as their experience using the Make Safe Happen app. These focus group discussions are referred to as enhanced focus groups throughout this study because of the additional participant requirements (ie, pretest and posttest survey, app utilization, and focus group discussions). Enhanced focus groups allowed for both qualitative and quantitative data collection to occur for each participant. Before the focus group, parents completed a Web-based pretest and posttest survey and downloaded and used the Make Safe Happen app for 7 to 10 days. Parents completed a Web-based consent before beginning the pretest and a written consent before the focus group discussion. Following the Make Safe Happen app download, participants accepted the app's terms and conditions. Participants were assigned a unique identification (participant ID) number which allowed for linking of the participant's pretest, posttest, and app usage data. Participants could remove their participant ID following the focus group discussion. If the participant refused to enter the participant ID or removed the ID before completing all parts of the study, they were deemed ineligible. App utilization and analytic data for each participant were collected using Google Analytics (GA), a free Web-based analytic platform. Similar to traditional focus groups, participants were engaged in a discussion facilitated by a moderator. The focus group discussions were a part of a larger study to evaluate the effectiveness of the Make Safe Happen app on safety knowledge, actions, and behavioral intentions [20]. The study was approved by the Research Institute at Nationwide Children's Hospital Institutional Review Board.

Recruitment

Participants for this study were recruited by a market research firm, using its panel of individuals who had previously opted in to help with research studies. After identifying panelists that may be eligible, the market research firm screened participants for eligibility over the phone. To be eligible, participants needed to be the parent or legal guardian of at least one child aged 0 through 12 years who lived with them most of the time. The child age range was selected based on the available age categories within the Make Safe Happen app, which allows users to filter child injury prevention recommendations and content for children aged 0 through 12 years. To meet study eligibility criteria, participants had to be ≥ 18 years, comfortable answering questions in English, own a smart phone, and willing to download and use the Make Safe Happen app for 7 to 10 days. If parents had previously downloaded or used the Make

Safe Happen app, they were not eligible for participation. Participants reflected a mix of genders, races, and ethnicities.

Pre- and Posttest Survey

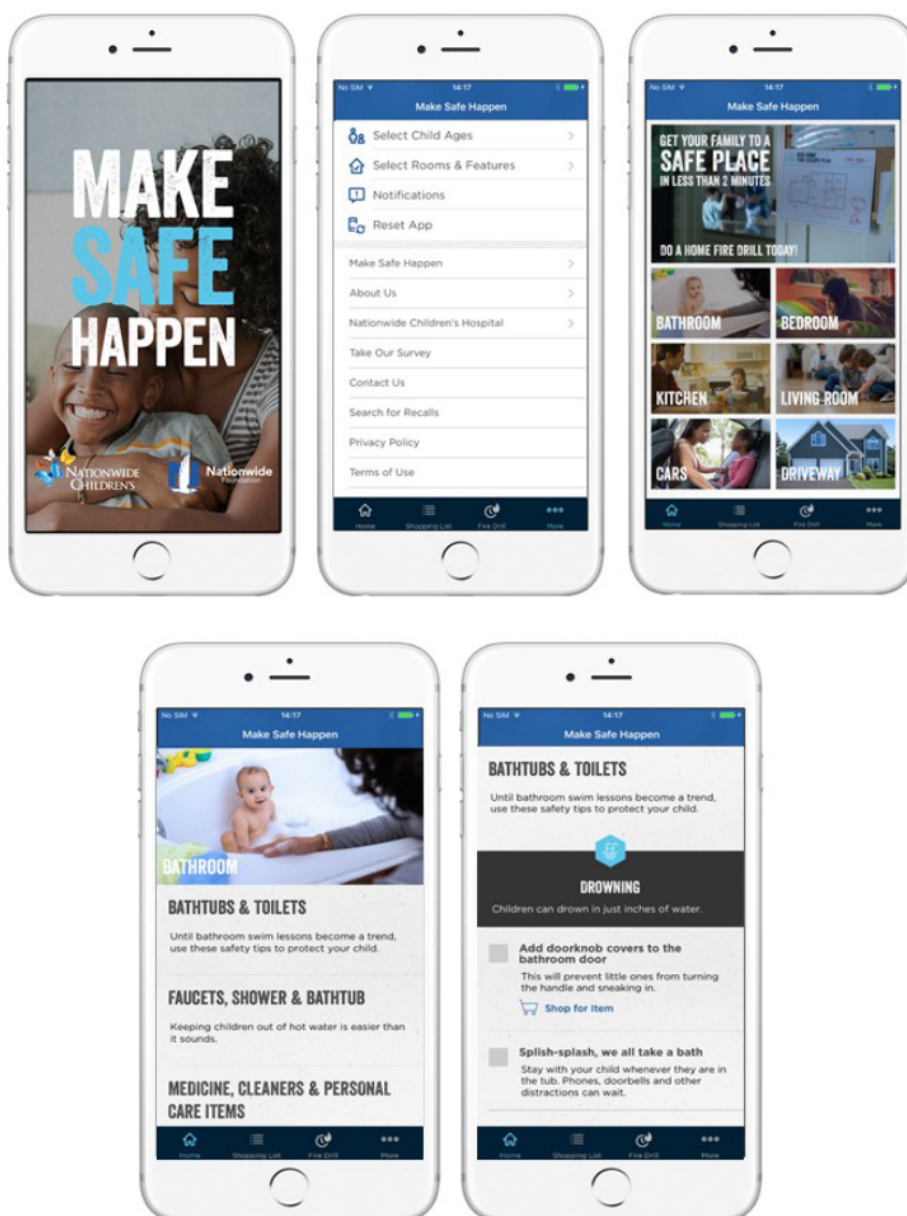
Following telephone recruitment and screening for eligibility, eligible participants were emailed a unique pretest survey link containing a Web-based consent form and questions regarding their safety behaviors, safety knowledge, safety device acquisition and use, and behavioral intentions to adopt future safety actions.

The Make Safe Happen App, Actions, and Google Analytics Linkage

Following completion of the pretest survey, participants were asked to download and use the Make Safe Happen app. General features of the app include the ability for users to tailor safety information by their child’s age (ie, 0 to 11 months, 12 to 23 months, 2 to 4 years, 5 to 9 years, and 10 to 12 years) and customize their experience by selecting features of their home

(ie, standard rooms, garage, basement, stairs, and hallways). The Make Safe Happen app allows users to identify injury hazards with customized room-by-room checklists, links to purchase safety products best suited to the features of their homes via a Web-based global retailer, create shopping lists, and set reminders to encourage consistent safety behaviors. Within each room, users can select injury prevention topics; once clicked, the user will view checklists containing prevention tips and tasks for each injury prevention topic (Figure 1). Injury prevention tasks include the option to add a safety product to their shopping list, shop for products (linking the user directly to the Amazon search for that product), and the ability to add reminders to the calendar (including reminders to change batteries and test devices such as smoke detectors and carbon monoxide alarms). The Make Safe Happen app was available for free download from the Google Play store or the Apple App store. Participants downloaded the Make Safe Happen app version 2.2.0.

Figure 1. Make Safe Happen Mobile App.



Upon completion of the pretest survey, participants received a unique study app identification (app ID) number and instructions via email to download the Make Safe Happen app onto their mobile phone. Participants entered the app ID, a 6-digit alphanumeric code, into the Make Safe Happen app so their actions in the app could be linked to their pretest and posttest survey data. After a period of 7 to 10 days of app use, participants were emailed a unique posttest survey link. Participants' app usage was collected by using GA. When a participant checked an item off in the app, a data point linked to the participant ID was recorded in GA. The participant ID also allowed for data collected from nonstudy users (those without an app ID) to be separated from the study participant app analytics.

Focus Group Discussion Themes

Participants who completed the pretest, app download, and posttest survey were invited to attend 1 of the 5 in-person focus group discussions. A total of 5, 90-min in-person focus group discussions were completed during October 2016 in Columbus, Ohio. Groups of 8 parents were organized according to the age of the index child (2 groups for parents with children aged <2 years and 1 group for parents with children aged 2 to 4 years, 5 to 9 years, and 10 to 12 years). For participants with multiple children, the index child was assigned to the group that contained the least number of parents at enrollment; these parents were asked to only discuss the index child during the focus group discussions. While waiting for the focus group discussions to begin, they completed a brief survey collecting the participants' *home safety* and *app experience rating*. Data reported are for participants that completed all parts of the study.

A professional focus group moderator (AS) led each session through focused conversation, using a discussion guide developed by the study team to ensure critical questions and probes of interest were discussed. The research team observed the focus group discussions through a one-way mirror. Discussions were audio-taped, transcribed by a professional transcription service, and proofed for accuracy by the research team and moderator. At the conclusion of the focus group discussions, participants received a Make Safe Happen-branded gift bag containing home safety information. Participants were paid US \$150 to thank them for their time. Results from the focus group discussions were paired with corresponding data collected from the pretest and posttest surveys, user experience questions, and GA and presented accordingly under each thematic subsection.

Outcomes and Measures

The enhanced focus group design aimed to explore parents' (1) injury prevention awareness and home safety behaviors; (2) Make Safe Happen app user experience; and (3) motivation for taking injury prevention or safety actions as well as the challenges that may inhibit these safety behaviors.

Injury Prevention Awareness and Home Safety Behaviors

Injury prevention awareness was measured by responses to 17 multiple choice questions asked in each of the pretest and posttest surveys based on content delivered in the Make Safe

Happen app. One point was given for each correct answer, and the total of correct answers was summed and divided by the total number of questions (17) for each participant to calculate the *total safety knowledge score*. The *mean total safety knowledge score* for all participants was derived by calculating the mean of the *total safety knowledge score*.

Home safety behaviors were determined via responses to questions on both the pretest and posttest surveys that measured the participant's *repeated safety behaviors*, which are safety behaviors that are recommended to be done repeatedly such as locking up medications, and safety behaviors, which are behaviors that are typically completed once such as installing a smoke alarm. The frequencies of the participants' *repeated safety behaviors* and *safety behaviors* were measured by responses to 14 multiple choice questions and 15 multiple choice questions, respectively. A *home safety rating* was collected during a written exercise before the start of the focus group discussions and was measured by a 5-point Likert scale, where 1 indicated *Everything is childproofed*, 3 indicated *Safe, but room for improvement*, and 5 indicated *Nothing is childproofed*.

Make Safe Happen App Participant Usage and Actions

From September 29, 2016, to October 13, 2016, GA data regarding participants' *sessions*, defined as the number of times the app was opened and at least 1 or more action was taken within the app as well as the number of app screens viewed, were collected. In addition, data of completed *app safety actions*, actions completed within the app such as *checking off* items, creating calendar reminders, or adding safety devices to a shopping list, were collected. GA provides individual and aggregate data for the total number of app sessions, screens viewed, the average number of screens viewed per session, and the average duration of time of each session for the focus group participants. GA does not generate the total amount of time spent on the app per individual. Each parent's *app experience rating* was collected before the focus group on the written survey and was measured by rating the Make Safe Happen app on a scale of 1 (positive) to 5 (negative). Using a Likert scale where 1 indicates dislike and 5 indicates liked a lot, parents provided a *rating of features* for the room-specific checklists and the ability to customize the app based on rooms and features of their home.

Motivation for Prevention and Challenges to Home Safety

During the posttest survey, parents were asked to select the safety tasks that they had completed in and around their home as well as the reasons why they had not made other changes to their home during the past week. Before the start of the focus groups, parents completed a brief one-page app experience survey which asked them to describe the emotions and feelings they had regarding their app experience as well as open-ended questions regarding the features they liked the most and the least.

Data Analysis

Survey response data were analyzed by using SPSS statistical software 24.0 (SPSS Inc) and SAS Enterprise Guide version 7.1 (SAS Institute, Inc). A thematic analysis was conducted by

a process similar to that recommended by Braun and Clarke [21]. AS and OK used the focus group transcripts to identify and analyze important themes. Transcripts were created from audio recordings of the focus group discussions. Members of the study team reviewed the transcripts beginning at the section of each transcript corresponding to the questions asked by the moderator. Initial codes were

created based on the parents' discussion for each question asked by the moderator. Similar and dissimilar responses were grouped, unique or different comments were noted, and patterns addressing the key questions of interest were summarized to extract important themes. These themes were refined and reorganized after review, keeping in mind the key objectives of the research. Any disagreements were resolved via discussion. The results are presented under each respective section: (1) injury prevention awareness and home safety behaviors; (2) Make Safe Happen app user experience; and (3) motivation for prevention and challenges to home safety.

Pretest and posttest difference of the *mean total safety knowledge score* was analyzed with the chi-square test using $\alpha=.05$. Statistical methods were not applied to *all repeated safety behaviors* and *all safety behaviors* because of small frequencies that lacked statistical robustness. This study was approved by the Institutional Review Board at the Nationwide Children's Hospital.

Results

Overview

Participants who completed both the pretest and posttest surveys and downloaded and used the app were invited to attend 1 of the 5 focus group discussions (N=49). A total of 9 participants were dismissed immediately before the focus group discussions to maintain small group sizes. Dismissal was determined based on the time of arrival, and the first 8 participants to arrive were invited into the discussions. The remaining participants were paid before dismissal. A total of 40 parents participated in 1 of 5 focus groups consisting of 8 parents within each group with 58% (23/40) mothers and 43% (17/40) fathers. Parents were, on average, aged 35.8 (SD 6.0) years, mostly white, non-Hispanic (65%, 26/40), members of a 2-parent household (75%, 30/40), educated (Bachelor's degree or more; 75%, 30/40), and employed full time (65%, 26/40). Most parents reported owning their own home (68%, 27/40) and living in their home for ≥ 5 years (35%, 14/40). Parents had an annual household income of \geq US \$80,000 (51%, 20/39) and reported feeling they are *meeting ends easily or very easily* with their income (63%, 25/40; Table 1).

Injury Prevention Awareness and Home Safety Behaviors

Pretest and Posttest Survey

Following app use, the *mean safety knowledge score* significantly increased from 63% (10.7/17) at pretest to 81%

(13.7/17) at posttest ($P<.001$). The percent of participants who completed all repeated safety behaviors increased by 20.0%, from 48% (19/40) at pretest to 68% (27/40) at posttest, and the percent of participants who completed all safety behaviors had a larger increase of 45%, from pretest (15%, 6/40) to posttest (50% (20/40); Table 2). On the posttest survey, one parent did not use the app within the study period, and over 60% of parents (62%, 24/39) reported that they were already following *safety behavior*.

Focus Group Discussions

During the focus groups, parents reported that they could be doing more to prevent injuries in their homes and that they became more aware of the different ways they could make their homes safer, following app use. On average, participants gave their homes a *home safety rating* of 2.7 (range 2.5-2.9), just better than *Safe, but room for improvement*. Parents discussed that they had taken several safety measures such as installing outlet covers, doorknob covers, baby gates, cabinet locks, window stops, and blind cord shorteners; securing cleaning products; securing furniture to the wall; and checking fire alarm batteries and believed these actions had helped prevent injuries. All parent participants reported that they were motivated to install safety devices; however, the type of safety devices mentioned for installation differed by child age.

During the focus group discussions, parents of younger children (aged 0 to 2 years) were particularly motivated to install, test, and/or purchase safety devices such as TV and furniture anchors, carbon monoxide alarms, oven locks, corner guards, and window locks. Parents of children aged over 2 years were motivated to improve home fire safety and were especially interested in testing, installing, and purchasing products such as smoke alarms, fire extinguishers, and fire escape ladders, as well as preparing for a home fire by practicing a home fire drill using the Make Safe Happen app:

I had added the tethers to all the furniture when my seven-year-old and my five-year-old were young, but...now we have a nine-month-old, and we had to purchase other furniture...I thought I was golden and all that, but there was a good reminder...and there was one TV that we didn't have attached to the wall...I didn't even know there was a water temperature thing you could do. I'd never heard of that before, either. So, I need to look more into that. [Parent of a child aged 0 to 2 years]

We only had our really old fire extinguisher, and it's...in the garage...this made me think, like "Oh, we should probably have one out there and one in the house," and we haven't checked it...It probably doesn't even work...I hadn't thought about that at all, and I'm pretty safety-conscious, so that's one thing that's on the list to get. [Parent of a child aged 10 to 12 years]

Table 1. Demographic characteristics of enhanced focus group participants.

Demographic characteristics	Focus group participants (n=40)	Parents of children <2 years (n=16)	Parents of children 2-4 years (n=8)	Parents of children 5-9 years (n=8)	Parents of children 10-12 years (n=8)
Age (years), mean (SD)	36 (6)	34 (5)	32 (3)	37 (7)	41 (60)
Number of children <18 years in household, mean (SD)	2 (1)	2 (1)	2 (1)	2 (1)	3 (1)
Gender, n (%)^a					
Fathers	17 (43)	7 (44)	3 (38)	4 (50)	3 (38)
Mothers	23 (58)	9 (56)	5 (63)	4 (50)	5 (63)
Race or ethnicity, n (%)					
White, non-Hispanic	26 (65)	12 (75)	5 (63)	4 (50)	5 (63)
Black, non-Hispanic	10 (25)	2 (13)	2 (25)	3 (38)	3 (38)
Other	4 (10)	2 (13)	1 (13)	1 (13)	0 (0)
Education, n (%)					
≤High school or General Education Development	1 (3)	0 (0)	1 (13)	0 (0)	0 (0)
Some college	9 (23)	4 (25)	3 (38)	1 (13)	1 (13)
≥Bachelor's degree	30 (75)	12 (75)	4 (50)	7 (88)	7 (88)
Employment, n (%)					
Full Time	26 (65)	12 (75)	4 (50)	6 (75)	4 (50)
Part-Time	5 (13)	2 (25)	1 (13)	2 (25)	0 (0)
Stay at home parent	8 (20)	1 (6)	3 (38)	0 (0)	4 (50)
Other	1 (3)	1 (6)	0 (0)	0 (0)	0 (0)
Household, n (%)					
Two Parent	30 (75)	15 (94)	4 (50)	5 (63)	6 (75)
Single Parent	10 (25)	1 (6)	4 (50)	3 (38)	2 (25)
Home ownership, n (%)					
Own	27 (68)	12 (75)	2 (25)	6 (75)	7 (88)
Rent	13 (33)	4 (25)	6 (75)	2 (25)	1 (13)
Time in current household, n (%)					
≥5 years	14 (35)	4 (25)	2 (25)	5 (33)	3 (38)
3-4 years	12 (30)	7 (44)	2 (25)	1 (13)	2 (25)
1-2 years	10 (25)	3 (19)	4 (50)	1 (13)	2 (25)
≤11 months	4 (10)	2 (13)	0 (0)	1 (13)	1 (13)
Income^b, n (%)					
<\$20,000	1 (3)	0 (0)	1 (13)	0 (0)	0 (0)
\$20,000-\$39,999	5 (13)	1 (6)	3 (38)	1 (13)	0 (0)
\$40,000-\$59,999	8 (21)	3 (19)	0 (0)	0 (0)	5 (63)
\$60,000-\$79,999	5 (13)	3 (19)	2 (25)	0 (0)	0 (0)
≥\$80,000	20 (51)	9 (56)	1 (13)	7 (88)	3 (38)
Livability, n (%)					
Meet ends with difficulty or with great difficulty	3 (8)	4 (25)	1 (14)	1 (13)	0 (0)
Just get by	12 (30)	0 (0)	4 (43)	0 (0)	5 (33)
Meet ends easily or very easily	25 (63)	12 (75)	3 (29)	7 (88)	3 (38)

^aTotal percentage may not add to 100 because of rounding.

^bIncome missing n=1 because participant preferred not to answer.

Table 2. Percentage of mean safety knowledge score and of participants who completed all safety behaviors.

Study Measures	Pretest	Posttest
Mean safety knowledge score ^a	63	81
All repeated safety behaviors, n (%)	19 (48)	27 (68)
All safety behaviors, n (%)	6 (15)	20 (50)

^a $P < .001$.

Make Safe Happen App User Experience

Make Safe Happen App Participant Usage and App Safety Actions

There were 229 app sessions during the study period for the 40 participants who completed the focus group discussions. During these app sessions, 3314 screens were viewed averaging 14.5 screens per session for an average duration of 8 min and 24 seconds. Participants completed 1972 *app safety actions*. A total of 42% (17/40) of parents completed all tasks for at least 1 room in the app. Of the standard 4, the bedroom (22%, 9/40) and kitchen (20%, 8/40) were most commonly completed within the app by participants. Participants set a total of 19 calendar reminders. Testing smoke alarms had the greatest number of set reminder actions (n=7), followed by testing carbon monoxide alarms and replacing smoke alarm batteries, where n=3 for both, and 1 person reported completing the action to replace carbon monoxide alarm batteries (Textbox 1).

Focus Group Discussions

Most parents (73%, 29/40) reported that they had a positive experience while using the app. On average, parents gave the app an *app experience rating* of 2.1. Parents of children aged less than 2 years had a particularly positive experience, with an average *app experience rating* of 1.7, whereas the average among parents of children aged 2 years and older was 2.3. Almost all parents (93%, 37/40) indicated they felt *informed* while using the app. Other common emotions reported were positive, including feeling *encouraged* (58%, 23/40), *empowered* (40%, 16/40), and *engaged* (40%, 16/40):

Informative of things I didn't know about but also made me feel I should push to make my home safer and be more alert. [Parent of a child aged 0 to 2 years]

It was very detailed. I'm a checklist person and I love that about it! It made me thinking about things in different areas that I wouldn't have thought of. [Parent of a child aged 0 to 2 years]

I thought it was easy to use, but I really liked how it was organized by room, because it wasn't so overwhelming. [Parent of a child aged 10 to 12 years]

During the discussions, parents reported that they typically only checked off items in the app checklist after they completed the *app safety action*; *app safety actions* added to the participant's *mental checklist* were not checked off in the Make Safe Happen app checklist and thus would not be recorded as an *app safety action* in GA. Parents liked the option to add the Poison Help Number to their contacts; however, only about one-third (14/40) of them reported adding the number to their mobile phones and only 20% (8/40) actually completed that *app safety action*. During the discussion, some parents said they already had it in their mobile phone contacts and others said they would "Google it" if they needed to call the number. In addition, parents liked the shopping list and calendar functions of the Make Safe Happen app, yet they reported that they did not use these features (Table 2). Parents reported not using the shopping features because they either do not often use their phones to shop or because they needed to discuss their purchases with their spouse or partner. Participants who reported not using the calendar feature either do not use the calendar on their mobile phone or already have a plan to regularly change their smoke alarm (or carbon monoxide alarm) batteries.

Parents provided a *rating of features* for the room-specific checklists and the ability to customize the app, both scoring means of 4.5 (liked a lot). Parents of children aged below 5 years seemed likely to keep using the app, whereas parents with children aged 5 years or above seemed less likely to continue to use the Make Safe Happen app:

It has good information...I think [I'll] keep it around, is because I know even if you were to

have everything checked off, it's just good to look at that list just to reaffirm it. [Parent of a child aged 0 to 2 years]

I think I'll keep it, just because as my kids get older, I can change the ages on it and it will adjust the differences that might be applicable to their age groups. [Parent of a child aged 2 to 4 years]

I think once I went through all the rooms and set the calendar reminders, I think the only reason may be to keep it would be—like the fire escape plan, as the kids get older, let them practice and use the phone. [Parent of a child aged 5 to 9 years]

Textbox 1. The Make Safe Happen app safety actions as recorded in Google Analytics.

Index child age

- 12-23 months (n=16)
- 2-4 years (n=8)
- 5-9 years (n=8)
- 10-12 years (n=8)

Selected child age in app (study participants were able to select the ages of all their children in the app, including the index child age)

- 0-11 months (n=9)
- 12-23 months (n=10)
- 2-4 years (n=18)
- 5-9 years (n=18)
- 10-12 years (n=13)

Rooms completed

- Any room (a total of 17 participants completed all of the tasks for at least one room; n=17)
- Bathroom completed (n=5)
- Basement completed (n=3)
- Bedroom completed (n=9)
- Cars completed (n=4)
- Driveway completed (n=4)
- Fireplace completed (n=3)
- Garage completed (n=2)
- Kitchen completed (n=8)
- Laundry Room completed (n=6)
- Living Room completed (n=5)
- Playroom completed (n=1)
- Stairs & Hallways completed (n=6)
- Yard completed (n=1)

Set reminder

- Total set reminders (n=19)
- Testing smoke alarms (n=7)
- Testing carbon monoxide alarms (n=3)
- Replacing smoke alarm batteries (n=3)
- Replacing carbon monoxide alarm batteries (n=1)

Check off safety actions (n=1741)

Shop for (n=39)

Shop for shopping list (n=19)

Shop for amazon (n=14)

Social share (n=3)

Added poison help number to contacts (n=8)

Total app safety actions (n=1972)

Table 3. Self-reported parental barriers to take safety actions.

Barriers to taking safety actions	Statistics, n (%) ^a
Intend to make changes in near future	34 (87)
Already follow these safety recommendations	24 (62)
Do not have time to make changes	13 (33)
Do not think the information is relevant to me	10 (26)
Cannot afford safety products now	9 (23)
Did not take safety action or actions for some other reason	6 (15)
Am not ready to follow safety recommendations	4 (10)

^aTotal does not add to 100% because participants could select more than one barrier.

Motivation for Prevention and Challenges to Home Safety

Pretest and Posttest Survey

On the posttest survey, one-third of the parents (33%, 13/39) reported not having enough time to make the recommended changes, whereas approximately one-quarter of parents reported not being able to afford these changes (23%, 9/39) or that they did not think the recommendations were relevant to them (26%, 10/39). However, almost 90% (87%, 34/39) of parents reported intending to make changes in the future (Table 3).

Focus Group Discussions

Parents described feeling overwhelmed with the amount of safety tasks included in the Make Safe Happen app.

It was overwhelming. I was like, oh my gosh, we're failing. [Parent of a child aged 0 to 2 years]

For parents of children of all ages, making the safety tasks easier would motivate them to complete injury prevention tasks. They said they would be more likely to complete these safety tasks if they had more time, reminders, easier access to safety products, less expensive products, and assistance with installation of safety devices. Parents also mentioned that some parents and guardians or family members may be another barrier to taking safety actions:

A barrier is actually...my husband...when I bring stuff up, he's like, "Why? We didn't have fire ladders when we were a kid, so why?" ...I begged for Christmas for in-laws to buy a fire extinguisher, and he's like, "Why do we need one in the basement?" [Parent of a child aged 0 to 2 years]

I think cost could potentially be something that would maybe put someone—not be able to do everything. Especially with the window stop sand the fire escape ladders. That's a large expense, and if you have a lot of upstairs rooms. [Parent of a child aged 5 to 9 years]

Additionally, some parents mentioned seeing the risks of not doing tasks or a near miss situation would motivate them to further take safety actions in their home:

This last week has been really cool, like where I want the windows open at night, but then I'm looking at it, like, I guess they could [fall out]...so then I was, "I

guess it's not worth the risk," so I did close up the windows and lock 'em, since we don't have bars or anything in there for now...It did make me conscious. [Parent of a child aged 0 to 2 years]

I never did the TV strap...I've never really had a close call with it, but I guess you don't want to have a close call, because that might be it...I can lift up my TV with...one hand...I guess maybe I didn't believe it, that it could kill a kid. [Parent of a child aged 2 to 4 years]

Discussion

Principal Findings

This study demonstrates that an injury prevention mobile app, Make Safe Happen, can be used to improve parental safety knowledge and positively influence parental behavior by motivating parents to complete safety actions to make their home safer for their children. By using enhanced focus groups to combine qualitative and quantitative data, this study was able to deeply explore parental knowledge, behaviors, and decisions regarding child injury prevention in and around the home following the use of the Make Safe Happen app. Although previous work has highlighted successful injury prevention strategies that incorporate parental education, behavior change, and environmental modification [8-10], this methodology allowed for further exploration of each component following app use. Our findings suggest that the Make Safe Happen app may be a valuable resource that can provide parents with the knowledge and resources needed to encourage the completion of child injury prevention tasks in and around the home. To our knowledge, this study is the first to utilize enhanced focus groups to evaluate a child injury prevention app developed to help parents and caregivers keep their children safe in and around the home.

Strategies to prevent home injuries to children include increasing parental safety knowledge and environmental modification and facilitating behavior change [5]. Effective injury prevention interventions may incorporate all 3 components as increasing awareness and knowledge may facilitate behavior change including environmental modification such as the installation and proper use of safety devices. Similar to other research evaluating technologies developed to increase child injury prevention knowledge and behaviors [22,23], parents in our

study reported a significant increase in injury prevention awareness measured by their *meansafety knowledge score* and completed 45% more home *safety behaviors*, following the use of the Make Safe Happen app. Following app use, parents stated the app content helped raise their awareness regarding the safety of their homes, the need to make their homes safer, and the ability to know the safety measures needed to improve their home safety.

Although removing hazards and installing safety devices can reduce the risk of home injury [4], parents may find it difficult to complete these tasks because these modifications often take time, money, resources, and may vary by child age and developmental stage [11,24,25]. Parents of younger children (aged 0 to 2 years, with no previous older children) may have felt more overwhelmed by the information presented because they may not have previously thought about and/or taken steps toward preventing injuries in their homes. However, these parents gave the app a more positive *app experience rating* and were most motivated to improve the safety of their home by installing safety devices.

Although we were able to view the app analytics to confirm that parents opened the app, viewed screens, and completed actions within the app, these actions do not correlate to the actions completed within the parent's home. During the focus group discussions, parents shared that while they used the app and explored the content, they did not physically mark the action as completed in the app until the action was completed in their home. Thus, items added to a *mental checklist* would not be documented as completed in the app if they simply read and acknowledged that this task was something they wanted to do. Similarly, parents reported liking certain app features, such as adding the Poison Help Number to their contacts, even though they decided not to use the features during the study period. Following use of the app, parents stated they would be more likely to complete tasks around their home that could prevent child injuries if they had more time, more reminders, easier access, and less expensive products as well as assistance to complete these tasks. Future directions could explore opportunities to incorporate additional reminders and resources such as discounts on safety products and installation services to help motivate task completion. Although continued app use following the study is unknown, parents of children aged below 5 years expressed an interest in continued app use and reported a positive app experience, stating they felt informed, encouraged, empowered, and engaged while using the app.

Limitations

This study has several limitations. First, our sample consisted of predominately white non-Hispanic participants, and there was no control or comparison group for this portion of the study, thus limiting the generalizability of these findings. In addition, participants were existing members of a research panel. Participants may have agreed to participate because they were active technology users or had an interest in injury prevention

or research, which may have introduced self-selection bias. For the purposes of the focus groups organization, participants were asked to only discuss the child(ren) that was within that age group, although parents may have had additional children in other age groups and this additional parenting experience or knowledge may have biased some of their discussions. However, parents were asked to use the app as they naturally would if they had found it on their own. In addition, the content within the Make Safe Happen app focuses more heavily on injury prevention information relevant to younger children. Therefore, parents with only older children may have not been exposed to all injury prevention topics. Although participants were aware that their app use was being monitored, they were not reminded or prompted to use the app during the study period, which could have increased app use during this limited period of 7 to 10 days. Finally, no observed safety behaviors or long-term outcomes such as app usage were collected, thus limiting our understanding of participant app usage and safety behavior change following our study period.

Despite these limitations, this study brings to light important information regarding parental attitudes, knowledge, and behaviors regarding child injury prevention in the home. Mobile delivery is a feasible and wide-reaching option to provide home injury prevention information to parents. This methodology provides a cost-effective approach to obtain valuable, qualitative, and quantitative data regarding one's understanding and practice before the intervention (Make Safe Happen app use), actual app usage, and detailed discussions concerning their perceived barriers and motivators for injury prevention. Future directions may explore the benefits of additional reminders, notifications, and links to resources within the app. Additional research should investigate continued app use and user engagement and motivators for the completion of home injury prevention tasks for parents with children of all ages.

Conclusions

The combination of the qualitative and quantitative data greatly enriched our understanding of parents' attitudes, knowledge, and behaviors regarding the use of a child injury prevention mobile app, Make Safe Happen. Following app use, parents had an increase in knowledge and self-reported home safety behaviors. Although parents had a positive app experience, barriers to home safety such as time as well as access to and cost of safety products remain challenges delaying or preventing the completion of some home safety tasks. The Make Safe Happen app may provide parents and caregivers with the information and motivation needed to help prevent child injuries in and around their homes. The enhanced focus group approach is a valuable and cost-effective method that allows for rich data capture and provides a deeper investigation into the actions, behaviors, and decision making of parents regarding child injury prevention in and around the home. Future research should evaluate long-term user engagement and behavior change for parents with children of all ages following the use of a mobile app designed for child injury prevention.

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Conflicts of Interest

None declared.

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Abbreviations

GA: Google Analytics

TV: television

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Original Paper

Determination of Personalized Asthma Triggers From Multimodal Sensing and a Mobile App: Observational Study

Revathy Venkataramanan¹, MSc; Krishnaprasad Thirunarayan¹, PhD; Utkarshani Jaimini¹, MSc; Dipesh Kadariya¹, BSc; Hong Yung Yip¹, MSc; Maninder Kalra², PhD; Amit Sheth¹, PhD

¹Ohio Center of Excellence in Knowledge-enabled Computing, Wright State University, Dayton, OH, United States

²Dayton Children's Hospital, Dayton, OH, United States

Corresponding Author:

Amit Sheth, PhD

Ohio Center of Excellence in Knowledge-enabled Computing

Wright State University

377 Joshi Research Center

3640 Colonel Glenn Highway

Dayton, OH, 45435

United States

Phone: 1 9372390625

Email: amit@knoesis.org

Abstract

Background: Asthma is a chronic pulmonary disease with multiple triggers. It can be managed by strict adherence to an asthma care plan and by avoiding these triggers. Clinicians cannot continuously monitor their patients' environment and their adherence to an asthma care plan, which poses a significant challenge for asthma management.

Objective: In this study, pediatric patients were continuously monitored using low-cost sensors to collect asthma-relevant information. The objective of this study was to assess whether kHealth kit, which contains low-cost sensors, can identify personalized triggers and provide actionable insights to clinicians for the development of a tailored asthma care plan.

Methods: The kHealth asthma kit was developed to continuously track the symptoms of asthma in pediatric patients and monitor the patients' environment and adherence to their care plan for either 1 or 3 months. The kit consists of an Android app-based questionnaire to collect information on asthma symptoms and medication intake, Fitbit to track sleep and activity, the Peak Flow meter to monitor lung functions, and Foobot to monitor indoor air quality. The data on the patient's outdoor environment were collected using third-party Web services based on the patient's zip code. To date, 107 patients consented to participate in the study and were recruited from the Dayton Children's Hospital, of which 83 patients completed the study as instructed.

Results: Patient-generated health data from the 83 patients who completed the study were included in the cohort-level analysis. Of the 19% (16/83) of patients deployed in spring, the symptoms of 63% (10/16) and 19% (3/16) of patients suggested pollen and particulate matter (PM_{2.5}), respectively, to be their major asthma triggers. Of the 17% (14/83) of patients deployed in fall, symptoms of 29% (4/17) and 21% (3/17) of patients suggested pollen and PM_{2.5}, respectively, to be their major triggers. Among the 28% (23/83) of patients deployed in winter, PM_{2.5} was identified as the major trigger for 83% (19/23) of patients. Similar correlations were not observed between asthma symptoms and factors such as ozone level, temperature, and humidity. Furthermore, 1 patient from each season was chosen to explain, in detail, his or her personalized triggers by observing temporal associations between triggers and asthma symptoms gathered using the kHealth asthma kit.

Conclusions: The continuous monitoring of pediatric asthma patients using the kHealth asthma kit generates insights on the relationship between their asthma symptoms and triggers across different seasons. This can ultimately inform personalized asthma management and intervention plans.

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KEYWORDS

personalized digital health; medical internet of things; asthma management; patient-generated health data; pediatric asthma; asthma control; medication adherence; childhood asthma; understanding and treatment of asthma

Introduction

Background

Asthma is a chronic inflammatory lung disease affecting 26 million people in the United States, of which 6 million are children [1]. It is a multifactorial disease, with exposure to different triggers manifesting as symptoms of varying intensities, which demands a personalized diagnosis and management plan [2]. Timely feedback and intervention are not possible with infrequent clinical visits because most of the asthma-exacerbating factors are in the patient's environment and are not tracked meticulously [3,4] or because of the lack of medication adherence [5]. Continuous tracking and assessment of a patient's condition, environment, and adherence to a prescribed care plan can improve asthma control and quality of life [6].

Although many studies have shown the effectiveness of continuous monitoring, only a few are being evaluated to benefit traditional health care practices [7,8]. Propeller Health [9] provides personalized alerts based on inhaler usage and location to primarily improve medication adherence. ENVIROFI [10] and azma.com [11] send a notification to subscribed users when the outdoor environment forecast is poor. Chu et al [12] developed a ubiquitous warning system that sends alerts to health care providers based on a patient's location if the outdoor environment is poor. Finkelstein et al [13] developed a Web-based approach that captures the patient's forced vital capacity test and asthma symptoms and sends alerts to hospitals when these parameters are abnormal. AsthmaGuide [14], a home management ecosystem, enables doctors to observe the correlation between symptoms and environmental data. They have classified wheezing sounds as asthmatic wheezing and nonasthmatic wheezing. They also send personalized alerts to patients based on pollen and air quality forecast, but no causal relationships are identified. The existing studies analyze the data pertaining to the outdoor environment to identify the causes of asthma symptoms or improve medication adherence, but these studies have not used a large cohort of pediatric patients in a clinical setting and have not monitored and analyzed a comprehensive set of factors such as the lung function measurements, activity limitation, and data pertaining to the indoor environment to personalize asthma management plan.

kHealth Asthma Framework

The researchers at Knoesis (Ohio Center of Excellence in BioHealth and Innovations) developed kHealth [15] (Multimedia Appendix 1), a multisensory framework for continuous monitoring of patients' health signals and environmental data. The kHealth kit collects multimodal data using low-cost sensors and mobile apps, and kHealth methodology analyzes them for personalized health management plan. kHealth asthma [16] is an adaptation of kHealth framework and methodology for asthma, which monitors the pediatric patients receiving asthma care at the Dayton Children's Hospital (DCH). The motivations

behind kHealth asthma kit are to (1) identify the personalized triggers from the comprehensive data collected by kHealth kit and rank their influence on asthma, which the paper focuses on, and (2) provide actionable insights to clinicians for better decision making related to asthma management based on specific patient data. It is designed to assist patients in self-monitoring and self-appraisal of asthma care, with an intent to incorporate self-management, prediction, and intervention [17]. This paper presents a cohort-level analysis of patients deployed over the entire year to evaluate the ability of low-cost sensors in identifying the major triggers for their asthma symptoms. Specifically, 1 patient from each season was chosen to illustrate the personalized determination of triggers by gathering anecdotal evidence.

Methods

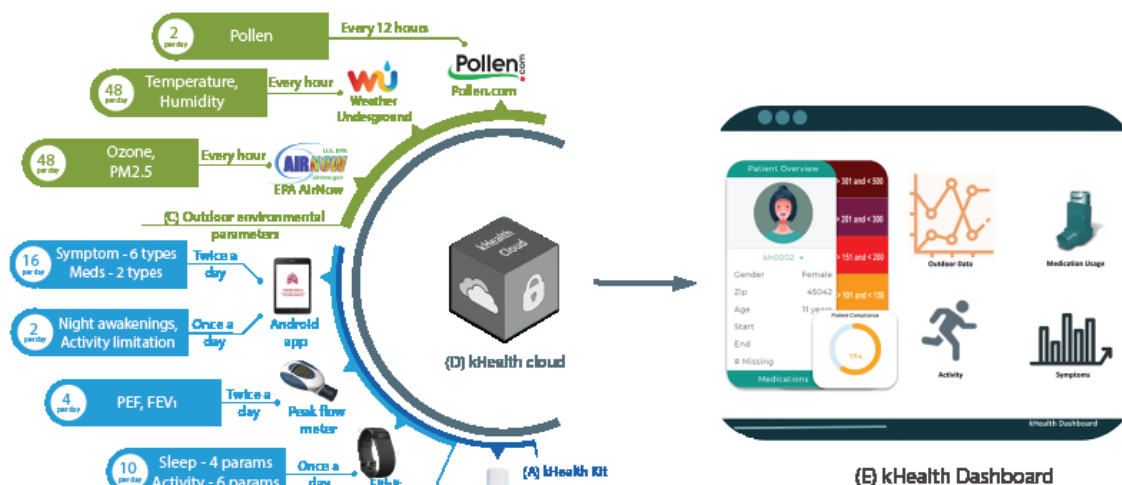
The kHealth asthma framework consists of the kHealth kit, kHealth cloud, and kHealth Dashboard. The study design, including these components, their use for data collection, and the data analysis are discussed below. Other applications for which kHealth has been adapted include postbariatric surgery monitoring, postsurgery monitoring of acute decompensated heart failure, and dementia.

kHealth Components

kHealth Kit

The kHealth kit components are shown in Figure 1. The list of components are as follows: (1) tablet with an Android app; (2) Fitbit; (3) Peak Flow meter; (4) Foobot, the indoor air quality monitor; and (5) Web services to collect data on outdoor environment based on the patient's zip code. The questionnaire presented by the kHealth Android app on the tablet collects the following data: (1) 6 types of symptoms: cough, wheeze, chest tightness, hard and fast breathing, cannot talk in full sentences, and nose opens wide [18]; (2) medication intake (rescue inhaler and controller medication) with yes or no option, (3) nighttime awakenings because of asthma symptoms, and (4) activity limitation because of asthma symptoms. The data on symptoms and medications are collected twice a day, and data on nighttime awakenings and activity limitation are collected once a day (Multimedia Appendix 2). Furthermore, Fitbit is used to collect more granular data for sleep and activity [19]. The lung function measurements (peak expiratory flow [PEF] and forced expiratory volume in 1 second [FEV₁]) are recorded by the Microlife peak flow meter [20] twice every day. For a given patient's zip code, outdoor environmental parameters are collected at different intervals—pollen is collected every 12 hours, whereas particulate matter (PM_{2.5}), ozone, temperature, and humidity are collected every hour. Pollen is collected from pollen.com [21], PM_{2.5} and ozone from EPA AIRNow [22], and temperature and humidity from Weather Underground [23]. Foobot collects indoor temperature, humidity, PM_{2.5}, volatile compounds, carbon dioxide, and global pollution index every 5 min.

Figure 1. The kHealth framework with the kHealth kit, kHealth cloud, and kHealth Dashboard, showing the frequency of data collection, the number of parameters collected, and the total number of data points collected per day per patient. (A) Dark blue; the kHealth kit components that are given to patients. (B) Light blue; the kHealth kit components that collect patient-generated health data. (C) Green; the outdoor environmental parameters and their sources. (D) The kHealth cloud (gray). (E) The kHealth Dashboard. Throughout the kHealth ecosystem, all data are anonymized and associated with respective randomly assigned patient IDs. FEV₁: forced expiratory volume in 1 second; PEF: peak expiratory flow; PM2.5: particulate matter.



Validation of Kit Components

Our tablet questionnaire is based on the Asthma Control Test (ACT) questionnaire [24] adapted for Android app and was developed under the supervision of the clinician (the question text was adjusted to make it user friendly). The questions were tested with the patients and iteratively refined using the preliminary work of the evaluation. While recruiting and consenting young patients, the nurse educates both the patient or guardian and the child on the correct way to use the kHealth kit. Given that the child is using kHealth kit under adult supervision and the sensors are reasonably robust, we expect the data to be reliable, and the parent and child team to be trustworthy. Our data and experience suggest that peak flow values measured by Peak Flow meter can vary dramatically in the 3 trials conducted before picking the maximum value. However, it was possible to distinguish normal state from asthmatic state using the max peak flow value so obtained. Previous studies have reported feasibility of peak flow measurement in 5-year-old children [25,26]. The outdoor environmental parameters are collected from EPA AIRNow, Weather Underground, and pollen.com, which are reputed sources, and already published works have used their data [27-29]. We have relied on existing feasibility studies for Fitbit [30,31], but we performed our own for Foobot [32]. In our recent data collection, all the components of the kHealth kit except Foobot (indoor air quality monitor) worked as advertised by the vendor. Although Foobot gave reliable results in our feasibility study, the device suffered electronic interference in the patient's environment, leading to unreliable results.

kHealth Cloud

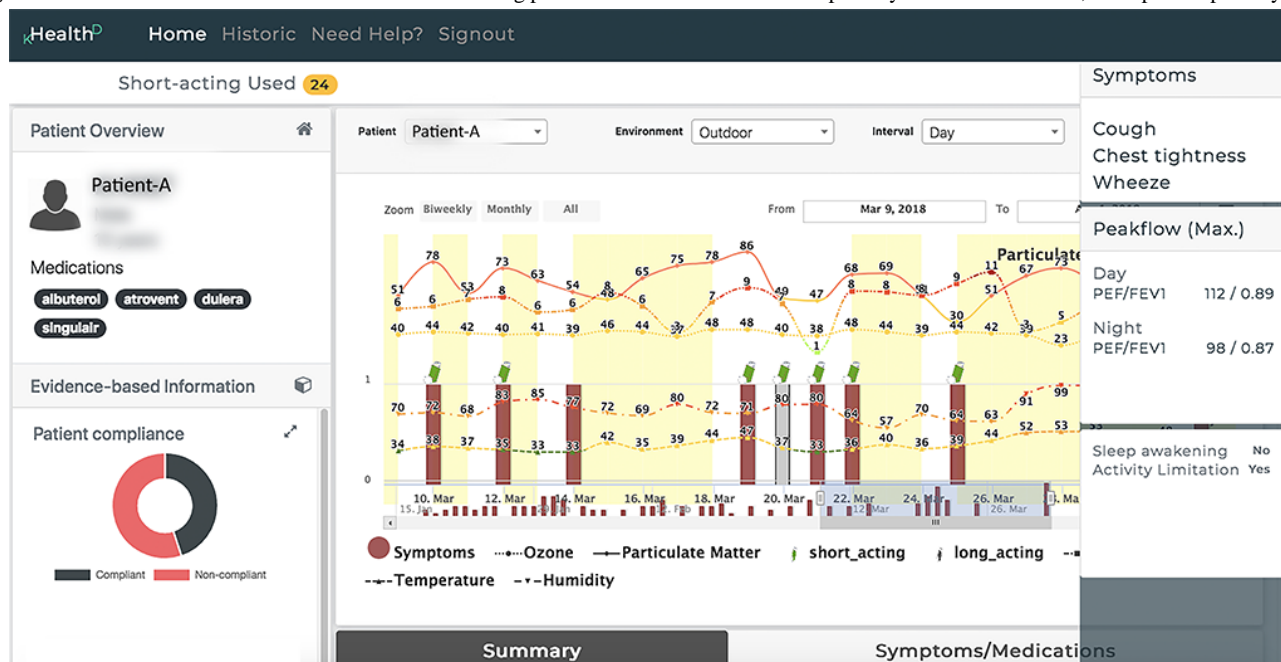
The multimodal data collected from various sources are brought together on the secure kHealth cloud store. The data on outdoor

environment, indoor air quality, activity, and sleep are collected from their respective application programming interface (API) server and stored directly in the kHealth cloud. The data collected using the kHealth app, which includes the patient's symptoms, medication intake, PEF, and FEV₁ readings, are synced in real time with Firebase, a Google cloud database [33]. Firebase provides active data listener for client side, which offers data persistence over the network failure and resyncs to the cloud when the network is restored. Data security is maintained in Firebase using a set of data access rules and user authentication. Data synced to Firebase are then fetched and stored into the kHealth cloud. This process forms a pipeline for seamless and reliable data streaming from the kHealth app to the kHealth cloud. All data stored in the kHealth cloud are then made available to Knoesis researchers and clinicians for real-time analysis. Each patient's identity is anonymized by the nurse coordinator who obtains the patient's consent; no patient-identifiable data are stored anywhere in the kHealth framework.

kHealth Dashboard

Because the kHealth kit collects multimodal data at different frequencies, integration and visualization of these data are essential to derive useful insights. kHealth Dashboard [34] (Figure 2) is a visualization and analysis tool designed for use by a clinician and a researcher to review individual and aggregated data and explore the potential association between patient's asthma symptoms and their environments. With real-time data available in the kHealth cloud, kHealth Dashboard allows real-time monitoring of a patient's asthma condition. This granularity of data presents the clinician with a better picture about patient's asthma condition than in traditional episodic clinical visits (see Multimedia Appendix 1 for demo video).

Figure 2. A screenshot of the kHealth Dashboard visualizing patient A's data. FEV1: forced expiratory volume in 1 second; PEF: peak expiratory flow.



Study Design and Participants

The children within the age group of 5 to 17 years and diagnosed with asthma (through standard clinical procedures) by our clinician were recruited from the DCH. The research nurse practitioner, under the guidance of the clinician, approached the parent of the child to participate in our study. The parent, along with the child, was consented to participate in our study. The recruitment for the study was random, with the motive of maximizing participation and done on a first-come-first-serve basis. The tablet with Android app, Peak Flow meter, Fitbit, and Foobot were given to each patient, and based on the patient's zip code, outdoor environmental data were collected. The part of data collection, which requires the patient to be actively involved (such as responding to Android app questionnaire and taking Peak Flow meter readings), was referred to as *active sensing*. The data collection from Fitbit, Foobot, and outdoor Web services, which do not require active patient involvement, was referred to as *passive sensing*.

Inclusion criteria [35] were children (1) diagnosed with asthma through standard clinical procedure by our clinician from DCH, (2) aged between 5 and 17 years, and (3) willing to participate in this study.

Of 107 patients, 24 patients were excluded from the analysis, as they did not complete the study, allowing us to analyze data from the remaining 83 patients. Both our National Institutes of Health (NIH) and National Institute of Child Health and Human Development (NICHD) proposal and our approved institutional review board (IRB) protocol explicitly indicate 2 populations: (1) consented patients and (2) a subgroup of patients who completed the evaluation (with adequate compliance in data collection). These 24 patients were ignored because they did not complete the study and did not provide adequate data for us to perform any meaningful analysis and offer sensible conclusions. We have explicitly mentioned in our approved IRB protocol that only the patients who consented and patients

who completed the study will be included in our analysis. There has been no selection bias based on data provided by or collected from a patient in either the protocol or the study presented in this paper. No patients who completed the study were ignored from this analysis. Of the 83 patients who completed the study, 63 were recruited for a month, and 20 were recruited for a 3-month period. The 1-month study was designed to validate the efficacy of this method, and the 3-month study was included to obtain sufficient data and determine the association between various asthma-relevant factors and asthma symptoms. The enrollment of a patient for 1 or 3 months depended on their willingness.

This Health Insurance Portability and Accountability Act-compliant study has been approved by DCH's IRB. Given the multifactorial nature of asthma, we sought to monitor as many variables as practically possible, subject to our constraints of practical implementation (eg, using technology that can be deployed at the patient's home) and cost (our NIH and NICHD proposal and protocol called for purchasing 30 kits for proposed patient evaluation at approximately US \$500 per kit).

Preliminary work for this effort was done in 2014 when mobile apps and low-cost sensors became viable [36]. When the NIH and NICHD proposal was written following the preliminary work, there were no reported efforts involving the use of multiple sensors (that can be used outside a clinical facility and at a patient's home) and mobile apps (to record patient's symptoms and collect sensor data). The wearables were just becoming popular, and the concept of patient-generated health data (PGHD) was relatively new. For the studies reporting on the collection and evaluation of personalized data for pediatric asthma patients, our study collects more extensive types of data at a higher frequency. Specifically, evaluation in the study by Merchant et al [37] involved 89 patients, with 2 types of data or parameters (medication and ACT score) observed for 12 months per patient, and Bender et al [38] involved 27 patients, with 1 parameter observed for 2 months. Our study involves 83

patients (63 patients for a 1-month duration and 20 patients for a 3-month duration), with 10 data types (not including Foobot and Fitbit), with each data type collected between 2 and 24 times a day.

Study Procedures

Henceforth, the 6 asthma symptoms (cough, wheeze, chest tightness, hard and fast breathing, cannot talk in full sentences, and nose opens wide), nighttime awakenings, activity limitation, rescue medication intake, and abnormal PEF or FEV₁ value will be collectively referred to as *asthma episodes*, a usage that is consistent with 2 previous studies [39,40]. Specifically, asthma can affect lung function and can manifest as lower values for PEF and FEV₁ parameters [41]. Therefore, the reduction of PEF and FEV₁ values beyond 1 standard deviation of the mean is treated as an episode of asthma. The duration of the seasons has been chosen to aid the analysis based on the historical pollen data. Although the deployments started in December 2016 and are still ongoing, the data only from December 2016 to February 2019 have been included in the analysis.

Maximum values of outdoor environmental data (ozone and PM2.5) over a day were considered to identify the correlation between triggers and asthma episodes. The healthy range for each outdoor parameter is as follows: 0 to 2.4 for pollen [42] and 0 to 50 for ozone and PM2.5 [43]. Any value above or below the healthy range on the day with asthma episodes, or the previous day, is counted as a contributor to the patient's asthma episodes. We chose a 48-hour window because inflammation and late allergic reaction in asthma are characterized by prominent participation of eosinophils, and previous studies have demonstrated an exaggerated response in asthma patients up to 48 hours after exposure [44]. We analyzed concrete patient cases to obtain insights about asthma triggers, patient behavior, and their condition from evidence collected by kHealth Asthma technology in different seasons.

Results

Cohort-Level Analysis

Although we collected extensive Foobot data, the results on the influence of indoor environment were inconclusive because of

deficiencies in our instructions such as (1) clarity on the placement of Foobot and (2) potential for electrical interference when some patients did not power the device as required by the manufacturer. In the study results recorded thus far, the outside environmental data provide the most reliable signals for asthma control. Furthermore, the sleep and activity data from Fitbit did not provide corroborative evidence for asthma signs because of several confounding factors (could be due to asthma symptoms or school routine or that Fitbit was not worn or powered). In contrast, self-reported data regarding activity limitation obtained through the Android app-based questionnaire proved to be more reliable. The results of cohort-level data analysis for all the completed patients (n=83) deployed in each season for the detection of a wide variety of triggers for asthma episodes using kHealth kit are shown in Table 1.

Among the 19% (16/83) of the patients deployed in spring, 63% (10/16) of the patients were affected by pollen, 16% (3/16) were affected by PM2.5, and 5% (1/16) were affected by pollen and PM2.5 (being present together). In addition, 17% (14/83) of the patients were deployed in fall, of which pollen turned out to be the major contributor for 29% (4/14), PM2.5 for 21% (3/14), and pollen and PM2.5 (being present together) for 14% (2/14). For 28% (23/83) of the patients deployed in winter, PM2.5 turned out to be the contributor for 83% (19/23). The 3-month deployments across 2 seasons enabled us to study the patient's asthma in 2 different environments. For 29% (24/83) of the patients deployed across seasons, 50% (12/24) did not exhibit any symptoms. Moreover, 13% (3/24) indicated PM2.5 as their major trigger, 13% (3/24) indicated combination of pollen and PM2.5 to be the trigger, and 25% (6/24) of the patients had varying environment and too few symptoms to arrive at a conclusion. We observed meaningful (and useful according to our clinical partner) correlation between asthma symptoms and factors such as pollen and PM2.5. However, similar correlations were not observed for factors such as ozone level, temperature, and humidity. Personalized insights gathered using the kHealth kit are explained in detail in the Discussion section by choosing 1 patient from each season for illustration. The cohort-level and adherence statistics have already been presented in our previous study [45].

Table 1. Significant triggers captured by kHealth for each season at cohort level (N=83).

Season	n (%)	Pollen, %	PM2.5 ^a , %	Ozone, %	Pollen and PM2.5, %	Temperature, %	No symptoms, %	Redeployment required, %
Spring	16 (19)	63	19	— ^b	6	—	12	—
Summer	6 (7)	17	33	—	33	—	17	—
Fall	14 (17)	29	21	—	14	—	36	—
Winter	23 (28)	—	83	4	—	9	4	—
Between seasons	24 (29)	—	12	—	33	—	50	25

^aPM2.5: particulate matter.

^bNot applicable.

Personalized Analysis

The probability of symptoms, given the triggers for patient A, is shown in Table 2. Patient A was monitored for 3 months from winter to spring; thus, the deployment duration is divided into 2, based on the presence and absence of pollen. The patient experienced symptoms in the presence of PM2.5, suggesting that PM2.5 was contributing to the patient’s asthma. In the presence of both pollen and PM2.5, the patient experienced higher number of severe symptoms such as chest tightness and nighttime awakenings, that is, the combination of pollen and PM2.5 aggravated patient’s asthma, as evidenced by cumulative increase in asthma symptoms. The rescue medication has also been included, as it could prevent or suppress the symptoms that could have occurred otherwise, such as wheezing. The Discussion section provides detailed patient information and calculations (see Figure 3 for formulas and Multimedia Appendix 3 for terms and definitions).

The probability of symptoms, given the triggers, for patient B, are shown in Table 3. Patient B was monitored in winter for 3

months when pollen was absent, and ozone was in a healthy range. The values suggest that PM2.5 was contributing to patient’s asthma, but the probabilities calculated are low as the patient took controller medication to reduce symptoms. The rescue medication is also included, as it can prevent or suppress the other symptoms. Discussion section provides detailed patient information and calculation (see Figure 3 for formulas and Multimedia Appendix 3 for terms and definitions).

The probability of symptoms, given the triggers for patient C, are shown in Table 4. Patient C was monitored for 36 days in fall when pollen, PM2.5, and ozone were in an unhealthy range. All the 3 triggers appear to be contributing to patient’s asthma. The patient was on an oral steroid that controlled the asthma episodes in the later part of the deployment, which explains the low probability values. The rescue medication is also included, as it can prevent or suppress the other symptoms that could have occurred. The Discussion section provides detailed patient information and calculation (see Figure 3 for formulas and Multimedia Appendix 3 for terms and definitions).

Table 2. Probability of symptoms, given the triggers, for patient A.

Symptoms	Probability (symptoms pollen and PM2.5 ^a)	Probability (symptoms no pollen and PM2.5)
Cough	0.66	0.52
Wheeze	0.72	0.88
Chest tightness	0.28	0.12
Activity limitation	0.28	0.64
Nighttime awakenings	0.33	0.04
Rescue medication intake	0.55	0.48

^aPM2.5: particulate matter.

Figure 3. Formulae used to calculate the personalized triggers for patient-A, patient-B, and patient-C. PM2.5: particulate matter.

1) Patient - A

$$Probability (symptom | pollen and PM2.5) = \frac{Number\ of\ days\ symptom,\ pollen\ and\ PM2.5\ occurred\ together}{Number\ of\ days\ pollen\ and\ PM\ 2.5\ occurred\ together}$$

$$Probability (symptom | no pollen and PM2.5) = \frac{Number\ of\ days\ symptom,\ no\ pollen\ and\ PM2.5\ occurred\ together}{Number\ of\ days\ no\ pollen\ and\ PM\ 2.5\ occurred\ together}$$

2) Patient - B

$$Probability (symptom | PM2.5) = \frac{Number\ of\ days\ symptom\ and\ PM2.5\ occurred\ together}{Number\ of\ days\ PM\ 2.5\ occurred}$$

3) Patient - C

$$Probability (symptom | pollen, ozone and PM2.5) = \frac{Number\ of\ days\ symptom,\ pollen,\ ozone\ and\ PM2.5\ occurred\ together}{Number\ of\ days\ pollen,\ ozone\ and\ PM\ 2.5\ occurred\ together}$$

Table 3. Probability of symptoms, given the triggers, for patient B.

Symptom	Probability (symptoms PM2.5 ^a)
Wheeze	0.51
Activity limitation	0.25
Nighttime awakenings	0.02
Rescue medication	0.54

^aPM2.5: particulate matter.

Table 4. Probability of symptoms, given the triggers, for patient C.

Symptoms	Probability (symptoms PM2.5 ^a , pollen and ozone)
Cough	0
Wheeze	0.22
Activity limitation	0.11
Rescue medication intake	0.22

^aPM2.5: particulate matter.

Discussion

Principal Findings

The kHealth kit is able to identify personalized triggers for each season for all the patients. As expected, pollen was the major contributor for the patients with asthma who were deployed in spring and fall. In winter, PM2.5 was the major contributor for most patients.

To illustrate the determination of personalized triggers and its dependence on the seasons, 1 patient with a relatively high number of asthma episodes was chosen for each season. Patient A's deployment period straddled 2 seasons, winter and spring, which permitted the study of asthma in both the presence and absence of pollen. The other 3 patients were deployed exclusively within 1 season: patient B in winter, patient C in fall, and patient D in summer. The days the patients did not answer the questionnaire were excluded from the analysis. We identified the most likely trigger for the patient's asthma episodes. Once a reliable personalized model associating triggers with asthma episode is developed, it can be used to guide an action plan including preventive or remedial measures, as well as design targeted evaluations for better personalized care. IRB protocol defined 2 classes of users with access to patient data. The first class consisting of the physician and nurse who already had the patient's clinical and personally identifiable information continued to have that access, in addition to the kHealth-collected data. The second class consisted of researchers who have access to the data collected by kHealth kit, but all privately identifiable data that clinician or nurse have access to was replaced by a serially chosen identifier. Specifically, the researchers also did not have access to the patient's address or location. In fact, the gender, the weight, and the age information of the individual patient were intentionally deleted from the paper to remove personally identifiable data as stipulated in the approved IRB protocol.

Winter to Spring

Patient A was diagnosed with severe asthma and monitored for 13 weeks, encompassing winter to spring 2018, and answered the questionnaire for 46 days, enough to identify the personalized triggers. The patient was prescribed albuterol and Atrovent (as rescue medication), as well as Dulera and Singulair (as controller medication). The patient took rescue medication for 24 days; experienced cough, wheeze, or chest tightness for 39 days; had limited activity for 26 days; showed abnormal PEF or FEV₁ for 2 days; and was 15% adherent in taking controller medication. During the deployment period, PM2.5 was varying throughout, pollen was absent in the first half and present in the second half, and ozone was in a healthy range throughout. On the basis of the presence and absence of triggers in the patient's environment, we calculated the probability of PM2.5 and pollen or PM2.5 alone being the trigger for the given symptom.

The patient experienced symptoms in the absence of pollen, indicating that PM2.5 is contributing to the patient's asthma symptoms (Table 2). In the presence of pollen, the patient experienced higher number of severe symptoms such as chest tightness (chest tightness is more severe than wheeze [46]) and nighttime awakenings. The rescue medication intake was higher in the presence of pollen, which could have suppressed wheezing. For this patient, the presence of pollen or PM2.5 in the unhealthy range appears to be the primary contributing factor for asthma episodes. The combined presence of pollen and PM2.5 is associated with increased intensity of asthma episodes as evidenced by cumulative increase in number of symptoms. The pollen was in an unhealthy range for 20 days and PM2.5 for 41 days out of the 46 days the patient experienced asthma episodes. When validated with the clinician, the patient was identified to be allergic to pollen using the skin test. The ACT scores before and after the deployment confirmed that the patient's asthma control was suboptimal.

Through continuous monitoring, we found that PM2.5 and pollen were the contributors to the patient's asthma episodes, and the patient had poor adherence to controller medication. To

improve asthma management, the intervention can be personalized by alerting the patient about high pollen and PM_{2.5} forecast. Furthermore, notification can be sent to improve the adherence to the controller medication. If asthma episodes recur even after being adherent toward controller medication, the clinician can intervene with a modified asthma action plan.

Winter

Patient B was classified as having moderate asthma and monitored for 13 weeks in winter of 2017-2018. But data from only the first 9 weeks were available for analysis, as the patient did not answer for 4 weeks toward the end of the deployment. The patient was prescribed albuterol (as rescue medication) and Singulair (as controller medication) and answered the questionnaire for 50 days, of which the patient experienced asthma episodes for 45 days. Patient B experienced wheezing for 27 days, activity limitation for 15 days, nighttime awakenings on 1 day, took rescue medication for 24 days, had abnormal PEF or FEV₁ values for 6 days, and was 50% adherent toward controller medication. Only PM_{2.5} was in an unhealthy range during the deployment period, whereas ozone was in a healthy range, and pollen was absent.

From Table 3, it can be observed that PM_{2.5} contributed to the patient's wheeze and led to the intake of rescue medication. The patient did not experience symptoms on all the days the PM_{2.5} was in an unhealthy range because of patient's adherence to controller medication, which was 50%. In consequence, the patient can be proactively notified when PM_{2.5} is forecast to be in the unhealthy range and may also be reminded to take prescribed medication. Of the 45 days the patient experienced asthma episodes, PM_{2.5} was in an unhealthy range for 40 days. To enhance asthma management, the patient can improve adherence toward controller medication and avoid exposure to PM_{2.5} when it is high. If this does not help, the patient should be reevaluated to adjust the asthma control plan. To identify the patient's reaction to other triggers, the experiment needs to be repeated in other seasons.

Fall

Patient C was diagnosed with moderate asthma and monitored for 5 weeks and 4 days in the fall of 2017. The patient answered the questionnaire 33 out of 36 days of deployment, of which the patient showed asthma episodes for 17 days. The patient was prescribed albuterol (as rescue medication), Symbicort and Singulair (as controller medications), and prednisone (oral steroid). The patient had cough and wheeze for 11 days, had activity limitation for 4 days, took rescue medication for 6 days, showed abnormal PEF or FEV₁ for 9 days, and had an adherence of 63% toward controller medication. The outdoor environment remained uniform with respect to pollen, ozone, and PM_{2.5} throughout the deployment.

Higher intake of wheeze and rescue medication was observed in the initial stages of the deployment. Because pollen, PM_{2.5}, and ozone were present throughout the deployment, all the 3 triggers appear to be contributing to the patient's asthma symptoms (see Table 4, and we were not able to separate the triggers on the basis of the data we have). The patient also took oral steroids to control the asthma episodes, which reflected in

the later part of the deployment by significant reduction in the number of asthma episodes. Of the 17 days the patient experienced asthma episodes, PM_{2.5} was in an unhealthy range for 13 days, pollen for 16 days, and ozone for 7 days. The kHealth framework has the potential to aid patient C in self-management of asthma by alerting the patient when pollen or PM_{2.5} can exacerbate asthma and reminding the patient to take medication to improve adherence. Furthermore, the clinician can also be notified when the patient takes the oral steroid, an indication of poor asthma control, to enable timely intervention. To exonerate some factors and identify triggers precisely, the experiment should be repeated in the season when pollen is absent.

Summer

Patient D had mild asthma and was monitored for 4 weeks and 3 days in the summer of 2018. The patient was prescribed albuterol (as rescue medication) and Asmanex and Singulair (as controller medications). Patient D had answered the questionnaire for 29 out of 30 days and experienced asthma episodes for 6 days. The patient experienced cough, wheeze, chest tightness, or hard and fast breathing for 5 days; activity limitation and nighttime awakenings on 1 day; and the adherence toward the controller medication was 70%. The lung function measurements were normal throughout the study period. Out of the 6 days the patient suffered from asthma episodes, pollen was in an unhealthy range for 3 days, ozone for 4 days, and PM_{2.5} for 6 days. On the basis of observations, PM_{2.5} is suspected to be the major contributor, followed by ozone and pollen. However, this patient had sparse asthma episodes to identify the triggers precisely. In general, none of the patients deployed in summer had sufficient asthma episodes.

Limitations

The objective of this study was to show the ability of kHealth kit to identify personalized triggers for each asthma patient and demonstrate the statistical significance of our findings for each patient across different seasons. However, to maximize participation in the study, all eligible pediatric patients who volunteered were enrolled on a first-come-first-serve basis to test the efficacy of continuous monitoring using low-cost sensors for asthma management. Therefore, the period of observation of patients did not necessarily coincide with season transitions. This turned out to be a limitation for contrasting the patient's lung function and asthma episodes in allergy and nonallergy seasons. Furthermore, as the deployment was on a rolling basis, the patient deployment periods did not coincide. As such, we were unable to combine results from several patients for the same period and provide statistical significance. However, we are optimistic that we can repeat our experiments considering various allergy seasons and patients' susceptibilities, especially given the 63% kit adherence that shows that this technology is acceptable to the patients and can monitor their asthma behavior in different seasons. Because of electrical interference, the data from the Foobot had to be excluded. Although the Fitbit data were reliable, the reason for reduced activity measured by Fitbit could be due to asthma or school routine or because Fitbit was not worn or powered. Hence, Fitbit did not provide originally envisioned insights in our analysis. Our observational study

involved collection of the largest variety of PGHD (sensor data and mobile app answers) and environmental data, offering us the possibility of identifying likely, but not definitive, triggers for an individual patient. However, we are at best able to make inferences based on co-occurrence of symptoms and triggers and hesitate to make any claims about causality beyond saying these correlations provide a good basis for generating a hypothesis for a more extensive randomized controlled trial (RCT). Determining the true causes is beyond the scope of this paper.

Conclusions

The infrequent clinical visits, as practiced by traditional health care protocol, are unable to provide timely feedback and enable intervention. Through continuous monitoring, kHealth kit can provide detailed insights to the clinician about the personalized triggers for asthma patients and their adherence toward the prescribed asthma control protocol. Specifically, for patients such as patient A whose deployment spanned 2 seasons, the kHealth kit suggested, with evidence, the relevant triggers along with the patient's adherence to the prescribed asthma action plan. This can aid the clinician in tailoring the asthma control protocols for a patient, thereby leading to better asthma management. Furthermore, kHealth kit was able to capture triggers across different seasons, which was evident from the determination of the variety of personalized triggers for the patients chosen from different seasons.

Future Work

We plan to repeat the observational trial for different seasons for each patient. Redeployment will be carried out for winter

patients to discover potential triggers in other seasons and also for spring and fall patients to disambiguate among multiple triggers by exonerating some. In addition, 2 separate 1-month deployments in 2 different seasons (allergic and nonallergic) will be attempted again as the earlier experiments yielded sparse data, and 1-month deployments that straddle across 2 seasons will be avoided in future. Moreover, 25% (21/23) of the entire patient cohort did not experience any asthma episodes. Eventually, with the kHealth system, we expect to identify for each patient triggers across seasons that cause worsening of the patient's asthma and thereby aid the clinician with insights about triggers and patient adherence for a personalized action plan.

This study has also helped us design a future study involving self-management and intervention. As Foobot was giving unreliable data, it will be discontinued in our future studies with a replacement that will provide a reliable measure of indoor air quality that is sensitive to secondhand smoke exposure. The Android questionnaire will be updated to disambiguate the reason for reduced activity as it could have been due to asthma or normal school routine without extracurriculars or because of the Fitbit not being worn or powered. The data from the Peak Flow meter proved to be reliable, and a clear distinction could be observed between asthmatic and nonasthmatic days. As the data sources for outdoor environmental data were also reliable, it will be continued. Android app questionnaire will be replaced with a chatbot to improve ease of use [47,48]. As to our future study, we are now working with the School of Medicine at the University of South Carolina that has access to a larger cohort of patients under the care of a larger number of clinicians and specialists. This study will provide a better foundation to formulate a hypothesis for an RCT, which is our next step.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Links to websites and demo videos.

[[DOCX File, 12KB - pediatrics_v2i1e14300_app1.docx](#)]

Multimedia Appendix 2

The questionnaire used in the kHealth Asthma Android app.

[[DOCX File, 12KB - pediatrics_v2i1e14300_app2.docx](#)]

Multimedia Appendix 3

Terms and definitions.

[[DOCX File, 13KB - pediatrics_v2i1e14300_app3.docx](#)]

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Abbreviations

ACT: Asthma Control Test
DCH: Dayton Children's Hospital
FEV1: forced expiratory volume in 1 second
IRB: institutional review board
NICHD: National Institute of Child Health and Human Development
NIH: National Institutes of Health
PEF: peak expiratory flow
PGHD: patient-generated health data
PM2.5: particulate matter with diameter less than 2.5 micrometers
RCT: randomized controlled trial

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Original Paper

What Women With Disabilities Write in Personal Blogs About Pregnancy and Early Motherhood: Qualitative Analysis of Blogs

Michelle L Litchman¹, PhD, FNP-BC, FAANP; MJ Tran¹, MBA, BSN; Susan E Dearden¹, MPHc; Jia-Wen Guo¹, PhD, RN; Sara E Simonsen¹, PhD, CNM, MPSH; Lauren Clark¹, PhD, RN

College of Nursing, University of Utah, Salt Lake City, UT, United States

Corresponding Author:

Michelle L Litchman, PhD, FNP-BC, FAANP

College of Nursing

University of Utah

10 South 2000 East

Salt Lake City, UT, 84112

United States

Phone: 1 801 585 9612

Email: Michelle.Litchman@nurs.utah.edu

Abstract

Background: More than 1 in 10 women of reproductive age identify as having some type of disability. Most of these women are able to become pregnant and have similar desires for motherhood as women without disability. Women with disability, however, face greater stigma and stereotyping, additional risk factors, and may be less likely to receive adequate reproductive health care compared with their peers without disability. More and more individuals, including those with disability, are utilizing the internet to seek information and peer support. Blogs are one source of peer-to-peer social media engagement that may provide a forum for women with disability to both share and obtain peer-to-peer information and support. Nevertheless, it is not clear what content about reproductive health and pregnancy and/or motherhood is featured in personal blogs authored by women with spinal cord injury (SCI), traumatic brain injury (TBI), spina bifida, and autism.

Objective: The objective of this study was twofold: (1) to examine the information being shared in blogs by women with 4 types of disabilities, namely, SCI, TBI, spina bifida, and autism, about reproductive health, disability, health care, pregnancy, and motherhood; and (2) to classify the content of reproductive health experiences addressed by bloggers to better understand what they viewed as important.

Methods: Personal blogs were identified by searching Google with keywords related to disabilities, *SCI*, *TBI*, *spina bifida*, and *autism*, and a variety of keywords related to reproductive health. The first 10 pages of each database search in Google, based on the relevance of the search terms, were reviewed and all blogs in these pages were included. Blog inclusion criteria were as follows: (1) written by a woman or care partner (ie, parent or spouse) of a woman with a self-identified diagnosis of SCI, TBI, spina bifida, or autism; (2) focused on the personal experience of health and health care during the prepregnancy, prenatal, antepartum, intrapartum, and/or postpartum periods; (3) written in English; and (4) published between 2013 and 2017. A descriptive and thematic qualitative analysis of blogs and corresponding comments was facilitated with NVivo software and matrix analysis.

Results: Our search strategy identified 125 blogs that met all the inclusion criteria; no blogs written by women with spina bifida were identified. We identified 4 reproductive health themes featured in the blog of women with disabilities: (1) (in)accessible motherhood, (2) (un)supportive others, (3) different, but not different, and (4) society questioning motherhood.

Conclusions: This analysis of personal blogs about pregnancy and health care written by women with SCI, TBI, and autism provides a glimpse into their experiences. The challenges faced by these women and the adaptations they made to successfully navigate pregnancy and early motherhood provide insights that can be used to shape future research.

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KEYWORDS

disabled persons; pregnancy; blog; women's health; parenting; mothers; spinal cord injury; autism; traumatic brain injury

Introduction

Background

Among women of reproductive age, approximately 12% identify as having some type of disability [1]. Most women with disabilities are able to become pregnant and fertility rates are similar among those with and without disability [2,3]. According to a large study of 10,718 women who responded to the US National Survey of Family Growth from 2006 to 2010, those with and without disability have similar attitudes about motherhood [4]. In addition, childless women are equally likely to want a child and intend to have a child, whether or not they have a disability [4].

Pregnancy and early motherhood for women with disabilities carry increased risk for poor maternal and neonatal outcomes [5-14]. The complicated web of social and biological disease risks accrues synergistically. Using a syndemic framework [15,16], the interplay of social, biological, and structural factors that place women at risk for compromised reproductive health outcomes mutually informs and reinforces disadvantage. Compared with women without disability, women with disability encounter challenges that heighten their reproductive risks. Risks include physical and emotional abuse, being overweight or obese, and decreased physical activity, inadequate emotional support, smaller social networks [17,18], substance abuse [19-24], higher levels of stress [25-27], depression and anxiety [28,29], and special needs related to their care [30]. Negative synergies ensue. *Syndemic suffering* [31] refers to the depletion of personal and material resources as individuals and their social networks respond to interactive disability-specific biological factors and social disadvantages. When women experience chronic stigma and increasing ill-health in a negative cycle of interactive disadvantage, disability scholars coin this a trajectory of *recursive cascades* [22].

The measurable outcomes of syndemic relationships between social circumstances, disability, and women's reproductive outcomes are numerous and most often negative. Pregnant women with disabilities may be at higher risk for stillbirth, preterm birth, low birth weight, fetal growth restriction, and cesarean delivery, as well as medical complications such as venous thromboembolism and recurrent urinary tract infections [5-14]. Women with disability may also be at higher risk for postpartum depression [6] and less likely to breastfeed their infants than women without disability [7]. During pregnancy, women with disability are more likely to visit an emergency department, be admitted to the hospital, experience medical complications, and be readmitted within 3 months of their delivery [32,33] and are less likely to receive early prenatal care [33].

Enacting disability as a form of embodied difference can trigger personal and social consequences, from discrimination and stigmatization to support and collective action [34]. Social relationships help shape the experiences of women with disability. In contemporary society, women seek information and support through peer relationships in word-of-mouth informal communication, as well as in electronic formats mediated by the internet and known as electronic word of mouth

(eWOM) [35]. In general, women, more than men, use social media to communicate with others, seek social support, and share personal experiences [36-38]. Both women with and without disability exchange advice, perspectives, and humor about pregnancy and motherhood through social media, including Web-based diaries or blogs. Personal blogs (Web-based diaries) are one type of eWOM that provides an asynchronous format allowing bloggers to communicate with many readers who can access the information at their convenience [39]. Blogs can also offer a format for peer-to-peer social media engagement in which users can give and receive support and information about disability and pregnancy. Bloggers, particularly women bloggers, tend to share personal experiences to seek social support or to simply share their life experiences [36-38]. By creating and sharing tacit and experiential knowledge, women create a public space for the expression and construction of their perspectives, values systems, and interactions with health care, disability, and pregnancy-related social entities [40-42].

Objective

Women with intellectual disabilities report enjoying social media and having positive experiences using social media to develop friendships, form a social identity, and build self-esteem [43]. Women with physical disabilities who had been pregnant in the past decade cited the value of receiving information from other women who had experienced disability and pregnancy and the importance of seeking peer support [44]. As a research resource, blogs offer unsolicited first-person accounts in a naturalistic environment about pregnancy and disability topics that women choose to describe to a public audience. The purpose of this study was to examine blog content written by women who have experienced or have a desire to experience pregnancy and/or motherhood who are living with a spinal cord injury (SCI), traumatic brain injury (TBI), spina bifida, or autism. Our goal was to capitalize on the information contained in these blogs as a means of understanding the experience of pregnancy, delivery, postpartum recovery, and early motherhood among women with disability. Personal blogs have been examined using a systematic approach in other studies [45]. Although health blogs may be viewed as anecdotal information, aggregated data collected from multiple health blogs can provide insight into the public narrative about the intersection between reproduction and disability [46-48] and support the need for further focused research on topics of value to women with disability.

Methods

Methodology

Before beginning this systematic appraisal of blogs, an institutional review board (IRB) approval was sought and the study was acknowledged as nonhuman subject research through the University of Utah (IRB number 00105240). To maintain the privacy of individuals who published the blogs and were not individually consented for this research, we deidentified the content in the blogs and blog comments by anonymizing the details and quoted text before inclusion in this study to reduce the risk of bloggers being reidentified. To learn more about the

perspective about pregnancy among individuals with disabilities, we selected 4 key types of disabilities as the target of our study. These included conditions resulting in impairments in movement and/or cognition and spanned developmental disabilities and acquired disabilities. Specifically, we selected SCI, TBI, spina bifida, and autism. We sought to include acquired and congenital conditions that impair either physical or cognitive abilities. Methods for the blog appraisal were similar to those reported in previous research [45].

Blogs Selection for Study Inclusion

Using a consensus process, the research team decided upon keywords to use for blog searches. Personal blogs were systematically identified by searching Google using a specific search strategy for each keyword related to disability. Disabilities of interest included SCI, TBI, spina bifida, or autism. Both full terms and their acronyms (ie, SCI and TBI) were used in the search. We also used tetraplegia for SCI.

We developed a data extraction sheet containing the following inclusion criteria: (1) written by a woman or care partner (ie, parent or spouse) of a woman with a self-identified diagnosis of SCI, TBI, spina bifida, or autism, (2) focused on the personal experience of health and health care during the prepregnancy, prenatal, antepartum, intrapartum, and/or postpartum periods, (3) written in English, and (4) published between 2013 and 2017. There were no limitations on the blogger's country of origin. Forums were omitted. The data extraction sheet was pilot-tested with 10 blogs and refined as needed to determine which blogs would be retained for analysis. Initially, 12,600 records were identified. A total of 296 blogs (eg, personal, news outlet, corporate, and foundation) were then identified. In the final step, 215 personal blogs were reviewed for inclusion by at least 2 independent reviewers (MLL and MJT). Unanimous agreement between at least 2 independent reviewers on the final blogs for inclusion was required. Using this method, the first 10 pages of each database search in Google were reviewed for the presence of eligible blogs by 3 of the authors (MLL, MJT, and SD). Exclusion criteria were applied to remove blogs that were duplicates and those that were not personal blogs. The remaining 125 personal blogs that met the inclusion and exclusion criteria were forwarded for qualitative descriptive analysis.

Qualitative Descriptive and Thematic Blog Analysis

Using principles of qualitative description [49,50], the investigators developed and discussed inductive descriptive codes and code definitions. The first 15 blogs were initially read by 2 independent investigators (MLL and MJT), and the initial blog corpus for coding dictionary development was formed. Open coding of successive blogs using a line-by-line analysis was used to apply existing codes or develop new codes for segments of blog text using NVivo 11 software (QSR

International) [49]. Codes were reviewed in a constant comparative process and clustered into categories representing similar constellations of blog content. Through a process of group analysis, all investigators then reviewed blog data, codes, and categories. Matrices organized codes by disability type stratified by reproductive health context (ie, preconception, prenatal, and postpartum) and resulted in the identification of overarching themes about women's reproductive experiences and disability [51,52]. In the final analytic step, the research team reviewed the coded data again thematically, explicitly assessing blog text for content by disability type in the different reproductive health contexts.

Results

Overview

Of the 296 website records identified, a total of 125 blogs met the inclusion criteria and were included in this qualitative analysis. Preferred Reporting of Items for Systematic Reviews and Meta-Analyses guidelines [53] were used to describe the blog inclusion process (see Figure 1). None of the identified blogs were written by a care partner; all were written by the women themselves. The majority of blogs analyzed were written by women with SCI and TBI. There were no blogs by women with spina bifida that were identified. There was 1 distinctive blog written by a woman who was diagnosed with autism following pregnancy. She reflected upon how her symptoms predated pregnancy and early motherhood, thus indicating a likelihood of her autism being present during pregnancy. Her situation was unique and clarified a different perspective of pregnancy and motherhood with a disability. It was not always overtly clear if the bloggers with TBI or autism used wheelchairs; however, all blogs written by women with SCI mentioned the use of wheelchairs. Of the blogs included, only 1 discussed abortion, 1 discussed miscarriage, and 3 mentioned breastfeeding (see Table 1 for additional blog characteristics).

In total, 4 key themes about the reproductive perspectives of women with disabilities resulted from the qualitative analysis: (1) (in)accessible motherhood, (2) (un)supportive others, (3) different, but not different; and 4) society questioning motherhood. How each theme was expressed across the reproductive contexts and by women with different disabilities is further described below. Themes by disability category and reproductive health context are described in Table 2.

(In)accessible Motherhood

Women with disabilities face different challenges and barriers when considering or preparing for pregnancy. Adaptations were necessary to make motherhood more accessible because of the universal design of standard baby products. However, women showcased a sense of pride in successfully adapting baby products to realistically fulfill their motherhood needs.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram.

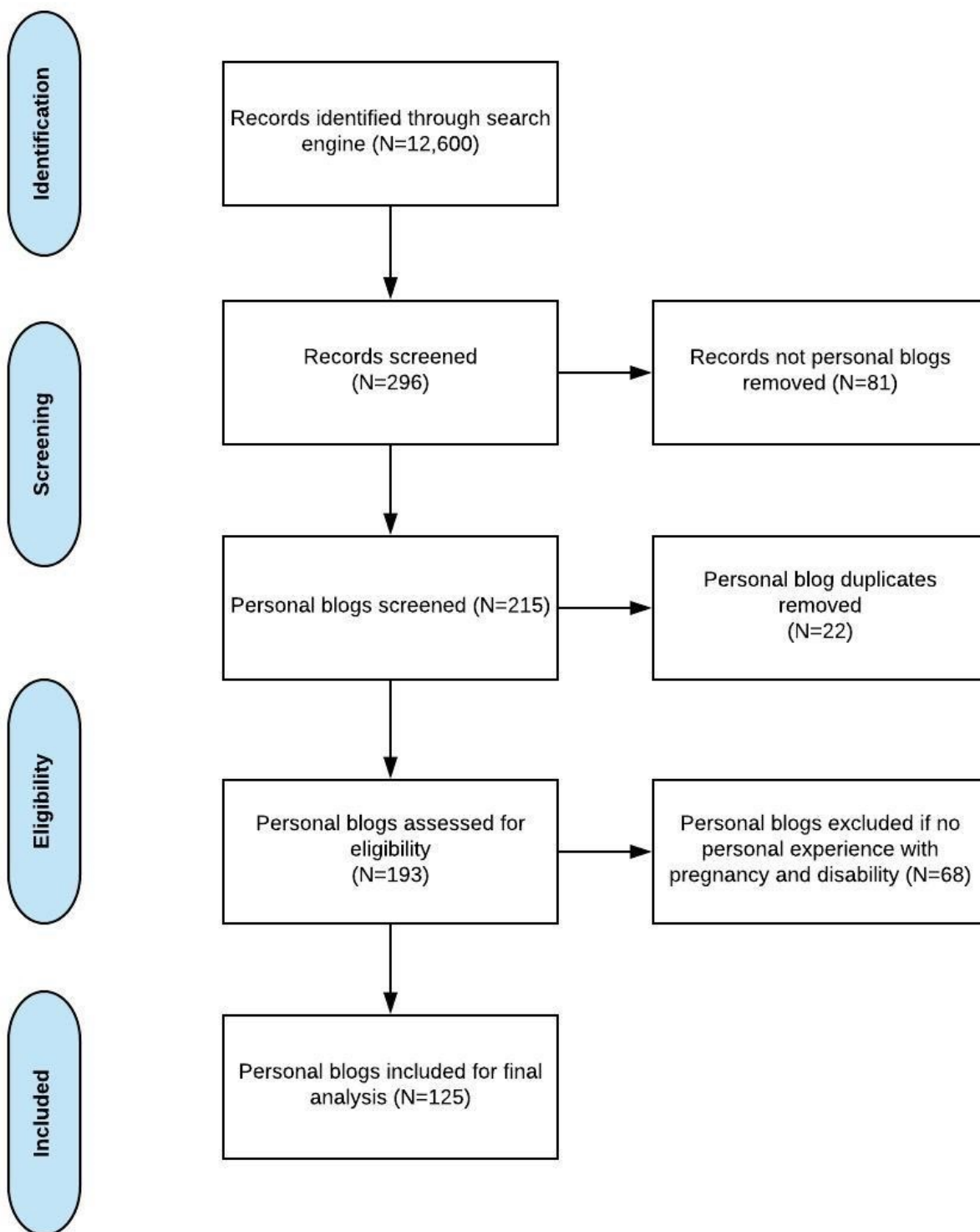


Table 1. Blog Characteristics.

Blog characteristics	Disability type				Total
	TBI ^a	SCI ^b	Spina bifida ^c	Autism	
Blog posts, n (%)	37 (30)	83 (66)	— ^d	5 (4)	125 (100)
Blog post word count, average (range)	1185 (212-2057)	356 (202-1297)	—	925 (800-1612)	—
Blog posts with comments, n (%)	11 (50)	8 (36.4)	—	3 (13.6)	22 (100)
Women bloggers, n (%)	3 (12)	19 (76)	—	3 (12)	25 (100)
Prepregnancy-related blog posts, n (%)					
Surrogacy	0 (0)	3 (100)	—	0 (0)	3 (100)
Artificial insemination	0 (0)	1 (100)	—	0 (0)	1 (100)
Invitro fertilization	1 (100)	0 (0)	—	0 (0)	1 (100)
Prenatal-related blog posts, n (%)	0 (0)	6 (100)	—	0 (0)	6 (100)
Antepartum-related blog posts, n (%)					
Pregnancy	38 (50)	37 (48.7)	—	1 (1.3)	76 (100)
Abortion	0 (0)	1 (100)	—	0 (0)	1 (100)
Miscarriage	0(0)	1 (100)	—	0 (0)	1 (100)
Intrapartum-related blog posts, n (%)					
Cesarean delivery	0 (0)	4 (100)	—	0 (0)	4 (100)
Vaginal delivery	1 (16.7)	5 (83.3)	—	0 (0)	6 (100)
Home birth	0 (0)	1 (100)	—	0 (0)	1 (100)
Postpartum-related blog posts, n (%)					
Early motherhood	0 (0)	18 (100)	—	0 (0)	18 (100)
Developmental milestones	0 (0)	18 (100)	—	0 (0)	18 (100)

^aTBI: traumatic brain injury.

^bSCI: spinal cord injury.

^cNo blog posts were identified for women living with spina bifida.

^dN/A: not applicable.

Prepregnancy

Women in wheelchairs secondary to SCI reported emotional readiness to have a child but needed to consider the physical ramifications and potential adaptations. Surrogacy was discussed in 2 cases of SCI where the woman's health status made pregnancy infeasible. In 1 case, discussions of surrogacy were complicated by the fact that Medicare (the federal health insurance in the United States for people with disabilities and older adults) does not cover the costs of surrogacy, resulting in 1 couple trying to sell their home and occasionally purchasing lottery tickets to achieve their reproductive health goals. In another case, the husband and wife were actively seeking surrogacy and were hopeful that they would become parents sometime soon.

In contrast, women with autism did not describe physical concerns related to pregnancy but expressed apprehension about their emotional capacity to care for a child. Concerns about difficulty coping with a newborn, such as changes in schedule and concerns about their ability to connect emotionally with their baby, were described.

Pregnancy

During pregnancy, some mothers reported a need for a larger wheelchair to accommodate the weight of their growing fetus. Pregnancy-related weight gain complicated transfers to and from the wheelchair, such as getting in and out of a car or going to the bathroom. In some cases, this reduced the woman's independence. Some women experienced challenges with going uphill in a wheelchair during pregnancy because of the increased weight and changes to their center of balance; anti-tip bars were used as a safety net.

Table 2. Theme by reproductive health context and disability category.

Theme and reproductive health context	Blogs by disability category		
	SCI ^a	TBI ^b	Autism
(In)accessible motherhood			
Prepregnancy	✓	— ^c	✓
Pregnancy	✓	✓	—
Delivery	—	—	—
Early motherhood	✓	✓	—
(Un)supportive others			
Prepregnancy	✓	✓	✓
Pregnancy	✓	✓	—
Delivery	—	—	—
Early motherhood	✓	—	—
Different, but not different			
Prepregnancy	✓	✓	✓
Pregnancy	✓	✓	—
Delivery	✓	—	—
Early motherhood	✓	✓	✓
Society questioning motherhood			
Prepregnancy	✓	—	✓
Pregnancy	—	—	—
Delivery	—	—	—
Early motherhood	—	—	✓

^aSCI: spinal cord injury.

^bTBI: traumatic brain injury.

^cNot applicable.

Medical exam tables were not always easily accessible during medical appointments. Women described needing their partners to help with transfers to and from medical exam tables, when such tables were not accessible. The majority of women with SCI described their maternity care provider as being inexperienced in caring for pregnant women with SCI, particularly during labor and delivery. Only 1 blogger discussed taking a prenatal class, noting that she had to make adaptations to what was taught to meet her own unique needs. The blogger shared that the class was tailored to childbearing mothers without disability and did not help to address her fears or provide relevant information about unique adaptations that would be necessary for her. She expressed interest in receiving tailored information about labor positions and newborn care and feeding for women with physical disability.

Early Motherhood

Mothers with disabilities reported using *life hacks* and practice to adequately manage their baby safely in an able-bodied world. Baby changing tables were lowered to accommodate those in a wheelchair. Some wheelchair-bound mothers reported practicing different techniques for holding the newborn while in a wheelchair, wheelchair mobility while holding a baby (given additional weight), transferring the baby, and best positions for

comfort. Such practice was reported with the use of weighted dolls as well as without the dolls. One mother stated:

I can finally get the car seat in alone...I'm sure I would have been able to do it all along, we just never had the chance to "practice"! But I am soooo excited!

She also provided a 7-step process which included reclining the passenger seat down and twisting her body to face the back seat and placing the car seat in its base. To increase easy access to her child's nursery, another mother redesigned her home, offering an accessible and comfortable environment to provide direct care to her baby when needed. Her blog highlighted how she planned the remodel and how the changes helped her to more easily care for her baby.

(Un)supportive Others

Although most women reported consistent and positive support from family and friends during pregnancy and motherhood, the quality of support they received from health care providers was mixed. However, despite mixed feelings about health care provider support, women reported being proactive about their needs and perseverance to achieve with their pregnancy and motherhood.

Prepregnancy

All women bloggers who became pregnant reported doing so with a supportive partner. Family members, when mentioned, appeared to provide instrumental and emotional support. One woman stated:

I have a lot going for me. I already know what lots of people don't paralyzed women (and me in particular) can conceive and deliver children normally. I have a supportive and loving husband who wants to have a child with me. I have many friends – some with greater problems than I have who will be there for me. I have decades of experience working around my paralysis and playing to my strengths.

Some women delayed announcing their pregnancy to family and friends to prevent worry or because they were not sure how the pregnancy would be received. One woman described feeling more comfortable sharing her pregnancy news on the Web versus in person. In announcing her pregnancy, she celebrated the fact that by becoming pregnant, she was dispelling misperceptions that she was asexual or incapable of enjoying a sexual relationship, disconnecting pregnancy to motherhood.

In some instances, women were advised by their health care provider to abstain from having children and felt that their providers viewed women with disability as high-risk maternity patients. Women attributed this high-risk designation to health care providers' lack of experience in caring for women with physical disabilities or to a biased view that women with disabilities should not have children. One woman with autism expressed, "Autistic people are people with their own wants and needs and goals, and we can make our decisions about what is and is not in our best interest." Several bloggers reported interviewing multiple health care providers until they found one who supported their desire to become pregnant.

Pregnancy

Among women in wheelchairs, identifying offline and Web-based peers they could relate to offered them a sense of shared experience. In some cases, the desire to find a peer was the rationale for starting their blog. The individuals who commented on the blogs included both women with similar disabilities and others who could not be identified as having a disability or not. Comments from those who self-identified as having a disability indicated that reading about peers with similar experiences was validating. For example, a television program about a woman in a wheelchair who delivered a baby provided a sense of inspiration for some but caused worry for others, as the televised woman required bed rest.

Experiences with health care providers varied. Some women reported experiencing a shared decision-making process in planning for a cesarean or vaginal delivery. In some cases, women reported interviewing obstetricians either to determine those who had the most experience providing pregnancy care for women with their same disability or to find a health care provider with whom they felt the most comfortable. One mother stated:

I didn't know any other moms in wheelchairs. I found an amazing doctor, but I was his first patient with a physical disability. We were going to learn the process together.

In contrast, some women reported having providers who were not supportive. Some women felt that their health care provider believed they should not be pregnant or would be unable to care for a child. One mother stated:

The unknown of paraplegic deliveries gets labeled as high-risk to doctors. Even though I didn't feel I was high-risk, I heard their admonitions and dutifully went for a prenatal consultation with the most respected obstetrician I could find.

The proximity of the health care provider to the woman's place of residence was also taken into consideration, as women wanted to be able to access health care quickly and easily if needed.

Early Motherhood

Some women relied heavily on others to support them throughout pregnancy, whereas other women who were previously independent considered accepting help from others for the first time during pregnancy. One woman stated:

The combined experiences of pregnancy and motherhood seemed to soften some lingering bitterness in me, and I became more grateful for help whenever it came my way. Help was not there all the time, however.

Different, But Not Different

Although women with disabilities faced challenges related to their abilities, they reflected on their experiences and milestones as being similar to those experienced by women without disability. Furthermore, becoming pregnant as a woman with disability offered membership in a unique group and the bloggers expressed a sense of unity with their peers who shared this experience.

Prepregnancy

When expressing desires for pregnancy, women shared feelings of excitement but also reported apprehension about their ability to nurture a child and simultaneously manage their own disability. Some women had to stop medications before becoming pregnant whereas others worried about the potential need for bed rest. One woman indicated she was unsure if her paralysis would hinder her ability to push during delivery. Another woman considered surrogacy as a way to mitigate health risks, stating:

I thought one of the hardest parts of deciding surrogacy would be finding a compassionate man to support my choice. However, my husband was completely supportive of my decision, even while we were dating. When we became ready to start our family, we realized that surrogacy was going to be the only option for us.

Information-seeking behavior about reproductive health and pregnancy was common. Some women with autism highlighted the fact that those with autism are often very intelligent. One

woman stated, “One theory I like is that we actually make great mothers because we research, research, research whenever we know we’re going to be encountering something new!” In a contrasting case, a woman who was diagnosed with autism after pregnancy indicated that she may not have been emotionally ready to raise a child, although she did not realize it at the time. The woman stated:

When you’re undiagnosed and going into parenthood, many issues can arise. However, becoming a parent when you know your disability can hinder your parenting abilities; this creates an entirely different dilemma.

Given the timing of her autism diagnosis, she did not have the opportunity to prepare for motherhood with an understanding of her autism diagnosis. The disability-specific experiences of women in the preconception context involved considering whether pregnancy was a good choice and whether they would be up for the perceived challenges of parenting with a disability. As women blogged about these considerations, they expressed emotions and concerns specific to their unique situations. Yet, some concerns were common among other women contemplating motherhood.

Pregnancy

Bloggers reported experiencing common pregnancy symptoms such as food cravings, heartburn, morning sickness, and fatigue. Bloggers also reported planning and participating in baby showers, shopping for baby items, and receiving baby gifts from friends and family. Pregnancy appeared to be relatively uneventful for some. One woman stated, “Throughout my pregnancy, I was still able to live completely independently.” Many women were told that they were categorized as *high-risk*, which may have increased the frequency of their medical appointments. However, the bloggers did not directly discuss the frequency of appointments. There was no mention in the blogs of women with SCI about common pregnancy complications in this population, including urinary tract infections, decubitus ulcers, constipation, increased spasticity, deep vein thrombosis, and alterations in pulmonary function [54,55]. In addition, no women with SCI mentioned increased urinary frequency or increased need for self-catheterization. However, 1 woman with SCI did offer advice on the need to stock up on supplies in case self-catheterization was needed.

There were multiple women with SCI who wrote about sadness or frustration when strangers were unaware of their being pregnant. They relished the opportunity to socially rejoice in their pregnancy but lamented the lack of notice. Some women wondered if strangers assumed that they had gained weight as a result of being in a wheelchair or felt that people had a hard time imagining that a woman in a wheelchair might possess the capability to conceive or be pregnant. One woman was direct about the perception that sexual intimacy and paralysis were incommensurate, indicating, “If I offer to share that I am pregnant with a stranger, the response is often a silent combination of confusion and disbelief.”

In a single case, 1 mother opted to have an abortion. Comments from blog readers without disability who had also undergone

abortion indicated that the experience did not differ from others who had experienced an abortion, indicating feelings of isolation. A mother with SCI indicated that she had miscarried her second pregnancy near the second trimester expressed feelings of sadness, but mostly guilt because of her body’s betrayal and inability to sustain a full-term pregnancy. In this same instance, the woman shared that her partner reassured her by suggesting:

It just happens that way sometimes. The baby is weak and just doesn’t thrive and that’s all it is.

Women with disability may seek out abortion, experience miscarriage, and have a variety of common emotions after these experiences.

Delivery

Most women perceived that their delivery was *normal*. Some women with SCI reported experiencing a vaginal delivery with a short labor and tolerable pain because of paralysis, which was viewed positively. For those with SCI who had some lower abdominal sensation, an epidural was pursued; although, at times, it was challenging to insert because of spinal hardware. One woman indicated:

Although I cannot feel pain below my injury site, my body is experiencing it all. Due to this, I was given an epidural to help my body endure the pain after childbirth even though I knew I wouldn’t feel a thing.

In a singular case, 1 woman had an uncomplicated delivery at home with a midwife and doula and reported a good experience. Other women had planned cesarean deliveries, though no one individual mentioned multiple cesarean deliveries. There were no reports of planned vaginal deliveries that resulted in cesarean delivery. However, 1 woman indicated a shared decision-making process between herself and her obstetrician resulting in the decision to pursue a planned cesarean delivery owing to her inability to push because of the titanium rods in her spine. There were no mentions of in-patient lengths of stay; however, 1 woman was required to be on bed rest following delivery because of hypotension. Furthermore, some women indicated that the utilization of intrapartum anesthesia required some adjustments on the basis of SCI, and the women and their health care providers problem solved these challenges, including the unusual decision in 1 case to administer general anesthesia during delivery. Another woman experienced an adverse event, a spike in temperature and uncontrollable shaking, which she attributed to her body releasing more Oxytocin than normal to compensate for her paraplegia. There were no specific details about women with autism or TBI and their labor or delivery.

Early Motherhood

All bloggers indicated that they were able to provide direct newborn care and celebrated their baby’s milestones. Breastfeeding was mentioned by 3 different bloggers; it is unknown if the other women were breastfeeding or not. Of the 3 women who did breastfeed, 1 indicated that she did not experience challenges with breastfeeding, although she did report the use of pillow props to support positioning, a technique also used by women without disability. There were no mentions of not to breastfeed because of disability or disability-related

challenges. The blogs of women with autism or TBI contained no mention of breastfeeding at all. Additionally, there were no mentions of use of a breast pump, mastitis, or breastfeeding problems in any of the blogs.

Mothers used both unique and standard ways to carry their child while in a wheelchair. For example, 1 mother used an airplane seatbelt to attach a baby basket carrier to her wheelchair whereas other mothers used baby carriers. One mother wrote:

My greatest ally in managing a newborn on my own was a baby sling. Being in a chair and trying to carry a baby felt like having both arms and both legs tied behind my back. The baby sling freed up my arms and allowed me to work and do other things while holding the baby. I learned how to do almost anything wearing my sling, including using the toilet.

Women also blogged about the challenges of transitioning to motherhood, reflecting on challenges they believed that they shared with other mothers. One woman with autism emphasized how the transition to motherhood may be particularly challenging for those with autism, writing:

Babies have demanding round-the-clock needs; they are everything that an autistic person would have difficulty coping with. Time alone and carefully crafted routines no longer existed. My body was no longer my own; transformed first by pregnancy then by postpartum hormones and breastfeeding.

Schedule challenges are likely not unique to women with autism but perhaps may be more disruptive to women with autism who adhere to routines to manage their needs. We found no mentions about postpartum depression or depressive symptoms in any of the blogs reviewed.

Society Questioning Motherhood

Women experienced misconceptions or misunderstandings from others, including questioning whether or not a woman with a disability should conceive, deliver, and care for children. Yet, women refused to give up the opportunity to experience motherhood.

Prepregnancy

Some women blogged about others questioning their ability to be or become a mother. For those in wheelchairs, this was often rooted in misconceptions about whether or not they were infertile or could and/or would engage in sexual intercourse. One woman, in an attempt to reconstruct social norms, stated “With adaptations, many moms with paralysis are capable of raising children.” Other women in wheelchairs indicated that they would not let society get in their way of becoming mothers. One woman stated:

One day, when our children are old enough, we will tell them the story of the nonconventional delivery, and we will share how hard we—their father and I—worked to make their existence possible. Because that’s what parents do: they find a way to make possible the impossible.

On the contrary, 1 blogger with autism wrote about ongoing social resistance to parenthood targeting people with disabilities.

Referencing the historical record of involuntary sterilization of women with disabilities, she indicated that she would be fearful if she publicly announced she had autism and was pregnant because of the backlash she would receive.

Early Motherhood

Although questions and concerns about dealing with the challenges of motherhood were discussed, many women expressed their excitement about being a mother and gratitude for their supportive partners. A concern about public scrutiny of the emotional and physical abilities of women with autism to care for a child was noted by 1 blogger with autism, who wrote:

The biggest issue occurs when people in authority misinterpret us [women with autism] and call in Child Protective Services, when in reality, nothing is wrong. Ultimately, we are individuals, influenced by being autistic, influenced by being female, but in the end, still individuals.

Women blogged about how society expected them to face emotional or physical challenges during pregnancy and motherhood; however, the women themselves expressed overall feelings of capability in bearing and caring for children.

Discussion

Principal Findings

In this study, we sought to learn more about first-person publicly available accounts of prepregnancy, pregnancy, delivery, postpartum recovery, and early motherhood as written in the blogs of women with SCI, TBI, spina bifida, or autism. We examined personal stories about encounters with the health care system as well as the ways women used blogging to convey information and offer support to other women with disability and their families. Blogs represent an important piece of the public narrative about the intersection between disability, reproduction, and motherhood. Although we selected 4 key types of disabilities as the focus of our work to represent both acquired and congenital disabilities, our systematic search of personal blogs resulted in locating more blogs written by women with SCI and TBI than those with autism. We identified no blogs written by women with spina bifida meeting our search criteria.

In contrast to results from other studies that highlight the challenges faced by women with disabilities in achieving their reproductive goals [56-58], some of the blogs analyzed in this study included a more positive representation of women’s experiences. Although women wrote about negative interactions with providers, we also identified bloggers who felt that their experiences were empowering and who wrote about self-advocacy to achieve their reproductive goals with healthy outcomes. Across blogs, we identified numerous women with disability who had strong desires for motherhood, who had the support to pursue these desires, and who were able to successfully navigate a health system in pursuit of pregnancy. Women wrote that their disability did not compromise their pregnancy experience. Women even mentioned some ways in which their disabilities contributed to better experiences, such

as the inability to feel pain during labor for some women with SCI or the structured, organized approach of women with autism as a positive attribute of parenting. Of note, most women seemed to be navigating health care for pregnancy and birth without formal collaboration between their maternity health care providers and their disability-specific providers.

Results derived from this blog analysis offer guarded yet positive counterpoints to the recursive cascades of disability, poor health outcomes, and insufficient social and structural support [59]. We suggest 3 possible interpretations of these results juxtaposed against the premise of syndemics theory that social, biological, and structural factors increase the risk for compromised reproductive health outcomes by reinforcing disadvantage [15,16]. First, the altruism of bloggers in paying forward their experiences to benefit others is an effort to build social capital within the reproductive-aged community of women with disability. Similar efforts identified in other social media health research [60] are unaccounted for in the syndemics theory. In this analysis, bloggers noted difficulties and challenges in their reproductive health choices and outcomes. Despite describing some negative experiences, women addressed how they navigated care using self-advocacy and social support to achieve desired outcomes. Overall, the blogs went beyond simply describing difficulties, as bloggers detailed the ways in which their choices and *life hacks* could benefit other women in similar situations.

Second, social media posts tend toward positive self-representations [61,62], a phenomenon that could mute the presentation of difficult experiences or poor reproductive health outcomes fueled by the interaction between disability and disadvantage. Selective overrepresentation of positive experiences in personal blogs could possibly account, to an unknown degree, for our findings. Yet, the value and uniqueness of blogs also argues for their inclusion in research for several reasons. Blogs allow for detailed and complete stories to be told. Blogs have been used previously to learn more about how individuals share clinical data with family and friends [45], the caregiving perspective [63], and the lived experience of having a chronic condition [64]. Blogs humanize the experience of reproductive health by providing access to the positive experiences, joys, and achievements of women with disability to counterbalance the negativity of published medical research or health care providers. As some suggest, blogs put the *public* back into public health [65]. This rich source of data can be used in addition to or as a precursor to qualitative interviewing.

A third explanation for the generally positive pregnancy and disability spin in blogs is that online social support transmitted through the blogging endeavor and eWOM may offset the isolation and social disadvantage that women with disability experience. This social support effect has been documented among adults with chronic pain [66], a population with similar situational disadvantages. Social media platforms can contribute and facilitate knowledge sharing [41,42]. By analyzing those personal experiences, we identified several unmet needs of women with SCI, TBI, and autism, such as a need for more accessible exam tables, a need for larger wheelchairs as pregnancy advances, and a need for supportive health care providers who respect women's choices to make autonomous

decisions about whether to have children. Women bloggers offered suggestions and possible solutions to some common challenges. For example, several life hacks offered tacit knowledge to a community of women who may have similar disabilities or challenges in pregnancy and early motherhood. Although the tacit knowledge or personal experience is informal and lacks a robust evidence base, these suggestions may provide a starting point for further research and potential integration into the care of women with disability.

Use of blogs for research purposes has some limitations. For example, bloggers may comprise an atypical sample of the population of women with SCI, TBI, or autism. Bloggers are likely to have higher levels of literacy, be more technologically adept, and have higher levels of education [47,67]. Given the nature of our data collection methods, we were not able to extract demographic factors from bloggers beyond their self-identified disability types. Reviewing blogs clearly does not provide a comprehensive overview of the experiences and challenges faced by women with disability. Thus, our findings should be interpreted in this context. All bloggers in our study who mentioned partners described that they were supportive. It is important to note that none of the 5 blogs written by women with autism mentioned partners in their blog. We did not identify (1) financial concerns such as the increased medical costs for a high-risk pregnancy for the woman or infant, except for surrogacy; (2) lack of access to medical providers, although some struggled to find the right provider for them; (3) significant complications experienced by the mother or infant throughout pregnancy or delivery; or (4) postpartum depression. These concerns, commonly identified in the research about pregnancy and disability, were absent in this sample. For example, autonomic dysreflexia is a major concern during pregnancy and labor among women with SCI, particularly those with lesions above the T6 level [55]. However, we did not observe any specific references to autonomic dysreflexia among women with SCI in our blog analysis. Similarly, postpartum depression is often identified in women with autism but was not identified in the blogs of autistic women reviewed for this study [68]. In addition, our findings may not be generalizable to women with disability who do not write or read blogs, women with more complex medical histories, or women with disabilities other than SCI, TBI, and autism. Our search strategy did not identify blogs written by women with spina bifida and identified very few blogs by women with autism. It is possible that our search strategy did not identify all possible blogs. Alternatively, it is also possible that women with spina bifida and autism are not blogging to the same extent as women with SCI or TBI.

Application of findings from this study may advance research and practice. Women with disability who have been able to achieve pregnancy and motherhood have much to share with their peers who desire this experience. Using women with disabilities as health navigators has been recommended by other authors who have suggested that these navigators could help others to recognize their own potential for giving birth, understand the importance of advocacy and support during pregnancy and birth, share information, provide guidance on interacting with maternity providers, and help women manage their fears [69]. Future research may specify survey and

interview questions on the basis of what women with disability highlighted as important personal and social resources for successful pregnancy and motherhood and challenges they encountered. Research is warranted to explore how other social media tools are being used in this context or could be utilized to help enhance information sharing and social support among women with disability. Some informational resources exist for some types of disability but for others, more information and resources are needed. Having all pregnancy-related resources in one Web-based location would be beneficial for both women with disabilities and the health care providers who care for them.

Finally, tools to help women communicate with their providers about their unique needs and challenges would help to improve their health care experience from preconception through early motherhood. Such tools need to be developed and evaluated.

Conclusions

This study of personal blogs written by women with SCI, TBI, and autism about pregnancy and health care offers a glimpse into their reproductive experiences, challenges, and adaptations and provides a foundation for future research to address the unique needs of women with disabilities.

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Conflicts of Interest

None declared.

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Abbreviations

- eWOM:** electronic word of mouth
IRB: institutional review board
SCI: spinal cord injury
TBI: traumatic brain injury

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Original Paper

Procedures to Select Digital Sensing Technologies for Passive Data Collection With Children and Their Caregivers: Qualitative Cultural Assessment in South Africa and Nepal

Brandon A Kohrt^{1,2,3}, MD, PhD; Sauharda Rai^{3,4}, MA; Khanya Vilakazi⁵, MSc; Kiran Thapa⁶, MPH; Anvita Bhardwaj^{1,7}, BS; Alastair van Heerden^{8,9}, PhD

¹Division of Global Mental Health, Department of Psychiatry and Behavioral Sciences, George Washington School of Medicine and Health Sciences, Washington, DC, United States

²Department of Global Health, Milken School of Public Health, George Washington University, Washington, DC, United States

³Research Department, Transcultural Psychosocial Organization Nepal, Kathmandu, Nepal

⁴Jackson School of International Studies, University of Washington, Seattle, WA, United States

⁵Research Department, Human Sciences Research Council, Pietermaritzburg, South Africa

⁶Department of Health Policy and Management, College of Public Health, University of Georgia, Athens, GA, United States

⁷Department of Population, Family and Reproductive Health, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, MD, United States

⁸Human and Social Development, Human Sciences Research Council, Pietermaritzburg, South Africa

⁹Medical Research Council/Wits Developmental Pathways for Health Research Unit, Department of Paediatrics, Faculty of Health Science, University of the Witwatersrand, Johannesburg, South Africa

Corresponding Author:

Brandon A Kohrt, MD, PhD

Division of Global Mental Health

Department of Psychiatry and Behavioral Sciences

George Washington School of Medicine and Health Sciences

2120 L Street NW, Suite 600

Washington, DC, 20037

United States

Phone: 1 4048951643

Email: bkohrt@gwu.edu

Abstract

Background: Populations in low-resource settings with high childhood morbidity and mortality increasingly are being selected as beneficiaries for interventions using passive sensing data collection through digital technologies. However, these populations often have limited familiarity with the processes and implications of passive data collection. Therefore, methods are needed to identify cultural norms and family preferences influencing the uptake of new technologies.

Objective: Before introducing a new device or a passive data collection approach, it is important to determine what will be culturally acceptable and feasible. The objective of this study was to develop a systematic approach to determine acceptability and perceived utility of potential passive data collection technologies to inform selection and piloting of a device. To achieve this, we developed the *Qualitative Cultural Assessment of Passive Data collection Technology* (QualCAPDT). This approach is built upon structured elicitation tasks used in cultural anthropology.

Methods: We piloted QualCAPDT using focus group discussions (FGDs), video demonstrations of simulated technology use, attribute rating with anchoring vignettes, and card ranking procedures. The procedure was used to select passive sensing technologies to evaluate child development and caregiver mental health in KwaZulu-Natal, South Africa, and Kathmandu, Nepal. Videos were produced in South Africa and Nepal to demonstrate the technologies and their potential local application. Structured elicitation tasks were administered in FGDs after showing the videos. Using QualCAPDT, we evaluated the following 5 technologies: home-based video recording, mobile device capture of audio, a wearable time-lapse camera attached to the child, proximity detection through a wearable passive Bluetooth beacon attached to the child, and an indoor environmental sensor measuring air quality.

Results: In South Africa, 38 community health workers, health organization leaders, and caregivers participated in interviews and FGDs with structured elicitation tasks. We refined the procedure after South Africa to make the process more accessible for low-literacy populations in Nepal. In addition, the refined procedure reduced misconceptions about the tools being evaluated. In Nepal, 69 community health workers and caregivers participated in a refined QualCAPDT. In both countries, the child's wearable time-lapse camera achieved many of the target attributes. Participants in Nepal also highly ranked a home-based environmental sensor and a proximity beacon worn by the child.

Conclusions: The QualCAPDT procedure can be used to identify community norms and preferences to facilitate the selection of potential passive data collection strategies and devices. QualCAPDT is an important first step before selecting devices and piloting passive data collection in a community. It is especially important for work with caregivers and young children for whom cultural beliefs and shared family environments strongly determine behavior and potential uptake of new technology.

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KEYWORDS

child development; confidentiality; culturally competent care; developing countries; global health; mental health; mobile phones; wireless technology

Introduction

Background

The recognition of early child development as a domain of global importance and the inclusion of specific child development indicators in both the Sustainable Development Goals (SDGs) [1] and the United Nations Secretary General's Global Strategy for Women's, Children's and Adolescents' Health [2] has refocused attention on a life-course perspective and the need to ensure that children meet their developmental potential. Assessing children's developmental progress and caregiver-child relationships longitudinally is expensive and time-consuming, with few existing, valid methods available to effectively measure and monitor at a population level [3]. Paper-based tools require careful quality assurance and quality control review, which double data entry time burden. Traditional approaches to audiovisual recordings can be equally time consuming because of required transcription and structured coding. These existing limitations point to the potential gap that could be bridged by using newer technology.

The use of mobile technologies to leverage their capabilities and functionality to support public health care is called mobile Health (mHealth) [4]. mHealth in low- and middle-income countries (LMICs) first started with strengthening the data system on computer-based platforms but has transcended to data collection, training, facilitated communication among health workers, decision support, supervision, and health promotion in recent years [5,6].

Among the first steps to transform mHealth potential into transformative public health impact is the United States' National Institutes of Health's toolbox. The toolbox comprises a validated set of freely available measures that can be used to quickly (within 2 hours or fewer) assess cognitive, sensory, motor, and emotional function in a diverse range of contexts [7]. All measures are available electronically for use on an iPad. Rather than requiring highly trained research staff to simultaneously monitor time, record responses, and interact with the child, these electronic assessments simplify test administration and reduce cognitive load, thereby improving data accuracy.

As technology advances, new avenues of exploration in the application of technology to early child development are emerging. The Language Environment Analysis (LENA) system is a comprehensive assessment of the home linguistic environment of infants and children. The LENA system consists of a small child-safe recorder that is worn, in a comfortable custom-designed vest, by the child during the day. Recordings are translated into data about the linguistic environment, which can be viewed and analyzed using specialist software [8]. Other developmental uses include tools for enhanced early education, for example, educational magic toys, which make use of augmented reality technology [9,10]. The growing array of baby wearables that track heart rate, movement, breathing, and other physiological measures also holds promise for improving child health research and its public health impact in LMIC [11-14].

Although the toolbox and other app versions of psychometric tests are well described [7,15,16], little has been written about how other mother and child assessment methodologies can benefit in a similar way from technological progress. Naturalistic observation, caregiver and clinical interviews, direct assessment, and coding of interactions are still primarily the global tools of choice. The challenge is that many of the issues of interest are best examined through methods that require manual collection and coding of unstructured data. For example, caregiver-child attachment is time-consuming to code and requires high levels of training and honed skills for coding the observational audio-visual recordings. Such demands are barriers to scaling up the method for widespread use.

Accurately and reliably measuring child development to track progress toward meeting the SDGs requires a suite of research tools that go beyond mobile apps and are acceptable, confidential, safe, nondisruptive, and have utility. One avenue of exploration is passively collecting, transforming, and analyzing data generated by mobile phones, wearables, and other small sensors that can be embedded in the environment [17]. Advancements in the fields of digital sensors, computation, storage, and communications have turned mobile phones into powerful mobile sensing devices [18]. Among the sensors included in modern mobile phones are accelerometer, altimeter, digital camera, microphone, Global Positioning System (GPS), Bluetooth proximity, and oximeter among others [19].

Analyzing the digital traces produced by these sensors could enable the assessment, detection, and monitoring of key developmental processes in an automated, expeditious, and scalable manner. Although single-sensor-based systems are useful, they are often limited in both accuracy and the number of behavioral activities that can be tracked. To counteract this limitation, multisensor systems are now preferred [18]. Using the ecological systems theory as a foundation [20], Table 1 presents an overview of the types of sensors and information that could be obtained about a child’s world through the collection and analysis of these passive data producing sensors.

Although it may technically be feasible in certain contexts to collect these diverse data sources, acceptability will vary due to, among other things, the intrusiveness of the approach. User-centered studies suggest that technologies intended for intimate personal use need to comply with a number of factors if they are to be deemed usable and acceptable and sustain user engagement [21]. Taking into account both human and technical aspects, 6 factors have been found to influence adoption [22]; they include (1) supporting fundamental human needs such physiological and safety needs; (2) cognitive load—ease of use, perceived risks, and fears; (3) social factors—privacy, cultural acceptance, and influence over social interactions; (4) physical aspects—device size, conform, and appearance; (5) participant demographics—age, gender, and culture influence preferences and perceptions toward devices; and (6) technical expertise of the user—with more expertise increasing confidence and use.

These principles inform a growing body of evidence for the feasibility and usefulness of sensor devices in maternal and child research. Cameras and the PhotoVoice methodology have, for example, been used with children aged as young as 3 years to gain a better understanding of how they perceive their community, relate to being orphaned, and understand their infection with HIV [23,24]. First-person photography, through body-worn cameras, has also shown promise as a novel methodology for capturing the world through the eyes and perspective of the child [25].

The work of Mehl [26], whose electronically activated recorder yields valuable acoustic logs of people’s day-to-day experience, is an example of how audio data generated from a microphone could give valuable insight into a child’s life. The LENA system builds on this idea by using a small audio recorder, worn by the child through the day, to periodically sample the auditory environment. These audio data are loaded into the LENA system and are immediately translated into information about the environment of the child [27].

Radio-Frequency Identification Devices (RFID) is the primary approach used so far to track interpersonal proximity. RFID tags are activated in the presence of a receiver and can generate a small radio frequency that is recorded by the receiver. For example, an RFID-based system was implemented to track the spread of hospital-acquired infections in the pediatric ward [28]. The same RFID system was used in France to better understand face-to-face contact between students to better understand how these interactions shaped social networks and facilitated the propagation of infectious disease [29].

One limitation of the current literature base is that most of these studies are currently being produced in high-income countries in controlled laboratory or hospital settings. Furthermore, many do not provide a method for establishing participants’ understanding of technology and the data that can be collected and mined from these devices.

Objective

This study, therefore, aims to develop a systematic method to inform understanding of how families and caregivers from LMICs perceive the suitability and acceptability of a range of passive digital data collecting sensors that could be incorporated into the home environment. The findings from this approach should be able to directly inform selection of devices and passive data collection strategies with the greatest likelihood of adoption for home-based interventions. We refer to our proposed systematic approach as the *Qualitative Cultural Assessment of Passive Data collection Technology* (QualCAPDT).

Table 1. Passive digital sensors and an example of the type of information they could produce at each level of ecological systems theory.

Ecological level	Activity	Sensors	Information
Individual (child)	Movement	Accelerometer, altimeter, gyroscope, and GPS ^a	Activities of daily living
Individual (child)	Physiology	Electrocardiogram, electromyograph, electroencephalogram, electrodermograph, oximeter, and thermometer	Assessment of toxic stress
Microsystem (peers, family, and caregiver)	Interaction	Wi-Fi proximity, Bluetooth proximity, microphone, digital camera, and digital video	Nurturing care
Exosystem (neighborhood, mass media, and extended family)	Environment	Digital camera, digital video, and environmental sensor	Air, noise, and water pollution
Macrosystem (culture, social conditions, and economic system)	Human development	Microphone	Language development and exposure to cultural practices

^aGPS: Global Positioning System.

Methods

Settings

Research was conducted in South Africa and Nepal. These countries are ideal sites to develop a procedure that can be used to select devices and data collection approaches that will be acceptable and feasible in settings with low-literacy populations unfamiliar with passive sensing technology. The countries have high rates of poverty and childhood morbidity and mortality with limited access to specialized child health and mental health services. Moreover, the countries are exemplified by large health disparities and poor outcomes with traditional health delivery approaches, thus necessitating greater use of technology.

Moreover, there are preliminary successes for mHealth in these settings. In South Africa, mHealth is increasingly used for HIV/AIDS prevention and care, including home-based testing and counseling to promote treatment engagement and adherence [30,31]. Text messaging through mobile phones has been used to collect feedback on maternal-child health services throughout South Africa and resolve areas of poor-quality care [32]. mHealth in Nepal has worked in different capacities such as improving communication and coordination between health workers in rural areas and district hospitals, strengthening community-based surveillance systems, and improving maternal and neonatal health outcomes [33,34]. Furthermore, mHealth has been successful in achieving targets for reduced maternal mortality through increased health facility attendance and institutional delivery in Nepal [35]. However, in both countries, passive sensing data collection has received limited attention and would benefit from qualitative exploration before selecting and piloting new approaches. Furthermore, methods used to determine cultural acceptability and feasibility before selecting devices for pilot could be of great benefit throughout LMICs, other low-resource settings, and a context with diverse cultural groups.

In South Africa, the study was conducted in the Sweetwaters region of the Greater Edendale Area of Pietermaritzburg, KwaZulu-Natal. This location has been the site of ongoing research on public health initiatives led by the Human Sciences Research Council (HSRC). The Sweetwaters area is emblematic of rural regions in South Africa that have suffered high rates of maternal HIV and mother-to-child transmission. However, through public health programs, these rates have dramatically reduced over the past decade. In Nepal, the study was conducted in Sankhu, Manamaiju, and Phutung, which are all located approximately 30 to 60 min away from Kathmandu. These areas were heavily affected by the 2015 Nepal earthquake. Sankhu was devastated with more than 100 persons killed on the day of the first earthquake. Sankhu, although having access to Kathmandu, lacks child health specialty services, and there are no local mental health services. Manamaiju was comparatively closer to the city but did not have mental health services in their local health posts. Research in these sites was conducted in 2016 to 2017.

Qualitative Cultural Assessment of Passive Data Collection Technology

We developed the QualCAPDT procedure by adapting methods commonly used in cultural anthropology [36,37]. We had 2 objectives in the development of QualCAPDT. The first was to have a systematic process that could be replicated in other settings to evaluate the acceptability and perceived utility of different passive data collection strategies before development or adaptation of the technology. The goal was to avoid selection of data collection platforms before receiving input from end-user communities, which would lead to potential waste of resources for technologies that would not be adopted. The second was to gain information about how participants viewed, among other issues, the ethical risks they would be exposed to by participating in a study that collected passive digital data about their behavior in their homes. A crucial outcome was to protect people's ethical rights in research because passive data collection of daily family life is an invasive process. Our hope was that QualCAPDT would provide insight into privacy, confidentiality, and the major ethical responsibilities researchers have in this new technological age of health interventions.

To frame our 2 objectives, we used the following domains, adapted from Buenaflor and Kim's 6 human factors [22], to guide all participant discussions about the devices and data under review:

- Domain 1: *Confidentiality* referring to the degree to which the device would protect personal information; this was an ethical domain we added to the 6 human factors.
- Domain 2: *Safety* referring to concerns that the device would pose health risks or put a child or family at the risk of mugging or theft; this domain captures Buenaflor and Kim's first human factor—safety.
- Domain 3: *Social acceptability* referring to the degree to which family members and neighbors may have negative responses to introduction of the device; this reflects the third human factor—social factors—and human factor 5—demographic perceptions.
- Domain 4: *Noninterference* referring to the degree to which the device would negatively impact physical functioning, activities, or daily routines; this reflects the fourth human factor—physical aspects.
- Domain 5: *Utility* referring to the perceived benefit of the device for improving caregiver and child health, development, and mental health; this incorporates aspects of human factor 2—ease of use—and human factor 6—technical expertise.

Step 1: Development of Videos

Narrative focus group discussions (FGDs) are a technique commonly used in cultural anthropology and public health [38-40]. In narrative FGDs, participants are typically read a story or scenario at the beginning of the session, then they comment according to probes provided by the facilitator. Given the lack of familiarity with passive data collection devices among community health workers and caregivers in rural South Africa and Nepal, we felt that narratives about the devices would have been insufficient for participants to understand the technology and types of data capture. Therefore, videos ranging

in length from 3 to 6 min were produced, demonstrating the technologies in the local settings.

In South Africa, the production of the videos was conducted by a group of research assistants over a period of a month. In Nepal, the video production task was assigned to a team of independent contractors, and they took around 1 month to produce the final cuts. Five videos, each demonstrating a technology, were produced in both countries. Separate videos were produced for South Africa and Nepal so that participants could relate to the experiences of persons in the video. Videos were in the local languages of the participants, isiZulu with English subtitles in South Africa and Nepali in Nepal.

The video content was similar between the 2 countries. The videos provided images of the technology, a scenario in which a researcher explains the technology to a rural family with a small child, and, when possible, an example of the output of the technology that could be used for health interventions. In Nepal, the video was prefaced with information on the role of female community health volunteers (FCHVs) as these would be the individuals managing the devices. Screenshots from the South Africa and Nepal videos are provided in [Figure 1](#). Individual videos are indexed below as Multimedia Appendices.

Step 2a: Conduct Video Focus Group Discussions

After the videos were produced, they were integrated into the FGDs with community health workers and caregivers (see [Figure 2](#) for timeline). FGDs were conducted in isiZulu in South Africa and Nepali in Nepal. In both countries, the FGDs for community health workers began with general questions about health needs of children and their daily routines, including any health and development concerns that were common in that community. The FGDs then transitioned to showing videos. After the videos, the groups rated attributes using anchoring vignettes (step 2b) followed by card ranking tasks (step 2c), and then, supplemental interviews were conducted with other stakeholders (step 3).

In South Africa, the FGDs were organized through a community outreach team that works and lives within the community where the participants were sampled. An equivalent of US \$5 was issued out to each participant as reimbursement for the time

that they spent in the FGD. The FGDs were conducted within the community in a central community hall. All FGDs were conducted by qualitative interviewers using IsiZulu as a medium of communication. The videos were projected onto a wall using a projection system connected to a laptop. The 4 FGDs took a period of 9 days for completion due to the availability of both the community hall and the participants in these groups.

In Nepal, the FGDs were scheduled with the help of FCHV. One of the FCHV was contacted by phone 2 days before the FGD and were asked to gather participants for FGDs. The participants were provided nonmonetary compensation, for example, household items such as soap, toothpaste, brush, and lunch, for their time and effort. For FCHV FGDs, the data were collected in a quiet office room in a health care facility. Caregiver FGDs took place in 1 of the caregiver's homes. One of the authors (KT) moderated the discussions along with a research assistant who did note-taking. The discussions were held in the local language. We also audio recorded the FGDs after receiving consent from all the participants. The FGD guide was semistructured. The videos were shown in a laptop where participants were seated just in front so that everyone could see and hear what was happening in the video. In addition to the use of anchoring vignettes (described below), several probes were used during the FGDs to elicit responses from different participants.

Some examples of follow-up questions post video including probes used in both sites are shown below:

- What do you think of the device? (PROBE: Have you seen such device before? How do you like the device overall?)
- What do you think are the barriers to using this device? (PROBE: Electricity problems, incite arguments in a family, etc)
- Can you think of any example of how this device is useful? (PROBE: What information could this device collect, and how can you use that information?)
- How feasible do you think it is to use these devices in your community? (PROBE: How many people in your community use mobile phones regularly? What cultural practices might hinder the use of the device? Do you think there is risk of theft or breakage of the devices?)

Figure 1. Screenshots from videos demonstrating passive data collection devices in South Africa and Nepal.

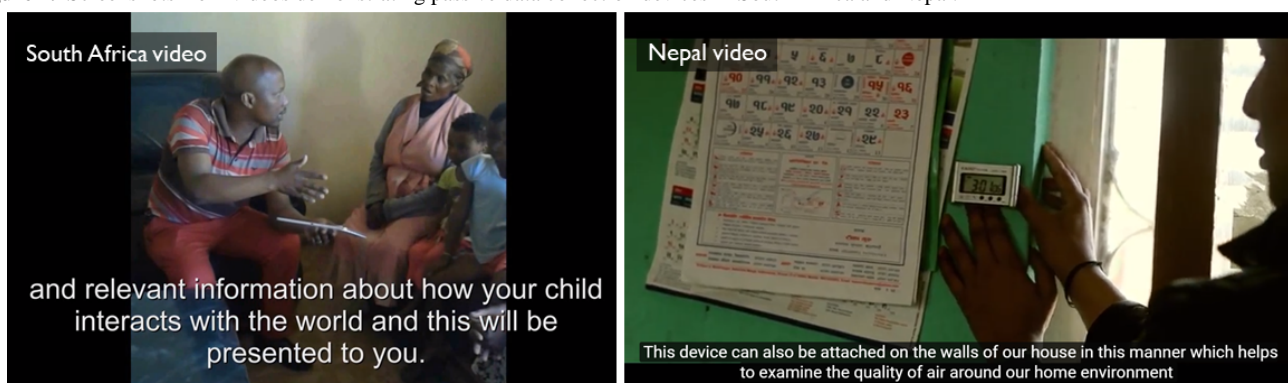
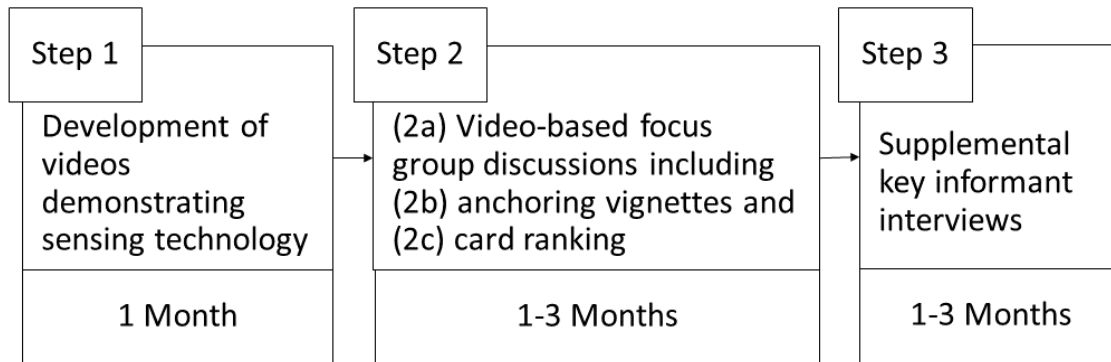


Figure 2. Qualitative Cultural Assessment of Passive Data collection Technology (QualCAPDT) process timeline of piloting in South Africa and Nepal.

Step 2b: Rating of Preferences Through Anchoring Vignettes

Anchoring vignettes are a structured elicitation tool commonly used in anthropological research, health behavior studies, and public opinion polls [41-43]. As individuals may have a social desirability bias toward responding in the affirmative, anchoring vignettes can be used to normalize a range of responses [44]. When initially piloting preferences for the devices in this study (unpublished), we found that few women had negative responses. Therefore, we created 2 vignettes to anchor the response options. For each criterion, there was 1 vignette that ranked the device high on the criterion and 1 vignette that ranked the device low on the criterion. For example, in Nepal, we referred to Maya and Asha, with Maya vignettes having a concern about the device and Asha being supportive about the device on that attribute. Then, participants were asked to say whether they felt that women in their community were more likely to be like Maya or Asha (see Figure 3). The anchoring vignettes were presented in isiZulu in South Africa and in Nepali in Nepal.

When doing the rating according to the anchoring vignettes, participants are encouraged to describe their thought process and discuss as a group why they are making certain decisions. This process is based on techniques from anthropological research on cultural domain analysis [45]. In this process, participants prompted to describe *attributes* that lead to categorizing in a certain way. For example, what are the *attributes* of a device that lead to it being categorized more closely to Maya's perspective in one domain but then closer to Asha's perspective in another domain. This type of prompting reduces the likelihood that a device is ranked all toward Maya on every domain or all toward on Asha on every domain. Through this prompting, the participants consider each domain independent of the others and identify the attributes that

contribute to the device's categorization in each domain. This is rich qualitative information, which often came in the form of participants debating the ways in which community members think more like Maya or Asha.

Step 2c: Card Ranking Task

After rating with anchoring vignettes, we used a card sort ranking task at the end of the FGD [36]. In this activity, each device had a unique card with a photograph of the device, and participants were asked to sort those cards according to each of the attributes. For example, the 6 devices were ranked in order from most to least confidentiality, and similarly, all devices were ranked from the most to least useful for child health promotion. This is a forced-choice approach in which participants have to make cognitive decisions to up- or down-rank certain devices. During this process, participants are encouraged to describe the thought process and decision making that influences their ranking. The cards were images of the devices and did not include written language. Discussions during the card ranking were conducted in isiZulu in South Africa and in Nepali in Nepal.

Example prompts and probes during the card ranking task were as follows:

- Example probe for confidentiality: Among all the devices we just discussed, which device do you think protects most of your personal information? And next? And next?
- Example probe for safety: Of all the devices, which one do you think can be safely placed anywhere at home and will not be prone to breakage or theft? And next? And next?
- Example probe for acceptability: Of all the devices, which one do you think will be most accepted by you and your family members? And next? And next?
- Example probe for noninterference: Of all the devices, which one do you think most hinders with your daily activities? And next? And next?

Figure 3. Anchoring vignette elicitation technique to rate devices by attribute domains. (The anchoring vignettes, including all data collection materials and videos, were presented in the local language of participants: isiZulu in Kwa-Zulu Natal, South Africa, and Nepali in Kathmandu Valley, Nepal. Names and illustrations should be adapted to local cultural context).

Use of anchoring vignettes about Maya and Asha for device attribute rating by community members

I am now going to tell you made-up story about two women in your community and how they feel about the device we just discussed. I want you to tell me if the women in your community are more like Maya or more like Asha.



Maya

“When the video camera was installed in the home, **Maya** became very concerned about what her husband would say. She did not want even the health worker to see what happened in her home.”

“**Asha**, however, wanted the camera to help the health worker better understand her child’s development. She explained the purpose of the camera to her husband and he also supported it.”



Asha

Do you think that women in your community are more like Maya’s response (worried about confidentiality with this device) or more like Asha (who is not worried about confidentiality)? Point to the area on the line that represents the women in your community.



Like
Maya

1

2

3

4

5

6

Like
Asha



Step 3: Use of Supplemental Interviews and Data Collection

In addition to the FGDs structured around the videos with anchoring vignettes and card sort ranking, we conducted additional key informant interviews to explore other themes that would reflect community norms, preferences, and perceived utility and feasibility of the devices. In some of these individual interviews, the videos were also used to elicit discussion.

Example questions from the supplemental interviews were as follows:

- How would families feel if you collected information about conversations between family members using these technologies?
- What information could be collected around mealtime activities?

- What are the main times of day when caregivers and children are together, and what information could be collected then?
- Whose permission do we need to keep this device at home?

In South Africa, the supplementary interviews were conducted with local organizations that work in the early childhood development sphere. The participants were recommended by the South African principal investigator who had extensive experience working in the area or by research assistant based on collaborating organizations working in the area of child health and/or mobile technology. These participants were not reimbursed for their time because they were professionals often collaborating in research and health initiatives in the area. The participants were contacted through the community outreach team for available times when the interview could be conducted. Supplemental interviews in South Africa were conducted in English because they were often with organizational staff

educated in English who were South African but may not have been native to Sweetwaters.

In Nepal, for FCHV interviews, the contact information of the FCHV was obtained from local health facility. They were contacted 2 days before the day of data collection and scheduled the time. For caregivers' interviews, we obtained the contact information from FCHV. The interviewees were provided nonmonetary compensation as with the FGDs, for example, household items such as soap, toothpaste, and brush, for their time and effort. The data were collected in a quiet room in a FCHV or caregiver's home. One of the authors (KT) and 2 research assistants were involved in conducting interviews. We also audio recorded the entire interview after written consent from the interviewee. The interview guide was semistructured. When videos were shown, a laptop was used. The information generated from interviews differed from FGDs in that interviews helped us to identify attitudes and perceptions of individuals in depth as opposed to coming to a general consensus in FGDs. In addition, the interviews may have also differed from other standard semistructured interviews in that participants watched videos of technologies without group discussions and the use of multiple probe questions. Supplemental interviews were all conducted in Nepali.

Passive Data Collection Devices Evaluated

We used the QualCAPDT method to assess the suitability and acceptability of 8 approaches to collecting passive digital sensor data from 5 devices about caregivers and children in the home. They ranged from invasive approaches that produce rich data to less-invasive approaches that result in less rich data.

Device 1: Video Recorder (Two Approaches)

There were 2 forms of video recording presented to participants. One was a continuous recording with a camera mounted in the living room of the home. Families were shown that data would be stored on secure digital cards that would be removed and reviewed by the researcher together with the family. The participants were also told that a time-lapse version was possible in which video would be captured every 15 min for 30 seconds. The participants were told that neither data collection platform would record sound. The South African video demonstrating video recording is available in [Multimedia Appendix 1](#) and the video from Nepal is provided in [Multimedia Appendix 2](#).

Device 2: Audio Recorder (Two Approaches)

Similarly, participants were presented with technology that could collect audio from the home environment. It was explained to participants that the technology could be set to record continuous or episodic audio, with an example of the latter being recordings made every 15 min for 30 seconds. The videos demonstrated a fixed recording device in South Africa ([Multimedia Appendix 3](#)) and a mobile recording device in Nepal ([Multimedia Appendix 4](#)).

Device 3: Wearable Camera (One Approach)

A wearable time-lapse camera was demonstrated as a technology that could be used to capture images from the child's point of view. Videos demonstrated how children could wear the devices (see screenshots in [Figure 4](#)). The images captured on the devices in the children's daily life were presented in the video. The South Africa wearable camera video is provided in [Multimedia Appendix 5](#), and the video from Nepal is provided in [Multimedia Appendix 6](#).

Device 4: Bluetooth Beacon (One Approach)

A Bluetooth beacon was displayed in a video as a way to evaluate when the target caregiver and target child are in close proximity. This was illustrated through a small coin size plastic toy that could be attached to the child and that sent out a signal that could be received by a mobile phone carried by the caregiver. A mock output was shown in the video to simulate data that could be reported on time the caregiver and child spend together. The video demonstration for South Africa is provided in [Multimedia Appendix 7](#), and the video demonstration for Nepal is provided in [Multimedia Appendix 8](#).

Device 5: Environmental Sensor (One Approach)

Finally, a room-based environmental sensor was presented as a technology that could report on temperature, humidity, and air quality within the home. The devices were fixed in the home, and families were told they could be placed in any room in the household that they preferred to assess air quality. The video demonstrating the environmental sensor in South Africa is provided in [Multimedia Appendix 9](#), and the video for Nepal is provided in [Multimedia Appendix 10](#).

Figure 4. Screenshots of videos demonstrating wearable time-lapse camera for children. Red arrows point toward the wearable device on the child.



Participant Recruitment

In South Africa, 38 participants were recruited for 4 FGDs. Participants included health organization workers, community health workers, and caregivers. Caregivers were deemed eligible if they had a child in their care who resided with them in the household. Of the 4 FGDs conducted, 2 FGDs were with health organization workers and community caregivers (n=17) and 2 were with caregivers (n=21).

In Nepal, 69 participants were recruited. There were 5 FGDs for FCHV, inclusive of 32 participants. Caregivers (all women) participated in 3 FGDs (n=18 participants). Data for the ranking task were also collected from the health volunteer and caregiver focus groups (n=50). In addition, 10 individual key informant interviews were conducted with FCHV, and 9 individual key informant interviews were conducted with caregivers. FCHV and caregivers were selected in Sankhu, Manamaiju, and Phutung. FCHV were identified from the roster of local government health facilities, where they report activities monthly. Every FCHV from 2 health facilities was selected for the study. The caregivers were selected based on referrals from FCHVs.

Data Analysis

The audio recordings of FGDs and interviews were translated into English. The translated transcripts were loaded in NVivo version 12 (QSR International Pvt Ltd) for qualitative data analysis [46]. A framework coding analysis approach was used [47]. A priori codes included the devices (continuous audio recording, continuous video recording, environmental sensor, episodic audio recording, episodic video recording, proximity beacon, and wearable beacon) and device attributes initially used for the anchoring vignettes (acceptability, confidentiality, noninterference, safety, and utility or benefit). Additional a priori codes included themes from the qualitative interviews (*community health activities*: child development and behavior, child health program, community health worker activities, and information collection and *technology readiness*: mobile phone usage and other technology usage). Using the a priori codes, 2 coders (authors BAK, who was familiar with the Nepal context, and KV, who was familiar with the South Africa context) read and coded the same 4 transcripts (1 FGD from South Africa, 1 interview from South Africa, 1 FGD from Nepal, and 1 interview from Nepal).

The coders then used coder comparison within NVivo to determine areas of common versus discrepant coding. This was used to redefine the codes where needed. Additional code themes also emerged. These included *feasibility* and *health risks and injury* under attributes. Feasibility was added to address comments regarding whether the tools could be used but did not address acceptability or other attributes. Health risks was added to distinguish safety as an area where a person may be endangered by using the device through theft or assault versus health risks such as radiation or other perceived health consequences. Under community health activities, codes for *context of community and facilities* and *family and caregiver behaviors* were added. Under technology readiness, *barriers to technology use* and *facilitators of technology use* were added.

All referenced quotations are provided in a supplemental file (see [Multimedia Appendix 11](#)).

The 2 coders then coded 4 new transcripts with the same breakdown by country and qualitative type to establish interrater reliability. The 2 authors achieved 0.80 interrater reliability. Subsequently, the coders reviewed half of the remaining qualitative dataset. Additional information on the qualitative process is available in [Multimedia Appendix 12](#), using the consolidated criteria for reporting qualitative research framework [48].

Statistical analysis was performed on the card sort data for South Africa and Nepal datasets using median and interquartile range with inference testing using the Wilcoxon Rank Test. This approach was selected because the data elicited through the ranking tasks were nonparametric in distribution. Statistical analyses were performed with Statistical Package for Social Sciences version 24 [49].

Ethical Approval

Ethical approval for the study was provided by the HSRC Research Ethics Committee in South Africa (REC6/18/05/16) and the Nepal Health Research Council (#241/2016) in Nepal. In addition, Duke University (Pro00074454) provided ethical approval for data analysis by US-based team members working with deidentified data from the sites. Participants in both sites completed written consents forms, which were also read to participants by research assistants because of low literacy rates among some groups in the study regions.

Results

Process Development for Qualitative Cultural Assessment of Passive Data Collection Technology

The QualCAPTD process was first conducted in South Africa (see [Textbox 1](#)). The procedure followed the steps as described in the Methods section above. During FGDs, the first part of the discussion was about child development, child health, and caregiver-child interaction. Then, the group watched all the videos in sequence; after watching all videos, they received paper forms to rate the devices on the attributes using the anchoring vignettes, and then, they ranked the devices on all of the attributes. After turning in the forms, the participants discussed the devices. The ratings with anchoring vignettes and ranking task evoked questions from participants, which suggested that when completing the forms, there may have been confusion about what the devices can and cannot do. Therefore, the procedure was modified for use in Nepal.

In Nepal, the first part of the FGD involved a similar discussion about child health and development and caregiver-child interactions. However, to increase understanding of the devices and clarity when discussing, rating, and ranking, we modified the procedure from the South Africa approach. Instead of showing all videos at once followed by completion of all rating and ranking, in Nepal, each video was shown with a break in between for rating and discussion, then ranking was done at the end after all videos had been shown, discussed, and rated (see [Textbox 2](#)). The Nepal procedure for devices went as follows:

first, show one video; second, ask the group to discuss what was seen in the video and have open question and reflection; and third, introduce the rating on attributes with anchoring vignettes, the rating is completed as a group with each scoring discussed, nothing is written down by the participants, but the facilitator records the group consensus for device and attribute. Then, the group proceeds to the next video and rating discussion. After all videos have been shown, rated, and discussed, the participants are given the picture cards of the devices and asked to rank them according to each of the attributes. This is done individually by participants, and the scores are recorded for analysis. The next section describes the analyses of the ranking tasks in the 2 countries.

Device Ranking

For the 88 focus group participants, ranking data were collected for all 7 data collection approaches (devices) across our 5 domains of inquiry (see Figure 5). In South Africa, 28 of the 38 participants' data were usable for the ranking analysis, and there were significant ranking differences for the utility attribute ($n=28$, interrelated samples, chi-square, Friedman test, and $P<.001$). In South Africa, differences were significant only at the $P<.05$ level for confidentiality, safety, and noninterference. Rank orders were not significantly different for social acceptability in South Africa. The device rankings were significantly different across all 5 attributes for the Nepal sample

($n=50$, interrelated samples, chi-square, Friedman test, and $P<.001$).

Qualitative Discussion Results

Qualitative findings from the video-centered (step 2) and anchoring vignette discussions ($n=88$) and interviews ($n=26$; step 3) were analyzed by domain and device. As there may have been confusion about the devices when ranked and rated individually by South African participants, the qualitative group discussions provided below may provide a better reflection of group attitudes and preferences.

Domain 1: Confidentiality

Regarding confidentiality, in South Africa, the wearable time-lapse camera and Bluetooth beacon were considered confidential in the qualitative discussions. In Nepal, the home-based environmental sensor was ranked the most confidential, followed by the Bluetooth proximity beacon. The home-based continuous video stream was the least confidential. In both countries, continuous audio recording was a concern because of capturing yelling at children and husbands yelling at the participants. In addition, if a husband knew that his wife had been recorded throughout the day, he may ask to review the audio recording. Mothers-in-law in Nepal were also considered to be interested in hearing the recordings, then spreading information to others in the community. Participants used the Nepali idiom, *ek kaan, dui kaan, maidan*, roughly translatable as "one ear, then two ears, then everywhere."

Textbox 1. Pilot procedure for Qualitative Cultural Assessment of Passive Data collection Technology through focus group discussions in South Africa.

Pilot procedure for Qualitative Cultural Assessment of Passive sensing Data Technology focus group discussions in South Africa:

- *Step a.* Group discussion about child health, child development, and caregiver-child interactions.
- *Step b.* Participants were shown all of the videos demonstrating the devices. No discussion was held between videos.
- *Step c.* Participants are given attribute rating forms with anchoring vignettes and device ranking; participants complete the forms independently for all devices. Participants are required to have sufficient literacy to read the forms and write answers.
- *Step d.* Participants return forms and have group discussion about devices.

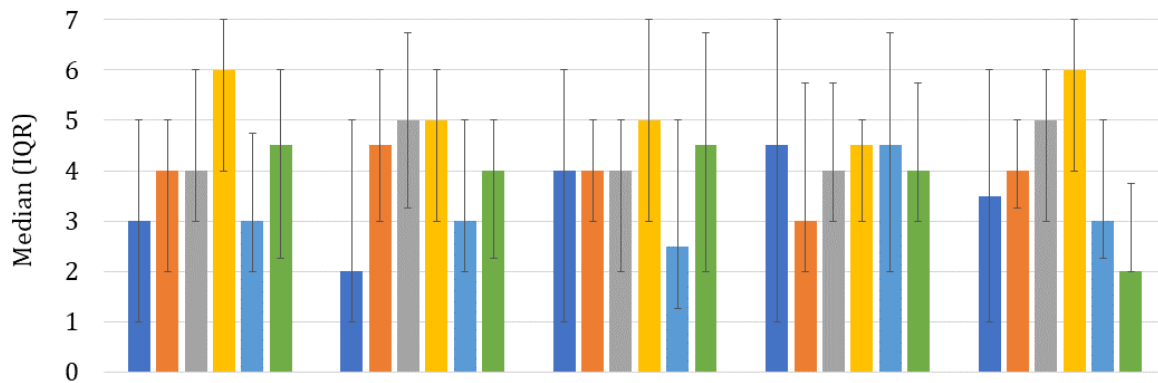
Textbox 2. Refined procedure for Qualitative Cultural Assessment of Passive Data collection Technology through focus group discussions in Nepal.

Refined procedure for Qualitative Cultural Assessment of Passive sensing Data Technology focus group discussions in Nepal.

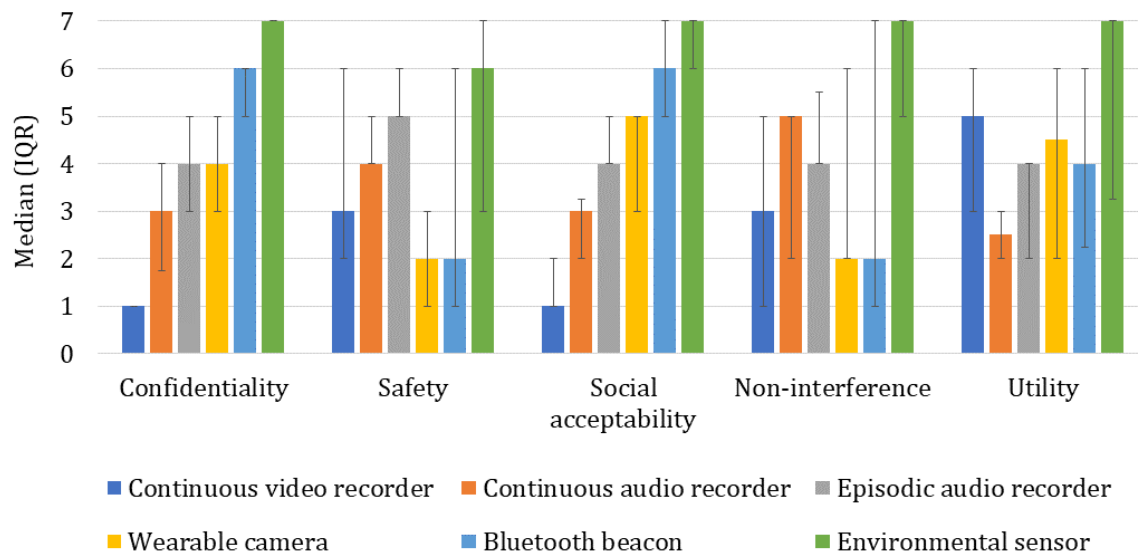
- *Step a.* Group discussion about child health, child development, and caregiver-child interactions.
- *Step b.* The first video is shown.
- *Step c.* The group has an open discussion about what was seen on the video and can ask questions about the devices.
- *Step d.* As a group, the participants have a facilitated discussion to rate the device on each attribute using the anchoring vignettes. The group produces a consensus rating score for each attribute.
- *Step e.* Steps *b* through *d* are repeated for the remaining devices.
- *Step f.* Each participant is individually given a series of cards representing each device. They are asked to rank the cards for each attribute. No literacy skills are required, and each participant produces her own ranking.

Figure 5. Card sort ranking results for attribute domains by country and device. IQR: interquartile range. South Africa (n=28); Nepal (n=50). Chi-square, Friedman test for ranking comparisons: South Africa: confidentiality (p=0.01), safety (p=0.01), social acceptability (p=0.17), non-interference (p=0.80), utility (p<0.001); Nepal: confidentiality (p<0.001), safety (p<0.001), social acceptability (p<0.001), non-interference (p<0.001), utility (p<0.001).

South Africa



Nepal



Device 1: Video Recorder

Community health volunteers were concerned that mothers and their families would not allow the continuous video recording in the home because the family members would be afraid that others would disclose their confidential information (see Multimedia Appendix 11, qualitative code reference: CONF_CVR_Q01). Codes in parenthesis correspond to the qualitative reference number for the quotes provided in Multimedia Appendix 11. Respondents in South Africa reported that husbands may assume information will be shared with the police (CONF_CVR_Q04). Some women felt that the home-based video recording would actually put them in greater danger (CONF_CVR_Q05). Others wanted the camera to only be in the child’s room (CONF_CVR_Q06). A health worker in South Africa explained that she would be like community members in her community who would cover up the camera and not use it (CONF_CVR_Q07). Caregivers in Nepal were concerned about continuous video recording catching images

of interpersonal violence (CONF_CVR_Q02). Some caregivers expressed that persons with bad behavior would not want others to know about this (CONF_CVR_Q03). Some caregivers and community health workers in Nepal explained that if families understood that only health workers used the information, then there would not be confidentiality problems (CONF_CVR_Q08). The health workers echoed this (CONF_CVR_Q09).

Device 2: Audio Recorder

Similar to the attitudes toward continuous video recording, participants were concerned that continuous audio recording would breach confidentiality (CONF_CAR_Q01, Q02, Q03). Caregivers expressed concern that having the continuous audio recording would incite arguments in the home. Some caregivers felt that the audio recording would have a negative impact over time by reducing the amount of emotional expression and by hearing negative things from others (CONF_CAR_Q04).

Device 3: Wearable Camera

Caregivers and health workers described their concerns about confidentiality when children wear the first-person time-lapse camera that takes photographs at preset intervals, such as every 30 seconds. With the child moving around the home and community while wearing the time-lapse camera, there was concern among community health workers in South Africa that they would capture nudity, drug use, and criminal activity (CONF_CWC_Q04). One concern was that the child would enter a room when the parents were being intimate and record this in the photographs. Caregivers did point out, however, that the child wearing a time-lapse camera would capture less compromising information than the continuous video recording (CONF_CWC_Q01). Similar to the continuous home video recording, South African health workers were concerned that the time-lapse camera worn by the child would capture images of domestic violence. The South African health worker also recommended GPS coordinates as an alternative data point that would be less of an invasion of privacy (CONF_CWC_Q02). Similar to the recommendations of other health workers, 1 Nepali community health volunteer emphasized the need for education of families about the child wearing the time-lapse camera and for all of the devices in general, which would assuage some concerns about confidentiality (CONF_CWC_Q03).

Devices 4 and 5: Bluetooth Beacon and Environmental Sensor

There were no confidentiality concerns about Bluetooth proximity beacons or environmental sensors.

Domain 2: Safety

Device 1: Video Recorder

Most discussions of safety focused on fear of theft. In South Africa, the home-based continuous stream video was considered the least safe, and no device was clearly ranked as the safest. Caregivers in Nepal reported that others could come into the house and steal the video camera (SAFE_CVR_Q01). In Nepal, where the respondents had recently experienced a major earthquake and were living in temporary housing, caregivers felt that they did not have a place to store the technology (SAFE_CVR_Q02). There were also concerns that the children could break the home video recorders (SAFE_CVR_Q03).

Device 2: Audio Recorder

There were no safety concerns.

Device 3: Wearable Camera

There was fear that children could break the wearable time-lapse camera that they would be wearing (SAFE_CWC_Q01). As the child wears the device, there was fear that others may steal the device from the children when the child is outside the home (SAFE_CWC_Q02, Q03). Other caregivers had similar concerns that the child would break the device or it would be stolen (SAFE_CWC_Q04). Program staff in South African health organizations had concerns that children would be mugged and the device stolen (SAFE_CWC_Q06). Similarly, in Nepal, the wearable camera was considered the least safe because the device could be stolen (SAFE_CWC_Q05).

Device 4: Bluetooth Beacon

The Bluetooth proximity beacon was considered a safety risk because it could be stolen from the children. In the qualitative interviews, the caregivers reported that they were afraid the Bluetooth beacon would be stolen from their children. Another safety concern in the qualitative interviews was that children—especially boys—would break the devices.

Device 5: Environmental Sensor

For safety, in Nepal, the environmental sensor was considered the safest. In subgroup comparisons in Nepal, community health workers rated the environmental sensor as less safe than how the caregivers rated it. In qualitative interviews, the community health workers reported that others may steal the environmental sensors to use in their own homes, whereas caregivers were not concerned that community members would steal the environmental sensors from one another.

Domain 3: Acceptability

There were no differences for social acceptability in the ranking task in South Africa sample, but the qualitative discussion suggests group preferences as described below. In Nepal, the environmental sensor and Bluetooth proximity beacon were the highest ranked and the home-based video the least acceptable. The Nepali respondents highlighted that the head of household and mother-in-law would need to consent to the using of the sensing devices and that they were least likely to accept the video recording in the home. Mothers-in-law often dictate the behavior of other women in the home, and not seeking support from mothers-in-law risk verbal and physical violence from the mothers-in-law. Respondents felt that head-of-household and mothers-in-law would support the environmental sensor because it would provide useful information for the household air quality, which would impact everyone's health. Heads of household would also find the proximity beacon acceptable because it would not provide sensitive information about the family.

Device 1: Video Recorder

To use the devices in the home, participants in both countries reported that permission from the husband would be needed. In South Africa, the male head-of-household would need to grant permission (ACPT_CVR_Q04). An experienced health organization worker in South Africa pointed out that the most vulnerable children, for example, those being sexually abused, would be least likely to have the male head of household give permission (ACPT_CVR_Q05). To make it acceptable, it was told that the benefit would need to be explained. South African community health workers said that preventing violence against children would encourage families to accept the devices (ACPT_CVR_Q06). In Nepal, permission from mothers-in-law was also important (ACPT_CVR_Q01, Q02). Community health volunteers in Nepal stated that mothers-in-law who perform a majority of the child care may not consent because they would be criticized by the family members (ACPT_CVR_Q03).

Device 2: Audio Recorder

A South African health organization worker pointed out that getting families to consent to using an episodic audio recorder—or any of the devices—requires the same rapport building and long-term relationships that are needed for any

health research activities (ACPT_EAR_Q02). Caregivers and health workers explained that all adult household members would need to consent for the continuous audio recording. Moreover, 1 health worker said that even adolescents would need to provide permission (ACPT_CAR_Q01). Caregivers in Nepal recommended getting permission from all adult household members before using the episodic audio recorder (ACPT_EAR_Q01).

Device 3: Wearable Camera

There were limited concerns about being able to obtain husbands and mothers-in-laws' consent for using the child's time-lapse camera in Nepal (ACPT_CWC_Q01). A community health worker, based on her expectations of gender and power in the community, stated that the child's father's permission would be needed (ACPT_CWC_Q02). Community health workers in Nepal were concerned about what would happen if the device was brought to school (ACPT_CWC_Q03). In addition, 1 community health volunteer in Nepal was concerned that it reflects negatively upon parents to send their children with the time-lapse camera (ACPT_CWC_Q04). This health worker continued to say that the child's peers would not find it acceptable, and eventually, the child would be socially ostracized (ACPT_CWC_Q05).

Device 4: Bluetooth Beacon

In both countries, there were no concerns about the permission needed for using the beacons (ACPT_PRX_Q01, Q02).

Device 5: Environmental Sensor

Participants in both countries did not express concern about getting husbands or mothers-in-law consent for the environmental sensor, which they considered low risk. In Nepal, the community health volunteers compared installing a mobile sensor in the home with conducting the polio vaccination program. As with the polio program, consent from the mother would be adequate to deploy the sensor (ACPT_ENV_Q01). However, the males would be harder to convince than females, with the women in the family more likely to see the advantages of the devices for their children's health (ACPT_ENV_Q02).

Domain 4: Noninterference

No single device stood out in South Africa as not interfering, but the qualitative discussion suggested that the continuous stream audio recorder was the most interfering. In Nepal, the environmental sensor was ranked highest, and the wearable time-lapse camera and Bluetooth proximity beacon were the most interfering. The main concern of caregivers was that the devices would be interfering because they would be attached to the children's clothing. In subgroup comparisons in Nepal, the caregivers considered the continuous audio recording as interfering in daily activities, whereas they did not consider the wearable time-lapse camera or Bluetooth beacon as disruptive as community health workers did.

Device 3: Wearable Camera

The main concern in terms of disruptiveness of the device was related to the child's time-lapse camera, which could interfere with the child's activities, as noted by respondents from both countries (INTF_CWC_Q01-Q05).

Domain 5: Utility

In South Africa, the wearable time-lapse camera was the most useful and the environmental sensor was the least useful. In Nepal, the environmental sensor was ranked as the most useful for child health and well-being. Both health workers and caregivers were very concerned about pollution and the impact on child health. They wanted to be able to monitor how much exposure the children had to pollution, given the frequency with which their children were getting respiratory infections. The continuous stream audio recorder was ranked the least useful. In both countries, both caregivers and community health workers were interested in observing children's lives around and outside the home. The wearable time-lapse camera was seen as a way to understand more about what children were doing. Parents were interested also because they reported that grandparents assumed the majority of child care responsibilities and they interacted with the children primarily in the morning and evening, so the wearable time-lapse camera would allow them to learn more about their children's lives—especially for preverbal children. In Nepal, in subgroup comparisons, the caregivers ranked the wearable time-lapse camera as more useful than the health workers did. Another aspect of wearable time-lapse camera utility was as a teaching tool. Both caregivers and health workers reported that having more information about their own behavior and interaction with children could help them to improve how they care for their children. Some commented that hearing themselves yell at children may help them reduce the behavior. Regarding utility, both caregivers and health workers reported that they did not see the technology as a substitute for face-to-face interaction. They preferred face-to-face interaction for getting health information and engaging with community health workers in the home.

Device 1: Video Recorder

Caregivers described the perceived benefit of being able to observe children's physical activity in the home as well as how other adults behave toward children and if there is any abuse occurring in the home (UTLT_CVR_01-CVR04). A South African health worker pointed out that the video could be proof of abuse even when the family denies it. This is especially important for preventing rape and associated potential HIV transmission (UTLT_CVR_05-06). The video was seen as a way to check on their children's health (UTLT_CVR_07). South African health workers also raised the possibility that the video would capture sexual abuse in the home (UTLT_CVR_Q10). The community health workers in South Africa described how the video could help them better educate mothers and other caregivers about addressing child care needs while also maintaining other household responsibilities (UTLT_CVR_Q11). The video could also lead to suggestions about sleeping arrangements for children in the household (UTLT_CVR_Q12, Q13). Tracking sleep of school children through the video was important for a South African health worker (UTLT_CVR_Q14). FCHVs in Nepal reported the advantage for their home health work in being able to observe the daily activities (UTLT_CVR_Q08, Q09). In Nepal, the caregivers and FCHVs also perceived home-based continuous video as a monitoring tool to watch everyday risks the children might face such as falls and playing in dirt, and they could use

observations from the video to correct negative behaviors of their child.

Device 2: Audio Recorder

In South Africa, community health workers reported that hearing parent-child communication as well as harsh communication in the household would be helpful for their work (UTLT_CAR_Q07). Caregivers in Nepal commented on the benefit to audio recording above and beyond that, which is obtained through video only (UTLT_CAR_01). Regarding health condition, the caregivers mentioned the audio from children with cough and cold symptoms, although it was debated whether video or audio would be preferable for this (UTLT_CAR_Q02, Q03). The audio recordings were also seen as advantageous for behavioral change among caregivers and other family members (UTLT_CAR_Q04). Some community health workers in Nepal commented that having domestic arguments recorded could facilitate their health promotion work and talk about communication in the household (UTLT_CAR_Q05, Q06). A caregiver in Nepal thought it would be helpful for older children (UTLT_CAR_Q08, Q09). The episodic audio recorder was perceived by health workers to help understand the auditory environment in which the child is living and its potential impact on child development, learning, and behavior (UTLT_EAR_01). The audio snippets could be used to determine the types of interactions caregivers and children are having (UTLT_EAR_02). Caregivers also felt that they could learn more to make sure that the child was getting the appropriate exposure to positive auditory stimulation, including language exposure for preverbal children (UTLT_EAR_Q03, Q04). The audio snippets could also be used to identify potential abuse (UTLT_EAR_Q05).

Device 3: Wearable Camera

Community health workers preferred the child's wearable time-lapse camera over the audio recordings because of the information it would provide on activities (UTLT_CWC_01). A South Africa caregiver preferred it over audio because it would not capture private speech or yelling at the child (UTLT_CWC_Q02). Compared with the continuous video recorder in the home, caregivers liked the child's wearable time-lapse camera because it provides information from wherever the child went rather than being restricted to the home (UTLT_CWC_Q03, Q04). Health workers in South Africa liked how the child's wearable time-lapse camera would provide information about the child's diet and nutritional intake (UTLT_CWC_Q08, Q09). Some caregivers perceived that the wearable time-lapse camera would capture images of a kidnapper if the child were abducted (UTLT_CWC_Q10). In Nepal, caregivers felt that the utility of continuous recording was limited because children spend time in many different rooms. Therefore, the wearable time-lapse camera was more beneficial (UTLT_CWC_Q05). In contrast, compared with continuous video recorder, 1 caregiver in Nepal felt that the child's wearable time-lapse camera would not capture as much useful information as the continuous video in the home (UTLT_CWC_Q06). Similarly, another caregiver preferred the continuous video to the child time-lapse photography (UTLT_CWC_Q07).

Device 4: Bluetooth Beacon

In South Africa, a health worker appreciated the concept of tracking mother and child time together based on the rationale that bonding is important for child development (UTLT_PRX_01). Similarly, caregivers in Nepal appeared to value time together with children, especially mother and child; therefore, something could be gained from tracking that with the Bluetooth proximity beacon (UTLT_PRX_Q02, Q03). In general, in both sites, the caregivers conceptualized the Bluetooth beacon as a tracking device that would allow them to find the child if mother and child were separated or if the child was kidnapped (UTLT_PRX_Q04, Q05).

Device 5: Environmental Sensor

The environmental sensor was considered to have major utility by Nepali participants, given the high rates of respiratory illness morbidity and mortality. Caregivers reported that they could use the information to adjust when they go outdoors and when to wear a mask (UTLT_ENV_Q01, Q02, Q03). With major campaigns to change cookstoves and indoor cooking, the environmental sensor was considered useful to detect air quality related to cooking (UTLT_ENV_Q04). Community health workers in Nepal were interested to use this information to educate families about air quality within different rooms in the house (UTLT_ENV_Q05).

Discussion

Principal Findings

Process for Qualitative Cultural Assessment of Passive Data Collection Technology

We found that the QualCAPDT procedure could be implemented in low-resource settings where populations would benefit from passive sensing data for health and development interventions. The procedure produced both quantitative and qualitative results that could be used to select devices for piloting. This is helpful to determine devices that would be culturally appropriate. The process also reveals what concerns would need to be addressed in the development and use of such devices for passive sensing data collection. The procedure can be feasibly implemented in communities with low literacy rates. We piloted the procedure in South Africa but made further modifications when implemented in Nepal to optimize feasibility for use with illiterate caregivers and to increase the understanding about devices for the participants when completing the ratings and rankings.

In South Africa, upon original administration of the anchoring vignettes, participants completed all the vignettes after watching all the videos. In contrast, in Nepal, the anchoring vignettes were completed after each individual video was shown. We made this modification because in South Africa, the participants had confusion about the devices, and by the time they watched all videos, there was some difficulty remembering the different features of the devices when rating them. The approach of discussing each video immediately after presentation allows for immediate recall of the features. This also allows the group to develop areas of consideration that can be incorporated when watching the subsequent videos. The goal of this process is for

persons unfamiliar with the different technologies to discuss potential application in their local context; therefore, it was important to give them time to consider each device individually. This likely facilitated a clearer group understanding of the devices before proceeding to the ranking activity in step 4. Moreover, the modified process used in Nepal allows for low literacy and illiterate populations to participate. In the modified procedure for Nepal, no reading or writing was required and the card ranking task only required sorting pictures of the devices. Going forward, we recommend the Nepal approach of watching each video and discussing as a group to produce more well-formed and well-considered ratings. This likely contributed to the clearer ranking outcomes observed in Nepal compared with South Africa.

Misperceptions generally improved from the South Africa to Nepal implementation. However, there were still misunderstandings, which highlights the need to do more to clarify what devices *can do* and *cannot do*. This clarification is important to get accurate ratings. In South Africa, participants thought proximity beacons could locate kidnapped or lost children. In both countries, participants thought home-based or wearable cameras would allow for surveillance of sexual predators. Participants in South Africa thought proximity beacons could locate children if they were kidnapped, and this may have led to higher expectations of benefit. In Nepal, the home-based video was thought to be similar to a closed-captioned television security camera and, therefore, may have led to higher ratings on the utility ranking. These perceptions would need to be addressed if such technologies were implemented to manage expectations of participants in health programs. This also illustrates why a method such as QualCAPDT is helpful to illuminate potential misinterpretations.

Recommendations for Implementing Qualitative Cultural Assessment of Passive Data Collection Technology

Given the development and piloting of QualCAPDT in South Africa and Nepal, we have the following recommendations for using the procedure in other settings (see also [Table 2](#)):

- *Step 1: Use qualitative interviews to assess the landscape of current needs for beneficiaries who would later use the technology.* This may be health workers, parents, educators, or others with a home-based component of their programs. The formative qualitative work should determine current technology use and potentials for new devices and/or data collection approaches with existing devices. The goal of Step 1 is to have contextual information to better inform device selection and data collection strategies as well as the relevant device attributes that will need to be assessed (eg, protecting confidentiality, minimizing interference with other activities, and perceived benefit to end users).
- *Step 2: Select the attributes that will be assessed in the QualCAPDT process.* In our study, our a priori attributes were confidentiality, acceptability, safety, nondisruptiveness, and perceived utility. However, we found that adding an attribute on health impacts during the qualitative analysis was helpful to split the safety construct into issues related to theft and risk of violence versus impact of the device on health (eg, through perceived radiation exposure). In future studies, the attributes should reflect the characteristics of devices and needs of the projects. Buenafior et al's 6 factors found to influence adoption (supporting fundamental human needs, cognitive load, social factors, physical aspects, participant demographics, and technical expertise of the user) [22] can be helpful to determine attributes. We caution developers that the wording of the attributes should be easily intelligible to beneficiaries in low-resource settings.
- *Step 3: Develop a range of candidate technologies and data collection approaches to demonstrate in videos.* Some devices or data collection approaches may be excluded at this stage based on the formative qualitative work in Step 1 and consideration of attributes from Step 2.
- *Step 4: Produce brief videos to demonstrate the technology.* This should be short (fewer than 5 min) so that multiple can be shown in FGDs with sufficient time. The setting of the videos should as closely approximate the context of end users. We found it helpful to illustrate what the technology is and how it is used in the home, what type of data are being collected, and how those data will be potentially used by health workers. On the basis of the experiences in South Africa and Nepal, it is also helpful to describe the limitations of the devices, for example, a tool such as a passive Bluetooth beacon has a limited range that would not allow tracking a child lost away from home or abducted.
- *Step 5: Develop anchoring vignettes to ask about the attributes for each device.* These anchoring vignettes should describe contrasting preferences for each attribute, for example, Maya does not want the device in her home because her family would be concerned about privacy, but Asha thinks her family would agree to allow it. Then, ask "Are the women in your community more like Maya or Asha?" and "Why?" It is helpful to create visuals of persons representing the different anchors so that participants can point to how close their community is to either of the anchors (see [Figure 3](#)).
- *Step 6: Create picture cards with the different technology that can be used for the ranking tasks.* This is helpful so that participants do not need any literacy skills to participate in the card sorting.
- *Step 7: Pilot the process with approximately 2 FGDs.* This is helpful if the team has not previously used structured elicitation tasks. The facilitators can practice their approach including explaining anchoring vignettes and card ranking. In addition, the participants may raise questions about what is demonstrated in the videos. From the questions, the facilitators may learn what else needs to be explained in the subsequent FGDs.
- *Step 8: Conduct FGDs with the full proceedings recorded for transcription, translation, and subsequent qualitative data analysis.* The FGD should begin with first discussing general issues separate from the technology but related to the theme of the future technology use. Then, the first video should be shown. This should be followed by a general discussion of the device and data collection in the video. After open discussion, the participants go through the anchoring vignettes as a group for each attribute. The facilitator records the group consensus for each attribute

and reasons for that rating. Then, the next video is shown and steps repeated. After all videos are shown, discussed, and rated, the participants are given the pictorial cards of the devices, and they go through the ranking process. The rankings for each individual participant are documented.

- *Step 9: Qualitatively analyze the FGDs.* The qualitative analysis should be conducted first to prevent bias introduced by reviewing the ranking scores. Although the a priori attributes should be used, there should also be an opportunity to introduce new attributes (eg, adding “health” in our experience). Then, quantitative data can be analyzed using techniques such as Wilcoxon Sign-Rank test. The data from both should then be synthesized and summarized using recommended approaches for mixed-methods research [50,51].
- *Step 10: Conduct supplementary interviews.* Although we conducted our supplemental interviews before the analysis, it is preferable to follow qualitative and mixed-methods research recommendations to share results with members of the target group to collect their interpretation of the findings [48]. This can be helpful to discuss issues and concerns that may not have arisen in the formative work. For example, concerns related to sexual violence against young children was not part of the planning of our project but arose in the FGDs and would need to be discussed with stakeholders before proceeding to final selection of the technology and data collection process.

Ultimately, this approach is helpful to prepare for future passive data collection. It will work best when there is adequate piloting

and incorporation of user-centered design principles. This will increase the likelihood that the passive sensing data collection is acceptable, feasible, and beneficial to promote child health and development and caregiver-child relations.

Device Preferences

We found that in South Africa and Nepal, there was interest in observing the world from the child’s perspective through wearable cameras that could be placed on the children and then have the caregivers review the photographs. In terms of utility, caregivers were open to using the technology to help them gain insight into their behavior with their children and then find ways to improve such behavior. Health workers also felt that sensing data could help them better educate parents. As this was a primary goal of the sensing technology, it was reassuring that both caregivers and health workers were open to this aspect of technology use.

In Nepal, there was a consistent concern across the ranking, rating, and interviews that devices attached to the children could be easily stolen and that by being attached to clothing, they would interfere in daily life in some way. For safety, we had expected that concerns about technology making children sick in some manner or being a health risk. However, safety was understood in terms of risk of theft. Participants in Nepal felt that devices attached to children could easily be stolen and may put them at risk. There were also concerns about what devices could be stolen from the home.

Table 2. Recommended steps for Qualitative Cultural Assessment of Passive Data collection Technology.

Steps for Qualitative Cultural Assessment of Passive Data collection Technology	Description
Step 1: conduct formative interviews	Conduct interviews with beneficiary population about roles, responsibilities, and current technology use
Step 2: determine criteria/attributes	Determine criteria for potential technologies to be evaluated
Step 3: select candidate technologies	Select a range of candidate technologies to fulfill the needs of the target population
Step 4: develop videos	Write scripts explaining technologies and then produce videos to illustrate what technologies will do; also include descriptions of what the technologies will not be able to do
Step 5: develop anchoring vignettes	Develop anchoring vignettes for each technology based on identified criteria/attributes
Step 6: develop cards for ranking tasks	Develop visual illustrations of candidate technologies for ranking tasks to minimize literacy skills needed to recognize the technologies; consider using pictures from videos that participants will be shown
Step 7: pilot videos and refine (eg, add clarifications of “can do” vs “cannot do”)	Pilot test videos with beneficiary representatives to determine what is perceived about the use of technology; consider developing additional “can do” and “cannot do” explanations to modify the videos or to be used by the FGD ^a facilitators, for example, proximity beacons cannot track location of children away from the home
Step 8: conduct FGDs	Conduct FGDs showing videos, include anchoring vignettes and card ranking, and allow for “can do” and “cannot do” discussion
Step 9: analyze qualitative data, then analyze quantitative data	First analyze data qualitatively using a priori themes based on attributes and allow for addition of new themes and attributes; then, quantitative analyze individual participant ranking scores of devices for each attribute using Wilcoxon Rank or other appropriate statistical tests
Step 10: conduct supplemental interviews	Conduct supplemental interviews to obtain feedback from stakeholders and collect their interpretation of findings from the qualitative data and ranking statistics

^aFGDs: focus group discussions.

A major issue for consent was that the majority of household members would need to be involved in the consenting process to allow for use of passive data collection technologies. In Nepal, social acceptability was predominantly dependent upon what the head-of-household and mother-in-law would find permissible and helpful. Most women felt that the environmental sensor and proximity beacon would be approved by these authority figures.

In Nepal, it was striking how much the environmental sensor was consistently the highest ranked device across all attributes. Both caregivers and health workers strongly desired to have information about pollution and air quality. As with other cities in South Asia and East Asia, there is increasing public health awareness about the impact of pollution. Using a rating procedure by residents, Kathmandu is ranked as the fifth highest city in the world in the Pollution Index Rate, as a reference, Delhi is 14 and Beijing is 23 [52]. In addition, children—and adults—have high rates of respiratory infection morbidity and mortality, with pneumonia being the leading cause of death for children under 5 years [53]. In addition, the environmental sensor was seen as preserving confidentiality, having a low risk of theft, being acceptable to heads-of-household and mothers-in-law, and not interfering with other activities in daily life. This suggests that future studies that wanted to explore air quality and child health at the household level would have high buy-in from participants and family members. This type of research could also support advocacy of families to politicians about addressing environmental health.

In South Africa, health workers reported that they were already using phones in the home, so that may help to have them transition to more mobile technology to improve their work. Although environmental influences on child development stood out in the Nepal findings, a concern in the South Africa study was the goal to protect children from sexual violence. They were interested in ways in which the sensing technology could collect information on sexual perpetrators including relatives and that the technology could be used to prevent perpetration of sexual violence because community members would be aware of the data collection.

Contributions of the Qualitative Cultural Assessment of Passive Data Collection Technology Procedure to Future Passive Sensing Data Research

The methods that we used for this study incorporate techniques from social sciences and cultural anthropology that are useful for conducting mHealth studies in similar settings in the future. Use of technology in health-related research and intervention is already an integral part in developed countries and has been growing in pace in developing countries such as Nepal [54-56]. However, adaptation and contextualization of these technologies in these settings itself requires a rigorous process. These settings have populations with limited or no exposure to complex technologies, and the available infrastructures are also limited. Explaining technologies to potential beneficiaries through videos instead of traditional didactic methods helps in better understanding as they are more likely to grasp its concept when watching how it works. The use of anchoring vignette with a third-person character simplifies the comparative process and

minimizes the social desirability biases [44], that is, the responses are external to the individual and participants are not bound to present themselves as someone agreeable, which is very important in some cultural settings. Asking them about their thoughts embedded in fictional characters will lead to more honest and rich answers in relation to future end-user behavior. These processes will help researchers and implementers in selecting technologies that the community understands, acknowledges, approves, and considers useful.

During the last 5 to 10 years, there has been substantial research energy invested into the field of mHealth [6]. Immediate and plentiful opportunity existed to leverage and embed mobile phones into the global health system. The mHealth research agenda was aided by the fact the mobile phones were ubiquitous and easy to use and understand. For example, receiving a health system-generated medication reminder via short message service felt familiar and required no further explanation. However, as we move beyond the phone and begin to harness embedded sensors and invisible technologies that are not well understood, better methods will be required to facilitate full understanding between the researcher and the participant. The QualCAPDT process offers 1 approach to ensuring that all technology introduced into the home to support maternal and child health and development is not done so at the cost of full consent and understanding of those providing these rich yet intrusive data. Ultimately, the QualCAPDT procedure can be used to identify devices and passive data collection approaches to further advance tailored messaging to caregivers and health workers [57] for the goal of improved physical, mental, and developmental well-being of children and their caregivers.

Limitations

One limitation is that the development of the QualCAPDT procedure evolved over time and modifications were made both within and between countries over time. Therefore, statistical comparisons between rankings in South Africa and Nepal are not appropriate. Another limitation was that we did not specify different developmental stages of children when considering responses. The respondents likely would have had different qualitative responses and rankings if they considered the child health and development needs of infant versus adolescent. For the most part, the respondents appeared to consider toddlers and early childhood in making their responses.

Conclusions

In settings where populations have limited prior exposure to passive data collection, methods are needed to determine what may be acceptable and have high perceived local value. Through the use of videos to demonstrate local implementation of technologies and subsequent structured elicitation tasks, we assessed norms and preferences in settings with high public health need for child development and caregiver mental health interventions. Future steps in our research will be using the current findings to develop and pilot passive data collection with children and caregivers. The future research will illuminate how well the qualitative elicitation method captured key community expectations and concerns. Ultimately, a structured qualitative elicitation procedure is an important method for selecting new research technologies.

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Authors' Contributions

BAK and AvH obtained the funding, conceptualized the project, and drafted the manuscript. BAK, AvH, SR, and AB designed the research tools and data collection protocol. AB adapted the structured elicitation tasks and developed the data collection procedure for the anchoring vignettes and ranking tasks. BAK and KV conducted the qualitative data analysis. BAK conducted the quantitative analyses. KT and KV conducted the fieldwork and data collection. SR supervised the video production, data collection, and data management for the Nepal team. All authors approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Video recorder demonstration video for South Africa.

[[MP4 File \(MP4 Video\), 28MB - pediatrics_v2i1e12366_app1.mp4](#)]

Multimedia Appendix 2

Video recorder demonstration video for Nepal.

[[MP4 File \(MP4 Video\), 53MB - pediatrics_v2i1e12366_app2.mp4](#)]

Multimedia Appendix 3

Audio recorder demonstration video for South Africa.

[[MP4 File \(MP4 Video\), 9MB - pediatrics_v2i1e12366_app3.mp4](#)]

Multimedia Appendix 4

Audio recorder demonstration video for Nepal.

[[MP4 File \(MP4 Video\), 42MB - pediatrics_v2i1e12366_app4.mp4](#)]

Multimedia Appendix 5

Wearable camera demonstration video for South Africa.

[[MP4 File \(MP4 Video\), 13MB - pediatrics_v2i1e12366_app5.mp4](#)]

Multimedia Appendix 6

Wearable camera demonstration video for Nepal.

[[MP4 File \(MP4 Video\), 58MB - pediatrics_v2i1e12366_app6.mp4](#)]

Multimedia Appendix 7

Bluetooth beacon demonstration video for South Africa.

[[MP4 File \(MP4 Video\), 7MB - pediatrics_v2i1e12366_app7.mp4](#)]

Multimedia Appendix 8

Bluetooth beacon demonstration video for Nepal.

[[MP4 File \(MP4 Video\), 44MB - pediatrics_v2i1e12366_app8.mp4](#)]

Multimedia Appendix 9

Environmental sensor demonstration video for South Africa.

[[MP4 File \(MP4 Video\), 5MB - pediatrics_v2i1e12366_app9.mp4](#)]

Multimedia Appendix 10

Environmental sensor demonstration video for Nepal.

[MP4 File (MP4 Video), 32MB - [pediatrics_v2i1e12366_app10.mp4](#)]

Multimedia Appendix 11

Qualitative data quotations.

[XLSX File (Microsoft Excel File), 30KB - [pediatrics_v2i1e12366_app11.xlsx](#)]

Multimedia Appendix 12

Consolidated criteria for reporting qualitative research (COREQ) items.

[PDF File (Adobe PDF File), 38KB - [pediatrics_v2i1e12366_app12.pdf](#)]

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Abbreviations

FCHVs: female community health volunteers

FGDs: focus group discussions

GPS: Global Positioning System

HSRC: Human Sciences Research Council

LENA: language environment analysis

LMIC: low- and middle-income countries

mHealth: mobile health

QualCAPDT: Qualitative Cultural Assessment of Passive Data collection Technology

RFID: radio-frequency identification devices

SDGs: Sustainable Development Goals

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Original Paper

Features and Educational Content Related to Milk Production in Breastfeeding Apps: Content Analysis Informed by Social Cognitive Theory

Suhail Sidhu¹, BS; Kaoer Ma¹, MS, MA; Anna Sadovnikova^{1,2}, MPH, MA, IBCLC

¹LiquidGoldConcept, Inc, Ypsilanti, MI, United States

²School of Medicine, University of California, Davis, Sacramento, CA, United States

Corresponding Author:

Anna Sadovnikova, MPH, MA, IBCLC

LiquidGoldConcept, Inc

Ypsilanti, MI,

United States

Phone: 1 916 905 3544

Email: anna@liquidgoldconcept.com

Abstract

Background: Low milk production is one of the main reasons for premature breastfeeding cessation. Smartphone apps have the potential to assist mothers with promoting, interpreting, tracking, or learning about milk production. It is not known whether breastfeeding apps contain high-quality, engaging, and diverse content and features that could be used by mothers to increase their breastfeeding self-efficacy and answer their questions about milk production.

Objective: The overarching objective of this study was to identify and evaluate features and content within breastfeeding apps that could be used by mothers to increase breastfeeding self-efficacy and answer their questions about milk production. The secondary objectives were to quantify the diversity of representation of breastfeeding experiences within breastfeeding apps and to define the type of organization that is most likely to create free apps and/or apps with high-quality, engaging, and diverse features and content related to milk production.

Methods: Breastfeeding apps were identified in the Apple App Store. All features that assist mothers with tracking, promoting, or interpreting milk production in the first 0-6 months postpartum were noted. Every screen containing educational information about milk production was identified and saved for review. Images of mothers and caretakers within the selected screenshots were assessed. Three scoresheets informed by Social Cognitive Theory were created to evaluate all identified features, educational content, and images representing the breastfeeding experience.

Results: Forty-one breastfeeding apps were reviewed. Only seven apps contained both features and educational content related to milk production. Thirteen apps that contained educational content related to milk production received a mean combined content and cultural diversity score of 15.3 of 78. Of the 48 photos reviewed in screenshots that contained educational content on milk production, 87.5% (n=42) were of white women and their infants. For-profit companies and large organizations were most likely to create free apps and apps that received high scores on the combined content and diversity or features scoresheet, respectively.

Conclusions: Features and educational content related to milk production and breastfeeding imagery within breastfeeding apps were evaluated using three novel scoresheets informed by Social Cognitive Theory. Few apps contained both features that promote breastfeeding self-efficacy and high-quality, engaging, educational content with images of diverse caretakers. Thus, it is likely that parents, especially those from minority or low-income groups, have limited options when selecting a breastfeeding app. App developers could use the scoresheets and findings in this review to develop breastfeeding apps that assist mothers with interpreting, tracking, or learning about milk production through high-quality and engaging features, content, and imagery.

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KEYWORDS

milk production; milk supply; human lactation; breastfeeding; breastfeeding app; smartphone app; Social Cognitive Theory; breastfeeding self-efficacy

Introduction

Breastfeeding significantly reduces maternal and infant morbidity and mortality [1]. Despite the fact that the World Health Organization and the American Academy of Pediatrics recommend exclusive breastfeeding for 6 months, only 24.9% of mothers in the United States reach the 6-month goal [2-4]. Racial and socioeconomic disparities are reflected in breastfeeding rates: Black and low-income women are less likely to initiate breastfeeding in the hospital and breastfeed exclusively for 6 months [5]. The majority of women stop breastfeeding due to perceived or real low milk production [6,7].

A health behavioral intervention that focuses on maternal self-efficacy is an effective strategy for increasing breastfeeding rates [8]. A mother's breastfeeding self-efficacy could improve if she had the ability to track, interpret, and learn about her milk production [9]. Women are turning to their smartphones [10] to seek out "emotional, informational, technical, and consultative-type breastfeeding support," information about milk production [11], and visual representations of breastfeeding skills [12]. It is not known whether features and content related to milk production within breastfeeding apps are engaging, diverse, and of high quality or lead to increased breastfeeding self-efficacy [13].

The overarching objective of this study was to identify breastfeeding smartphone apps that contain high-quality, engaging, and diverse content and features that mothers could use to increase their breastfeeding self-efficacy and answer their questions about milk production. The secondary objectives were to quantify the diversity of representation of breastfeeding experiences within breastfeeding apps and to define the type of organization that is most likely to create a free app and apps with high-quality, engaging, and diverse features and content related to milk production.

Methods

Identification of Breastfeeding Apps and General Characteristics of App Developers

Between August and October 2017, breastfeeding apps were identified in the Apple App Store using the search term "breastfeeding." Apps were downloaded onto an iPhone and explored by author SS for 10 minutes to ensure that the app fit the inclusion criteria (Table 1). The Google Play Store was used to confirm that an app could also be downloaded on Android devices; however, availability on both platforms was not a prerequisite for inclusion because the authors only had access to iPhones. To ensure comparability with previous reviews of breastfeeding apps, general information about the app and the app developer was collected from the App Store, by emailing the creators, browsing through the app developer's page on LinkedIn, and using third-party sites like Bizapedia (Multimedia Appendix 1).

Selection of Features and Content Related to Milk Production

SS reviewed every interface of each app on three separate occasions (average of 60 minutes per app) to ensure that all possible features were included for review (Multimedia Appendix 2). A feature was defined as an opportunity for user interaction with the app (eg, a button). After identifying all the features available in each app, SS documented features that could assist mothers with promoting, tracking, or interpreting milk production in the first 0-6 months postpartum. The principal investigator, a board-certified lactation consultant and a physician-scientist trainee studying milk production regulation, trained SS to identify features that are relevant to milk production promotion, tracking, and interpretation. A literature search in Medline was conducted to confirm that the selected features were relevant to milk production.

The authors developed a scoresheet with eight milk production content categories using two textbooks on breastfeeding [16,17] as guides (Multimedia Appendix 3). The eight content categories are listed below: (1) Hospital practices that promote breastfeeding initiation; (2) Reasons for a delay in lactogenesis II; (3) Normal milk production timeline, volume, and measurement; (4) Supply and demand physiology; (5) Maternal or infant nutritional requirements; (6) Breastfeeding techniques that support or interfere with milk production; (7) Maternal or infant biological, physiological, or behavioral causes of perceived or real low-milk production between 0 and 6 months postpartum; and (8) A description of foods, medications, or supplements that have the potential to increase milk production. AS provided training to SS on how to identify relevant content within each of the eight categories. AS and SS independently took screenshots within each app to capture educational content related to milk production, reviewed the compiled screenshots, scored all the content, and resolved discrepancies by referring to two textbooks on breastfeeding [16,17].

Development of Scoresheets to Score Features and Content Related to Milk Production and Images of Breastfeeding Experiences

Social Cognitive Theory is the most common health behavior theory used in self-efficacy instruments that increase breastfeeding rates [8]. The three core components of Social Cognitive Theory that relate to improved breastfeeding self-efficacy are *motivation*, *observation*, and *repetition*. For a new mother to learn the skill of breastfeeding, she must be intrinsically *motivated* to learn, *observe* ideal examples of the behavior by mothers like her, and receive positive reinforcement from credible sources to *repeatedly* perform the said behavior [8,18,19]. The authors applied these three principles in the development of the scoring system used to evaluate features and content related to milk production and images of the breastfeeding experience within selected breastfeeding apps.

Table 1. Inclusion criteria and rationale for selection of breastfeeding apps.

Criterion	Rationale
App appeared as a result on the App Store using the search term “breastfeeding”	“Breastfeeding” yielded >100 results, depending on the month of search. “Lactation” yielded only ~50 results, depending on the month of search.
App focused on breastfeeding education or tracking an aspect of the breastfeeding experience	Breastfeeding experience included nursing and pumping.
App had a summary rating on the App Store	The summary rating on the App Store gives a measurement of whether the app is used by the general public. The App Store ranks apps using an algorithm that considers a multitude of factors related to user engagement including the number of downloads, ratings, and updates; quality of ratings; user retention rate; and conversation rate. The App Store provides a special designation to apps ranked in the top 200 of their assigned categories. Top 200 apps are more likely to have higher user engagement in terms of the aforementioned metrics and serve as an objective measure of an app’s popularity by consumers [14,15].
App was available in English	Authors did not have funds to pay for translation.
App was available for download and use in the United States	Authors reside in the United States.

A 5-point scoresheet was developed to score features (Table 2) that assist mothers with promoting, tracking, or interpreting milk production. Features were included in the scoresheet only if they were relevant to tracking or interpreting milk production between 0 and 6 months postpartum; therefore, all the features included in the scoresheet received one point at baseline. Features that needed to be used frequently (*repetition*) and were interactive (*motivation*) received the highest possible features score. The assignment of points for each feature was determined independently by two raters (AS and SS).

A 72-point scoresheet was developed to evaluate educational content across the eight milk production categories (Table 3 and Multimedia Appendix 3). Three criteria were used to score the educational content within each of the eight categories: scope, quality, and engagement. The selected screenshots did not need to contain all the information from a category to receive full credit within that category. For example, within category

1 (Hospital Practices), selected screenshots would only need to contain a mention of the importance of skin-to-skin contact in relation to breastfeeding initiation to receive a point within the scope of content for that category. The quality of the content was determined by assessing in-text citations and referenced literature within the selected screenshots. AS downloaded and reviewed all referenced literature to ensure it was relevant to the content. Photos and videos are more likely than text to increase breastfeeding self-efficacy because they are *motivational* and are more likely to foster *repetition* and, thus, mastery of a task [18-21]. Therefore, if a screenshot contained educational images pertaining to the content within that category, two additional points were awarded. Videos were awarded three additional points because they are more likely to result in mastery of tasks relative to photos [22]. Two authors independently (SS and AS) assessed each screenshot with information about milk production and awarded points using the content scoresheet described in Table 3.

Table 2. Feature scoresheet informed by Social Cognitive Theory.

Measure	Points possible
Repetition (frequency)	
≥1/week	2
≥1/month but less than ≥1/week	1
<2/month	0
Motivation (interactivity)	
User engagement throughout activity	2
User engagement at the beginning or end of activity	1
Minimal user engagement	0
Milk production related	1
Maximum points/feature	5

Table 3. Content scoresheet informed by Social Cognitive Theory.

Content	Scope of content ^a	Quality of content ^b	Engagement with content	
			Videos ^c	Images ^d
Hospital Practices	0/1	0/1/2/3	0/3	0/2
Delay in Lactogenesis II	0/1	0/1/2/3	0/3	0/2
Normal milk production timeline or volume	0/1	0/1/2/3	0/3	0/2
Supply and Demand Physiology	0/1	0/1/2/3	0/3	0/2
Nutritional Requirements	0/1	0/1/2/3	0/3	0/2
Breastfeeding Technique	0/1	0/1/2/3	0/3	0/2
Biology or behavior	0/1	0/1/2/3	0/3	0/2
Foods or medications or supplements	0/1	0/1/2/3	0/3	0/2
Maximum total points possible within each evaluation criterion	8	24	24	16

^aIs this content presented? (0=No relevant content, 1=Relevant content present).

^bAre in-text, relevant citations included? (3 points/category) OR Is there a list of relevant references at bottom of screen or within the app? (2 points/category) OR Is the author is an “expert” (eg. MD, IBCLC, or PhD)? (1 point/category) OR There is no way to evaluate the quality of the content? (0 points/category).

^cAre there videos that assist the user in understanding the educational content? (0=No relevant videos, 3=Videos that assist the user in understanding the educational content are present).

^dAre there images that assist the user in understanding the educational content? (0=No relevant images, 2=Images that assist the user in understanding the educational content are present).

Table 4. Diversity scoresheet informed by Social Cognitive Theory.

Diversity of representation of the breastfeeding experience	Additional points/app
≥7 photos (3 points) OR 4-6 photos (2 points) OR 1-3 photos (1 point) of the breastfeeding dyad or caretakers in all the identified screenshots	3/2/1
<i>Of all of the identified photos:</i> ≥3 photos are of nonwhite or nontraditional caretakers ^a (3 points) OR ≥2 photos are of nonwhite or nontraditional caretakers (2 points) OR 1 photo is of a nonwhite or nontraditional caretaker (1 point)	3/2/1
Maximum points possible/app	6

^aFor the purposes of this evaluation, a nontraditional caretaker was defined by the authors as an individual who is not the mother (eg, grandmother, father, same sex partner, nanny, etc).

A scoresheet (Table 4) was developed to calculate the total additional points that an app could receive for including diverse representations of the breastfeeding experience within the selected screenshots containing educational content about milk production. If the selected screenshots contained images of breastfeeding dyads and nontraditional caretakers, additional points were awarded because the *observation* of successful breastfeeding experiences can increase breastfeeding self-efficacy [8,18-20,23-25]. To calculate the final score for educational content, we combined the scores from the content and diversity scoresheets (72+6=78 possible points), as the images selected for review of “diversity” were identified solely within screenshots with content related to milk production. Thus, the measure of diversity is within those screenshots and is not generalizable to the entire app.

Statistical Analysis

All data were analyzed using descriptive statistics. To test whether there was a difference between the mean features or combined content and diversity scores, apps were stratified by their rank (ranked vs unranked), platform availability (iOS exclusive vs available on iOS and Android), category (medical

apps vs all others including education, productivity, lifestyle, and health and fitness), and price (free vs not free). The organizations that created the apps were also stratified by the size of their business (large organizations with >10 employees vs small organizations) and registration status (for-profit organizations vs all others including governmental organizations, nonprofits, and individuals). The Wilcoxon rank sum test was used to test the difference between two groups. The Spearman correlation was performed to test the relationship between organization type and size; app characteristics; and the features, content, and combined diversity and content scores. Interrater reliability for the combined content and diversity score was calculated as percent agreement between two raters—a breastfeeding expert (AS) and a novice (SS). Significance was set at an alpha of 5%. Data are presented as mean (SEM).

Results

Selection of Breastfeeding Apps

Between August and October 2017, 105 apps were identified on the App Store by using the search term “breastfeeding” (Multimedia Appendix 4). Thirty-four apps were not

downloaded because they did not have enough ratings to generate a summary rating ($n=32$) or because they were not available in the United States ($n=2$). SS downloaded and performed an initial screening of the remaining 71 apps by interacting with each app from an end user's perspective to confirm that the inclusion criteria were satisfied (Table 1). Eighteen apps were excluded from further assessment because they were not available in English ($n=2$); were free trials that only allowed the user to use the app for a certain amount of time or number of uses or restricted certain features ($n=9$); or had technical errors that interfered with the app's functionality, rendering it impossible to use ($n=7$). Between November 2017 and August 2018, SS reviewed 53 apps that fit the inclusion criteria on three separate occasions to identify features and content relevant to milk production. In 2018, six apps were excluded from the review because they no longer existed ($n=4$) or were no longer available in the United States ($n=2$). Of the remaining 47 apps, six apps were removed from the dataset because they did not have educational content related to milk production (Multimedia Appendix 5). Thus, the final dataset contained 41 breastfeeding apps ($N=41$).

General Characteristics of Breastfeeding Apps

Of the 41 breastfeeding apps (Multimedia Appendices 6 and 7) in the final dataset, 85.4% ($n=35$) had features that mothers could use to track or interpret milk production and 31.7% ($n=13$) had educational content related to milk production. Of the 13 apps with educational content related to milk production, only six apps contained features that could be used to track or interpret milk production. Twenty-nine apps (70.7%) contained features related to milk production, but no educational content related to milk production. Most of the apps ($n=30$, 73.2%) were free to download and use. Approximately half of the apps reviewed ($n=21$, 51.2%) were only available on the iOS platform. The majority of the apps ($n=28$, 68.3%) were created by for-profit organizations. Over half of the apps ($n=25$, 60.9%) were created by organizations with fewer than 10 employees. The vast majority of the apps in our final dataset ($n=30$, 73.2%) were not ranked in the top 200 in the App Store in their respective category.

Features That Assist Mothers With Promoting, Tracking, or Interpreting Milk Production

Eighteen unique features related to promoting, tracking, or interpreting milk production were identified within 35 breastfeeding apps (Table 5). All 35 apps had a breastfeeding timer, 31 apps had a bottle-feeding timer, and 30 apps had a diaper-change tracker. The least common features were trackers for allergy ($n=2$), teeth ($n=3$), and baby's sounds ($n=3$). A baby sound recorder and photos of the baby received the highest features score possible of 5. The teeth-tracking feature received the lowest features score because, while teeth can interfere with breastfeeding, it is unlikely that many teeth will appear before the newborn is 6 months old; therefore, the tracking teeth feature would not be used frequently. Moreover, entering the date that a tooth first appeared on would not be as engaging as other

activities related to tracking, interpreting, or promoting milk production, such as taking or looking at a photo of a baby.

Characteristics of Apps Containing Features That Assist Mothers With Promoting, Tracking or Interpreting Milk Production

A total of 35 apps contained features that assist mothers with promoting, tracking, or interpreting milk production; these apps received an average features score of 27.3 (SD 11.3; range 4-47 of 51 possible points) when evaluated with the features scoresheet described in Table 5. Among apps that contained features related to milk production, those ranked in the top 200 in their respective category in the App Store (Figure 1) scored significantly higher ($P=.0096$) than apps that were unranked. Apps developed for both iOS and Android (Figure 1) received a significantly higher features score ($P=.04$) than apps developed just for iOS. There was no difference ($P=.55$) between the mean features scores of apps that were free and not free or the mean scores of apps ($P=.55$) created by small versus large organizations (Figure 1). Apps created by large organizations (>10 employees) were more likely to be on both iOS and Android platforms ($r=0.69$, $P<.001$). For-profit companies were more likely to create apps on both iOS and Android platforms ($r=0.41$, $P=.02$). Apps that had to be purchased ("not free apps") were more likely to be ranked in the top 200 in their respective category in the App Store ($r=0.43$, $P=.01$). There was no correlation between the price of the app and the size of the organization, the organization type, or platform. Additionally, we did not find a significant positive or negative correlation between the size of the organization and its status as a for-profit organization.

Content Related to Milk Production and Diverse Representations of Breastfeeding Within Breastfeeding Apps

Educational content related to milk production (Multimedia Appendix 3) was identified in 13 apps. Seven of these 13 apps also contained features that could assist mothers with promoting, tracking, or interpreting milk production. Since the diversity scoresheet could only be applied to screenshots that contained educational content about milk production, the scores from the content and diversity scoresheets were combined for all analyses. The average combined content and diversity score for all 13 education apps was 15.3 (SD 8.8). To the best of our knowledge, these apps were not created by infant formula companies. The Healthcare Provider's Guide to Breastfeeding app received the highest combined content and diversity score (32/78), while the Breastfeeding Management 2 app received the lowest combined content and diversity score (4/78). The app with the highest quality of content was the Health Care Provider's Guide to Breastfeeding, with 79.2% of all the content reviewed containing in-text citations or reference lists to relevant peer-reviewed literature. The apps with the lowest quality of content were Breastfeeding Central and Breastfeeding Management 2; the content reviewed in these apps did not have any references (Figure 2).

Table 5. Scores of 18 features related to milk production.

Unique feature (N=18)	Rationale	Score
Baby sound recorder [16,26]	Related to milk production (1 point) AND user engagement <i>throughout</i> activity (2 points) AND used ≥ 1 times/ <i>week</i> (2 points)	5
Photos (of baby) [16,26]	Related to milk production (1 point) AND user engagement <i>throughout</i> activity (2 points) AND used ≥ 1 times/ <i>week</i> (2 points)	5
Bottle-feeding timer [16,17]	Related to milk production (1 point) AND user engagement <i>at beginning or end</i> of activity (1 point) AND used ≥ 1 times/ <i>week</i> (2 points)	4
Breastfeeding timer [16,17]	Related to milk production (1 point) AND user engagement <i>at beginning or end</i> of activity (1 point) AND used ≥ 1 times/ <i>week</i> (2 points)	4
Breast-pumping timer [16,17]	Related to milk production (1 point) AND user engagement <i>at beginning or end</i> of activity (1 point) AND used ≥ 1 times/ <i>week</i> (2 points)	4
Diaper-change tracker [16,17]	Related to milk production (1 point) AND user engagement <i>at beginning or end</i> of activity (1 point) AND used ≥ 1 times/ <i>week</i> (2 points)	4
Sleep pattern [16,17]	Related to milk production (1 point) AND user engagement <i>at beginning or end</i> of activity (1 point) AND used ≥ 1 times/ <i>week</i> (2 points)	4
To-do list or reminders [27]	Related to milk production (1 point) AND user engagement <i>at beginning or end</i> of activity (1 point) AND used ≥ 1 times/ <i>week</i> (2 points)	4
Baby's mood [28]	Related to milk production (1 point) AND user engagement <i>at beginning or end</i> of activity (1 point) AND used ≥ 1 times/ <i>month</i> (1 point)	3
Allergy [29]	Related to milk production (1 point) AND either user engagement <i>at beginning or end</i> of activity (1 point) OR used ≥ 1 times/ <i>month</i> (1 point)	2
Doctor visits [30]	Related to milk production (1 point) AND either user engagement <i>at beginning or end</i> of activity (1 point) OR used ≥ 1 times/ <i>month</i> (1 point)	2
Growth [31]	Related to milk production (1 point) AND either user engagement <i>at beginning or end</i> of activity (1 point) OR used ≥ 1 times/ <i>month</i> (1 point)	2
Milestones [32]	Related to milk production (1 point) AND either user engagement <i>at beginning or end</i> of activity (1 point) OR used ≥ 1 times/ <i>month</i> (1 point)	2
Illness or temperature [33]	Related to milk production (1 point) AND either user engagement <i>at beginning or end</i> of activity (1 point) OR used ≥ 1 times/ <i>month</i> (1 point)	2
Baby's medication tracker [34]	Related to milk production (1 point) AND <i>minimal to no</i> user engagement (0 points) AND used < 2 times/ <i>month</i> (0 points)	1
Teeth [34-36]	Related to milk production (1 point) AND <i>minimal to no</i> user engagement (0 points) AND used < 2 times/ <i>month</i> (0 points)	1
Record weight/height/date of birth [16,17]	Related to milk production (1 point) AND <i>minimal to no</i> user engagement (0 points) AND used < 2 times/ <i>month</i> (0 points)	1
Record singleton/multiples birth [16,17]	Related to milk production (1 point) AND <i>minimal to no</i> user engagement (0 points) AND used < 2 times/ <i>month</i> (0 points)	1

Figure 1. Differences in mean feature scores, stratified by type of app, category (eg, medical or health and fitness), and organization. iOS: iPhone operating system; Org: organization. Asterisk indicates $P=.04$; double asterisk indicates $P=.0096$.

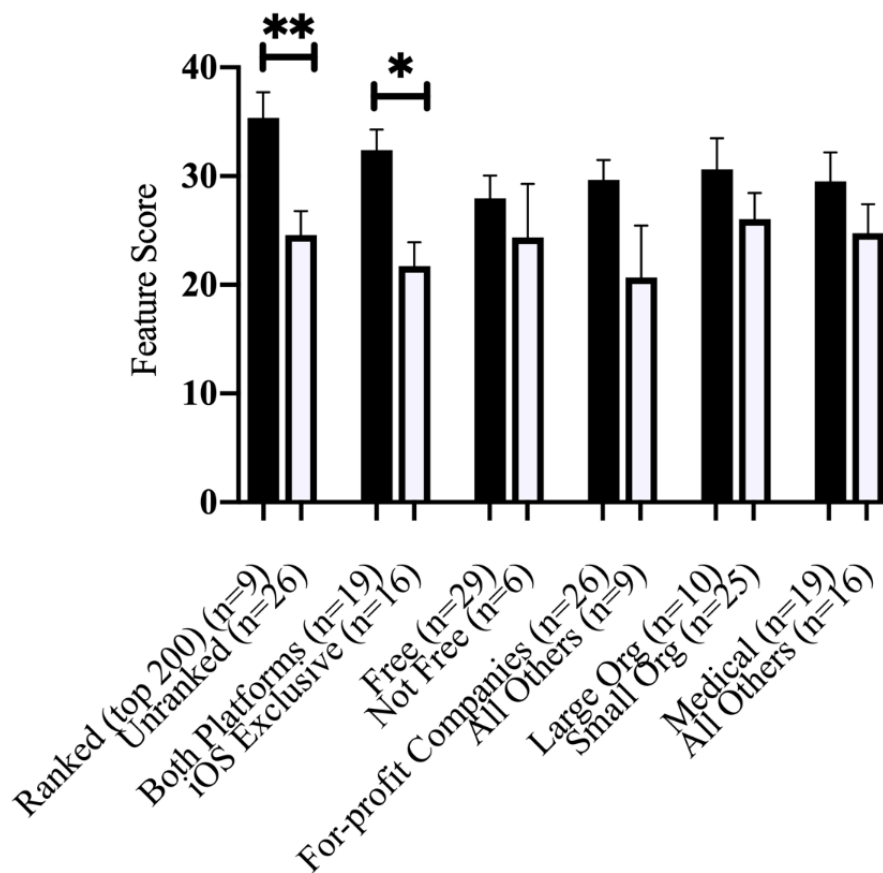
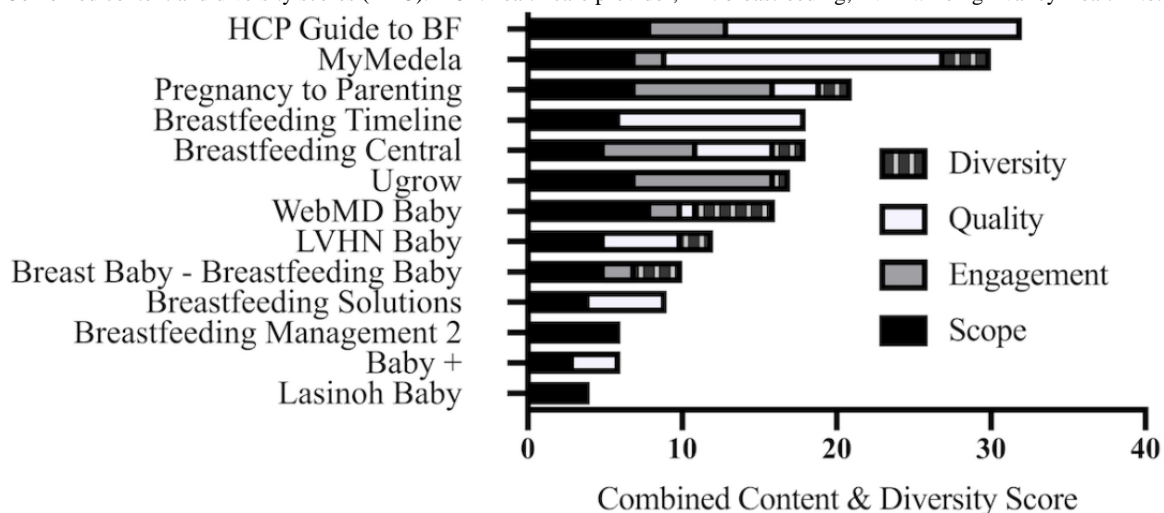


Figure 2. Combined content and diversity scores (n=13). HCP: health care provider; BF: breastfeeding; LVHN: Lehigh Valley Health Network Baby.

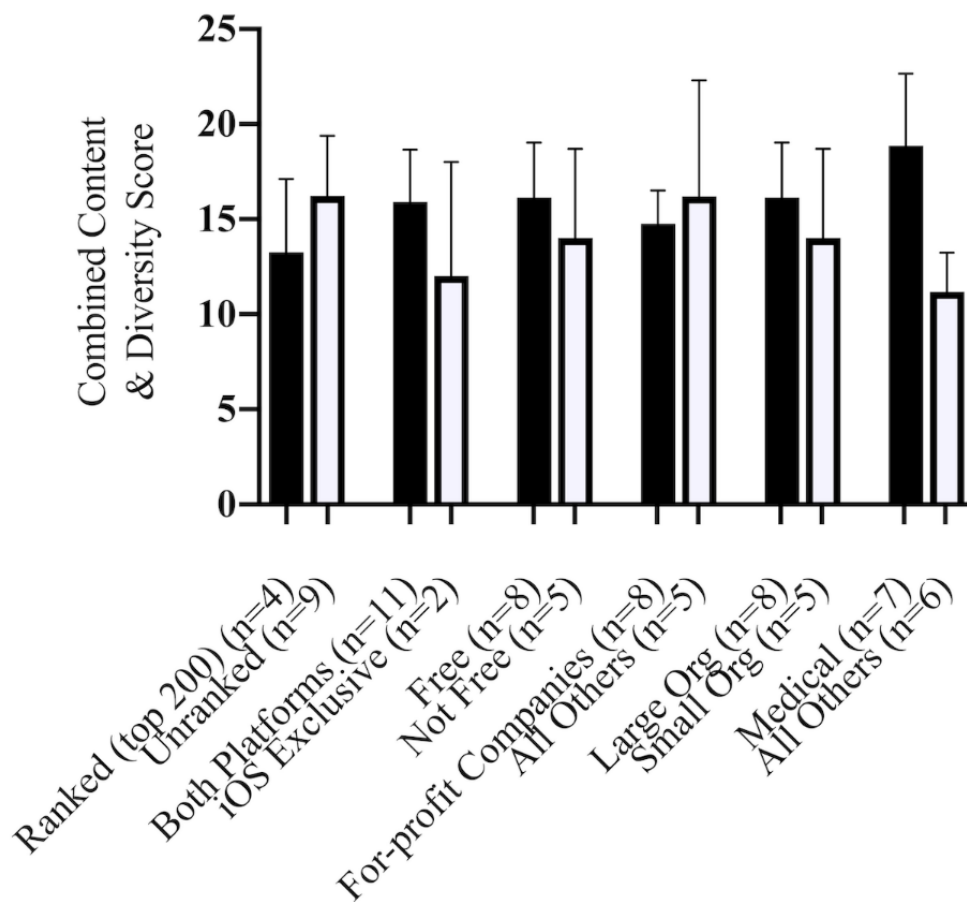


A total of 48 photos of the breastfeeding dyad were identified within the screenshots containing educational content related to milk production. Of these, 87.5% (n=42) were of white women and infants. Only 12.5% (n=6) of the photos were of nonwhite women (n=5) or of a nontraditional caretaker—the father (n=1).

The interrater percent agreement between AS and SS on combined content and diversity scoring was 90.23%. The

majority of disagreements between the authors was on scoring within the diversity scoresheet. Although diversity represented 8% of the combined content and diversity score, it represented over 20% of the disagreements between AS and SS. The discrepancies were due to disagreements about what aspects of diversity should be quantified (gender, race/ethnicity, and pumping vs direct feeding).

Figure 3. Differences in mean combined content and diversity scores, stratified by app type, category, and organization. iOS: iPhone operating system; Org: organization.



Characteristics of Apps Containing Educational Content About Milk Production

Among the apps that contained educational content about milk production, there were no differences (Figure 3) in the mean combined content and diversity scores between the apps that were free and not free ($P=.61$), created by for-profit companies and any other organizations ($P=.77$), developed by a small organization and a large organization ($P=.61$), or between apps ranked in the top 200 and unranked apps ($P=.88$). Large organizations (>10 employees) were much more likely to create free apps ($r=1.0$, $P<.001$). There was no correlation between the organization type and business size, platform, or price of the app.

Discussion

Principal Findings

In this novel breastfeeding app review, we identified and evaluated features and educational content related to milk production and quantified the diversity of images of breastfeeding experiences within selected screenshots. Although Social Cognitive Theory has been widely used to develop and implement successful health and breastfeeding interventions, to our knowledge, we are the first to use Social Cognitive Theory to inform our evaluation of features, content, and images within smartphone apps [8]. We identified a dearth of high-quality textual and multimedia educational content related

to milk production within selected screenshots of breastfeeding apps. Although previous breastfeeding app reviews did not specifically focus on content related to milk production, Taki et al used criteria centered around quality, comprehensibility, suitability, and readability to conclude that educational information within infant-feeding apps was not evidence-based [37]. Using these criteria, they found that 78% of infant-feeding apps (36/46) received a “low-quality” rating because the content was not credible or comprehensive [36]. The average combined content and diversity score among the 13 breastfeeding apps reviewed in our study was 15.3 of 78 points; thus, our findings of low-quality educational content within breastfeeding apps are in agreement with the conclusions of Taki et al about content in infant-feeding apps.

A review of milk supply or milk production educational materials in digital or print media or resources has never been performed. Our results indicate that there is ample room for improvement in the development and delivery of educational content related to milk production within breastfeeding apps. The majority of breastfeeding apps in our review did not reference peer-reviewed scholarly literature. For example, in the Pregnancy and Parenting app, an app by Lamaze International, the user was referred to a website that referenced “The Official Lamaze Guide: Giving Birth with Confidence.” Although most breastfeeding apps broadly covered content within all eight categories, the information provided was superficial and poorly cited. There was a surprising lack of images or videos to help describe educational content related

to milk production. As multimedia can be helpful in explaining difficult concepts, like supply-demand physiology or breastfeeding techniques [20,21], we hope that this review will stimulate developers to incorporate engaging breastfeeding educational content into apps.

The features, content, and general characteristics identified in this review can help consumers make informed breastfeeding app purchases by outlining features related to promoting, tracking, interpreting, or teaching about milk production. The top three features (breastfeeding timer, bottle feeding timer, and diaper changes) were included in 85.7% of all reviewed apps. However, only seven apps contained both features and educational content related to milk production. Among these seven apps, four were created by breast pump companies. Without high-quality educational content about milk production within apps containing features that allow for milk production tracking, mothers may interpret the data incorrectly and assume that they are not producing enough milk [6,7,9]. Thus, breastfeeding app creators could use the scoresheets and key findings within this review to develop apps that integrate features to promote breastfeeding self-efficacy with high-quality educational content related to milk production.

In line with the work of Schindler-Ruwisch et al, we found that for-profit companies and large businesses are more likely to create free breastfeeding apps [38]. Schindler-Ruwisch et al completed a content analysis of 53 breastfeeding apps in which they established that the majority of breastfeeding apps were free and developed by for-profit organizations [38]. Their review was limited in scope because the apps were not downloaded and explored; thus, features and educational content were not comprehensively assessed. Moreover, Schindler-Ruwisch et al did not investigate whether for-profit companies developed breastfeeding apps containing features that can assist with tracking milk production or high-quality educational content that aligns with a health behavior theoretical framework [38].

We found that large businesses were more likely to create apps that received a high combined content and diversity score and for-profit companies were more likely to create apps that received a high score on the features scoresheet. Likely due to the small sample size of our dataset, a large business (>10 employees) was not associated with for-profit status. Only one app (Similac; Abbot, IL) in our dataset was created by an infant formula company. Although Similac's features were evaluated, none of its content was related to milk production. Therefore, it was not included in our educational content review.

To our knowledge, we are the first to report a dearth of breastfeeding imagery diversity within smartphone apps. The lack of diversity in the portrayal of the breastfeeding experience has been reported within print and online media, television, and film [23-25]. Foss found that in television and film, breastfeeding was depicted in a positive light; however, the majority of the breastfeeding characters were educated, older Caucasian women [23]. In British newspapers and television programs, breastfeeding was associated with upper-class and celebrity parents, while formula feeding was a normal, not embarrassing or problematic, infant-feeding alternative [39]. The diversity scoresheet developed for this review is similar to

the method that Frerichs et al used for scoring breastfeeding images within popular magazines in the United States [25]. Frerichs et al awarded points to images if they contained pictures of a parent or parents with a baby, whether breastfeeding, bottle feeding, or not feeding [25]. Additionally, they awarded points to images of different races (white, African American, or other). The majority of the people pictured in the images identified by Frerichs et al within popular magazines were white (77.8%), with African Americans in 20.8% of the photos [25]. Frerichs et al concluded that this heterogeneity was representative of the US population, which was only 12.3% African American in 2000 [25]. Of the 241 images reviewed by Frerichs et al, the majority (n=197, 81.4%) were of the mother and her infant and 19% (n=46) were of fathers only [25]. In line with the conclusions of Foss and Frerichs et al, we speculate that it is unlikely that low-income women, minority women, and nontraditional caretakers (grandmothers, fathers, adoptive mothers, etc) would feel empowered to meet their infant-feeding goals using the breastfeeding apps in our review.

Limitations

The most significant limitation of our approach is the small sample size due to the narrow inclusion criteria and the inability to evaluate Android-exclusive apps. There was significant bias in the data-extraction process, as only one author (SS) identified features related to milk production. Some apps included in the review were based on a freemium business model, meaning that some sections and features of the app were available for free, while other features required a payment to be unlocked. All analyses in this review included features available only in the freemium version; thus, these apps were analyzed within the "free" category. It is unknown how the features and combined content and diversity scores of these apps would have changed if the premium features were unlocked and explored. Apps were divided into two categories: those created by for-profit companies and those created by all other organizations, including nonprofits, individuals, and government. Businesses whose employee information could not be found were assumed to have fewer than 10 employees and stratified into that group for analysis. Thus, our comparisons of different groups may not accurately represent the apps and app developers within that group.

The features, content, and diversity scoresheets were not validated in this study; thus, additional studies will be needed to validate our approach for feature and content evaluation related to milk production within breastfeeding apps. By design, the content scoresheet focused exclusively on assessing the leading cause of breastfeeding cessation—perceived or real low milk production. Thus, it is possible that apps with high-quality content on a different breastfeeding topic were misrepresented as "low quality" due to our targeted content evaluation. Another important limitation of the content scoresheet lies in its inability to encompass how comprehensively or correctly a certain topic was covered. For example, some apps provided dozens of examples of biologic causes of low milk production, while others only mentioned one. In both cases, these apps would receive a point for addressing content within the "Biology or Behavior" category. Incorrect or outdated information was frequently found in apps; however, this was not counted against

the developer, as the content scoresheet did not contain a quantitative way of measuring incidence of faulty information provision. The qualifications of the content creators within the apps were not further investigated by the authors. For example, a point was awarded within a category if the author had an advanced degree; however, we did not examine whether that individual's advanced degree was in a field relevant to the topic about which they were writing. The authors used percent agreement as the measurement of interrater reliability, which does not take into consideration chance agreement.

Finally, a substantial limitation of our approach is that none of scoresheets (features, content, and diversity) incorporated a method of evaluating user interface, user experience, or app design. At times, poor design obstructed our ability to efficiently evaluate content or assess features. We recommend that app developers conduct sufficient user testing to ensure easy identification of features and content, progress from one screen to the next in a logical manner, and minimalistic and simple design to reduce clutter on each screen.

Conclusions

To our knowledge, we are the first to identify and evaluate, using scoresheets informed by Social Cognitive Theory, the features and content related to milk production in 41 breastfeeding apps. We identified a dearth of high-quality, engaging, educational content related to milk production. The majority of the breastfeeding imagery within the screenshots containing educational content about milk production depicted white women; thus, it is likely that parents, especially those from minority or low-income groups, have limited options to choose from when selecting an app to reach their breastfeeding goals. For-profit companies and large organizations were most likely to create free apps that received high scores on the combined content and diversity or features scoresheet, respectively. The findings in this review will be useful for health care providers and parents when recommending or selecting breastfeeding apps, respectively, and for app creators when developing content and features to increase breastfeeding self-efficacy.

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Conflicts of Interest

AS is the Chief Executive Officer, President, and majority shareholder of LiquidGoldConcept, Inc. KM has received stock options from LiquidGoldConcept Inc.

Multimedia Appendix 1

Breastfeeding app and app creator/organization description.

[[PDF File \(Adobe PDF File\), 54KB - *pediatrics_v2i1e12364_app1.pdf*](#)]

Multimedia Appendix 2

Comprehensive list of features identified within breastfeeding apps.

[[PDF File \(Adobe PDF File\), 71KB - *pediatrics_v2i1e12364_app2.pdf*](#)]

Multimedia Appendix 3

Eight content categories related to milk production.

[[PDF File \(Adobe PDF File\), 63KB - *pediatrics_v2i1e12364_app3.pdf*](#)]

Multimedia Appendix 4

Breastfeeding app-selection process.

[[PDF File \(Adobe PDF File\), 53KB - *pediatrics_v2i1e12364_app4.pdf*](#)]

Multimedia Appendix 5

Reasons for excluding select breastfeeding apps.

[[PDF File \(Adobe PDF File\), 55KB - *pediatrics_v2i1e12364_app5.pdf*](#)]

Multimedia Appendix 6

General characteristics of breastfeeding apps and app developers.

[PDF File (Adobe PDF File), 56KB - [pediatrics_v2i1e12364_app6.pdf](#)]

Multimedia Appendix 7

Final breastfeeding app dataset (N=41).

[PDF File (Adobe PDF File), 53KB - [pediatrics_v2i1e12364_app7.pdf](#)]

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Abbreviations

SCT: Social Cognitive Theory

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Original Paper

Concerns of Female Adolescents About Menarche and First Sexual Intercourse: Mixed Methods Analysis of Social Media Questions

Nikkie Saldivar Hodgson¹, PhD; Elad Yom-Tov^{2,3}, PhD; William F Strong¹, PhD; Priscilla L Flores¹, MA; Giselle N Ricoy⁴, MSHS

¹University of Texas - Rio Grande Valley, Brownsville, TX, United States

²Technion, Haifa, Israel

³Microsoft Research, Herzeliya, Israel

⁴School of Osteopathic Medicine, University of the Incarnate Word, San Antonio, TX, United States

Corresponding Author:

Elad Yom-Tov, PhD

Microsoft Research

13 Shenkar St

Herzeliya,

Israel

Phone: 972 747111359

Email: eladyt@yahoo.com

Abstract

Background: Adolescents use social media for information on medical and social aspects of maturation.

Objective: The aim of this study was to investigate the concerns and information needs of adolescents regarding menarche and first sexual intercourse.

Methods: Questions about menarche or first sexual intercourse were obtained from Yahoo Answers, a community-based social media question-and-answer website. A total of 1226 questions were analyzed. We focused on 123 question pairs made by users who asked questions on both topics and reported their ages at each. Quantitative and qualitative analyses were performed on these question pairs.

Results: Qualitative analysis identified uncertainty as a significant theme for both menarche and first intercourse. Quantitative analysis showed that uncertainty was expressed in 26% (13/50) of menarche questions and 14% (7/50) of intercourse questions. Lack of communication was expressed in 4% (2/50) of menarche questions, compared with 8% (4/50) of intercourse questions. Ages at menarche and at first sexual intercourse were correlated, with women reporting menarche at the age of 13 years or younger being 2.6 times more likely to experience first sexual intercourse before the age of 16 years ($P < .001$, chi-square test). Older age at menarche was associated with greater lack of communication with parents (analysis of variance, $P = .002$).

Conclusions: The questions of adolescents on the topics of menarche and first sexual intercourse express anxiety and uncertainty and are associated with a lack of information and deficient communication with parents. The more normative and expected a behavior, the less these factors appear. Therefore, parents and educators should, to the extent possible, improve communication around these topics, especially when they occur at less typical ages.

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KEYWORDS

menarche; sexual intercourse; social media; infodemiology; infoveillance

Introduction

Background

Today's generation of adolescents is the largest in human history. With a population of 1.8 billion, 10- to 24-year-olds

now comprise over a quarter of the global population. Adolescents have been a neglected age group in health care owing to various socioeconomic, political, and cultural factors that may deprive this age group of information, services, and health care professionals who are age-appropriate,

gender-appropriate, nonjudgmental, and supportive [1]. Adolescents' search for care may be restricted owing to barriers such as fear, embarrassment, lack of knowledge, misinformation and myths, stigma, and shame [1]. As confidentiality regarding sexual and reproductive health (SRH) issues is a major concern to adolescents, they often turn to the internet for answers to their health-related questions [2]. Access to SRH information is vital as adolescents are significantly at risk for premature parenthood, serious injury and infections, mental disorders, and substance abuse [3]. According to Morris and Rushwan [1], "young people are reaching puberty earlier, often engaging in sexual activity at a younger age, and marrying later." As a result, adolescents are sexually mature preceding marriage for a longer time than ever before, lending to the pivotal importance of adolescent SRH.

During adolescence, the adult self begins to emerge and one's self-identity is born [4]. The physical, emotional, and psychosocial changes occurring at this stage prompt numerous SRH questions [2]. At this time, a child begins making decisions independently of the parents and begins to build the foundation for future health and well-being. These decisions regarding sexual attitudes, values, and risk-related behaviors can be influenced by parental modeling of honest, transparent communication and conveyance of sexual information. However, sexual communication between the parent and adolescent often does not take place and barriers such as judgment, misinformation, and low self-efficacy [5] arise. The aim of this study was to explore concerns of adolescents surrounding SRH as it relates to menarche, first sexual intercourse, and psychosocial environmental influence.

Conceptual Framework for Adolescent Health

The onset of puberty has long been accepted as the starting point of adolescence [6]. Key social role transitions such as completion of education, commencement of employment, marriage, and child rearing have historically signaled the completion of adolescence and entry into adult life [6]. Improvements in childhood hygiene, nutrition, and health have resulted in downward trends in the age of onset of puberty. This trend has essentially ceased in the majority of high-income countries where the main age of menarche (used as a proxy marker for pubertal development) has largely stabilized at about 12 to 13 years [6]. At the same time, there has been a dramatic increase in the age at which adult social roles and responsibilities are being adopted. In most countries at present, adolescents are spending longer times obtaining an education and are marrying and having children later [7].

In this study, the intersection of biology and social context in adolescent SRH is examined as it influences health-related behaviors and health outcomes. An example of a health-related behavior is engagement in unsafe sexual activity. Adolescents make up a quarter of the sexually active population in the United States and acquire half of all sexually transmitted infections [5]. Adolescents are also at risk for unintentional pregnancy. These health behaviors have significant consequences for adolescent health, their future life determinants, and a long-term impact on their families and communities [5].

Methods

Data and Data Collection

We extracted, using a crawler, a sample of question pairs from Yahoo Answers [8], a community-based social media question-and-answer website, such that each pair was made by the same user (albeit at different times). We required that 1 question in the pair contained the words *first period* and a phrase that could indicate an age (ie, "I'm XX," "XX year," or "XX year old," where XX are numbers between 0 and 30), and the second question in the pair contained the word *sex* and phrases that would indicate first intercourse (ie, *lose* or *lost* within 10 characters of the word *virgin*, *virginity*, *boyfriend*, or *first time*).

The extracted questions were independently labeled by 2 of the authors such that 100 questions were labeled by both, and the remaining questions by one of the authors. Each question was labeled as to whether the first question in a pair was related to menarche and separately whether the second question was related to first intercourse. In addition, for those questions labeled in the affirmative, the labelers extracted the age of menarche or first intercourse, if the asker provided it in the question. Agreement among the raters was estimated for the 100 questions labeled by both using Cohen kappa statistic [9].

After filtering, the questions were paired according to the anonymized user identifier provided by Yahoo Answers.

These data are particularly reliable because previous studies [10,11] showed that anonymity provides for honesty when matters of health are at stake. Many reliability studies have demonstrated that such data are particularly reliable because the subject wants credible information and advice about their problems and concerns [12].

This study was approved by the Institutional Review Board of the Technion.

Analysis

A narrative approach was used to analyze the dataset to determine the distrust adolescent females have regarding parent-adolescent communication about menarche and first sexual intercourse. We subjected the content of all the questions and comments of each subject to a QSR NVivo analysis [13] to identify recurring themes within the dataset. Specifically, transcripts of the questions were coded to identify consistent repetition of relevant words, phrases, sentences, and sections. On the basis of this coding of the transcripts, categories were created and sorted into themes. Categories were then labeled on the basis of the connections between the codes that made them up.

The data were then subjected to quantitative analysis on the variables of menarche and first intercourse.

Results

Data

A total of 1226 questions were analyzed. Of those, 270 were judged to discuss menarche and 147 were judged to discuss first

intercourse. A subset of 123 users asked questions in both the menarche and first intercourse sets and reported ages therein.

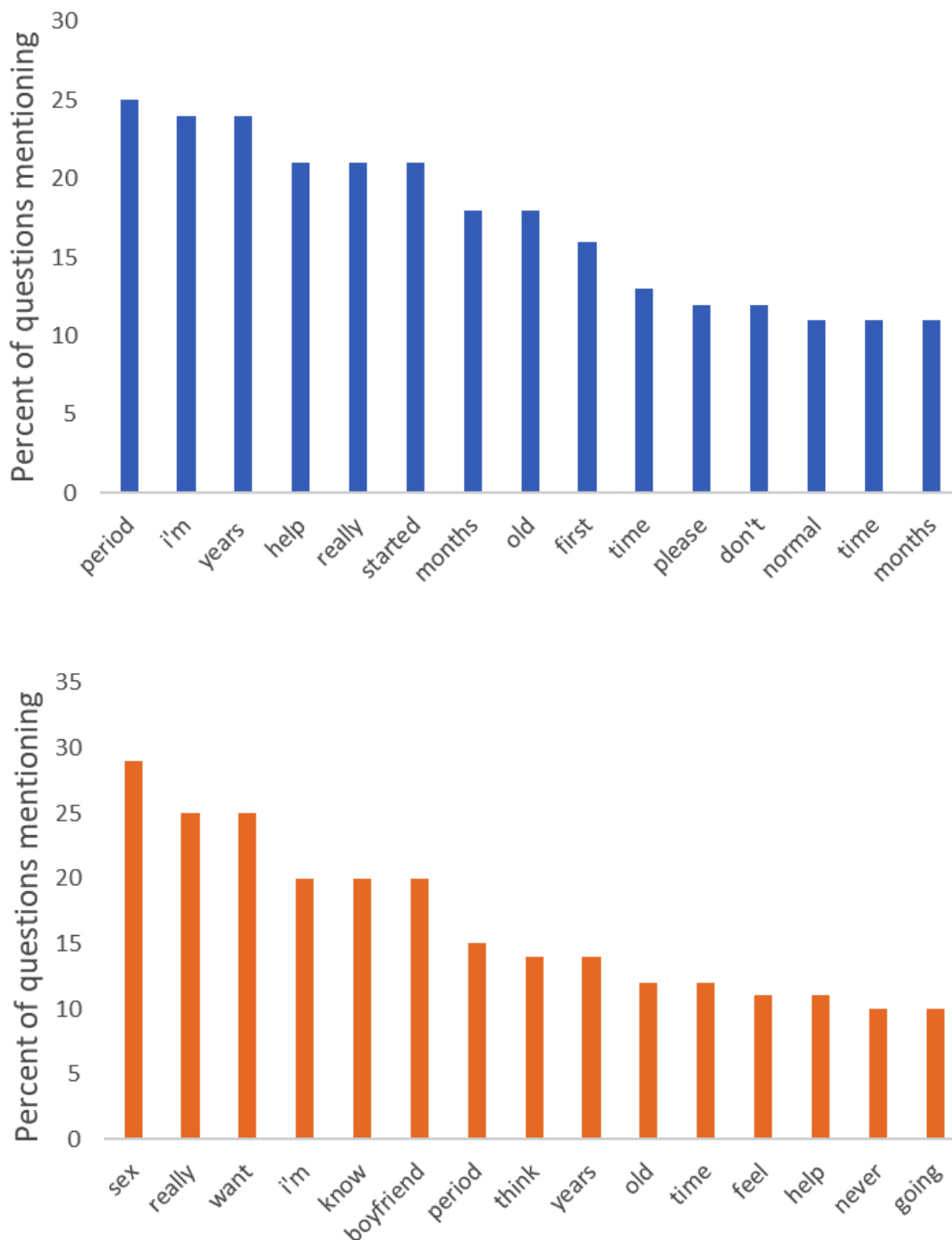
Cohen kappa agreement among raters for whether the first posting was menarche-related was 0.72 ($P < .001$). The agreement for whether the second posting was about first intercourse was 0.87 ($P < .001$). These values are considered very high.

Qualitative Analysis

Figure 1 shows the most popular words in menarche and, separately, first intercourse questions. In the qualitative analysis,

we identified 1 significant theme from the participants' narratives as it relates to menarche and first sexual intercourse: uncertainty. This theme is supported by the following subthemes: lack of accurate information about their own growth and development and a lack of communication with family and peers. The results led to insights for fostering a transparent, honest climate for sexual communication.

Figure 1. The most popular words for menarche (top) and first intercourse (bottom). All words that appeared 10 or more times, excluding stopwords, are shown.



Uncertainty

This theme is based on the presence of anxiety, worry, and fear about becoming fully developed, a full-fledged adult, and a woman. These changes during adolescence create confusion about what is normal as it relates to menarche and first sexual intercourse. The following are examples of questions asked on the community-based question-and-answer website demonstrating the theme of uncertainty used in our dataset:

1. "I'm going to a sleepover tonight but I'm on my period. I'm 13. I don't know what to do because I don't want people to find out. Help!!"
2. "I'm 13 years old and 10 months and my period came from 10 months and until now I don't have any period. I'm a virgin. I'll be going to the GYNO and I'm little bit scared but will the doctor examine me? If yes, what should I do, like shave, wipe the discharge? Please help me. Take your time answering, I'm scared."
3. "Ok so I'm 13 and I really want to have sex, is 13 ok? I'm really confused. Can you help me? I am scared and confused. I know I'm young, but I'm like obsessed with it. Can you help me?"

Lack of Information and Lack of Communication

In the narratives, there is a lack of clarity about the experience of menstruation and sexual desire/activity and a lack of communication for support and knowledge from parents and peers, which in turn creates myths and misconceptions. The following are examples of questions asked on the community-based question-and-answer website demonstrating the subtheme of lack of information and lack of communication used in our dataset:

1. "Okay I live with my dad, and like NEVER see my mom, or my grandparents or my aunt, and I don't really feel comfortable telling my dad or either my grandparents are worse! I don't feel comfortable confronting my dad face to

face, and emailing him or writing a note to him, seems kind of stupid (no defense), but how do I tell my dad I started my period? Next month will be my 4th period, please help. Like 3 years ago (btw I'm 14 now) he got my aunt to buy me some pads and talk to me about it. Please give me hints and/ or tips on how to tell him or even your own personal stories! Also I'm really shy so I don't feel comfortable talking to any friends moms about it! BUT PLEASE HELP ME!"

2. "Help!!!!!!!!!! I'm 11 yr. 12 in August, I have no idea what to do. I told my mom, but she said it's kind of early for me... I'm the only one in my class, who has started and how am I supposed to hide it? I just take it..Help!!! I need somebody, I feel really alone. I know if I tell one of my 3 sisters they are going to tease me and say awwwww you are growing up. I just have no idea what to do!!! OMG!"
3. "I'm 18 and my mom made me an appointment for the gyno because I have irregular periods...at the time she made it I had never had sex before...last night was my first time...she filled out the sheet and everything saying no I'm not sexually active and all that...I'm not telling her that I had sex last night. I do not plan on having sex again anytime soon considering it was a big mistake last night. Since it was my first time and I'm not going to be doing it all the time. Now do I have to tell the gyno I have had sex? If so, should I just leave the sheet checked no and then tell them I filled that out before it happened?"

Quantitative Analysis

A total of 270 women reported their age in their menarche question, and 147 women reported their age in their first intercourse question. The distribution of ages is shown in Figure 2. The agreement between the cumulative distribution of reported age of menarche and the distribution reported in the literature [14] is 0.94 ($P < .001$). The agreement for first intercourse (compared with a study by Martinez and Abma [15]) is 0.95 ($P = .01$).

Figure 2. Distribution of age at menarche and age at first intercourse as reported in the questions.

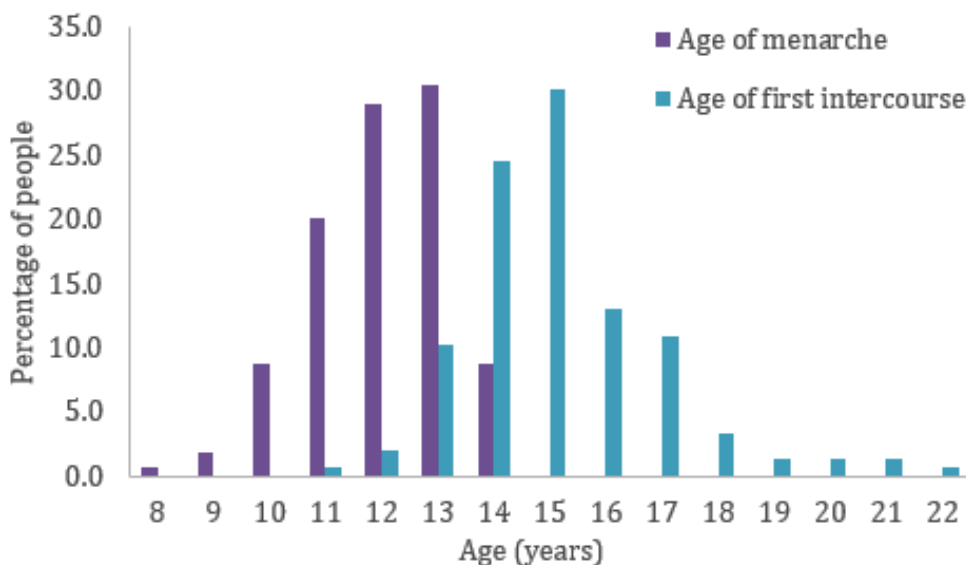


Figure 3. Correlation between the age of menarche and the age of first intercourse (n=123). The dotted line shows a fit of a second-order polynomial with $R^2=0.1$.

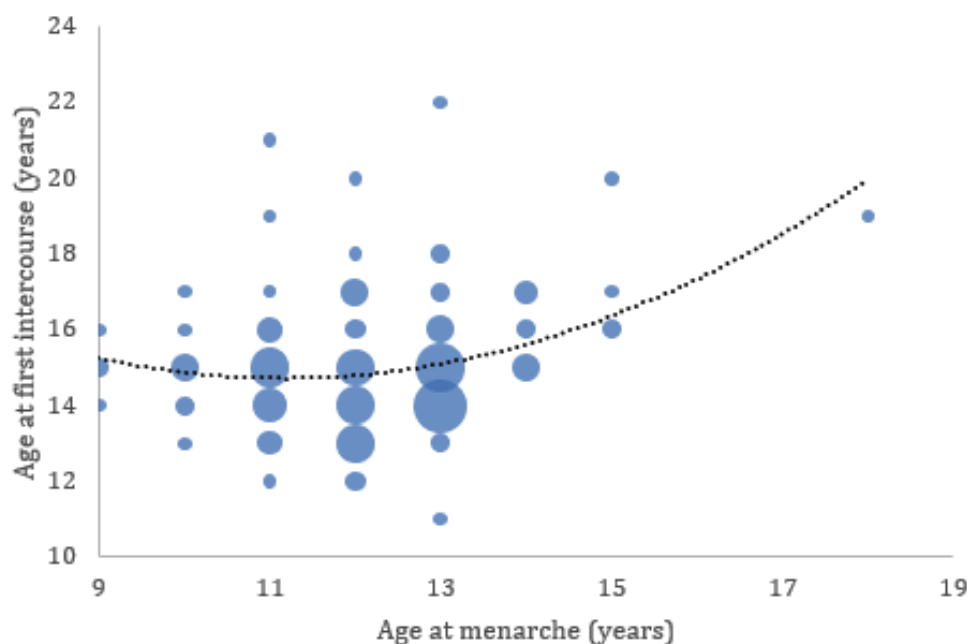


Figure 3 shows the correlation between the reported age of menarche and the age at first intercourse. As the figure shows, there was no association between the 2 ages for women whose age at menarche was 12 years or lower. However, when the age at menarche was higher, so was the age at first intercourse. Specifically, we found that women reporting menarche at the age of 13 years or younger were 2.6 times more likely to experience first sexual intercourse before the age of 16 years ($P<.001$, chi-square test). This finding is compared with literature that identifies adolescent females experiencing early menarche as twice as likely to have had intercourse by the age of 16 years than adolescent females with late menarche [16].

Following the themes identified in the qualitative research, we coded 50 question pairs for uncertainty about future effects, lack of information, and lack of communication with parents. Strikingly, 86% (43/50) of menarche questions and 44% (22/50) of first intercourse questions contained requests for information. Uncertainty was expressed in 26% (13/50) of menarche questions and 14% (7/50) of intercourse questions, and lack of communication was expressed in 4% (2/50) of menarche questions compared with 8% (4/50) of intercourse questions. An analysis of variance model found statistically significant interactions only between age of menarche and lack of communication (with higher ages reporting more communication problems; $P=.002$).

Discussion

This study examined the concerns and information needs of adolescents regarding menarche and first sexual intercourse as evident from questions on a social question-and-answer website, Yahoo Answers. Although online data have been used to study aspects of population health and especially health communication [17], we suggest that the use of online data, particularly social media, to study aspects of younger adult

health is advantageous because of these young adults make extensive use of such media, particularly for sensitive topics [11], such as sexual health.

This study's quantitative research shows that the older the adolescent female was at menarche, the older she was at first intercourse, as demonstrated in the previous literature [16]. The age at menarche can be attributed to additive genetic effects, dominance effects, and unique environmental effects, including, but certainly not limited to, *in utero*, population health, socioeconomic status, and psychosocial factors [18]. Our qualitative research explored the psychosocial environmental influences and found that the most significant and recurring theme regarding menarche and first sexual intercourse in questions asked by adolescent females in our dataset was uncertainty. The recurring, significant subthemes were lack of information and lack of communication. We can determine that adolescents are uncertain about what is normal and the impact that their behaviors (menarche and sexual intercourse) will have on their livelihood, their families' livelihood, and their communities' livelihood. This uncertainty, lack of information, and lack of communication is influenced by the adolescent's sexual socialization via their relationship and level of communication with parents, peers, and health care providers. Educators also play an important role in communicating information [19]. Though in many cases they are challenged in developing programs to effectively help adolescents to understand their uncertainties, surveys show that educators have become a more important source of information in recent years [20].

As a child enters adolescence, he or she is faced with all sorts of new information about sex, reproduction, culture, and societal expectations. Parents are vital agents of sexual socialization for children and adolescents. As per Bronfenbrenner's ecological systems theory [21], qualities of an adolescent's environment (including the family system) will reciprocally and dynamically

influence development. It is generally considered that parent-adolescent communication is associated with more responsible SRH among adolescents. According to Hutchinson et al [22], parents who communicate with their children about sex can positively influence sexual behaviors. Parent-adolescent sexual communication, especially mother-adolescent conversations, plays a protective role in more responsible SRH behaviors among adolescents that is more significant for female adolescents [5,23]. For example, 1 study identified “design and implementation of family-based approaches to improve parent-adolescent sexual risk communication as one means of reducing HIV-related sexual risk behaviors among inner-city adolescent females” [22]. Although adolescents may attempt to get their SRH information from other means (ie, peers or the internet), it is important for parents to discern that information, falsify the myths, and confirm the facts. In addition, it is important for the conversation about SRH to begin early and continue into emerging adulthood in the early twenties, where the riskiest behavior is likely to take place [24]. According to the literature [24], the parent-adolescent dialogue about SRH is one that, if begun early, is normative and healthy. Often, parents are inclined to shy away from discussing SRH because they are not comfortable doing so [25] and tend to delay discussions with their child until they believe they are already engaging in sexual behavior. Parents who do not take the time to enhance their own information and skills on SRH, are likely to disseminate inaccurate information resulting in less successful parent-adolescent communication and less positive impact on their child’s SRH [26]. It is important for parents to communicate that they value their child’s or adolescent’s interest and opinions about SRH and be comfortable empowering their child or adolescent with SRH information, be it from themselves or a health care provider.

We found that menarche questions are primarily a request for information about current experiences, with less of an emphasis on future effects. This may be partly due to younger women finding it easier to communicate with parents on issues considered *normal* at their age, compared with teenagers who are older at the time of menarche. Many first sexual intercourse questions request information. However, here lack of communication is greater, reflecting an uneasiness to reveal highly personal behaviors to parents [27].

The media is also an important agent of socialization for adolescents and can also give adolescents contradictory messages. As adolescents are concerned about confidentiality regarding SRH, the internet serves as an accessible, anonymous, and interactive modality to explore sensitive or taboo topics that they may not feel comfortable asking parents or health care providers about. For example, the community-based question-and-answer website this study used to collect data is one in which any user of the website can supply *answers*. The major potential drawback to this mode of information is potentially inaccurate information and abusive language or content [2]. Religious beliefs, race, ethnicity, and education are other agents of sexual socialization within the family that can influence an adolescent’s sexual self-identity [28].

The barriers adolescents face (ie, societal norms, confidentiality concerns, and embarrassment) accessing SRH care may explain why nearly one-fourth of young people say that they have not discussed sexual topics with a parent [5]. We believe that strategies, programs, and policies that aim to create a more supportive environment for adolescents to foster safer, more accessible, and informative care should be developed. Overall, 1 study showed that adolescents describe a beneficial health care provider to be friendly, which can be improved via service provider training and assured confidentiality [29]. Interventions can also be aimed at the parents of adolescents so that they learn what SRH information to discuss with their adolescents and how to convey that information to their adolescents. These interventions can help parents view themselves as valuable sources of information who can help shape their children’s sexual socialization and acquire information and skills that make them more effective communicators [30]. Parents can model transparent, honest communication by being an approachable and attentive parent, including becoming aware of verbal and nonverbal behavior, tone of voice, content of verbalizations, warmth, and respect, which encourage more frequent and spontaneous conversations about SRH. As other literature divulges, further research on prevention of risky adolescent SRH should be aimed to inform programs and policies that target younger, at-risk adolescents [31]. Health care professionals and parents should recognize, consider, and invest in sources of sexual education to promote SRH responsibility in adolescents as parent-adolescent communication is a sexual health determinant and can influence the uncertainty that a female adolescent encounters at menarche and sexual maturity.

Conflicts of Interest

None declared.

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Abbreviations

SRH: sexual and reproductive health

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Original Paper

Usability and Acceptability of a Text Message-Based Developmental Screening Tool for Young Children: Pilot Study

Pamela Ryden Johnson^{1,2}, MA, PhD; Jessica Bushar³, MPH; Margaret Dunkle⁴, BA; Sharon Leyden⁵, BSc; Elizabeth T Jordan⁶, RNC, DNSc, FAAN

¹Voxiva, Inc, Arlington, VA, United States

²Child Health Foundation, Timonium, MD, United States

³ZERO TO THREE, Washington, DC, United States

⁴Department of Health Policy, School of Public Health, George Washington University, Washington, DC, United States

⁵Prince George's County Health Department, Clinton, MD, United States

⁶College of Nursing, University of South Florida, Tampa, FL, United States

Corresponding Author:

Pamela Ryden Johnson, MA, PhD

Voxiva, Inc

1101 Wilson Boulevard

Arlington, VA, 22209

United States

Phone: 1 202 251 1423

Fax: 1 202 379 9117

Email: pamelajohnson999@gmail.com

Abstract

Background: Only 30% of parents of children aged 9-35 months report that their child received a developmental screening in the previous year. Screening rates are even lower in low-income households, where the rates of developmental delays are typically higher than those in high-income households. Seeking to evaluate ways to increase developmental screening, *Text4baby*, a national perinatal texting program, created an interactive text message-based version of a validated developmental screening tool for parents.

Objective: This study aimed to assess whether a text message-based developmental screening tool is usable and acceptable by low-income mothers.

Methods: Low-income mothers of infants aged 8-10 months were recruited from the Women, Infants and Children Program clinics in Prince George's County, MD. Once enrolled, participants used text messages to receive and respond to six developmental screening questions from the Parents' Evaluation of Developmental Status: Developmental Milestones. After confirming their responses, participants received the results and feedback. Project staff conducted a follow-up phone survey and invited a subset of survey respondents to attend focus groups. A representative of the County's Infants and Toddlers Program met with or called participants whose results indicated that their infants "may be behind."

Results: Eighty-one low-income mothers enrolled in the study, 93% of whom reported that their infants received Medicaid (75/81). In addition, 49% of the mothers were Hispanic/Latina (40/81) and 42% were African American (34/81). A total of 80% participated in follow-up surveys (65/81), and 14 mothers attended focus groups. All participants initiated the screening and responded to all six screening questions. Of the total, 79% immediately confirmed their responses (64/81), and 21% made one or more changes (17/81). Based on the final responses, 63% of participants received a text that the baby was "doing well" in all six developmental domains (51/81); furthermore, 37% received texts listing domains where their baby was "doing well" and one or more domains where their baby "may be behind" (30/81). All participants received a text with resources for follow-up. In a follow-up survey reaching 65 participants, all respondents said that they would like to answer screening questions again when their baby was older. All but one participant would recommend the tool to a friend and rated the experience of answering questions and receiving feedback by text as "very good" or "good."

Conclusions: A mobile text version of a validated developmental screening tool was both usable and acceptable by low-income mothers, including those whose infants "may be behind." Our results may inform further research on the use of the tool at older ages and options for a scalable, text-based developmental screening tool such as that in *Text4baby*.

KEYWORDS

developmental screening; EPSDT; ITP; low income; Medicaid; mHealth; mobile health; Text4baby; text messaging; PEDS:DM; WIC

Introduction

Less than one-third (30.4%) of the parents of children aged 9-35 months in the United States surveyed report that their child received a developmental screening in the previous year [1]. Screening rates are even lower among young children in low-income families and Medicaid, where the prevalence of developmental delays is higher than among children in higher income and privately insured families [2].

Low developmental screening rates among young children persist despite well-established benefits of early identification of developmental delays (when intervention may be most effective) [3,4]; the American Academy of Pediatrics (AAP) recommendations for periodic screening of young children (coinciding with the 9-, 18-, and 24- or 30-month well-baby visits) [4,5]; the fact that timely developmental screening is a core quality measure for children's health and a required benefit for children under 3 years of age in Medicaid as part of Early and Periodic Screening, Diagnostic and Treatment, which provides comprehensive and preventive health care services for children and adolescents [6,7]; ready availability of validated paper-based and online developmental screening tools [5,6,8]; and the fact that early development lays the very foundation for a child's growth and development and "lifelong trajectory" [7,9].

This pilot study explored an innovative use of mobile phones and text messaging to expand the availability of validated, parent-reported developmental screening, especially among low-income populations covered by Medicaid. The use of mobile phones and text messages may be a particularly effective way to reach young families at risk, since 100% of adults between the ages of 18 and 29 years and 92% of all adults with incomes below \$30,000 surveyed by the Pew Research Center in January 2018 reported that they owned a cell phone of some kind [10]. Further, in as early as 2011, a Pew survey found that "95% of 18-29 year olds use the text messaging feature on their phones" [11].

This pilot study addresses several gaps in the current literature. First, although paper-based and online developmental screening tools are well documented and evaluated [6,8,12], to our knowledge, there are no published assessments of the use of validated text messages by parents to report on the developmental milestones. In one study, as part of the Baby Steps program, researchers conducted a user study of 14 Hispanic families who received shortened versions of the Ages & Stages screening questions by text message [13]. The researchers found that parents liked the text-based tool and based on the user responses, concluded that "text messaging is a feasible tool for supporting parents in tracking and monitoring their child's development" [13]. A recent systematic review of multiple systematic reviews of mobile health (mHealth)

interventions (including text messaging) included no references to studies of developmental screening but concluded that text message reminders have a consistent impact on public health outcomes such as appointment attendance and improved treatment adherence for some chronic conditions [14].

Second, although the need for developmental screening is most acute among underserved, low-income populations, according to a recent review article, overall "research regarding the use of mHealth interventions for the populations that need it most remains sparse" [15]. This review [15] also cites the study partner *Text4baby* [16] as an exception that specifically targets low-income pregnant women and mothers of infants receiving Medicaid [15]. Since its launch in 2010, the free national text messaging service *Text4baby* has delivered more than 430 million messages with health and parenting tips (G Perez-Bonany, personal communication, Dec 2018), appointment reminders, and health surveys corresponding with the due date of the mother or the age of the infant [17,18].

Third, although there are many examples of assessments of the usability and acceptability of web-based health interventions, there are very few rigorous assessments of the usability of mHealth technologies [19]. This pilot study adapted measures from the Health IT Usability Evaluation Model, which is based on experience with the evaluation of Web-based programs and tested with several mHealth programs [19].

The aims of this pilot study were to build and assess the usability and acceptability of a text-based validated developmental screening tool for infants of low-income mothers as part of a plan to implement the lessons learned in a large-scale deployment and trial, potentially via an existing mHealth service such as *Text4baby*. Three hypotheses guided the study: (1) It is technically feasible to create a text-based version of an existing validated developmental screening tool; (2) low-income mothers will find text-based developmental screening usable, regardless of their infants' developmental status; and (3) low-income mothers whose infants "may be behind" may find using the tool and receiving immediate feedback about their infants' developmental status less acceptable than mothers who receive feedback that their infants are "doing well."

The pilot study also aimed to determine whether infants who "may be behind" in one or more developmental domain could be followed up after the mother received the results of the screening. The initial findings are presented here; additional findings and lessons concerning the follow-up and maternal actions following the screening will be presented in a subsequent paper.

Methods

Screening Tool

The study team built a text-based developmental screening tool on the *Text4baby* technology platform based on Parents' Evaluation of Developmental Status: Developmental Milestones (PEDS:DM), a validated paper- and Web-based screen [12]. The team then worked with the Maryland Department of Health and Mental Hygiene (MDHMH); Prince George's County's Women, Infants and Children (WIC) Program; and Infant and Toddlers Program (ITP) to pilot the tool with low-income mothers of infants aged 8-10 months. The MDHMH Institutional Review Board approved the study.

Technical Feasibility of a Text-Based Developmental Screening Tool

A number of validated tools are used to conduct developmental screening; most are paper-based tools and generally administered in a provider's office, daycare center, or other site. The most current list of accepted tools is presented in the 2018 Technical Specifications for the Child Core Set of health quality measures for Medicaid and the Children's Health Insurance Program [6]. AAP also provides links to validated screening tools and supporting documentation [5]. Although some of these tools have been adapted for online administration, to our knowledge, none are currently available in a text format.

Our study team selected its screening tool following a review of three validated tools [8] (Multimedia Appendix 1) that are also cited by AAP and Medicaid [5,6]. All three tools are characterized by the coverage of multiple mental, behavioral, and developmental domains; appropriateness for infants below the age of 12 months and through early childhood; consistency with AAP recommendations; use of parental responses based on their own observations; and accuracy and strong validation studies referenced in the review (>70% specificity and sensitivity) [8].

Of these three validated tools, the PEDS:DM is the most amenable to adaptation to an interactive text format. Each of the PEDS:DM questions for the target age is less than 160 characters long, so each question could be sent in a single text message (Table 1). Further, the PEDS:DM covers the six developmental domains (fine motor, expressive language, receptive language, gross motor, self-help, and social-emotional) with only six questions, each written at an elementary grade reading level [8,20]. In contrast, *Ages & Stages* [8] uses 30 questions written at the 3rd-12th grade level, a number of which exceed the 160-character limit of a text message and would require editing for length as well as reading level to be suitable for use in a text-based tool appropriate for the target audience.

The study team worked with PEDS:DM to incorporate the questions and responses (Table 1) and feedback (Table 2) in a text format, build the tool on the *Text4baby* technology platform, and check the text version for quality. Neither the wording of the PEDS:DM questions nor the scoring criteria were altered.

PEDS:DM is generally administered in a provider's office by staff or self-administered on paper or online. The study team

developed a plan with the ITP of Prince George's County to ensure that follow-up was offered in person or by phone to mothers whose infants' results indicated that they "may be behind."

Recruitment and Enrollment of Low-Income Mothers

The study team was able to reach and recruit low-income mothers by partnering with the Maryland WIC program, an income-qualified program "designed to help low-income pregnant, postpartum, and breastfeeding women, infants, and children 5 years old or younger who are at nutritional risk" [21]. The Maryland WIC program defines low income as US \$37,296 annually for a family of three people [21].

Staff in two WIC clinics in Prince George's County offered a flyer about the study to mothers of infants aged 8-10 months who were visiting one of the clinics for services. Interested mothers were invited to a private area of the clinic where members of the study team described the study, answered questions, and advised the mothers that after completing the screening, they would receive a US \$20 gift card and a gift bag with information about their baby's development. The study team members then confirmed the eligibility of interested mothers to participate in the study. To be eligible, a mother needed to be the primary caretaker of an infant aged 8, 9, or 10 months; above the age of 18 years; able to speak and read English; and in possession of a mobile phone that was regularly used, including for texting. Eligible mothers filled out a form providing informed consent and were enrolled as participants in the study. After enrollment, the study team members collected information on participant and infant characteristics including age, gender, insurance status, and ethnicity/race (Table 3).

Usability

To measure usability, the study used objective data generated by the technology platform that reflected efficiency and effectiveness (Table 4). Study participants were asked to initiate the interactive screening tool by texting "DM" to the *Text4baby* short code 511411; this generated an automatic reply with the first of the PEDS:DM screening questions, asking the participants to respond by text message. Each time a participant texted a response to a question, the platform automatically sent a text message with the next question. After participants answered all six screening questions, a study team member asked them to review the questions and their responses. If they wished to make changes, study staff asked participants to text "DM" again to retake the screening questions.

Following any changes made, participants confirmed their answers by texting "RESULTS." In response, they received a message listing areas where their infant appeared to be "doing well" and, if indicated, a second message with any areas where he/she "may be behind" (Table 2). The mothers then received a final text message with recommended actions. Following the screening, study team members also provided participants with a letter containing the results intended for the infants' primary pediatrician from the Infants and Toddlers Program (under Part C of the Individuals with Disabilities Education Act) or a qualified child care provider, a US \$20 gift card, and a gift bag that included a guide for parents on child development [22].

The *Text4baby* technology platform captured system data on measures of participant interaction. These data included a record of all questions and responses and date and time stamps for all outgoing and incoming texts.

Acceptability

To measure acceptability, beginning two weeks after the screening, study staff called all mothers and administered a phone survey (Table 5) to those who replied. This phone survey included questions related to participants' experience using the text-based PEDS:DM and receiving feedback about their baby's development via text.

Two subsets of mothers who participated in the phone survey were invited to attend one of two focus groups—one included seven mothers whose infants were “doing well” in all domains and the other included seven mothers whose infants “may be behind” in one or more domain. An independent evaluator facilitated the focus groups. Participants received a gift card to cover transportation and other costs. The aim of the focus groups was to provide context and insight into the usability and acceptability of the tool and learn about maternal actions following the screening (to be presented in a subsequent paper).

Analysis

Usability and acceptability were examined among participants overall and by the developmental screening status of their infants. Applicable systems and phone survey data were used

to assess each measure. In addition, observations made by mothers in the focus groups that related to usability and acceptability were included. A coding scheme was applied to qualitative data from interviews and focus groups to identify key themes.

Descriptive analyses were used to analyze quantitative systems and phone survey data. Where appropriate, quantitative analysis was performed using the Chi-square test. In many of the cases, there were too many zero cells, and therefore, statistical analysis could not be performed.

Results

Technical Feasibility

It was possible to take the existing validated PEDS:DM questions and program them on the *Text4baby* technology platform (Tables 1 and 2). Because the screening questions were already at a low reading level (second grade) and short (under 160 characters), it was not necessary to make any changes to their wording. Furthermore, because the response options were closed, simple, and clear (ie, “no,” “a little,” and “yes”), it was only necessary to add instructions (eg, “Reply 1 for no”). There were no changes in the thresholds for determining risk. The study team devised additional text messages to facilitate administration, deliver results, and provide appropriate feedback for the participants.

Table 1. Developmental screening tool: questions and response options. Responses in italics indicate that the baby is meeting the milestone.

Topic of message	PEDS:DM ^a questions for children aged 8-10 months	Response options	Text version	Characters (including spaces), n
Fine motor	Can your baby poke at things with just his/her first finger?	No, A little, <i>Yes</i>	Can your baby poke at things with just his/her first finger? Reply 1 for No, Reply 2 for A little, Reply 3 for Yes.	115
Expressive language	When you say your baby's name, does he or she stop and look at you?	No, Sometimes, <i>Most of the time</i>	When you say your baby's name, does he or she stop and look at you? Reply 1 for No, Reply 2 for Sometimes; Reply 3 for Most of the time.	136
Receptive language	How many different sounds, such as “muh,” “bah,” “duh,” or “guh” does your baby say?	None, One, <i>Two or more</i>	How many different sounds, such as “muh,” “bah,” “duh,” or “guh” does your baby say? Reply 1 for None, Reply 2 for One, Reply 3 for 2 or more.	142
Gross motor	Can your baby get around on hands and knees or by scooting on his or her bottom?	No, <i>Sometimes</i> , Yes	Can your baby get around on hands and knees or by scooting on his or her bottom? Reply 1 for No, Reply 2 for Sometimes, Reply 3 for Yes.	136
Self-help	Does your baby try to get to toys that are out of reach?	No, A little, <i>Yes</i>	Does your baby try to get to toys that are out of reach? Reply 1 for No, Reply 2 for A little, Reply 3 for Yes	111
Social emotional	Does your baby like to play peek-a-boo?	No/Never tried, <i>A little/Yes</i>	Does your baby like to play peek-a-boo? Reply 1 for No/Never tried, Reply 2 for A little/Yes.	93

^aPEDS:DM: Parents' Evaluation of Developmental Status: Developmental Milestones

Table 2. Developmental screening tool: feedback

Feedback	Results in text	Characters (including spaces), n
For mothers reporting 1/more met milestones	Based on your answers, your baby does well [using hands and fingers, listening, talking, using arms and legs, learning to take care of self, getting along with others]	Varied
For mothers reporting 1/more unmet milestones	Based on your answers, your baby may be behind [using hands and fingers, listening, talking, using arms and legs, learning to take care of self, getting along with others]	Varied
For mothers reporting all milestones met	Thanks, Mom! Keep up with how your baby is learning and growing. Go to www.pgc-itp.net ^a or call 301 265-8415 if you have questions.	128
For mothers reporting 1/more unmet milestones	Please call Prince George's Infants & Toddlers right away at 301 265-8415 for FREE help for your baby. Talk with baby's Dr. & childcare provider too.	148

^aWebsite currently unavailable.

Participants' Characteristics

A total of 81 low-income mothers of infants aged 8-10 months were recruited and enrolled in the study: 93% (75/81) of the mothers reported that their infants were on Medicaid, 2% (2/81) had no insurance, 4% (3/81) had private insurance, and 1% (1/81) did not know her child's insurance status (Table 3). Seventeen percent (14/81) of the mothers said that they had less education than a high school degree, 37% (30/81) had a high school degree, and 46% (37/81) had some college or higher education.

Nearly half of the mothers (49%, 40/81) indicated that they were Hispanic/Latina, 42% (34/81) identified as African American, and 5% (4/81) identified as white (non-Hispanic). In addition, 57% of the participants (46/81) listed English, 37% (30/81) listed Spanish, and 6% (5/81) listed another language as the first language spoken at home.

Of note, 15 mothers (19%) reported that their infant had been born prematurely compared to a statewide prematurity rate of 10.5% among all women and 12.5% among African American women in Maryland [23].

Most participants (91%, 74/81) reported using a mobile phone with internet access, and 9% (7/81) reported using a basic phone without internet access. Ninety percent of the participants (73/81) reported that they had a monthly texting plan that provided unlimited text messaging, 5% reported a monthly plan with limited texting (4/81), 1% (1/81) paid on a per-message basis, and 4% (3/81) did not know what their texting plan provided.

There were no statistically significant differences between subsets of these low-income mothers for any of the demographic and other characteristics except previous screening. Mothers who reported that their infant had been previously screened were significantly more likely to have infants who were "doing well" in comparison with those who did not report a previous screening ($P < .02$). Overall, 47% of the mothers reported that their infant previously received a similar screening (38/81); this proportion is higher than the national average and the Maryland statewide rate of 43% [1].

Usability

The assessment of usability of the screening tool focused on five objective measures of efficiency and effectiveness: initiation

of the screening tool, completeness of responses to screening questions, time required, ability to receive results, and follow-up of infants who "may be behind" (Table 4).

Several mothers had connectivity issues with their phones inside one of the clinics but were able to connect by moving closer to a window. One of the mothers received a message from her carrier that the carrier would charge her for text messages. Since the study protocol specified that messages would be free, the study team lent her an alternative phone to use for the study.

All participants—mothers whose infants "may be behind" or were "doing well"—were able to text "DM" to the short code 511411 on their mobile phones (100%, 81/81). All were able to initiate the screening and successfully trigger the first question. In addition, all were able to trigger and enter one of the indicated responses to each of the six questions (100%, 81/81). A total of 79% (64/81) successfully submitted responses to all six questions on their first attempt. The remaining 21% (17/81) submitted final responses on the second or, in the case of one mother, third time. Three of these participants required additional time because of technology/connectivity issues. Four restarted the tool during submission of the six responses because they made an error in one or more responses.

After entering all responses to the last question, a study team member asked all participants to review their responses. Among the fourteen participants who changed one or more of their responses when they answered the questions for a second time, 86% (12/14) changed their response to Question 1 ("Poke"). Response to Question 2 ("Baby's Name") was the second most frequently changed: Half of those who changed their responses (7/14) changed their response to this question.

One focus group participant described her confusion about the meaning of "poke" as follows:

I got kind of confused when they said poking. Poking, how? What does that mean? I had to re-read it again. I was thinking—Poke what?

Additionally, although only three participants changed their answers to Question 6 ("Peek-a-boo"), some expressed concern about this question in the focus groups:

Peek-a-boo? I did not understand. I had a hard time understanding what it was all about. Actually, that my baby was doing that.

Table 3. Demographic and other characteristics of participants and their infants.

Characteristics	All participants (N=81)	“Doing well” (N=51)	“May be behind” (N=30)	P value for “Doing well” vs “May be behind”
Mother’s age (years), mean (SD) ^a	27.6 (5.7)	27.9 (5.5)	27.1 (6.1)	.53
Mother’s education, n (%)				
Less than high school	14 (17)	10 (20)	4 (13)	.18
High school graduate	30 (37)	15 (29)	15 (50)	— ^b
Some college or higher	37 (46)	26 (51)	11 (37)	—
Mother’s race/ethnicity, n (%)				
Non-Hispanic/African American	34 (42)	23 (45)	11 (37)	.86
Hispanic/Latina ^c	40 (49)	24 (47)	16 (53)	—
Non-Hispanic, white	4 (5)	2 (4)	2 (7)	—
Other	3 (4)	2 (4)	1 (3)	—
Infant’s gender, n (%)				
Female	41 (49)	29 (57)	12 (40)	.14
Male	40 (51)	22 (41)	18 (60)	—
Language spoken at home, n (%)				
English	46 (57)	28 (55)	18 (60)	.70
Spanish	30 (37)	19 (37)	11 (37)	—
Other (eg, Amharic or French)	5 (6)	4 (8)	1 (3)	—
Infant born prematurely, n (%)				
Yes	15 (19)	9 (18)	6 (20)	.79
No	66 (81)	42 (82)	24 (80)	—
Infant’s source of health insurance, n (%)				
Medicaid	75 (93)	49 (98)	26 (87)	.30
No health insurance	2 (2)	1 (2)	1 (3)	—
Private insurance	3 (4)	1 (2)	2 (7)	—
Don’t know	1 (1)	0 (0)	1 (3)	—
Type of text message plan, n (%)				
For each text message	1 (1)	0 (0)	0 (0)	.12
Monthly for unlimited texts	73 (90)	47 (92)	27 (90)	—
Monthly for a limited number of texts	4 (5)	1 (2)	3 (10)	—
Don’t know	3 (4)	3 (6)	0 (0)	—
Screening status^d, n (%)				
All 6 milestones met	48 (59)	—	—	—
5 or fewer milestones met	33 (41)	—	—	—
Final screening status^e, n (%)				
All 6 milestones met	51 (63)	—	—	—
5 or fewer milestones met	30 (37)	—	—	—
Previous screening of infant, n (%)				
Yes	38 (47)	30 (59)	8 (27)	<.02
No	40 (49)	20 (39)	20 (67)	—
Missing	3 (4)	1 (2)	2 (7)	—

^aOne participant did not provide her age.

^bNot applicable.

^cMothers who provided another related term for race (eg “Spanish” or “Guatemala”) or who did not respond to the question were identified as Hispanic/Latina if they also indicated that they spoke Spanish at home.

^dAs submitted by mothers via the screening tool.

^eIn 3 cases, the mother indicated that she had made a mistake on a single question after she had received the results, which changed the infant’s screening status. The final screening status reflects the amended responses in these cases. This status is reflected in the letter prepared for the baby’s provider, a copy of which was also given to the mother.

Table 4. Usability of a text-based developmental screening tool.

Measures of efficiency and effectiveness	Overall (N=81)	“Doing well” (N=51)	“May be behind” (N=30)
Efficiency, n (%)			
Initiation of tool (participants able to text “DM” to 511411 and trigger developmental screening questions)	81 (100)	51 (100)	30 (100)
Responding to screening questions			
Participants able to trigger and respond to all 6 developmental screening questions	81 (100)	51 (100)	30 (100)
Attempts required to complete all 6 developmental screening questions			
Completed on first attempt	64 (79)	— ^a	—
Completed on second attempt	16 (20)	—	—
Completed on third attempt	1 (1)	—	—
Time required for completion (average amount of time to complete all 6 screening questions), min	4.39	4.38	4.4
Effectiveness, n (%)			
Receiving results (participants receiving results by text following completion of screening questions),	81 (100)	51 (100)	30 (100)
Follow-up of infants with one/more missed milestones: Did the mother of infant with one/more missed milestone meet/talk with ITP^b program?			
ITP representative met with mother (only)	—	—	3 (10)
ITP representative met with and reached the mother by phone	—	—	9 (30)
ITP representative reached the mother by phone (only)	—	—	16 (53)
ITP representative called but was not able to reach mother (did not meet with)	—	—	2 (7)

^aNot applicable.

^bITP: Infants and Toddlers Program.

To follow-up with the 30 mothers whose responses indicated that their infants “may be behind,” the study team took a number of steps that will be described in detail in a forthcoming paper: All 30 mothers received a text message encouraging them to call the ITP. On the days when an ITP representative was present in the WIC clinic during the study, she met with any mother whose infant had one or more unmet milestones. She also attempted to call all these mothers to administer the follow-up survey. By the end of the study, the ITP representative had met or talked with all but two of the mothers (93%, 28/30).

Acceptability

Acceptability of the screening tool was assessed by a phone survey by using subjective measures of ease of use, usefulness,

and satisfaction (Table 5). It was possible to reach and interview 80% of study participants (65/81). Almost all interview participants said that it was “Easy” (40%, 26/65) or “Very Easy” (58%, 38/65) to answer the six text message developmental screening questions; none said it was “Hard” or “Very Hard” (Table 5). As described by one focus group participant, “I have two kids and I’m on the phone or busy with kids. It’s easier to answer the questions on a phone than to have to talk on the phone.” A higher percentage of the participants whose infants were “doing well” said the text messages were “Very Easy” (70%, 28/40), compared to those whose infants “may be behind” (40%, 10/25). Because of the number of zero cells, it was not possible to perform statistical tests on these data.

Table 5. User assessment of the developmental screening tool.

User perceptions of ease of use, usefulness, and reported satisfaction	Overall (N=65), n (%)	Infants “doing well” (N=40), n (%)	Infants who “may be behind” (N=25), n (%)
Perceived ease of use			
How hard or easy was it to answer the six text messages that asked you questions about your baby?			
Very easy to answer the questions	38 (58)	28 (70)	10 (40)
Easy to answer the questions	26 (40)	12 (30)	14 (56)
Hard or very hard to answer the questions	0 (0)	0 (0)	0 (0)
Missing response	1 (2)	0 (0)	1 (4)
How did you feel about how much time (the screening questions) took?			
The right amount of time	62 (95)	38 (95)	24 (96)
Too much time	2 (3)	2 (5)	0 (0)
Needed more time	0 (0)	0 (0)	0 (0)
Missing response	1 (2)	0 (0)	1 (4)
Perceived usefulness			
Would you want to answer text questions like this again and get results about how your baby is doing when your baby is older?			
Yes	65 (100)	40 (100)	25 (100)
No	0 (0)	0 (0)	0 (0)
Would you recommend the text messages that asked you questions about your baby to a friend with a baby?			
Yes	64 (97.5)	39 (97.5)	25 (100)
Maybe	1 (2.5)	1 (2.5)	0 (0)
No	0 (0)	0 (0)	0 (0)
Satisfaction			
Overall, how did you feel about giving answer to the 6 text messages that asked questions about your baby and getting text messages with feedback about how your baby is learning and growing?			
Very good, it was helpful	52 (80)	33 (83)	19 (76)
Good, it was okay	12 (18)	6 (15)	6 (24)
Average, it was neither good or bad	1 (2)	0 (0)	0 (0)
Poor	0 (0)	0 (0)	0 (0)
Unhelpful	0 (0)	0 (0)	0 (0)
How much did you like or dislike getting text messages with results about how your baby is doing?			
Liked a lot, liked getting the feedback by text	37 (57)	25 (62.5)	12 (48)
Good, it was OK to get the feedback by text	25 (38)	15 (37.5)	10 (40)
Neither good or bad, I didn't care how I got the feedback	1 (2)	0 (0)	1 (4)
Disliked, I did not like getting the feedback by text <i>or</i> totally negative, I would not want to receive feedback by text again	0 (0)	0 (0)	0 (0)
Missing response	2 (3)	0 (0)	2 (8)

Among all participants, the time required to complete the developmental screening (ie, the time between first texting “DM” and submitting the final response) was 4 minutes and 39 seconds on an average. All but three of the phone survey participants who provided an answer (95%, 62/65) felt that the amount of time it took to answer the six text messages was “the right amount of time.” As one mother explained, “The questions were easy and I could answer them quickly.”

All but one of the mothers surveyed said they would recommend the text-based screening to a friend (97.5%, 64/65), and all mothers reported that they wanted to answer screening questions again when their baby was older (100%, 65/65).

Mothers were asked to assess the overall experience of answering the questions and getting results by text: 80% of all mothers interviewed reported that it was “very good, it was helpful” (52/65) and 18% reported that it was “good, it was okay” (12/65). Only one mother reported that it was “average,”

and no mother rated it as poor or unhelpful. When specifically asked to assess the value of obtaining results of the screening by text, almost all mothers responded that they liked receiving feedback by text “a lot” (57%, 37/65) or that it was “good, OK” (38%, 25/65). Although a lower percentage of respondents whose infants “may be behind” liked receiving feedback by text “a lot” or found it “good, OK” than the respondents whose infants were “doing well,” it was not possible to calculate statistics due to the number of cells with zero data.

Discussion

Principal Findings

The primary aims of this pilot study were to assess the usability and acceptability of a validated interactive text message-based tool for developmental screening of infants of low-income mothers as a strategy to make developmental screening more broadly available, particularly among low-income populations.

This pilot study found that it was feasible to create an interactive text-based screening tool based on a validated instrument, and low-income mothers of infants aged 8-10 months found the tool both usable and acceptable. The findings of this study are important because the ubiquity of mobile phones (100%) [10] and texting (95%) [11] among Americans aged 18-29 years creates the potential to make screening widely available to parents of infants, including those from low-income households and on Medicaid who are at a heightened risk of developmental delays especially in the early years.

Usability and Acceptability

Despite a long history of theory-based approaches for assessing the usability and acceptability of web interfaces, there is a paucity of literature on mHealth usability and the inherent challenges of mHealth usability assessments such as small screens and the lack of software that captures physical interactions with devices [19]. There are perhaps even greater challenges in capturing user experience in a text intervention. For example, users own a variety of devices from basic mobile phones to feature-rich mobile phones of varying sizes, and the screening tool may appear quite different depending on the device used. In addition, devices and platforms capture very limited data on interactivity beyond the time and content of interactive messages sent and received.

This study therefore focused on practical measures of performance reflecting actual use of the intervention and user assessments of their experience. The study found no differences in any of the measures of usability according to the infants' developmental status or any of the demographic or socioeconomic characteristics. All mothers were able to respond to all questions and complete the screening (100%, 81/81) including the 21% of mothers who wanted to change one or more responses (17/81). Challenges due to poor mobile coverage in one of the clinics did not prevent participants from successfully completing the screening.

With regard to acceptability, mothers, including those who received a report that their infant “may be behind,” valued the tool as well as the experience of using it and receiving results by text. Almost all mothers ranked the experience “very good”

or “good” and all but one said that they would recommend it to a friend. All mothers in the study expressed the desire to repeat the screening in the future when their infants were older.

There were several lessons learned that should be considered in future iterations and research. First, although the pilot study focused on infants aged 8-10 months, future research and implementation should extend the tool to cover additional ages recommended by AAP and Medicaid's Child Core Set of health quality measures [4-6]. Second, words matter. The wording of one of the screening questions was associated with the highest error rates and should be reviewed and tested. Third, although there was no difference in the measures of usability for Spanish and English speakers in this pilot study, future iterations should offer a choice of language to the users. Fourth, the observation that mothers whose infants “may be behind” were even less likely to report a previous screening suggests that this approach could potentially reach and identify infants at the highest risk of developmental delay, who do not have a medical home and who might otherwise not be identified in a timely way. Fifth, a critical concern in conducting a developmental screening is how to refer mothers whose infants “may be behind” for further screening and, if indicated, diagnosis and treatment for their infants as required and supported by the Early and Periodic Screening, Diagnostic and Treatment benefit of Medicaid [6]. The ability of the ITP representative to reach 93% (28/30) of mothers whose infants “may be behind” in person in the clinic or by phone for possible follow-up was therefore an important aspect of the study process. Clearly, this is only the first, albeit necessary, step to ensure that at-risk infants receive the required diagnosis and appropriate treatment in a timely manner.

Implementation and Evaluation Approaches

To our knowledge, this is the first study to use texting of a validated tool to conduct developmental screening in the United States and to assess such a tool with a low-income population largely enrolled in Medicaid. It is therefore important to incorporate the lessons learned in this study about usability and acceptability and test the effectiveness of this approach on a larger scale including in a randomized clinical trial [24]. Although many mHealth studies do not include an implementation component [15], this study was designed with a view toward large-scale implementation and evaluation.

The combination of broadly available mobile technology, a valid screen, and the partnerships put in place for this study—with *Text4baby*, the State of Maryland WIC program, and Prince George's County ITP program—provides a potential model for scaling up and further evaluation of an approach to promote widespread access to developmental screening and potentially reach at-risk populations. Large-scale mobile health programs such as *Text4baby* could make the developmental screening tool available to mothers enrolled in that program where follow-up is available from an infant's pediatrician or an early intervention program such as ITP. To connect parents of infants who “may be behind” to follow-up, this study suggests that phone calls, in this study's case, from the ITP to parents, following screening may be an effective method.

The text-based screening tool could also be used and evaluated in a medical home or other care setting. As noted in a recent

review of mobile health applications to promote early language development, “m-Health could provide a natural extension of interventions and messages delivered within the primary care setting” [9]. For example, the waiting room staff could ask a parent to trigger the screening tool by sending a text message to a designated number. The parent could then receive and review the results immediately with the infant’s pediatrician or another provider.

In both cases, there could be advantages of embedding developmental screening in a broader texting program such as *Text4baby*. Parents could be sent additional text messages with information about resources for child development and tailored parenting tips as well as reminders to attend well-baby visits, a strategy that has been shown to be effective in increasing attendance rates [25].

Limitations and Strengths

Limitations of this pilot study include its relatively small sample size and primary focus on descriptive data. Participants recruited from two WIC clinics located near a major metropolitan area had higher educational levels than the United States average levels [26]. Maryland also has one of the highest rates of developmental screening in the United States [1]. Study participants may not reflect the overall population of low-income mothers of infants in this age cohort, given that more than half the mothers reported that their infants had had an earlier developmental screening. As part of explaining the purpose of the study and assuring that participant consent was “informed,” the study team likely raised awareness of developmental domains beyond the information provided in the screening messages. In addition, this pilot study did not include an independent test of validity of the text version as compared to a more traditional format.

The study has several important strengths. Because of the partnership with WIC and its clinics in Prince George’s County, the study was able to reach and recruit low-income mothers

whose infants may be at elevated risk for developmental delays. Due to the partnership with ITP, it was possible to reach and offer follow-up to mothers whose infants “may be behind.” The study also focused on user experience and input in the early stages of development and testing of an innovative mHealth tool with lessons that should be incorporated in future implementation and research.

Conclusions

This pilot study addresses the low rates of developmental screening among low-income populations in the United States by investigating how to build on the dramatic growth in the coverage of mobile technology and the broad use of texting within this population.

The study concluded that a validated developmental screening tool delivered by text message to mobile phones is both usable and acceptable by low-income mothers of infants. The results and lessons learned in this study can inform further evaluation with larger sample sizes and at other recommended ages. It also offers insights for potential models for scalable implementation of validated developmental screening using text messaging to screen and support mothers of infants.

The combination of broadly available mobile technology and the partnerships put in place for this study with *Text4baby*, the State of Maryland’s WIC program, and Prince George’s County ITP program holds promise for scaling up and further evaluating a model to promote more widespread developmental screening.

This study contributes to the growing body of evidence supporting the feasibility as well as the effectiveness of using text messaging to address important health outcomes and disparities. Studies have documented the impact of text messaging programs on health knowledge, appointment attendance, vaccination compliance, and other health behaviors. The findings of this study extend mHealth research to support developmental screening and address services needed by at-risk populations.

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Dr Frances Page Glascoe, developer of Parents’ Evaluation of Developmental Status: Developmental Milestones (PEDS:DM), provided free access to PEDS:DM for study participants and made significant contributions as a consultant to the development of the prototype, the design and conduct of the study, and the development of a model to scale up development screening through a partnership with *Text4baby*. The author, MD, first suggested the idea of using text messaging to administer a valid parent-reported developmental screening tool in *Text4baby*. Amy Pirretti and Danielle Garfinkel at Healthy Mothers, Healthy Babies and Megan Hopkins, Josh Kench, Lalida Thaweethai, and Khadija Turay of Voxiva contributed to this study.

Conflicts of Interest

PRJ co-founded, held stock in, and served as a senior executive of Voxiva, recipient of the Small Business Innovation Research grant (#1 R43 HD072664-01A1) and *Text4baby*. PRJ is currently a stockholder in Welltok Inc, which acquired Voxiva and *Text4baby* in 2018.

Multimedia Appendix 1

Summary of developmental screening tools [6].

[PDF File (Adobe PDF File), 213KB - [pediatrics_v2i1e10814_app1.pdf](#)]

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Abbreviations

AAP: American Academy of Pediatrics

ITP: Infants and Toddlers Program

MDHMH: Maryland Department of Health and Mental Hygiene

mHealth: mobile health

PEDS:DM: Parents' Evaluation of Developmental Status: Developmental Milestones

WIC: Women, Infants and Children Program

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Original Paper

A 12-Week Electronic Mentoring Employment Preparation Intervention for Youth With Physical Disabilities: Pilot Feasibility Randomized Controlled Trial

Sally Lindsay¹, BA, MA, PhD; Elaine Cagliostro², BA, MA; Joanne Leck³, BMath, MBA, PhD; Jennifer Stinson⁴, RN, PhD

¹Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Department of Occupational Science & Occupational Therapy, University of Toronto, Toronto, ON, Canada

²Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, ON, Canada

³Telfer School of Management, University of Ottawa, Ottawa, ON, Canada

⁴Hospital for Sick Children, Bloomberg Faculty of Nursing, University of Toronto, Toronto, ON, Canada

Corresponding Author:

Sally Lindsay, BA, MA, PhD

Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital

Department of Occupational Science & Occupational Therapy

University of Toronto

150 Kilgour Road

Toronto, ON, M4G 1R8

Canada

Phone: 1 416 425 6220

Email: slindsay@hollandbloorview.ca

Abstract

Background: Youth with disabilities are at high risk of unemployment compared with youth without disabilities. They often encounter challenges in accessing vocational programs that meet their needs. One promising approach that could help to address barriers that youth encounter while also enhancing social support is through electronic mentoring (e-mentoring). Although there is an increase in e-mentoring for youth with disabilities, little is known about its impact for youth with physical disabilities.

Objective: This study aimed to assess the acceptability and initial impact of a Web-based peer electronic mentor employment intervention for youth with physical disabilities.

Methods: The *Empowering Youth Towards Employment* intervention was evaluated using a pilot randomized controlled trial (RCT). Youth, aged 15-21 years, with physical disabilities were randomly assigned to an intervention (ie, mentored) or control (ie, not mentored) group. Trained mentors (ie, near peers) with a physical disability led the online discussion forums and provided peer support and resources for 12 modules (1 topic per week over 12 weeks). Primary outcomes focused on self-determination, career maturity, and social support. We also explored program adherence and dosage, participant satisfaction, and areas for improvement.

Results: A total of 13 youth (mean age 17.3 years, SD 1.88; 54%, 7/13 female) completed the RCT. In the intervention group (n=9), 56% (5/9) of the youth were females, and in the control group (n=4), 50% (2/4) of the youth were female. Participants reported satisfaction with the program and that it was feasible and acceptable. Participants' mean engagement level with the program was 5.22 (SD 2.48) for the intervention group and 5.40 (SD 4.56) for controls. Participants in the intervention group demonstrated significant improvements in self-determination ($t_{12}=2.49$; $P<.04$) compared with the control group. No adverse events were reported.

Conclusions: The *Empowering Youth Towards Employment* is a promising intervention that enhances self-determination among youth with physical disabilities.

Trial Registration: ClinicalTrials.gov NCT02522507; <https://clinicaltrials.gov/ct2/show/NCT02522507> (Archived by WebCite at <http://www.webcitation.org/6uD58Pvjc>)

International Registered Report Identifier (IRRID): RR2-10.2196/resprot.8034

KEYWORDS

social support; mentor; employment; youth; disabled persons; rehabilitation; occupational therapy

Introduction

Background

Although many young people with disabilities are willing and capable of working, they encounter many personal, environmental, and socio-contextual challenges (eg, inaccessible jobs and discrimination) in finding and maintaining meaningful employment [1]. Their persistently low employment rates are about half or less compared with youth without disabilities [2-4]. Although youth with disabilities could benefit from employment training programs, they are often not tailored to meet the needs of youth with disabilities (eg, self-care at work, disclosing a disability, and requesting accommodations). Of the programs that are targeted toward people with disabilities, they often focus on youth with intellectual or developmental disabilities, whereas less attention has been paid to youth with physical disabilities [1,3,4]. There are limited evidence-based employment preparation programs for youth with disabilities in Canada [5,6]. For example, a systematic review by Hanif et al [5] focusing on employment preparation programs for youth with physical disabilities found only 8 empirical studies in this area. Although there is limited research on this particular population, the findings are promising and show potential to improve self-confidence, self-awareness, goal setting, and knowledge of career options [5]. Although some evidence suggests that vocational programs can influence employment outcomes for youth with disabilities, much further research is needed [5]. Focusing on youth with physical disabilities is important because they arguably have different needs regarding developmental tasks, social development, and role functioning [7,8]. Furthermore, this period of emerging adulthood is an optimal time to help youth develop critical job and independence skills [9].

Mentoring involves developing a relationship between a more experienced individual who serves as a role model and shares knowledge with a less experienced individual [10,11] and can help provide youth with informational, practical, and emotional assistance to enhance coping skills as youth transition to adulthood [12-15]. Mentoring has beneficial impacts on job training, educational attainment, social skills, self-esteem, self-efficacy, work ethic, and employment outcomes [16-18]. Mentoring is particularly useful for groups that are considered to be disadvantaged, such as youth with disabilities [15,19]. Research on mentoring programs among youth without disabilities shows that they are a cost-effective way to augment vocational and educational services while also promoting positive behaviors (eg, self-efficacy, quality of life, and employment skills) [12,20-23]. A meta-analysis focusing on youth without disabilities showed that the key ingredients of peer mentor interventions involve trained mentors, monitored implementation, structured activities, and parental involvement [20]. Until recently, most mentoring programs (in general and those specific to employment) have not included nor specifically

targeted youth with disabilities [15,18]. A common challenge with mentoring programs is that it is often difficult to meet face-to-face. Thus, having a Web-based format can help to overcome some of these challenges [24]. Peer electronic mentoring (e-mentoring) may be 1 way to help youth to gain valuable employment preparation skills in an accessible format. Research demonstrates that Web-based platforms can influence learning and behavior change [25-27]. Web-based formats are particularly relevant for youth, given that the majority of them seek information and communicate over the internet [28]. E-mentoring formats are also flexible in regard to matching participants to a mentor and asynchronous communication [29].

Rationale

This study addresses an important gap in the literature by offering a Web-based employment preparation intervention for youth with physical disabilities. Such youth often encounter different challenges compared with youth with invisible disabilities or chronic illnesses because their condition is often visible, and they also encounter difficulties in mobilities, speech, independence, coping, stigma, and social exclusion [30]. Our intervention aims to strengthen youth's employment preparation skills including self-determination, career maturity, and social support, all of which can have beneficial effects for employment outcomes [15,19,31-34].

Methods

Objective

Our main objective was to assess the feasibility, acceptability, and initial efficacy (ie, pilot randomized controlled trial, RCT) of an electronic mentor (e-mentor) employment preparation intervention for youth with physical disabilities for improving self-determination, career maturity, and social support compared with controls. A secondary objective includes exploring program adherence and dosage, participant satisfaction, and areas for improvement.

Design

A pilot RCT, with an embedded qualitative design [35], was chosen to test the feasibility and initial efficacy of the *Empowering Youth Towards Employment* intervention for youth with physical disabilities. This intention to treat design involves an intervention group that received employment preparation Web-based modules and a peer e-mentor. Meanwhile, the control group received the Web-based modules only (no mentor) but could interact with other participants within their group. We administered pre- and postsurveys (immediately following the completion of the intervention) for both groups (intervention and control). We followed the Medical Research Council Framework for the development and evaluation of RCTs to guide our design [36]. We focused on the development and feasibility phases to establish the theoretical underpinnings and modeling to test the feasibility of key intervention components

[36]. The qualitative data comprised open-ended survey questions and researcher's observation field notes.

The rationale, design, content, and length of our intervention was based on 2 systematic reviews focusing on employment preparation interventions for youth with physical disabilities [5] and best practices of peer mentorship for improving employment outcomes [15] and 2 scoping reviews on improving the inclusion of people with disabilities in the workforce [37] and mentoring practices for a diverse workforce [38]. We also conducted needs assessments regarding informational and social support for youth with disabilities [7,39].

Procedures and Randomization

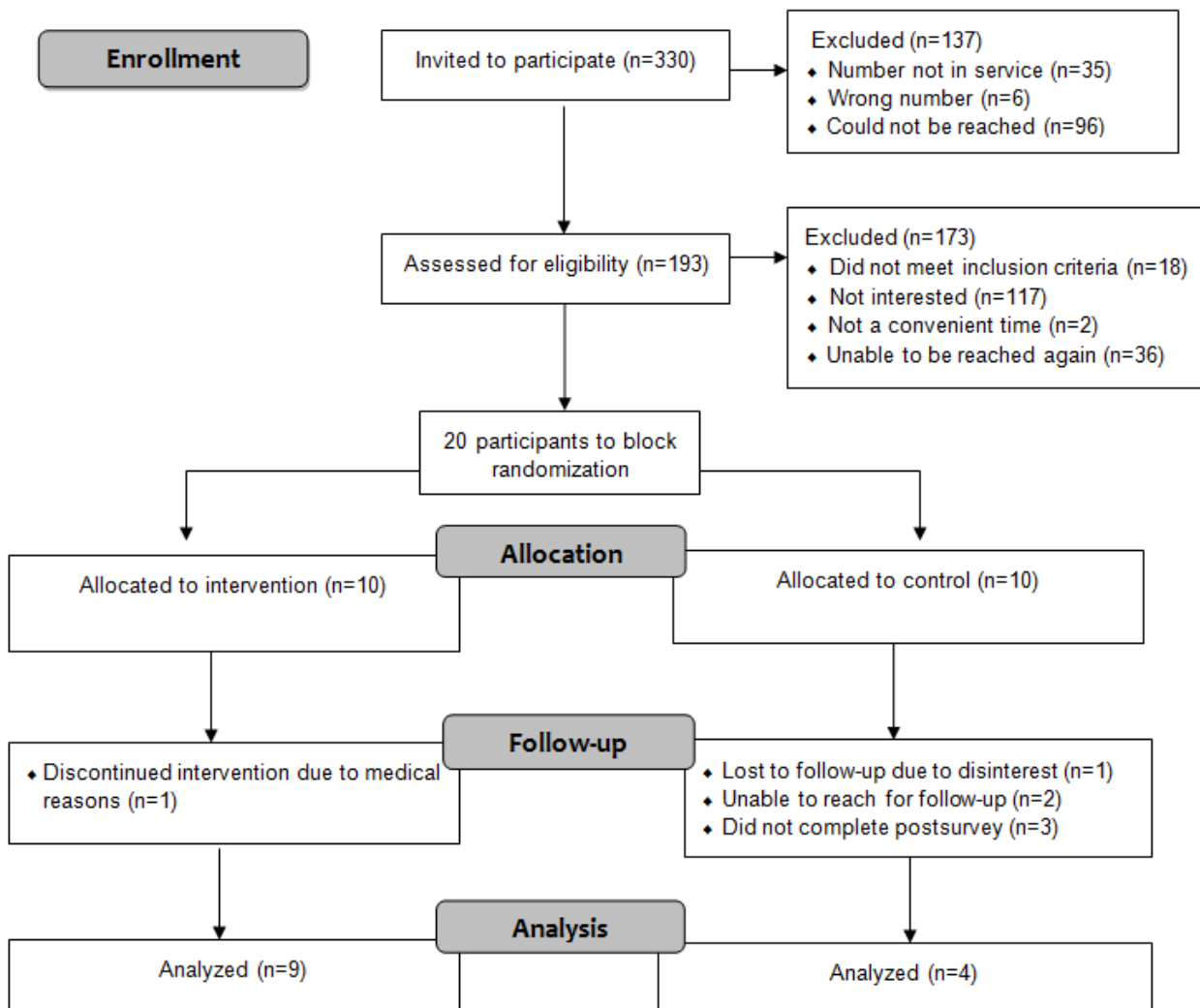
We received institutional research ethics board approval (from a pediatric hospital and a university). Eligible participants were sent an information letter and phone call from the research team. The research assistant screened all participants and obtained informed written consent before enrolling them in the intervention. Once participants consented, they were randomized into an intervention or control group using a block size of 10 [40]. Participants were then emailed the presurvey (see measures below). Next, a research assistant contacted participants to

inform them of their group assignment and instruct them on the procedures to be followed (see [Figure 1](#) for trial schema).

Intervention (Experimental Group)

The purpose of the intervention was to provide meaningful support and access to evidence-based employment resources so that youth can begin thinking about preparing for employment. The content and length of our intervention were evidence-informed by 2 systematic reviews, a scoping review, and a needs assessment conducted by our team [5,15,37,39]. It was cocreated with a knowledge user advisory group and consists of 12 modules (1 per week over 12 weeks) that were delivered by youth peer mentors in a password-protected online discussion forum (see [Multimedia Appendix 1](#) for topics). Each module contained informative resources and interactive materials (ie, articles and videos) that could be viewed at their own pace, homework, and discussions led by trained peer mentors. The group-based intervention involved up to 10 participants per group plus 2 mentors (ie, trained near-peers who have a physical disability). Youth were given access to a separate password-protected area of *AbilityOnline* website, a safe forum for youth with disabilities. It was important to note that we piloted the 12-week format before switching to a 4-week format (reported elsewhere) [6].

Figure 1. Search process flow diagram.



Youth mentors presented each of the topics to mentored participants in the same order using a script. To ensure treatment fidelity, each mentor received the same training and regular check-ins with project staff. They provided their own personal experiences and examples related to each topic and were instructed to respond to all posts while offering informational, emotional, and social support, which they received training in. The asynchronous discussion forum was available to all participants in the group (eg, intervention or control). Participants were instructed to log in to the forum at least once a week, which they could do at a time that was convenient for them. Mentors posted their availability (ie, when they would be in the forum) if participants wanted to discuss something in real time. To be considered for the role of a peer mentor, eligible young adults had lived experience with a physical disability, some employment experience, and have completed the 3-day Youth Peer Mentor Training program that runs out of a pediatric rehabilitation hospital [41]. Mentors also completed project-specific training (ie, active listening, perspective taking, confidentiality, maintaining boundaries, positive role modeling, trust building through interactive training, and mentoring) before starting. Mentors included 2 youth (1 male and 1 female, mean age 21.5 years) who had a physical disability. Mentors

introduced the topics in the same order and were trained to respond to participants’ comments in a similar supportive and positive-focused manner [6].

Control Group

The control group had access to a separate password-protected group within the Web-based forum that contained the modules only, and they did not receive peer mentorship [6]. Instead, a researcher posted the weekly discussion topics but was instructed to not reply to any participant posts. Youth participants within the control group could interact with other participants in their group, but such discussions were not facilitated by a mentor.

Recruitment

Participants were recruited from June to September 2016 through invitation letters sent from a pediatric hospital and disability organizations through referrals and advertisements. Potential participants also contacted us if they were interested in participating. Inclusion criteria involved the following: (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 (to screen for cognitive impairment), (5) have no paid work experience, and (6) youth with a physical disability (eg, cerebral palsy, spina bifida, muscular dystrophy, and spinal cord injury) [6]. Here, we refer to disability as impairment, activity limitation, and participation restriction, whereby a disability and functioning are shaped by interactions between health conditions and contextual factors [42]. Our rationale for this age group and also choosing youth without employment experience was that youth with disabilities often start their first job later than youth without disabilities [39]. Exclusion criteria involve those who recently completed or who are currently participating in another employment preparation or peer support intervention [6].

Information packages were mailed to 330 potential participants, and the research team followed up with potential participants via phone (n=298) or email (n=32) to assess interest and availability for the study. If youth were interested in participating in the study, they were then screened for eligibility by a researcher, and if eligible, they were required to sign a written consent or assent form before taking part in the study. We were able to reach and assess 193 participants for eligibility. A total of 173 participants were excluded (see Figure 1 for reasons). All the 13 participants who joined the study provided written consent, completed a presurvey, signed up for the intervention website, and completed the postsurvey after the completion of the intervention. A total of 20 participants expressed interest in the study, met the inclusion criteria, and provided written consent. Using a block size of 10, participants were randomly assigned into either the experimental (ie, mentored) or control group (see Figure 1 for trial schema).

A total of 7 participants dropped out of the study. Of the participants, 1 dropped out of the intervention group because of medical complications, and 6 participants dropped out of the control group (see Figure 1 for reasons). A total of 13 participants completed the intervention and postsurveys (9 intervention and 4 controls).

Outcome Measures

In addition to basic demographic information (see Table 1), participants completed 3 standardized measures at baseline and at completion of the study to explore self-determination [43], career maturity inventory attitude scale [43], and multidimensional scale of perceived social support [44]. These standardized measures have good internal consistency, construct-related and criterion validity, and test-retest reliability and have been widely used for youth with disabilities [43-46]. Given that the focus of this study was feasibility, these outcome measures were exploratory to examine variances to help determine appropriate outcomes and sample size for future full-scale RCTs.

The first outcome measure, Arc's Self-Determination Scale [46], consists of a self-report measure that assesses self-determination for adolescents with disabilities, with subscales on autonomy, acting on the basis of preferences and abilities (postschool directions), goal setting, and task performance (eg, "I make my own my own meals or snacks" and "I make long-range career plans"). The scale includes I do not even if I have the chance (0), I do sometimes when I have

a chance (1), I do most of the time when I have a chance, and I do every time I have the chance (3) [46].

The second outcome measure, Career Maturity Inventory Attitude Scale [43,45], is a 25-item agree (1) or disagree (0) scale where responses form the bases for 5 subscales relating to career decision making including orientation, involvement, independence, compromise, and decisiveness (eg, "there is no point in deciding on a job when the future is so uncertain," "I don't know what courses I should take in school," and "I keep changing my occupational choice") [45,47].

The third measure, Multidimensional Scale of Perceived Social Support, includes a 12-item questionnaire that captures perceived social support from various sources (ie, parents, siblings, friends, and peers). Example items include "there is a special person who is around when I am in need," "my family really tries to help me," and "I can count on my friends when things go wrong." The scale involves the following: very strongly disagree (0), strongly disagree (1), mildly disagree (2), neutral (3), mildly agree (4), strongly agree (5), and very strongly agree (6). Scores are summed for a total score, with higher scores reflecting higher values of social support [47].

Secondary measures include Web-based usage (ie, number of times logged in and length of time on the forum); how much they liked each topic, based on the Web-hosting *Drupal* platform analytics. We also describe adherence with the intervention, engagement (self-rated scale of 0-10, with higher scores reflecting higher engagement in the program), and satisfaction with the program as measured through open-ended questions in the postsurveys. Other parameters explored included recruitment accrual rates, program adherence, and satisfaction with the intervention, along with suggestions for improvement.

Data Analysis

Data were analyzed using IBM SPSS, version 25. Descriptive statistics were used to describe the sample characteristics at baseline using means and SD for continuous variables and frequencies and portions for categorical variables. *t* tests were conducted to compare baseline characteristics between the intervention and control groups. Separate analyses were conducted for each outcome. Holm's sequential correction will be applied to control for type I error. Effect sizes were determined using Cohen *d*, with 0.2 as indicative of a small effect, 0.5 medium effect, and 0.8 large effect. A level of .05 was used as the criterion for statistical significance.

Qualitative analysis of the open-ended survey questions and researcher's field notes involved 2 team members reviewing all data independently, and then, they compared the findings and analyzed them thematically through an open-coding, constant comparison approach [48]. Any discrepancies were resolved through discussion of the themes and reevaluated until consensus was reached. We kept a log of the key decisions made throughout the analysis to help improve the credibility of our findings [48].

Results

Sample Characteristics

A total of 13 adolescents (mean age 17.3, SD 1.88; 54% female; range 15-21 years) completed the study, which ran from July 2016 to December 2016. A total of 6 participants had cerebral palsy, 4 had muscular dystrophy, 2 had Charcot Marie tooth disease, and 1 had metabolic bone disease. A total of 6 participants in the intervention group and 4 in the control group used an assistive or mobility device. The majority of the

participants (6 intervention, 4 control) were currently enrolled in school. The remainder completed high school or were unemployed. There were no significant differences between the groups on demographic variables at baseline (see Table 1).

In regard to self-rated engagement in the intervention, there were no significant differences between the intervention (mean 5.22, SD 2.48) and control groups (mean 5.40, SD 4.56). Both groups spent a similar amount of time on the website (intervention: mean 1.1 hours, SD 1.3; control: mean 1.55 hours, SD 1.85).

Table 1. Demographic characteristics of participants and mentors.

Demographic characteristics	Participants		Mentors (n=2)
	Intervention (n=9)	Control (n=4)	
Age (years), mean (SD)	17.8 (1.7)	16.25 (1.89)	21.5 (1.5)
Sex (n)			
Male	4	2	1
Female	5	2	1
Disability type (n)			
Cerebral palsy	4	2	1
Muscular dystrophy	3	1	0
Charcot Marie tooth disease	2	0	0
Metabolic bone disease	0	1	0
Other physical disability	0	0	1
Use an assistive or mobility device (n)	6	4	2
Currently enrolled in school (n)	6	4	2
Total time spent on the website (hours), mean (SD)	1.1 (1.3)	1.55 (1.85)	6.38 (5.41)
Number of posts and messages, mean (SD)	6.77 (6.49)	3.0 (4.69)	35.5 (6.36)
Number of logins, mean (SD)	34.3 (59.0)	7.25 (3.68)	99.5 (85.55)
Self-rated engagement, mean (SD)	5.22 (2.48)	5.40 (4.56)	7 (0)

Although the intervention group logged in more times (intervention: mean 34.3, SD 59.0; control: mean 7.24, SD 3.68) and posted more messages on average than controls (intervention: mean 6.77, SD 6.49; control: mean 3.0, SD 4.69), the differences between the groups were not significant.

Primary Outcome Analysis

Our primary outcome for this study focused on the feasibility of the *Empowering Youth Towards Employment* intervention. *t* tests (between time 1 and time 2) were computed to examine differences on each outcome including self-determination, career maturity, and social support. Separate analyses were conducted for each outcome. There were no significant differences on outcome measures at baseline. After controlling for baseline scores, participants in the intervention group had significantly improved self-determination scores after the intervention compared with those in the control group ($t_{12}=2.49$; $P<.03$; $d=.70$; see Tables 2 and 3 for comparison of outcome measures between the 2 groups). There were no significant differences in career maturity or social support between the intervention and control groups following the intervention.

Program Adherence and Dosage

Mentors delivered the intervention as instructed in the protocol and posted a unique topic once a week. The researchers monitored this through the discussion boards. The mentor's role was also to respond to participant comments, which was done majority (82%) of the time. A total of 18% of the messages posted by participants did not get a response from mentors. A total of 2 of these messages were follow-up responses from participants on a specific topic. In a few instances, mentors posted a longer, more generic statement that addressed several different comments rather than addressing each specific participant.

The control group ran as planned, where a research assistant posted 1 topic per week, which included general information and discussion questions. The researcher who posted the topics in the control group did not respond to any of the participants' posts in the forum, as directed in the protocol. All 12 topics were posted at the beginning of the week as prescribed, and the full extent of the intervention was delivered to participants.

Participant Satisfaction With the Intervention

A total of 8 out of 9 (89%) of intervention group participants and 4 out of 4 (100%) of the control group participants said they would recommend the intervention to others. In their open-ended survey responses, participants described their level of satisfaction with the intervention and whether they would recommend it to others. Specifically, youth in both the intervention and control groups reported satisfaction with receiving information and feedback. A total of 3 participants in the intervention and 3 in the control group reported enjoying the information provided in the intervention, especially the employment preparation content and disability specific resources. For example, a participant in the intervention group commented that the intervention “gives a lot of advice on how to get to work where you want to and how to overcome the disability, which is helpful” [#1-09]. Furthermore, giving and receiving feedback was another aspect that participants (5 intervention, 1 control) appreciated. Such advice included feedback from peer mentors related to career strategies, overcoming disability-related challenges, and sharing

experiences related to the intervention topics. For example, 1 intervention group participant shared:

I was able to suggest some things I did that helped me with some of my issues which I hope helped my colleagues. [#1-03]

Participants also expressed contentment with the Web-based format of the intervention, stating it was “well-organized” [#1-02] and that the Web-based format “was the easiest one to learn from and get information from” [#1-05]. Furthermore, 7 participants in the intervention group had positive feedback regarding the social interaction and social support components provided through the intervention. For example, a participant shared that they “enjoyed connecting with...the mentors because it made the ideas of transition to postsecondary seem less daunting”[#1-05]. Another youth highlighted a benefit of the program:

It is very important to hear the opinions of people with disabilities. So, if someone feels alone they know they're not the only ones going through certain situations. [#1-02]

Table 2. Descriptive statistics on participant outcomes (time 1) by group.

Variable	Intervention group (n=9), mean (SD)	Control group (n=4), mean (SD)	t (df)	P value	Effect size (Cohen d)
Self-determination	22.3 (5.17)	14.5 (3.69)	3.35 (12)	.06	0.88
Career maturity	13.0 (3.27)	13.0 (7.02)	0 (12)	>.99	0
Social support	49.5 (21.07)	58.0 (17.7)	-1.005 (12)	.33	0.21

Table 3. Differences in outcomes between experimental and control groups (time 2).

Variable	Intervention group (n=9), mean (SD)	Control group (n=4), mean (SD)	t (df)	P value	Effect size (Cohen d)
Self-determination	23.0 (5.78)	13.5 (7.59)	2.49 (12)	.03	0.7
Career maturity	13.75 (3.10)	15.25 (4.11)	-0.71 (12)	.49	0.71
Social support	49.5 (21.07)	60.5 (13.27)	-0.946 (12)	.36	0.32

One of the main goals of the intervention was to provide employment resources and information to participants, which was deemed as helpful by most participants, such as participant #1-04, who stated:

The study was very informative and helped a lot with my plans for my career.

A participant in the control group also discussed that they enjoyed the program because “you get good information and tips“ [#2-03].

Areas for Improvement

Some participants had suggestions about how the intervention could be improved. For example, some participants noted that it would be helpful to have more prompts to keep them engaged throughout the 12 weeks. Lack of engagement was often associated with personal reasons (ie, too busy or forgetting to log in, too shy to participate, etc). For instance, a participant in the intervention group explained:

I enjoyed the program; however my summer became very busy and I regret not being able to engage in the program. [#1-02]

Another participant suggested:

Sometimes I forgot to check the website during the week so it would be helpful to receive an email reminding me to check any updates. [#1-03]

One participant in the intervention group who had logged in few times but did not post describes:

I needed greater clarity on time frame and expectations. I'm sorry I was a passive participant and did not engage in the discussions more. [#1-01]

A total of 3 intervention participants and 1 control group participant mentioned that they found it difficult to remember to log in to the website or had limited access to a computer, which made it difficult to participate on a regular basis.

Other participants wanted improvements to the website. For instance, a participant in the control group explained that they

found the “layout of the website was confusing...and hard to navigate” [#2-05]. Meanwhile, a participant in the intervention group suggested:

The website could have a better UI (User Interface) so it has a better feel. [#1-09]

Discussion

Principal Findings

Our findings show that the *Empowering Youth Towards Employment* intervention demonstrated acceptability and preliminary evidence of impact in 1 of the outcome measures within a sample of youth with physical disabilities. Youth with disabilities are considered a vulnerable population that has unique vocational needs [15]. Helping them to gain employment skills is important because they often encounter significantly higher unemployment rates compared with youth without disabilities [6,49]. Therefore, providing mentoring and resources within a Web-based forum is 1 potential way that can help to engage youth with disabilities within an accessible format [50]. Peer mentors can act as role models who help to normalize the experience of transitioning to work for those who have a disability. Knowing that others have gone through a similar experience may help to increase their motivation for pursuing vocational interests [51,52]. Youth may be more receptive to receiving information from a peer who is closer in age [52]. Previous research shows that mentoring is a promising mechanism that can help to enhance youth’s inclusion while also offering support and coping strategies [53]. Web-based platforms can also influence learning and behavior change [26]. Our study is novel in that it offers an employment preparation program through an e-mentor platform. Most previous studies focus on self-management and health-related outcomes.

Our results indicated significant improvements in self-determination (large effect) among the youth in the intervention (ie, mentored) group. Previous research shows that there is a strong link between mentoring and improvements in self-efficacy [54], self-determination [55,56], and self-confidence [57]. For example, Gregg et al’s [55] study explored the effectiveness of virtual mentoring to enhance the persistence of secondary and postsecondary students with learning disabilities in science, technology, engineering, and mathematics and found improved self-determination [55]. Indeed, helping youth to develop their self-determination and self-advocacy skills is important because it is critical for optimizing their participation and inclusion in society [58-60].

A total of 2 of the measures within our study, career maturity and social support, showed no significant improvement following the intervention. These findings are somewhat surprising and contrast other e-mentor interventions focusing on youth with visual impairments and blindness (using a mixed format including face-to-face and group-based activities, email, and phone calls) that found significant improvement in career decision making [61]. Another study involving 8 e-mentoring sessions to enhance the transition to college for youth with disabilities [62] found significant improvements in career decision self-efficacy. This discrepancy could be partly a result of the small sample size, differences in the disability types

explored, the length of the mentoring interventions, differences in the measures used, and lack of control groups in these studies.

Research shows that early vocational experiences are associated with the development of career maturity and vocational identity, contributing to a positive career trajectory [33,34]. Vocational maturity is characterized by the extent to which one is concerned with seeking out a career choice; investigating and planning for an occupation; stable occupational preference over time; realistic attitudes toward work; and habits, interests, and abilities that match one’s occupational preference [33,63]. Most studies exploring career maturity among youth with disabilities focus on the college age [31]. Given that the average age of our sample was younger, it could be that youth are still very early on in their development and need more time and experience to further develop their career maturity.

Our results also showed no significant improvements in social support within the time frame of this study. This finding could be a result of the social support provided by peer mentors (eg, encouragement and sharing experiences), perhaps acting as a mediating factor affecting self-determination [32]. For example, research shows that employment success can be achieved through social relationships [64] or perhaps, the participants in our study already had good support systems in place from family and friends. Some research suggests that the e-mentoring process lacks verbal communication cues, which result in more impersonal or superficial relationships between mentor and mentee, and therefore, more informal or conversational language should be used to encourage closeness [53,65]. Interestingly, participants expressed satisfaction in social interactions and support from the intervention in the open-ended survey responses.

Our findings highlighted participants’ satisfaction with the intervention, and the majority would recommend it to other youth. Somewhat surprising, however, is that their self-reported levels of engagement were somewhat lower than expected. This could have been because of the 12-week length of the program and many youth were busy with school and often found it difficult to participate as often as they would have hoped to. We observed that engagement levels, based on the number of posts per topic, decreased over the course of the 12-week intervention. We recommend that the research team and youth mentors check in more regularly with the participants to help keep them engaged throughout the intervention. Other studies on mentoring among youth with disabilities show that having small group activities [66] and family support [21,67] can help keep participants engaged, along with timely responses from mentors [65].

Our results showed lower than expected engagement levels, which suggest that the intervention may not be appropriate in its current form for youth with physical disabilities. The intervention could benefit from flexibility in the length of the program to increase acceptability to a larger group of youth. Some youth may have found it difficult to remain engaged for 12 weeks, especially with ongoing school commitments. Our findings are consistent with past research focusing on youth without disabilities, showing that maintaining engagement of participants within an e-mentor format can be challenging, and

engagement may decrease as the intervention progresses [68,69]. One topic per week may also not be enough interaction to keep youth engaged, as research shows that frequent and consistent contact is useful for a successful mentoring relationship [65,70,71]. Therefore, we recommend that a shorter, more condensed format, perhaps over the summer months when youth are not as busy with school, may be more suitable.

Limitations and Future Directions

It is important to consider the limitations of this study, which focused on the feasibility and initial impact of the intervention. First, we were underpowered in some of the analyses. Our sample size was small, and we recruited from only 1 site, which limits the generalizability of the findings. Second, some youth who completed a presurvey and participated in the discussion forum did not complete a postsurvey, which excluded them from the analysis. This was particularly the case for the control group. Therefore, it is important to note that more of the participants in the intervention group stayed in the study. The design of future interventions should consider how to maintain engagement of participants who are in the control group. Third, we included various types of physical disabilities, and each have different needs and concerns regarding preparing for employment and could have affected the results. Fourth, we were unable to determine the number of participants who looked at the resources and modules and the amount of time that they spent looking at them, which is an important factor that could influence the outcomes that we explored. Finally, the host website that we used for this intervention went through several upgrades during the course of the intervention that caused some technical difficulties that some participants experienced. This could have affected their participation and engagement in the study.

Future studies should be directed in several areas. First, given the relatively low self-rated engagement levels, future research should have specific engagement strategies to keep participants engaged (in both the intervention and the control groups). This could involve regular check-ins to see if participants need any help with posting, reminders to contribute to the discussion, or involving a variety of different components such as face-to-face or in-person components [19]. Further support may be needed for participants who are shy or reluctant to post. Finally, further research should explore whether any potential gains from this or other similar interventions last over the long term.

Conclusions and Implications

The *Empowering Youth Towards Employment* intervention is promising in that it enhances self-determination among youth with physical disabilities. There is a growing emphasis on the importance of including a process evaluation as part of an RCT [72]. This study shows that a process evaluation can provide valuable information about an intervention, which is critical if it going to be fully implemented into practice. Furthermore, findings from the process evaluation will help interpret the outcomes of the intervention. Our results show that the length of the intervention seemed too long for both the mentors and the participants. We recommend condensing the length of the intervention into a 1-month format that would also fit into the youth's schedule. It is important to balance addressing the primary mentoring goal of helping youth to develop employment-related skills with fostering a meaningful mentoring relationship with participants. We recommend that further mentor training and ongoing support is needed to help facilitate this. Furthermore, our results suggest that there is value in having peer mentors who have a disability. Most previous peer mentoring studies have a mentor that does not have a disability.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Overview of weekly topics.

[PDF File (Adobe PDF File), 43KB - [pediatrics_v2i1e12088_app1.pdf](#)]

Multimedia Appendix 2

CONSORT - EHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 3MB - [pediatrics_v2i1e12088_app2.pdf](#)]

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Abbreviations

e-mentor: electronic mentor

e-mentoring: electronic mentoring

RCT: randomized controlled trial

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Original Paper

A 4-Week Electronic-Mentoring Employment Intervention for Youth With Physical Disabilities: Pilot Randomized Controlled Trial

Sally Lindsay¹, BA, MA, PhD; Elaine Cagliostro², MA; Jennifer Stinson³, PhD; Joanne Leck⁴, PhD

¹Department of Occupational Science and Occupational Therapy, University of Toronto and Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, ON, Canada

²Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, ON, Canada

³Lawrence S Bloomberg Faculty of Nursing, Hospital for Sick Children, University of Toronto, Toronto, ON, Canada

⁴Telfer School of Management, University of Ottawa, Toronto, ON, Canada

Corresponding Author:

Sally Lindsay, BA, MA, PhD

Department of Occupational Science and Occupational Therapy

University of Toronto and Bloorview Research Institute

Holland Bloorview Kids Rehabilitation Hospital

150 Kilgour Road

Toronto, ON, M4G 1R8

Canada

Phone: 1 416 425 6220 ext 3654

Email: slindsay@hollandbloorview.ca

Abstract

Background: Youth with disabilities are more likely to live in poverty and be unemployed compared with youth without disabilities. Such trends are often a result of a lack of support, inaccessible jobs, environmental barriers, and discriminatory attitudes toward people with disabilities. Youth with disabilities also face barriers in accessing vocational preparation programs. One encouraging way that could help address challenges that youth encounter is by providing support through electronic mentoring (e-mentoring).

Objective: The objective of this study was to assess the feasibility of a 4-week Web-based peer e-mentoring employment intervention for youth with physical disabilities.

Methods: We conducted a pilot randomized controlled trial (RCT) to evaluate our intervention, *Empowering youth towards employment*. Participants included youth aged 15 to 25 years who were randomly assigned to an experimental (mentored) or control (nonmentored) group. 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 (3 topics a week for 4 weeks). Primary outcomes focused on implementation (ie, feasibility and acceptability), whereas secondary outcomes focused on effectiveness (ie, measures of self-determination, career maturity, and social support).

Results: A total of 28 youth (mean age 19.62, SD 3.53; 14/28, 50% female) completed the RCT in 3 intervention groups and 2 control groups (intervention n=18, control n=10). Participants reported satisfaction with the program and that it was feasible and acceptable. Youth's mean engagement level with the program was 6.44 (SD 2.33) for the experimental group and 5.56 (SD 3.53) for controls. Participants in the intervention group did not demonstrate any significant improvements in social support, career maturity, or self-determination compared with those in the control group. No adverse events were reported.

Conclusions: The *Empowering youth towards employment* e-mentoring intervention needs further testing with a larger sample and different length of formats to understand how it may have an impact on employment outcomes for youth with disabilities.

Trial Registration: ClinicalTrials.gov NCT02522507; <https://clinicaltrials.gov/ct2/show/NCT02522507> (Archived by WebCite at <http://www.webcitation.org/77a3T4qrE>)

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KEYWORDS

social support; mentor; youth; rehabilitation; occupational therapy

Introduction

Background

There is a growing literature highlighting the benefits of having a diverse workforce and, particularly, hiring people with disabilities [1]. Although there have been many encouraging improvements in this area, people with disabilities, and particularly youth, continue to experience lower employment rates compared with youth without disabilities. For example, the employment rate for youth in Canada aged 20 to 24 years with a severe disability is 35% and youth with a mild or moderate disability is 57% compared with 87% of youth without disabilities [2]. A similar pattern exists for youth aged 15 to 19 years where 40% of those with disabilities are employed compared with 51% of youth without disabilities [3]. Gaining employment skills is important because engagement in paid employment is a social determinant of health that is linked with improving independence and quality of life [4-6]. Many youth with disabilities would like to work and are capable of doing so but encounter many barriers in preparing for and finding employment [7-9]. Even more concerning is that 34% of youth with disabilities, aged 16 to 24 years, are neither working nor in school [10].

Employment preparation programs are often not designed to meet the needs of youth with physical disabilities [6,11]. Although some programs exist, they are mostly focused on youth with developmental or intellectual disabilities. Youth with physical disabilities arguably encounter different needs and challenges in terms of social development and role functioning [5,12]. A recent systematic review focusing on employment preparation programs for youth with physical disabilities highlighted that there is very limited evidence-based programming for youth [11]. Of the handful of studies in this area, youth with disabilities showed promise with improvements in self-confidence, goal setting, and knowledge of career options [11]. Given the various challenges that youth with disabilities encounter, more efforts are needed to help youth prepare for and engage in meaningful employment [7].

Mentoring is a potential way to strengthen the inclusion of youth with disabilities in employment while also offering meaningful social support [13-15]. A mentor refers to someone who is more experienced, acts as a role model, and shares experiences with a less experienced individual. Research shows that mentoring relationships have potential to offer informational, practical, and emotional support; self-determination; quality of life; and career development goals [13,16-21]. There is a small but growing literature on mentoring programs for youth with disabilities, most of which has focused on traditional face-to-face mentoring. A main challenge with this type of mentoring is that it is often difficult to find and access mentors [13]. Therefore, a potential advantage of electronic mentoring (e-mentoring) is that it is in a format that allows for flexibility in matching a mentor with a mentee and also has asynchronous communication [22]. E-mentoring can help to overcome inequities and provide opportunities to underserved groups such as youth with

disabilities [14,15]. Given that Web-based platforms can influence learning and behavior change [23-25], they may offer a promising way to help youth with disabilities to learn essential employment preparation skills. Our intervention aims to strengthen employment readiness skills of youth with disabilities, including their self-determination, career maturity, and social support, all which can improve employment outcomes [13,15,26-28].

Objectives

Our objective was to assess the feasibility (ie, pilot randomized controlled trial [RCT]) of a 4-week e-mentoring intervention focused on youth with physical disabilities for improving self-determination, career maturity, and social support compared with controls.

Methods

Design

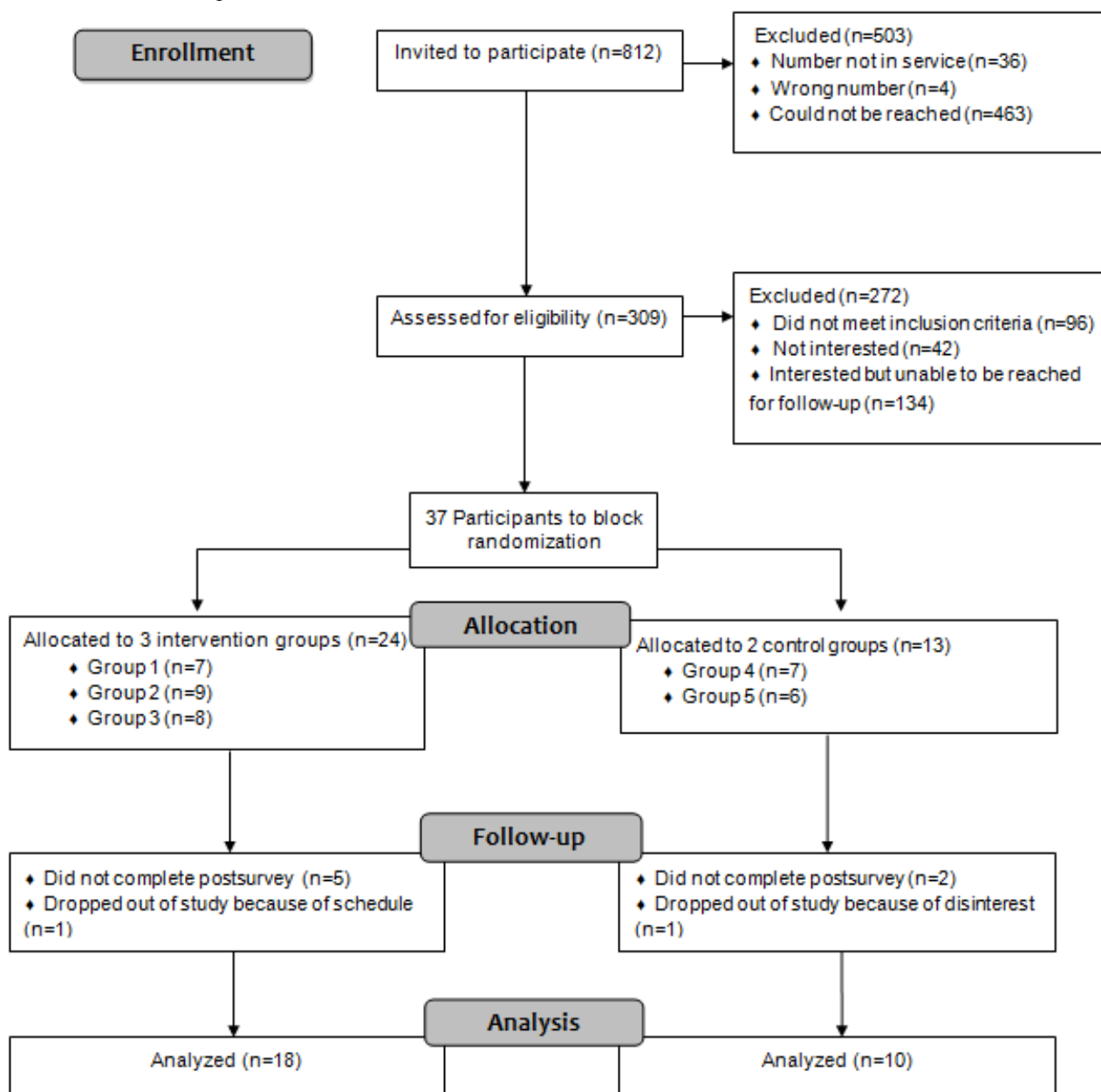
We used a pilot RCT with an embedded qualitative design [29] to assess the feasibility of the *Empowering youth towards employment* (ie, 4-week e-mentoring) intervention for youth with physical disabilities. We followed the Medical Research Council Framework for the development and evaluation of RCTs to guide our design [30]. We focused on the development and feasibility phase to ascertain the theoretical foundations and to assess the feasibility of intervention components [6,30]. The intervention group received mentorship from trained youth mentors who guided them through 12 module topics in a Web-based forum [6]. The control group only had access to the Web-based modules and did not receive mentorship.

The content of our intervention was based on several systematic reviews conducted by our team focusing on employment preparation interventions for youth with physical disabilities [11], improving the inclusion of people with disabilities in the workforce [31], and best practices of peer mentorship for improving employment outcomes for youth with disabilities [13]. Needs assessments with youth who have a physical disability also informed the types of informational and social support they look for in a Web-based format [12,32].

Sample and Recruitment

We recruited youth from a pediatric rehabilitation hospital from April 2017 to August 2018. A researcher sent invitation letters to potentially eligible participants meeting the following inclusion criteria: able to read and write in English, aged 15 to 25 years with a physical disability, have access to a computing device with internet access, currently enrolled in or recently completed a high school diploma in the applied or academic stream, and have no paid work experience [6]. We define disability as an impairment, activity limitation, or participation restriction whereby a disability and functioning are shaped by interactions between health conditions and contextual factors [33]. We excluded youth who had recently completed or who were currently participating in employment preparation or peer support intervention [6].

Figure 1. CONSORT flow diagram.



Our aim was to achieve a sample of approximately 80 participants (40 experimental and 40 control) [6] with an alpha of .05 and power of 80% based on the guidelines of Cohen [34] and Hertzog [35]. A total of 37 participants met the inclusion criteria and provided written consent. We used a block size of up to 10 participants who were randomly assigned into an experimental (ie, mentored) or control group (nonmentored; see Figure 1 for trial schema). We ran 5 different groups in the summers of 2017 and 2018, of which 3 were experimental and 2 were control. A total of 7 participants (5 experimental and 2 control) did not complete the postsurvey, and 2 participants dropped out of the study before completion. Moreover, 28 participants completed the intervention and postsurveys (18 experimental and 10 controls).

Setting

Youth received access to a password-protected area of a website, *AbilityOnline*, a safe forum for youth with disabilities.

Peer Mentors

Each intervention group had a paid mentor including youth (ie, near peers) who had lived experience with a physical disability, were currently enrolled in postsecondary education, and had completed a 3-day Youth Peer Mentor training program held at a pediatric rehabilitation hospital [36]. A total of 2 of the experimental groups had 1 male and 1 female mentor who led the discussions, and 1 group had 1 male mentor. We also held project-specific training sessions that taught mentors about active listening, perspective taking, confidentiality, maintaining boundaries, positive role modeling, and trust building [6]. We instructed the mentors to introduce the topics in the same order and to respond in a supportive and positive means [6].

Procedures and Randomization

Ethics approval was obtained from a pediatric hospital and a university. A research assistant screened all potential participants

for inclusion and obtained written informed consent before including them in the project. After participants consented, they were randomized into an experimental or control group, with up to 10 participants per group (see Figure 1) [6,37]. A researcher then emailed the presurvey to each participant via REDCap. She then informed them of their group assignment and gave them instructions on how to log in to the project website.

Intervention (Experimental Group)

The *Empowering youth towards employment* (ie, 4-week e-mentor) intervention was developed to provide social and informational support regarding employment preparation for youth with disabilities [6]. The evidence-informed content [11,13] was cocreated with a knowledge user advisory group consisting of youth with disabilities and parents [6]. The content involved 12 modules where 3 different topics were delivered each week for over 4 weeks. The topics included the following: introduction and goal setting, life skills, managing disability at work, family role in supporting employment, aspirations and expectations, volunteerism, finding a job, social networking and community resources, preparing for job interviews, learning from professionals with disabilities, career pathways and transitions, and referrals [6]. The modules included interactive materials and resources that youth could go through on their own and at their own pace. The experimental group had access to 1 or 2 trained peer mentors through a password-protected Web-based (asynchronous) discussion forum [6]. Each module topic was led by a trained mentor and held in a group-based format, involving up to 10 youth participants and 1 to 2 mentors [6]. The youth mentors used a script to introduce each topic in the same way; however, they were encouraged to share their own relevant experiences. An earlier pilot 12-week version of this intervention is reported elsewhere [6,38]. On the basis of participant feedback that the original format of the program was too long, we condensed the format from 1 weekly topic for 12 weeks to 3 topics per week over 4 weeks [38].

Control Group

Participants in the control group (up to 10 per group) were given access to a separate password-protected area of the Web-based forum where they could see the modules but did not receive peer mentorship. Each module topic was posted by a researcher with the same timing as the experimental group, but they did not reply to posts. Participants could interact with other participants in the control group through the discussion forum; however, this was not moderated [6].

Outcome Measures

Primary outcomes of this study focused on implementation of the 4-week Web-based peer mentoring intervention as measured by recruitment and withdrawal rates, adherence with the intervention (ie, length of time online and number of times logged in), proportion of completed questionnaires, and engagement and satisfaction (ie, self-rated engagement in the study, whether they would recommend the program to others, and open-ended questions to assess satisfaction) [6].

Secondary outcome measures of this study focused on the preliminary estimates of effectiveness of the 4-week Web-based mentoring intervention. In our pre-post surveys, we collected demographic information and the following standardized measures: career maturity inventory attitude scale [39,40], multidimensional scale of perceived social support [41], and self-determination [42]. Each of these measures have been used for youth with disabilities and have good test-retest reliability, internal consistency, and construct-related and criterion validity [40,42,43]. The *career maturity inventory attitude scale* is a 24-item scale including agree and disagree items relating to career decision making (orientation, involvement, independence, compromise, and decisiveness) [26,40]. The *multidimensional scale of perceived social support* is a 12-item questionnaire that captures perceived support from several sources [41]. The scores are summed for a total score where a higher score indicates higher perceived social support [41]. Finally, the *Arc's self-determination* [42] is a self-report measure for adolescents with disabilities, with subscales on autonomy, acting on the basis of preferences, abilities, postschool directions, goal setting, and task performance.

Data Analysis

We analyzed the data using IBM SPSS, version 25. We used descriptive statistics to describe sample characteristics at baseline using means and SD for continuous variables and frequencies for categorical variables. We performed *t* tests to compare the baseline characteristics between the experimental and the control groups, separate analyses for each outcome. Analyses were conducted using an intent-to-treat approach. Linear regression models were used to test the intervention effects on outcome measures using an analysis of covariance with posttreatment measures compared between groups using baseline scores as covariates. A level of .05 was used as the criterion for statistical significance. The Holm sequential correction technique was used to control for type I error. We calculated effect sizes using Cohen *d* where 0.2 indicates a small effect, 0.5 medium effect, and 0.8 large effect.

Qualitative data (ie, open-ended survey questions) were analyzed thematically [44] to explore reasons for their satisfaction or dissatisfaction with the program and areas for improvement.

Results

Sample Characteristics

A total of 28 youth aged 15 to 25 years (mean age 19.62, SD 3.53; 14/28, 50% female) completed the Web-based program, split between the intervention and control groups. In addition, 12 youth had cerebral palsy, 6 with Duchenne muscular dystrophy or other neuromuscular disorder, 7 with spina bifida, and 3 with other (nonspecified) physical disabilities. Moreover, 22 of the 28 youth (78%) used an assistive or mobility device, and 19 out of 28 youth (68%) were currently enrolled in school. There were no significant differences in demographic variables or comfort with computers and discussion forums between the experimental and control groups at baseline (see Tables 1 and 2).

Table 1. Demographic characteristics of participants and mentors.

Demographics	Participants		Mentors (n=3)
	Experimental (n=18)	Control (n=10)	
Age (years), mean (SD)	19.77 (3.49)	19.4 (3.56)	22 (2.64)
Sex, n (%)			
Male	8 (44)	6 (60)	2 (67)
Female	10 (56)	4 (40)	1 (33)
Disability type, n (%)			
Cerebral palsy	6 (33)	6 (60)	0
Duchenne muscular dystrophy and neuromuscular	3 (17)	3 (30)	0
Spina bifida	6 (33)	1 (10)	0
Other physical disability	3 (17)	0	3 (100)
Use an assistive/mobility device, n (%)	15 (83)	7 (70)	3 (100)
Currently enrolled in school, n (%)	11 (61)	8 (80)	2 (67)

Table 2. Participant use and engagement in the program.

Variable	Participants, mean (SD)		Mentors, mean (SD)
	Experimental	Control	
Comfort with computers	2.58 (0.65)	2.46 (0.66)	__ ^a
Comfort with discussion forum	1.54 (0.72)	1.62 (1.04)	—
Time spent on the website, hours	5.22 (4.95)	2.95 (2.47)	25.3 (22.3)
Number of logins	7.17 (6.00)	7.66 (5.02)	72.3 (78.05)
Number of messages	8.58 (6.02)	8.11 (4.85)	65.6 (46.49)
Self-rated engagement	6.47 (2.40)	5.56 (3.53)	7.25 (0.27)

^aNot applicable.

Time Spent Online

The experimental group spent more time online (mean 5.22, SD 4.95) compared with the control group (mean 2.95, SD 2.47) and posted slightly more (experimental: mean 8.58, SD 6.02; controls: mean 8.11, SD 4.85), although the difference was not significant (see [Table 2](#)). Meanwhile, the mentors spent an average of 25.3 (SD 22.3) hours online, mean of 72.5 (SD 78.05) logins to the website, and mean 65.6 (SD 6.49) posts. Both groups logged in a similar average amount (experimental: mean 7.17, SD 6.00; controls: mean 7.66, SD 5.02).

Recruitment

We sent information packages via mail or email to 812 potential participations. A researcher followed up with participants via phone or email about 1 week after initial contact to assess for potential interest in the study. Youth who were interested in taking part were screened for eligibility, and if interested, they signed a written consent form. We reached and assessed 309 participants for eligibility. A total of 503 potential participants were unable to be contacted to participate in the study (see [Figure 1](#) for reasons). Moreover, 37 participants were randomized (24 in the 3 experimental groups and 13 in the 2 control groups) and 28 completed the intervention or control and the postsurvey.

Engagement and Satisfaction With the Intervention

The experimental group reported a higher self-rated engagement (mean 6.44, SD 2.33) compared with the control group (mean 5.56, SD 3.53), although the difference was not significant. There was a significant difference between the experimental group reporting that they would recommend the program to others compared with fewer of the controls 100%, (18/18) experimental and 78% (7/9) controls ($P=.04$). In the open-ended survey comments, participants described what they liked most about the program, including the career and life-skills content, shared experiences with mentors and other participants, and the format of the intervention (see [Table 3](#)).

Secondary Outcome Analysis

Parameters for our secondary outcome analysis explored recruitment and accrual rates, satisfaction with the intervention, and suggestions for improvement. Marginal models were computed to examine group differences on each outcome. No significant differences on outcome measures were noted at baseline. After controlling for baseline scores, no significant differences were found in career maturity, self-determination, or social support between the experimental and control groups after the intervention (see [Table 4](#) for the comparison of secondary outcome measures between the 2 groups).

Table 3. Overview of themes and representative quotes. Quotes are provided in italics, the Participant ID is in brackets.

Theme	Experimental group	Control group
Engagement and satisfaction	<i>This is a topic I have to start thinking about...it initiated some good conversations between my mother and me. [#1-04]; It made me think about the things that are important for finding a job. [#2-08]</i>	<i>This program prepares you for how to find work and shows the different steps. [#5-02]; It covers things that school doesn't. [#3-07]</i>
Connecting and learning from others	<i>The responses from the mentors made me feel what I had to say meant something. It was so neat to learn from other's experiences and how I could relate. [#1-01]; (I liked) how there were other clients with a disability struggling with the same thing I am in terms of job searching that I can sort of relate to. [#2-02]; The different aspects and questions that were presented made me think about problem-solving skills...you don't feel alone and you get different viewpoints from others. [#2-04]; As someone who is preparing themselves for work, I found that reading the strategies that were provided by the other participants in the study group was very helpful to me, as I can utilize them and apply them to my own job search. [#1-03]</i>	<i>My favorite part of the program was reading other participants responses. [#4-06]</i>
Module content	<i>Most topics were very thought provoking which allowed me to develop thought-out personal answers. [#1-02]</i>	<i>Being able to read other posts and see the differences and similarities. I enjoyed the modules (power points) with useful knowledge. [#4-03]; I feel like the program did a good job of teaching how to get a career with a disability. [#3-07]</i>
Areas for improvement	<i>The website was challenging to use. [#5-03]</i>	<i>More people on at once and face-to-face interactions. [#5-03]; If there were more interaction and discussion, it would be more useful. [#4-06]; I already struggle with communicating to strangers so I was reluctant to comment on others posts. [#4-03]; I just hope next time the website works better...whenever I tried to log in I had a problem with my password. [#5-01]</i>

Table 4. Descriptive statistics on participant outcomes by treatment condition.

Variable	Pretreatment, mean (SD)		Posttreatment, mean (SD)		Test statistic <i>F</i> (<i>df</i>)	<i>P</i> value	Effect size (Cohen <i>d</i>)
	Experimental	Control	Experimental	Control			
Self-determination	17.76 (8.67)	22.77 (7.59)	17.94 (7.33)	25.50 (9.31)	3.01 (27)	.97	0.9
Career maturity	13.93 (4.59)	15.00 (4.27)	14.11 (4.55)	15.57 (4.57)	0.256 (27)	.61	0.32
Social support	56.82 (8.04)	55.22 (14.92)	51.82 (16.24)	59.22 (13.84)	2.10 (27)	.16	0.49

Discussion

Principal Findings

Improving the employment preparation skills of young people with disabilities is important for enhancing their inclusion in the workforce. Youth with disabilities continue to experience higher unemployment rates compared with youth without disabilities [7,45]. Consistent research shows that mentoring can help to improve academic and employment outcomes [13]. Offering peer mentorship through an accessible format may help to provide social support to youth with disabilities while engaging them to learn about employment preparation skills [6,13]. Our study addresses an important gap in the literature by offering a Web-based, group-based peer mentoring intervention to help youth with physical disabilities prepare for employment. Many youth with physical disabilities have difficulty accessing vocational training. A virtual learning environment can offer a space for participants to access key resources [46].

Our results indicate that the *Empowering youth towards employment* intervention was feasible and acceptable to the participants. Our findings show that the majority of participants were satisfied with the intervention and would recommend it to other youth. In the qualitative feedback, participants reported that the program was beneficial for employment preparation and interacting with other youth that have a disability, especially those in the experimental groups. Participants in the control groups reported satisfaction with content and employment readiness. These results are encouraging and help to show that there is a need for the content. Few participants within the control group described social interactions or sharing experiences with other youth, which could be because of the lack of a mentor to facilitate conversation. We also observed that among the few participants that posted in the control group, there was very little interaction between the participants. Previous studies show that having a moderator in a discussion forum can help participants to feel at ease while also providing information [46]. Given that both the experimental and control groups reported valuing the support provided, further work is

needed to fully tease apart how much these sessions were valued because of the mentor's presence or because of the contact with and shared information with peers and overall social support.

The findings revealed that the self-reported engagement in the study was somewhat lower than that expected for participants in both the control and experimental groups. Other research similarly shows that maintaining engagement of participants in an e-mentoring study can be difficult [47,48]. The relatively low engagement in our study indicates that the intervention format and length might need adjustment and further testing. We decided to have a 4-week version of this e-mentoring intervention to account for youth's busy schedules during the school year; thus, we ran our intervention in the summer months. Their low engagement levels could have been because of youth's involvement in other activities and because they lacked time to participate fully in the program. Future studies should consider how best to keep youth engaged, perhaps through reminders or having a variety of different components (face-to-face, either in person or through *Skype*, and Web-based, etc), or embedded in another type of therapy or educational program. It may also be helpful to organize more synchronous, group-based discussions.

The findings of our secondary outcomes showed no significant differences between the experimental and control groups on self-efficacy, self-determination, or social support. These results differ from the outcomes of our 12-week version (ie, 1 weekly topic) of this intervention [6], where we found a significant improvement in self-determination in the experimental group compared with the controls. Although other studies on e-mentoring interventions for youth with disabilities have shown significant improvements in self-determination [20,49], very few of these studies had RCT or other rigorous designs [14]. Of the few studies that have had an RCT design, that is, Ammerlaan et al [49] explored the impact of their interactive, group-based website for youth with juvenile arthritis, they also found no significant differences between the experimental and control groups on self-efficacy, quality of life, or self-management. Therefore, further testing and RCTs are needed to better understand how we can best design (ie, format, length and content) an intervention for youth with physical disabilities. In altering the original format of our intervention from 12 weekly topics [38] to 3 topics per week over 4 weeks (ie, the study reported here), we hoped to increase engagement and potential outcomes; however, this was not the case. Although youth reported that they liked this format, there were no significant improvements in the outcome we measured. These results suggest that it may take time to see a change in social support, self-determination, and career maturity. Further research is needed to continue testing the optimal dosage and format of the intervention.

Our nonsignificant findings contrast some other studies using an e-mentor approach for youth with disabilities. For example, Bell [50] focused on youth with vision impairments and found significant improvements in career decision-making. The format of their intervention involved several components including face-to-face, group-based activities, email, and phone calls [50]. Meanwhile, Kim-Rupnow and Burgstahler [51] had a Web-based group mentoring program for youth with various

types of disabilities and found significant improvements in career options, employment preparedness, perseverance, social skills, and self-advocacy. These previous studies suggest that several components are needed to help keep youth engaged in the program, an issue that was noted by the youth's self-reported engagement and also in their postsurvey comments. Most other research using an e-mentor intervention for youth with disabilities do not have a control group [14] and might account for some of the nonsignificant findings. Our results could also reflect that youth need more time to develop their career decision-making skills, which is something that may not be captured within a 4-week time frame.

Although the qualitative feedback from participants was encouraging regarding the social support they received during the intervention, this was not sufficient for detecting a significant difference in outcomes between the experimental and control groups. These findings may be because of it being a pilot and having insufficient power to detect changes. It could also be partly a result of the format or length of the intervention. For example, some youth expressed that they wanted more group-based and synchronous chats, which could help to improve their engagement and overall feeling of support. Other research on e-mentoring for youth with disabilities shows that such a forum can offer solution-focused support and shared experiences [52]. Previous studies show that a limitation of electronic forms of mentoring include that such forms of communication lack verbal cues and can result in impersonal relationships [14].

Limitations and Future Directions

There are several limitations within this study that are important to consider. First, given that this was a pilot feasibility RCT, the study may have been underpowered and we did not reach our original target sample size [6] that was recruited from 1 site, which limits the generalizability of the findings. Future studies should aim to recruit from more centers and also offer youth different timing options to maximize the sample size and power. We also recognize that the uneven distribution of experimental and control groups, which was because of a timing issue of recruitment (ie, during the summer months), could have affected the power and significance of the findings. We encountered issues with recruitment and had a low overall response rate. Future studies should consider recruiting through different mediums (ie, social media and Web-based forums), broadening the inclusion criteria (age range, disability type, and employment experience), and partnering with other organizations. Second, we were unable to establish how much time each participant spent reviewing the modules, which could influence their employment preparation skills, career maturity, and self-determination. Third, there were several technical difficulties with the website over the course of the study (ie, difficulties logging in, glitches because of website upgrades, etc). Fourth, there was staff turnover in the mentors who lead the discussion forum. Although they were provided the same training and had a similar level of experience, this could have affected outcomes. Fifth, we included various types of physical disabilities that differ in nature and how this could influence self-management of their condition [53] and youth employment. Future studies should consider focusing on a specific disability

type. Finally, the dosage of the intervention varied depending on how much people logged in and may have influenced outcomes. Other studies on e-mentoring for youth with disabilities have involved email, virtual environments, *Skype* video calls, and phone calls. Future research could consider incorporating some of these formats [14]. A recent review of e-mentoring for youth 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 [14]. Thus, future studies should consider offering more than 1 approach to maximize youth's engagement in the study. Further work is also needed to explore any potential gains from such interventions on employment over the longer term.

Conclusions

In conclusion, the *Empowering youth towards employment* intervention demonstrated that it is feasible and acceptable to the youth participants; however, we found no significant improvements in social support, self-determination, or career maturity compared with the controls.

Further adaptations to the format (including various components) and length of the intervention are needed to increase the acceptability to larger proportions of youth with physical disabilities. An RCT with an adequate sample size is required to assess the overall effectiveness of the program.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-eHEALTH checklist (V 1.6.1).

[PDF File (Adobe PDF File), 132KB - [pediatrics_v2i1e12653_app1.pdf](#)]

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Abbreviations

e-mentor: electronic mentor

e-mentoring: electronic mentoring

RCT: randomized controlled trial

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Original Paper

“If You Let Them, They Will Be on It 24 Hours a Day”: Qualitative Study Conducted in the United States Exploring Brazilian Immigrant Mothers’ Beliefs, Attitudes, and Practices Related to Screen Time Behaviors of Their Preschool-Age Children

Ana Cristina Lindsay^{1*}, DDS, MPH, DrPH; Carlos André Moura Arruda^{2*}, BA, MPH; Márcia MT Machado^{2*}, RN, PhD; Mary L Greaney^{3*}, MPH, PhD

¹Department of Exercise and Health Sciences, University of Massachusetts Boston, Boston, MA, United States

²Department of Community Health, School of Medicine, Federal University of Ceara, Fortaleza, Brazil

³Department of Kinesiology, University of Rhode Island, Kingston, RI, United States

* all authors contributed equally

Corresponding Author:

Ana Cristina Lindsay, DDS, MPH, DrPH
Department of Exercise and Health Sciences
University of Massachusetts Boston
100 Morrissey Boulevard
Boston, MA, 02125
United States
Phone: 1 6172877579
Fax: 1 6172877500
Email: Ana.Lindsay@umb.edu

Abstract

Background: The increasing prevalence of excessive screen time (ST) among children is a growing public health concern, with evidence linking it to an increased risk of overweight and obesity among children.

Objective: This study aimed to explore the beliefs, attitudes, and practices of Brazilian immigrant mothers living in the United States related to their preschool-age children’s ST behaviors.

Methods: A qualitative study comprising 7 focus group discussions (FGDs) was conducted with Brazilian immigrant mothers living in the United States. All FGDs were audio-recorded and professionally transcribed verbatim. The Portuguese transcripts were analyzed using thematic analysis.

Results: In total, 37 women participated in the FGDs. Analyses revealed that although most mothers expressed concerns for their preschool-age children’s ST, nearly all viewed ST as an acceptable part of their children’s daily lives. Furthermore, mothers perceived that ST has more benefits than disadvantages. The mothers’ positive beliefs about (eg, educational purposes and entertainment) and perceived functional benefits of ST (eg, ability to keep children occupied so tasks can be completed and facilitation of communication with family outside the United States) contributed to their acceptance of ST for their preschool-age children. Nevertheless, most mothers spoke of needing to balance their preschool-age children’s ST with other activities. Mothers reported using several parenting practices including monitoring time and content, setting limits and having rules, and prompting their children to participate in other activities to manage their preschool-age children’s ST.

Conclusions: This study provides new information on the beliefs, attitudes, and practices of Brazilian immigrant mothers living in the United States related to their preschool-age children’s ST. Study findings revealed several potentially modifiable maternal beliefs and parenting practices that may provide important targets for parenting- and family-based interventions aimed at limiting preschool-age children’s ST.

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KEYWORDS

Brazil; immigrants; mothers; child, preschool; screen time

Introduction

Background

The increasing prevalence of excessive screen time (ST) among children is a growing public health concern [1-3]. ST is time spent with any type of screen, including mobile phones, tablets, televisions (TVs), video games, computers, etc [4]. A growing number of studies have documented excessive ST (≥ 2 hours per day) among preschool-age children (aged 2 to 5 years) [4-11], and some studies have linked excessive ST to an increased risk of overweight and obesity among children [4,12,13].

Preschool-age children's increasing ST has prompted several countries, including the United States, to develop ST guidelines [4,14,15]. The American Academy of Pediatrics (AAP) ST guidelines updated in 2016 encourage parents and guardians of preschool-age children to limit ST to equal to or less than 1 hour per day [4]. In addition, AAP recommends that parents and guardians restrict ST during mealtimes and keep ST devices including TVs out of children's bedrooms [4]. Nevertheless, evidence shows that many children have more than 1 hour of ST daily, have TVs in their bedrooms, and watch TV during meals [16-18]. Moreover, research conducted in the United States has identified socioeconomic and racial and ethnic disparities in ST among children [18-21].

Much of the available research examining ST among children has focused on TV viewing and indicates that the amount of TV time and presence of a TV in a child's bedroom are associated with an increased risk of overweight and obesity [22-25]. Similarly, recent research is starting to document that the use of other ST devices is associated with an increased risk of overweight and obesity [12,13,26,27]. Several mechanisms have been hypothesized to explain this association, including the idea that ST displaces physical activity and contributes to its decrease [1,4,24]. It also has been hypothesized that ST leads to an increased energy intake due to eating during ST, and that exposure to food marketing affects children's food and beverage attitudes, preferences, purchase requests, and consumption (eg, advertisement of energy-dense and low nutrient-dense foods). Furthermore, it also has been hypothesized that ST contributes to reduced sleep duration and increased sedentary time (ie, low energy expenditure), which contribute to an increased weight status [4,12,24,26-28].

Interventions designed to reduce excessive ST in early childhood may have health benefits during childhood but may also help reduce chronic disease risks when healthy ST behaviors are carried into adulthood [13,29-31]. Many habits children develop during early childhood are established at home, making the home an important early social environment where children develop habits that impact their weight status and health [30-33]. Parents play a central role in establishing a home environment that promotes or hinders the process of children developing healthy habits including ST [34,35]. Evidence suggests that parents' beliefs, attitudes, role modeling, and ST parenting practices (eg, establishing and enforcing ST rules and monitoring ST) influence children's ST [34-36]. Recent studies have begun to document parental perceptions of young children's ST and

parental ST practices [33-36]. However, research examining parenting and early childhood ST among low-income, minority, and immigrant parents is still limited [8,19-21,26]. This research is needed to develop and refine interventions tailored to meet the needs of these population groups that are at increased risk of obesity and related chronic diseases [6,13,24,28].

Objectives

Brazilians are a rapidly increasing Latino immigrant population group in the United States, but only limited research has focused on health-related behaviors that may affect Brazilian immigrant children's health [37]. Brazilians share many cultural characteristics with other Latin American population groups but represent many different ethnic backgrounds, including Africans, Europeans, and native Brazilians [37,38]. Portuguese is the official language of Brazil and an important cultural difference between Brazilians and other Latin American population groups that primarily speak Spanish [38]. According to the 2006 to 2010 American Community Survey of the approximately 400,000 Brazilian immigrants living in the United States, nearly half live in the northeastern states, mostly in Massachusetts (MA, about 19%), New York, and New Jersey [37]. A recent study conducted in the Greater Boston area of MA found that 48.2% of Brazilian immigrant children (aged 3 to 12 years) were overweight or had obesity [39].

Understanding parents' beliefs, attitudes, and practices related to their preschool-age children's ST is essential for the identification of modifiable factors that can be addressed in interventions designed to discourage excessive ST and ultimately reduce the risk of obesity. No existing research conducted in the United States, to our knowledge, has examined Brazilian immigrant mothers' beliefs, attitudes, and practices related to preschool-age children's ST. This exploratory qualitative study addresses this research gap.

Methods

Study Design, Setting, and Sample

This study was conducted in 2 MA cities and is part of a larger ongoing mixed-methods research study (113 unique families to date) with Brazilian immigrant families living in the Greater Boston area, MA, examining parenting styles and parenting practices related to the risk of childhood obesity (eg, eating, physical activity, sleep, and ST) [40-44].

Focus group discussions (FGDs) were used to gain an in-depth understanding of mothers' beliefs, attitudes, and practices related to ST behaviors of their preschool-age children. FGDs were used, as they are valuable techniques for working in diverse cultural settings because of the rich information the discussion reveals [45].

Ethics and Consent

This study received ethical approval from the University of Massachusetts-Boston Ethics Board (IRB # 2013060).

Data Collection

Participants were recruited (March 2017 to August 2017) through flyers posted at local Brazilian businesses and

community-based social and health services agencies, as well as through announcements and events at predominantly Brazilian churches. Interested participants either called the telephone number listed on the flyers or spoke to the study staff at church events. The study staff assessed eligibility and invited women to participate if they had at least one child aged 2 to 5 years, were of Brazilian ethnicity, were born in Brazil, and had been living in the United States for at least 12 months. Participants also were recruited using a snowball sampling technique [43], with women enrolled in the study asking their Brazilian friends with preschool-age children if they would be interested in participating in the study.

Before each FGD, the moderator (ACL) explained in Portuguese the study's purpose, FGD procedures, and study confidentiality and obtained written and oral informed consent from all participants. A native Brazilian-Portuguese speaker (ACL), trained in qualitative research methods, moderated all FGDs in Portuguese using a semistructured discussion guide with questions adapted from previous studies [29,44]. The FGD guide explored participants' beliefs, attitudes, and parenting practices related to their preschool-age children's ST. The guide also explored mothers' beliefs, attitudes, and practices related to physical activity and sleep [43,44]. The guide was piloted in an FGD with 4 Brazilian immigrant mothers and then refined (eg, rewording some questions and changing the order of some questions) before use. Data from the pilot FGD were not included in this study.

Before each FGD, participants were asked to think about their preschool-age children when participating in the discussion. A trained, bilingual (Portuguese and English) research assistant (GDA) took notes during all FGDs, which were audio-recorded and lasted between 60 min and 80 min. The moderator and research assistant met for about 15 min after each FGD to identify new themes and review recurring themes that were entered into a grid that was used to follow emerging themes and to determine when data saturation occurred.

FGD participants completed a brief, self-administered questionnaire in Portuguese at the end of each FGD that assessed education, marital status, use of health care services including participation in government-sponsored health and nutrition programs (eg, Women, Infants, and Children and Supplemental Nutrition Assistance Program), and length of time living in the United States. Participants also completed the Short Acculturation Scale for Hispanics, a 12-item measure scale validated for use with Latinos, including Mexican Americans, Cuban Americans, Puerto Ricans, Dominicans, and Central and South Americans [46].

Data Analysis

A professional transcriptionist and native Brazilian speaker transcribed all audio recordings verbatim. After this, 2 experienced qualitative researchers and native Portuguese speakers (ACL and CAMA) analyzed the Portuguese transcripts using thematic analysis, an iterative process of coding the data in phases to create meaningful patterns [47,48]. Each researcher read several transcripts numerous times to become familiar with the content and generate initial codes [48]. They then independently coded transcripts manually but met regularly to

discuss coding and to identify and resolve disagreements in coding [48,49]. The coded text describing similar ideas was grouped and sorted to identify emergent themes and subthemes. Finally, salient text passages were extracted and translated into English to be used as illustrative quotes for the emergent themes. Descriptive statistics and frequencies were calculated for data collected in the sociodemographic survey using Microsoft Excel 2008 (Microsoft, Redmond, WA, USA).

Participants

A total of 7 FGDs (range of 4 to 7 participants per FGD) with Brazilian immigrant mothers (n=37) were held at the 2 local churches between April and August 2017. Of the 37 mothers, 7 (approximately 19%) were recruited through the use of snowball sampling technique.

Mothers were aged 26 to 41 (mean 35.3, SD 2.8) years. Most participants were married (34/37, 92%) and had 2 children (33/37, 89%). The majority (21/37, 72%) had graduated from high school and owned their own housecleaning business (34/37, 92%). Approximately half (19/37, 51%) reported a family income of US \$40,000 or less, which is considered as low income for a family of 4 in MA, whereas the rest reported an annual income between US \$40,000 and US \$60,000, which is considered to be a low-middle income [49]. Participants were from 3 main regions of Brazil (eg, the Southeast [eg, Espirito Santo, Sao Paulo, and Minas Gerais], the South [eg, Santa Catarina], and the Midwest [eg, Goias and Mato Grosso]), with the majority (22/37, 65%) from the state of Minas Gerais. In addition, the majority spoke Portuguese at home (34/37, 92%), watched TV in Portuguese (35/37, 95%), and reported that most of their friends were Brazilians (32/37, 87%). Mothers had lived in the United States for an average of 6.7 (SD 2.84) years, and their mean acculturation score was 1.43 (SD 0.77), indicating that they identified more closely with Brazilian culture than with that of the United States.

Results

Overview

A total of 7 FGDs were conducted before saturation, with no new themes or subthemes emerging during the last FGD. Thematic analysis identified 9 emergent themes with 11 subthemes related to ST, which were classified into 2 domains: (1) mothers' beliefs and attitudes toward their preschool-age children's ST behaviors (5 themes and 8 subthemes), and (2) the home's social and physical environment impacts on preschool-age children's ST behaviors (4 themes and 3 subthemes; see [Multimedia Appendix 1](#)). [Multimedia Appendix 2](#) shows themes and subthemes with representative quotes translated to English to illustrate findings.

Domain 1: Mothers' Beliefs and Attitudes Toward Their Preschool-Age Children's Screen Time Behaviors

Theme 1: Perceptions and Concerns About Preschool-Age Children's Screen Time Behaviors

All mothers reported that their preschool-age children had ST, with most reporting they had between 2 and 3 hours of ST per day. Mothers explained that ST occurred throughout the day

but that it was most common in the early morning when they (parents) were getting ready for work and in the evening when they (mothers) were preparing dinner or doing household chores, during dinner-time, and before their children's bedtime. Some mothers discussed that their preschool-age children had more ST on the weekends than during the week.

Moreover, most mothers reported that they had some concern about the quantity of their preschool-age children's ST. In addition, a couple of mothers felt that their preschool-age children were "addicted" to ST. These mothers stated that their children would often become emotional and "have meltdowns if their devices were taken away." In contrast, a few mothers reported not being concerned about their preschool-age children's ST because they perceived their children to be active and healthy.

Subtheme 1.1: Mothers Perceive Benefits and Disadvantages of Screen Time

Nearly all mothers spoke of ST having benefits for their preschool-age children, with most perceiving more benefits than disadvantages. Mothers viewed ST as a source of education and felt that their children's cognitive development benefitted from educational ST. In addition, several mothers mentioned that because their children are growing up in a digital era, learning digital skills from a young age will be beneficial when their children are older. A few mothers spoke with pride of their preschool-age children's skills using different digital devices (eg, mobile phones, tablets, and computers). Furthermore, mothers spoke of ST allowing their children to easily communicate with family and friends in Brazil using video chats. Several mothers mentioned that their children were able to get online on their own to communicate with relatives in Brazil.

Despite a generally positive view of ST, many mothers also felt that ST has negative consequences for their preschool-age children as it can interfere with children's outdoor play, sleep, interest in interacting with others, as well as family time. A few mothers also stated that ST, with the exception of watching TV, was a solitary activity for their preschool-age children, and they thought excessive ST might lead to decreased social interactions.

Theme 2: Reasons for Screen Time

Mothers reported 3 main reasons for their preschool-age children's ST: (1) entertainment, (2) education, and (3) as a parenting tool. The majority of mothers mentioned that their children used ST for entertainment, including watching videos and cartoons, playing electronic games, etc. Traditional TV sets, tablets, and mobile phones were the devices children used most often for entertainment. Most mothers also reported that their preschool-age children used ST to watch educational programs that taught them language and math skills (eg, counting, shapes). Many mothers allowed ST to safely occupy their children while they did household chores or ran errands with their preschool-age children. In addition, a few mothers used ST as a parenting tool to manage their preschool-age children's behavior in public.

Theme 3: Mothers Accept Screen Time as an Integral Part of Children's Daily Lives

Although most mothers reported that they had some concern about the amount of ST, most of them accepted ST as a part of their preschool-age children's lives. Mothers said that their children are growing up in a digital era, with widespread access to and of technology, and felt that it is important to recognize and accept that their children are growing up in different times and that technology is now an integral part of daily life.

Subtheme 3.1: Mothers Perceive a Need for Balance

Despite an overall acceptance of ST as an integral part of their preschool-age children's daily lives, most mothers felt that it is important to find a balance between allowing their children to have ST and encouraging them to be active and play outdoors. Nonetheless, the majority of mothers reported that they found this challenging.

Theme 4: Socioenvironmental Influences on Screen Time

As discussed below, mothers reported that their social and physical environment influenced their children's ST.

Subtheme 4.1: Increased Accessibility and Affordability of Technology in the United States

Mothers talked about the accessibility and affordability of technology in the United States (vs in Brazil) and said that this contributed to their preschool-age children's increased ST. Several mothers reported that although ST devices were less accessible and more costly in Brazil, technology had also become part of daily life of their family members and friends in Brazil.

Subtheme 4.2: Siblings Influence Preschool-Age Children's Screen Time

Several mothers mentioned that older siblings influenced their preschool-age children's ST behaviors. Mothers explained that their preschool-age children were exposed to multiple types of ST devices at a younger age than their older children, as older siblings had and used many types of ST devices.

Subtheme 4.3: Preschool-Age Children's Screen Time Is Influenced by Children's Friends

Nearly all mothers spoke of social pressures for children's ST and access to technology. They explained that within their children's social environments (eg, school, neighborhood, and social groups), ST was the norm and that this contributed to an expectation and acceptability of ST being part of daily life for their family.

Subtheme 4.4: Caregivers Influence Preschool-Age Children's Screen Time

Mothers with preschool-age children enrolled in daycare spoke of their children's daycare having policies related to the use of TV and personal ST devices (eg, limited TV watching, not allowing ST devices). Mothers felt that these policies reduced their preschool-age children's daytime ST. In contrast, a few mothers whose children were cared for by grandmothers or other relatives when they were working mentioned that their preschool-age children had excess ST during the day. Most of

these mothers felt that it was difficult to monitor and restrict their preschool-age children's ST when relatives were caring for them.

Subtheme 4.5: Adult Family Members and Parents' Friends Influence Mothers' Perceptions of Screen Time and Their Preschool-Age Children's Screen Time

Mothers spoke of their perceptions of ST and their management of ST being influenced by their husbands, family members, and friends. Some mothers mentioned that their husbands were less concerned about and more accepting of their preschool-age children's ST and that this made them wonder whether they were worried too much.

As discussed previously, a few mothers felt that having relatives care for their preschool-age children impacted their children's ST. Mothers reported that they often disagreed with relatives about the amount of ST their children should have but felt they have little control over their preschool-age children's ST when they are at work. In addition, some mothers reported valuing the opinion of their friends who limited ST and felt that if other parents were monitoring and limiting ST, it was easier for them to do the same.

Subtheme 4.6: Parents' Screen Time Behaviors Influence Children's Screen Time

Across all FGDs, nearly all mothers felt that their ST habits influence their preschool-age children's. They recognized the importance of adults modeling healthy screen use, but almost half acknowledged that they not always do this, with several mothers mentioning that they were "always on" their mobile phones. In addition, some mothers felt it was difficult to set and enforce ST limits for their children when they were often on their own devices.

Theme 5: Screen Time Is Influenced by the Weather

Across all FGDs, mothers reported that their preschool-age children have more ST during the cold weather when their children spent more time indoors and the days were shorter (getting dark earlier). Some mothers mentioned that their children have less ST during the warmer weather months (eg, summer) when they have considerably more opportunities to play outdoors.

Domain 2: The Home's Physical and Social Environment Impacts Children's Screen Time Behaviors

Theme 6: Screen Devices Readily Available at Home

Mothers reported having multiple ST devices at home including TV sets, video game consoles, tablets, iPads, and mobile phones. Mothers perceived that this widespread availability of and access to multiple types of ST devices (stationary and mobile) impacted their preschool-age children's ST throughout the day. Across all FGDs, mothers mentioned that the affordability of ST devices in the United States increased their children's access to these devices. Mothers spoke of having more disposable income since immigrating and mentioned that this afforded their families to have multiple types of ST devices. In addition, some mothers said that the availability of multiple ST devices (mobile and stationary) made it very challenging to manage their children's

ST. Some mothers viewed personal mobile devices as being more problematic to manage than traditional TVs.

Theme 7: Watching Television and Playing Video Games With Their Children

Some mothers reported that they and especially their husbands watched TV and played video games with their children. For example, several mothers mentioned that their husbands liked to watch sports (eg, soccer matches, car races) with their children. In addition, a few mothers stated that they often had the TV on in the background while their children were playing and when they were doing daily household chores.

Theme 8: Parenting Practices to Manage Children's Screen Time

The majority of mothers spoke of the importance of managing their preschool-age children's access to and use of ST devices. Mothers reported that they monitored their preschool-age children's ST (time and content), set limits, and implemented rules (eg, no TV during meals, no more than 1 straight hour of ST) to manage ST use. Mothers also spoke of prompting their preschool-age child to be active and play outdoors in an effort to reduce ST. Specific parenting practices used by mothers to manage their children's ST are discussed below.

Subtheme 8.1: Monitoring Screen Time and Content

Most mothers monitored the amount and content of their preschool-age children's ST to ensure that their children were viewing age-appropriate content. Moreover, although some mothers monitored the amount of ST, several reported that it was easy to lose track of ST when they were not at home or when they were busy at home.

Subtheme 8.2: Implementing Screen Time Rules Can Be Challenging

Some mothers reported having rules for ST such as time limits in the morning and evening, no ST during mealtime, etc. Furthermore, a few mothers mentioned hiding the TV remote control and their children's tablets as a strategy to reduce ST use. Nevertheless, several mothers acknowledged that setting limits and implementing rules are challenging. Finally, a few mothers reported using "warnings" as a strategy to help their preschool-age children transition out of ST to another activity. These mothers felt that giving their children a "time's up warning" helped avoid meltdowns. A few mothers admitted to making exceptions and "breaking set rules" and using ST when they needed a break.

Subtheme 8.3: Prompting Children to Do Something Else

Mothers spoke of prompting their children to do something else (eg, play outside, color, and play with toys) as a frequent strategy to reduce their children's ST or as a strategy to end ST.

Theme 9: Mothers' Confidence in the Ability to Manage Children's Screen Time

When queried on their ability to manage their children's ST, some mothers reported they were confident in their ability to monitor and limit their preschool-age children's ST. In contrast, others felt that managing their children's ST is challenging, with several mothers stating that it is easier to set a rule but

enforcing it in a sustainable way is more difficult. Moreover, a few mothers explained that parents need to agree on managing ST, and a few mothers said that sometimes their husbands would not set or enforce ST rules.

Discussion

Principal Findings

To date, there is a paucity of information available on how minority and immigrant parents perceive and manage their preschool-age children's ST [8,19-21,31]. In addition, to our knowledge, no studies have focused on ST of preschool-age children of Brazilian immigrant families living in the United States. To address this gap, this qualitative study explored Brazilian immigrant mothers' beliefs, attitudes, and practices related to their preschool-age children's ST behaviors. This information is essential for the development and implementation of culturally sensitive interventions that are compatible with Brazilian immigrant parents' and families' beliefs, attitudes, and practices related to children's ST.

Although we asked mothers to think of their preschool-age children when discussing the FGD topics, several mothers discussed these topics within the context of the whole family, including older and younger children. This contextual discussion is consistent with previous qualitative research, including our own [21,30,50,51], and indicates the importance of the family within Latino communities. It also suggests that the family should be considered the unit of change and that interventions focusing on promoting healthy ST will likely be more successful if they consider the entire family unit, including adults (eg, mothers, fathers, and other relatives such as grandmothers) and children (younger and older children).

Although most mothers in this study expressed concerns for their preschool-age children's ST, nearly all viewed ST as an acceptable part of children's daily lives. Mothers spoke of their children growing up in a digital world with widespread use of technology and mentioned that this was very different from when they were children in Brazil. These findings are consistent with previous research [13,28,52,53] and suggest that successful interventions will be those that acknowledge the current reality of ST as an integral part of a family's life and help parents identify positive ways to expose their children to ST in ways that are compatible with their developmental age. Interventions should focus on helping parents identify quality ST while adhering to current ST recommendations.

This study's findings revealed that mothers perceived that ST had more benefits than disadvantages. Overall, mothers perceived that the information and skills that their children are gathering and learning during ST would serve their children well in the future. Nearly all mothers reported that ST was an acceptable source of entertainment if not excessive. Mothers also mentioned that ST facilitated regular communication with family and friends in Brazil. Finally, mothers felt that allowing their children ST aided in their ability to manage household chores and complete errands as it kept their children occupied and safe. Previous research suggests that positive beliefs (eg, educational purposes and entertainment) and functional beliefs

(eg, mothers getting things done and regular communication with family living abroad) are important reasons for the parents' acceptance of ST for their young children [54-57]. This study's findings in tandem with the extant research further reinforce the importance of intervention messages incorporating parents' positive and functional beliefs of ST for their preschool-age children and framed within the social context of the day-to-day life of immigrant, working families.

Mothers in this study viewed that all family members as well as their friends and their children's friends influenced their preschool-age children's ST habits. In addition, mothers spoke of their social networks influencing their views and acceptance of ST as part of children's daily life. These findings concur with previous research documenting interpersonal influences on children's ST behaviors [58-60] and suggest the importance of addressing these influences to promote healthy ST behaviors among preschool-age children of Brazilian immigrant families.

Although more research is needed, it is worth noting that some mothers participating in this study reported that their husbands and partners did not perceive their preschool-age children's ST behaviors as problematic and expressed minimal or no concerns for their children's ST. In addition, most mothers reported their husbands watched TV and played video games with their children, which is consistent with previous research conducted among other populations [50,61]. This is important as research shows that children have increased ST when parents have ST themselves [50,61-64]. Moreover, many mothers participating in this study reported limited support from their husbands in their efforts to set up and enforce rules to limit ST. Previous studies suggest that mothers and fathers have different parental influences on their children's ST behaviors and both should be included in interventions [61-63]. Our findings, combined with those of previous research, suggest that future parenting interventions designed for Brazilian immigrant families should be family-focused and involve other family members, including fathers. In addition, interventions should address possible incongruent beliefs and concerns of parents within the same household and campaign for awareness among fathers of the adverse consequences of excessive ST for young children.

In this study, several aspects of the home's social and physical environment emerged as influences on preschool-age children's ST including the accessibility to and availability of multiple ST devices, which was perceived as providing young children having older siblings with early and frequent ST exposure. Furthermore, parents viewed their ST as influencing their preschool-age children's ST. The results of this study are similar to those of previous research that indicate an association between the home's social and physical environment and the development of children's early behaviors including ST [11,19,30,33,41,65]. This finding suggests that family-centered interventions should address not only children's but also parents', siblings', and other family members' ST and incorporate parental role modeling of healthy ST behaviors. Most Brazilian immigrant mothers participating in this study mentioned the importance of finding a balance for their children's screen use. These findings are important, and suggest that interventions should be designed to increase parents' awareness about the negative consequences of excessive ST

and highlight the importance of limiting their preschool-age children's ST.

Consistent with previous research [10,21,26,64-68], mothers participating in this study used several parenting practices such as monitoring time and content, setting limits and having rules, and prompting their children to do something else to manage their preschool-age children's ST. Previous research suggests that parental monitoring, especially maternal ST monitoring, is associated with less ST for children [56,62]. Similarly, previous evidence suggests that setting limits and having ST rules are associated with children's ST [34,56,62,63]. Nevertheless, several mothers in this study acknowledged that it can be challenging to sustain and enforce parenting practices to manage their children's ST, especially given the availability of multiple screen devices at home. These findings are supported by previous research [57] and suggest the need for interventions that promote the development of parenting skills to enhance parents' confidence to set and enforce family rules to promote healthy ST.

Limitations

Study results should be considered in light of study limitations. The findings are based on a nonrandom and purposeful sample of low-income, Brazilian immigrant mothers in 2 MA communities, which limits generalizability. There is also a possibility of selection bias as mothers with a heightened interest in or awareness of the importance of child health behaviors may have been more likely to participate in the study. Moreover, the use of snowball sampling to recruit participants might have resulted in the recruitment of study participants who share similar beliefs, attitudes, and behaviors related to ST of their preschool-age children. Thus, further research is needed to

increase generalizability and to explore whether results apply to a broader group of Brazilian immigrants. In addition, this study did not objectively assess children's ST and sedentary behavior, and this is a limitation, given that evidence suggests that parents' sedentary behaviors including ST influence their children's behaviors.

Finally, this study included only mothers, and this is a limitation given the increasing evidence suggesting the importance of including both parents in child health promotion and obesity prevention research and interventions [62,69]. Future research can address these limitations by exploring beliefs, attitudes, and behaviors of preschool-age children and their Brazilian immigrant parents (mothers and fathers) from other communities across the United States, selecting a larger sample size and employing multiple data collection methods, including both qualitative and quantitative methods, and objectively assessing parents' and children's ST.

Conclusions

This qualitative study provides new information on the beliefs, attitudes, and practices of Brazilian immigrant mothers living in the United States related to their preschool-age children's ST behaviors. Study findings revealed several potentially modifiable maternal beliefs, attitudes, and parenting practices that may provide important targets for parenting- and family-based interventions aimed at promoting children's healthy ST. Future research should explore Brazilian immigrant fathers' and grandparents' beliefs, attitudes, and parenting practices related to preschool-age children's ST. This information will be important for the design of ST interventions tailored to meet the needs of Brazilian immigrant children and families.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Emergent themes and subthemes identified in the analyses.

[PDF File (Adobe PDF File), 20KB - [pediatrics_v2i1e11791_app1.pdf](#)]

Multimedia Appendix 2

Emergent themes and subthemes with illustrative quotes.

[PDF File (Adobe PDF File), 40KB - [pediatrics_v2i1e11791_app2.pdf](#)]

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Abbreviations

AAP: American Academy of Pediatrics

FGD: focus group discussion

MA: Massachusetts

ST: screen time

TV: television

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Original Paper

A Free Virtual Reality Experience to Prepare Pediatric Patients for Magnetic Resonance Imaging: Cross-Sectional Questionnaire Study

Jonathan Ashmore^{1,2,3}, BSc (Hons), MSc, PhD; Jerome Di Pietro⁴, BA (Hons); Kelly Williams⁵, BSc, PGD; Euan Stokes², BSc; Anna Symons², DipHE; Martina Smith², BSc; Louise Clegg⁶, DCLinPsych; Cormac McGrath⁷, BSc (Hons), PhD

¹Department of Medical Physics and Bioengineering, NHS Highland, Inverness, United Kingdom

²Department of Neuroradiology, King's College Hospital, London, United Kingdom

³Centre for Neuroimaging Sciences, King's College London, London, United Kingdom

⁴Faculty of Life Sciences & Medicine, King's College London, London, United Kingdom

⁵King's College Hospital, London, United Kingdom

⁶South London and the Maudsley NHS Trust, London, United Kingdom

⁷Radiological Sciences & Imaging, Regional Medical Physics Service, Belfast Health and Social Care Trust, Belfast, United Kingdom

Corresponding Author:

Jonathan Ashmore, BSc (Hons), MSc, PhD

Department of Medical Physics and Bioengineering

NHS Highland

Old Perth Road

Inverness,

United Kingdom

Phone: 44 07760712289

Fax: 44 1463704542

Email: jonathan.ashmore@nhs.net

Abstract

Background: A magnetic resonance image (MRI) is a diagnostic test that requires patients to lie still for prolonged periods within a claustrophobic and noisy environment. This can be difficult for children to tolerate, and often general anesthetic (GA) is required at considerable cost and detriment to patient safety. Virtual reality (VR) is a newly emerging technology that can be implemented at low cost within a health care setting. It has been shown to reduce fear associated with a number of high-anxiety situations and medical procedures.

Objective: The goal of the research was to develop a VR resource to prepare pediatric patients for MRI, helping to reduce anxieties in children undergoing the procedure.

Methods: A freely accessible VR preparation resource was developed to prepare pediatric patients for their upcoming MRI. The resource consists of an app and supporting preparation book and used a series of panoramic 360 degree videos of the entire MRI journey, including footage from within the bore of the scanner. The app, deployed via the Android Play Store and iOS App Store, can be viewed on most mobile phones, allowing a child to experience an MRI in VR using an inexpensive Google Cardboard headset. The app contains 360 degree videos within an animated, interactive VR interface designed for 4 to 12-year-olds. The resource was evaluated as part of a clinical audit on 23 patients (aged 4 to 12 years), and feedback was obtained from 10 staff members. In 5 patients, the resource was evaluated as a tool to prepare patients for an awake MRI who otherwise were booked to have an MRI under GA.

Results: The VR preparation resource has been successfully implemented at 3 UK institutions. Of the 23 patients surveyed, on a scale of 1 to 10, the VR resource was rated with a median score of 8.5 for enjoyment, 8 for helpfulness, and 10 for ease of use. All patients agreed that it made them feel more positive about their MRI, and all suggested they would recommend the resource to other children. When considering their experiences using the resource with pediatric patients, on a scale of 1 to 10, the staff members rated the VR resource a median score of 8.5 for enjoyment, 9 for helpfulness, and 9 for ease of use. All staff believed

it could help prepare children for an awake MRI, thus avoiding GA. A successful awake MRI was achieved in 4 of the 5 children for whom routine care would have resulted in an MRI under GA.

Conclusions: Our VR resource has the potential to relieve anxieties and better prepare patients for an awake MRI. The resource has potential to avoid GA through educating the child about the MRI process.

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KEYWORDS

virtual reality; MRI; anxiety

Introduction

The claustrophobic and noisy environment of magnetic resonance imaging (MRI) can be difficult for patients to tolerate and at times can lead to patient movement during the scan or even to the scan being aborted. If the resultant images are undiagnostic, this may require the patient to be rescanned under sedation or general anesthesia (GA). Children represent a particularly sensitive patient group to such effects where the rescan rate and need for GA is considerably higher than in adults. In a recent study it was shown that the use of GA in pediatric MRI has risen from 21% to 28% over 3 years, an effect attributed to the increased use of 3 Tesla MRI systems, which produce superior image quality but have an associated increased sensitivity to patient motion [1].

Despite this increase, previous work has shown that appropriate preparation can successfully reduce the need for anesthesia in younger patients. In one study, through the effective use of multiple preparation resources, anesthesia rates were reduced from 47% to 27% [2]. A variety of methods have been reported to prepare children for MRI including the use of informational videos [3], mock scanners [4], play tunnels, vibrating mats with MRI scanner audio simulations [5], and the use of small scale models for demonstrating the MRI procedure to children [6]. Having a process to avoid anesthesia is also preferred among parents [7,8].

There are numerous benefits to both the patient and the institution in avoiding an MRI scan with GA. With an awake MRI, the risks of possible adverse reaction to GA or other forms of sedation are removed, which although unlikely can still occur [9]. Research has demonstrated that anesthesia can be highly anxiety-provoking for children and parents [10] because there is the need to fast prior to GA and a recovery period requiring them to remain in clinical care for typically 1 to 2 hours. Because the GA requires medical intervention, there are also significant costs associated with the equipment and clinical team required to administer the procedure.

In recent years, the use of virtual reality (VR) in medicine has undergone rapid growth with applications in surgery [11], teaching and training [12], anxiety reduction for medical procedures [13-15], and treatment for a variety of diseases [16-18]. This increase in popularity has been driven by the development of consumer-level VR headsets that use a standard mobile phone (eg, Google Cardboard and Daydream View, Google LLC; Gear VR, Samsung Electronics Co Ltd) or a PC (eg, Oculus Rift, Facebook Technologies LLC; Vive, HTC Corporation) for their computer processing. In particular, the

Google Cardboard format has potential for large-scale distribution, since most modern mobile phones have the technology to be incorporated into a simple, cheap headset to display content in the VR format. Distribution of content is now easily facilitated via YouTube, which has native cardboard compatibility, or Google Play for Android devices and the App Store for iOS devices. Creating VR content is also now more achievable with the availability of consumer-level 360° cameras that allow amateur film makers to create and easily distribute 360° footage for viewing within a VR headset.

In this paper, we report on a freely accessible resource that uses 360° video footage to acclimatize a pediatric patient for an upcoming MRI using VR. The resource was created as a tool to help lower anxiety associated with MRI, reduce motion-related image artifact, and decrease the need for GA by increasing awake MRI compliance.

Methods

The Virtual Reality Magnetic Resonance Imaging Journey

The VR resource was developed to facilitate preparation of pediatric patients for MRI in a number of settings. First, the resource was developed to be used by health play specialists in their role supporting extremely anxious patients. Second, the resource was to be available to patients with upcoming MRI appointments. Information was included in their appointment letter regarding how to download the resource. By using the resource at home, the child would be in a familiar and safe environment that may better facilitate learning and discussion. Third, we used the resource in the MRI waiting area for anxious patients and parents prior to their MRI. Finally, the resource was used during the anesthetic preassessment process several weeks prior to a patient's MRI under GA. In this setting, the resource may help guide the decision regarding whether an awake MRI is achievable. All these use cases were suggested by health play specialists and radiographers whose daily role it was to prepare patients for MRI. Both groups had active involvement in the design of the resource and informed the development from the beginning using relevant insights from their roles in health care. They highlighted the importance of showing the pathway that a child undergoes when having an MRI, specifically focusing on key parts of the journey to help the patient to understand and experience each aspect of their upcoming scan. These included (1) arriving at the reception and the waiting area, (2) participating in the MRI safety screening process, (3) highlighting where the radiographer sits during the scan, (4) introducing the children to the scan room, (5) allowing

them to experience being in the scanner, and (6) saying goodbye after their scan. All elements were captured via 360° video and incorporated into the resource. The use of 360° video rather than computer-generated content facilitated scalability to other sites that could capture custom footage for their own bespoke version. The resource was aimed at children between ages 4 and 12 years, an age group where appropriate preparation can greatly increase the chance that the child will tolerate and lie still for their scan. The resource was deployed as a free downloadable app and a supporting preparation book. Having the two helped facilitate the different interactions required by different patients and provided a choice of resource for the patient to access. The aim of the app was to produce a continually immersive VR experience of the entire MRI journey, easily accessible for home use. The preparation book helped facilitate a greater interaction between clinical staff and anxious patients. Rather than a continual immersive experience, it fostered discussion outside of VR and, when appropriate, the individual 360° videos could be displayed to the patient using the VR headset.

Incorporating the entire MRI journey into the resource was felt to be important since all elements in the journey can induce anxiety for a child. It was hoped that the virtual experience would better allow children to understand their role and the roles of others when coming for an MRI, helping them to feel involved with their own care. It was designed to highlight the expectation of them in the process and facilitated rehearsal of the procedure. The resource aimed to address common questions asked by children coming for an MRI (eg, concerns that the scanner may touch or hurt them). There was a focus to keep the content positive while realistic, using child-friendly terminology (eg, calling the head coil, used to acquire the MRI images, a helmet) together with highlighting that children could watch their own DVD during the scan.

All persons who appeared in the videos or photos provided consent for their footage and pictures to be used according to our standard hospital policies.

Capturing 360° Footage

The 360° degree video footage was captured on a 2016 Gear 360 camera (Samsung Electronics Co Ltd) controlled remotely using a Samsung Galaxy S7 mobile phone. For all footage outside the scanner, the camera was positioned using a monopod with tripod stand base at a typical six-year-old child eye height. This allowed for the feeling of being present from the child's perspective when the videos were viewed within a VR headset. Short video segments were captured where the radiographer and parent actors played out the role as though the child were attending for their scan. We tried to keep the footage length to a minimum time (ideally less than 1 minute) to ensure it

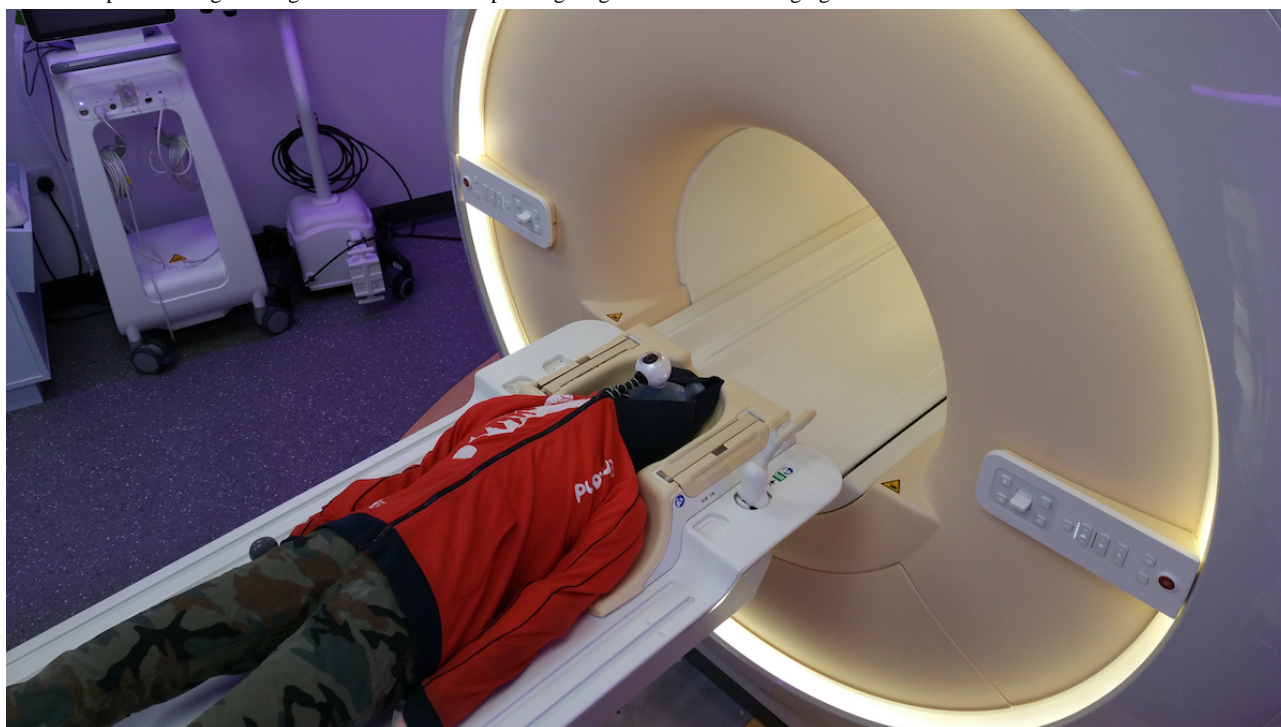
remained engaging for the intended young audience but still informative. Initial attempts were made to move the camera during the journey, but it was found that this movement when displayed in a VR headset created a feeling of nausea and this idea was abandoned. Instead stationary footage was taken from key steps of the journey, and the patient was "teleported" via interactions with the app or preparation book from one area of the radiology department to subsequent areas as they progressed along their journey.

The camera was found to function correctly within an operating 1.5T MRI scanner. Scanners tested included the Magnetom Aera 1.5T (Siemens Healthineers), Signa HDx (GE Healthcare), and the Ingenia and Achieva 1.5T (Koninklijke Philips NV). An initial investigation was undertaken by the Magnetic Resonance Safety Expert (MRSE; JA, CMcG) to assess the safety of the camera within the MRI system, and footage was obtained from within the scanner under direct supervision of the MRSE. It was found that the camera did contain some ferromagnetic components which led to mild attractive forces. The weight of the camera mostly overcame these forces except at the location of highest spatial gradient (at the flaring of the MRI scanner bore). To ensure the camera did not become a projectile, it was taped into place on top of a standard phantom that was supplied with the MRI system.

By fixing the camera onto the phantom, we ensured the scanner would receive a measurable signal allowing it to operate as normal. To provide the illusion of a body for the camera footage, an inflatable mannequin with the head sealed down was dressed in child's clothing, and the camera, attached to the phantom, acted as the head of the mannequin (see [Figure 1](#)).

The 360° footage was successfully obtained during scanner operation with the camera controlled via the Samsung Galaxy S7 phone from within the scan room. Footage was acquired for the localizer and approximately 1 minute of a spoiled gradient echo sequence. In this sequence, the flip angle was reduced to 1 degree to minimize specific absorption rate exposure to the camera. Initially, the camera showed no detrimental effects while in the scanner or after being removed. However, after approximately 10 sessions of capturing footage, the camera started to automatically shut down during footage acquisition within the scanner. At first it was thought the scanner was causing the camera battery to rapidly drain. However, when the camera was removed from the high magnetic field of the scanner, it would operate again as normal, and to the best of our knowledge there was seemingly limited battery drain and no permanent damage. We found it was possible to maximize the camera operating time for filming in the scanner by ensuring the camera was fully charged prior to filming (typically the maximum filming time would be 2 minutes).

Figure 1. Setup for filming 360 degree video within an operating magnetic resonance imaging scanner.



Footage was downloaded to the mobile phone, and the Samsung Gear 360 app was used to stitch the two images from the camera sensors into a single equirectangular image. This stitched image was then downloaded to a MacBook Pro for video postprocessing using the package iMovie v10.1.2 (Apple Inc). Editing steps included cropping the video timeline to remove unwanted footage from the start and end. Volume levels were modified to ensure consistency across the clips, and the volume of the operating scanner was reduced such that it was realistic to what a patient would experience during their scan. Audio from the DVD shown during the scan was not captured and instead was layered over the video during postprocessing to ensure the volume was appropriately set. The editing package iMovie outputs video with a 16:9 aspect ratio, and this was subsequently cropped to a 2:1 aspect ratio using the open-source video transcoder HandBrake (360° video has a 2:1 aspect ratio because the field of view is 360° along the horizontal direction by 180° along the vertical). The final 360° video was injected with metadata using the 360 Video Metadata Tool provided by Google.

The App

The app was created within the Unity development environment (Unity Technologies) and was deployed to both Android and iOS devices via hosting on Google Play and the App Store for free download. The app was designed with a VR format suitable for Google Cardboard-compatible headsets (VR mode) and for use in a standard non-VR format (tablet mode) for patients who did not have a Google Cardboard headset.

The app was designed to be fun and interactive, allowing the child to view the 360° videos in any order or repeat a single video. To maintain a child's interest, the videos were embedded and accessed via a stylized cartoon environment. A virtual character chosen to match the target patient age, complete with

voiceover, was created as a conscious design decision to enable engagement with the target audience.

In tablet mode, swipe and touch interactions were used for selecting and navigating within the 360° videos. In VR mode, the gaze selection method and standard Cardboard buttons were enabled for selecting, pausing, and exiting videos. An initial trial of the app highlighted that many users were not aware of the gaze feature typically used in a VR environment, so a tutorial was built into the app to help the user become accustomed to interacting within VR prior to starting their virtual MRI journey for the first time.

We undertook an iterative development cycle of testing to ensure that the app worked on a variety of devices and platforms. For VR, this required additional optimization to ensure that playback across a wide range of devices did not fall below 60 frames per second, where it is recognized that VR-based nausea can be experienced. Furthermore, to ensure the app supported devices across a range of technical specifications, the playback resolution of the video clip was downgraded from the original 4K resolution to 1920x960. This resulted in minimally reduced video clarity and sharpness but with the benefit of decreased download file size (from 480 MB to 161 MB). We found that this final build size was an important consideration because users often have limited storage capacity on their devices. To overcome this, a version of the app was created with the videos being streamed from a remote server rather than being embedded in the app. This was found to reduce the app size to 22 MB. However, to successfully play back the videos, a fast internet connection is required. We found the availability and reliability of such a network in a hospital setting to be limited at times, and given the additional costs of hosting a server from which to stream the videos, we decided not to release the streaming version of the app.

The Preparation Book

The preparation book was developed to support the app and allowed for closer interaction between the child and health play specialists, radiographers, and parents and to provide a choice of resource for the patient ([Multimedia Appendix 1](#)). It contained photos highlighting the same parts of the MRI journey as the app, maintaining consistency of persons acting as radiographers and parents. The electronic version of the preparation book contained hyperlinks to load the 360° videos of the MRI journey that were hosted on YouTube. When displayed using a mobile phone, the videos could be loaded directly from the preparation book and displayed in a Google Cardboard headset using the YouTube Cardboard functionality.

This preparation book was developed in Word (Microsoft Corporation) and exported to a PDF file format for easy distribution and better display on mobile and tablet devices. A shortened version was also developed for specific use within the radiology department to prepare a child immediately prior to their scan. This omitted the stages of arriving at the reception and the safety screening since it was typically given to patients after these stages were complete.

Implementation and Evaluation

Within the hospital, mobile devices were used with the Z4 mini-headset (BoboVR), and for home use, a disposable Google Cardboard version 2 headset (Access VR Solutions) was mailed to patients. The BoboVR Z4 mini had a faux leather face-pad making it cleanable and therefore the most suitable for use within a hospital environment where the risk of infection must be controlled. The head straps were removed from the headset such that the patient simply held the headset to their face. Given our resource had a maximum VR exposure time of approximately 5 minutes, simply holding the headset was preferred as this avoided the need for adjustments to the straps and allowed for rapid removal of the headset if the patient wanted to stop the experience (eg, if suffering from VR-based simulation sickness).

The evaluation of the resource was undertaken following the National Institute for Health and Care Excellence Evidence Standards Framework for Digital Health Technologies [19]. The goal of the evaluation was to gather anonymous feedback on the initial implementation helping to inform further enhancements of the resource to improve the patient experience. The evaluation is ongoing as part of a registered clinical audit in accordance with King's College Hospital standard policies and procedures.

We recruited 23 patients (median age 9 years, range 4 to 12 years) attending the Neuroradiology Department at King's College Hospital during the period November 2016 to February 2017. Patients voluntarily participated in an anonymous survey and were selected to include those who had never had an awake MRI (19/23) or had had an MRI more than 1 year ago (4/23). An upper age limit was set due to the nature of the resource, which was designed to be appropriate for users up to approximately age 12 years. The lower age range was set by the minimum age for which a child was booked to have an awake MRI during the evaluation period. Since the purpose of

the evaluation was to provide initial feedback on the resource, a patient group without medical complexities was chosen (ie, patients were excluded if they suffered from a physical or nonphysical disability such as cerebral palsy or autism, which may inhibit their interaction with the VR environment). Patients were identified through the radiology information system as having an appointment for an upcoming brain or spine MRI. The patient was either mailed a headset for them to trial the resource at home or were provided with the resource immediately prior to their MRI when they arrived for their scan. All patients voluntarily participated in an anonymous questionnaire (see [Multimedia Appendix 2](#)) which assessed their experience using the preparation resource with a standard 10-point or 5-point Likert scale.

Ten King's College Hospital staff were also surveyed including health play specialists (2/10), radiographers (7/10), and a health care assistant (1/10; see [Multimedia Appendix 3](#)). Staff were included if they had experience using the preparation resource during the patient evaluation period. The survey questionnaire used 10-point and 5-point Likert scales to evaluate staff experience using the resource in preparing children for an MRI.

The app was provided to 5 patients who were originally considered for an MRI under GA. After allowing the child to experience the app, it was thought that the GA could be avoided, and in these patients an awake MRI was attempted. All subsequent images were then evaluated for patient motion artifact.

Results

Versions of the preparation resource have been created for the MRI journeys for three UK hospitals including King's College Hospital, The Royal Belfast Hospital for Sick Children, and NHS Highland, freely available under the titles "My MRI at King's," "Virtual Reality MRI," and "My MRI at Raigmore," respectively.

All versions have the same interface/template and differ only in the embedded 360° videos or photos, which are specific to each hospital site. Sample images are shown in [Figures 2](#) and [3](#) that highlight the cartoon style interactive interface and stills from the 360° videos. Also shown are the corresponding sections from the preparation book.

The results of the patient questionnaire are shown in [Multimedia Appendix 4](#), which highlights a positive response to the preparation resource. An unexpected outcome of the patient feedback was the impact the app had on parents, several of whom commented on the feedback forms that the app allowed them to better understand their child's upcoming MRI, helping to reduce their own anxieties and enabling them to better prepare their child.

The results of the staff questionnaire appear to highlight that staff members believe the preparation resource to be a useful tool ([Multimedia Appendix 5](#)). All ten staff members surveyed answered questions 1 through 8, while question 9 was not answered by health play specialists since they have limited involvement in directly scanning patients.

Figure 2. Screen shots from the 'Where the Radiographer Sits' stage of the MRI preparation resource: (a) app cartoon interface, (b) corresponding 360° video, and (c) corresponding page from the preparation book.

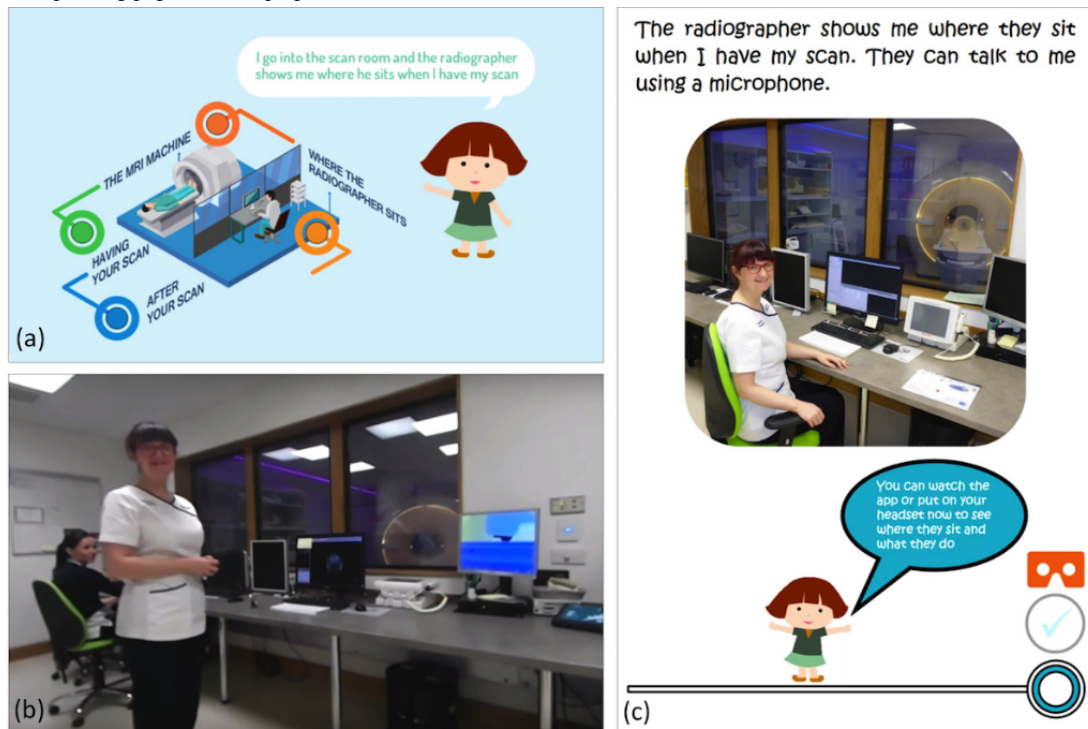
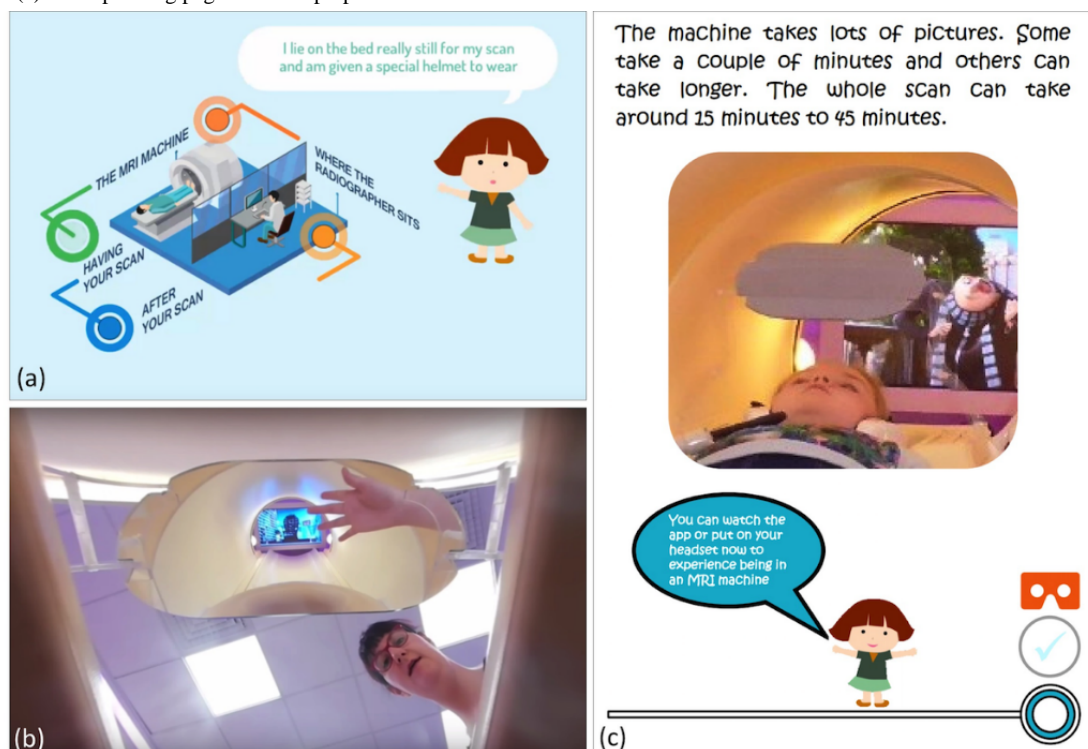


Figure 3. Screen shots from the 'Lying Down, Having Your Scan' stage of the MRI preparation resource: (a) app cartoon interface, (b) corresponding 360° video, and (c) corresponding page from the preparation book.



Of the 5 patients originally booked for MRI under GA, 4 were able to tolerate an awake MRI. In one case, the child's anxiety levels prohibited them from entering the scan room, and GA had to be administered. In all cases, no movement was noted by the scanning radiographer or suggested in the radiology reports.

Discussion

Principal Findings

In this paper we report the technical aspects involved in creating our preparation resource that uses 360° video footage displayed via an inexpensive VR headset to create an immersive virtual

MRI scan experience. Our evaluation highlights both patients and staff responding positively to the resource and the potential it has as a tool to reduce the need for GA.

While acquiring the 360° footage, we experienced some of the well-known pitfalls of creating VR content, many of which are previously described in a similar use of VR to prepare patients for anesthetics procedures [15]. This includes inadvertently inducing feelings of nausea in the viewer by acceleration in the VR environment. Although not fully understood and with a variety of causes, VR sickness can be triggered by conflicting sensory inputs from the visual system, vestibular system, and nonvestibular proprioceptors [20]. Additionally, there is a need to be conscious of filming close to objects and people—the VR equivalent to invading personal space.

These issues are well described in the VR literature and are key aspects to consider if a VR experience is to feel immersive and fulfill the place and plausibility illusion [21]. In a practical sense, when obtaining 360° footage we found it important to undertake quality control of the content. This was done by immediately viewing the footage within a VR headset so we could assess for any VR-specific issues and correct them immediately rather than realizing these issues at a later date.

There has been limited research involving the use of VR in children, and concerns remain regarding its safe use. These concerns include the potential for physical harm, since VR encourages the user to undertake movements while being blinded to the actual physical environment; VR-based simulation sickness [22]; and the potential effect VR has on the child's vision and balance [23]. To address these concerns, the use of VR equipment often comes with an age restriction from the manufacturer. In the case of the equipment used in this work (Google Cardboard-based headsets), the manufacturer suggests their headset "can be used by children but under adult supervision." For our purposes, the time spent in VR was limited to approximately 5 minutes (the length of the resource). This is similar to the maximum exposure introduced by other research groups aiming to protect younger children from any adverse effects [24]. These risks were documented in a risk assessment and explained to the parents prior to use. If at any point the patient felt uncomfortable with the experience, the headset could be removed immediately.

We developed two methods to deliver our 360° video content to patients. First, we created an app for free download from the Android Google Play and iOS App Store. We considered deploying to other VR platforms that provide a higher quality and more immersive VR experience (eg, Samsung Gear VR, Google Daydream, Oculus Rift, and HTC Vive environments). However, given the low cost and greater potential for distribution, the Google Cardboard format was in our view the best choice, enabling hospital workers and patients' families to easily download and use the app with no previous experience with VR. Furthermore, deployment to Android and iOS enables the app to be viewed in tablet mode, which can be useful for patients who do not have a Google Cardboard headset or cannot tolerate the VR environment. Examples include postoperative patients or patients with physical disabilities who cannot easily move.

In younger patients and where there was support from trained clinical staff, the preparation book enabled a closer interaction between staff and child, something that is particularly important for children with high levels of anxiety associated with MRI. Preparation books are widely used by health play specialists in hospitals, and children respond well to seeing visual images and having age-appropriate information that allows them to understand and process what will be happening to them. The preparation book presented here aimed to be an interactive resource. The electronic version linked directly to the 360° videos for viewing within a VR headset. By offering a selection of preparation resources (eg, app or preparation book), choices are provided and individual learning needs for patients of different ages are better met. The need for age-appropriate resources has previously been noted in the literature [7].

Patient and staff surveys highlighted the potential benefit of the preparation resource as a source of information for relieving patient anxieties but also as an enjoyable experience for the child. This enjoyment could be in part due to the novelty factor of VR, where the child may have engaged more with the content due to them experiencing the technology for the first time. In our evaluation we did not assess for any previous exposure to VR or 360° video content, and therefore as the technology becomes ubiquitous, there is potential for our resource to be less engaging and less effective. Literature, however, shows that traditional resources such as preparation booklets and mock scanners reduce patient anxiety in MRI, and numerous studies have measured the benefits of such preparation with patient questionnaires, heart rate measurements [25], or blood prolactin and cortisol levels after the scan [26]. In one study, however, it was found that such preparation had potential to increase anxieties [27].

The only negative patient feedback was from a 12-year-old who felt the app was too babyish. Similarly, the staff survey suggested from their experience the applicable maximum age for the resource was 11 years. On a positive note, the staff survey highlighted that in some cases staff felt the preparation resource potentially reduced patient motion and scan time due to increased compliance. A similar result has been previously reported in a prospective controlled study where patient preparation resources have shown significant reductions in patient motion [5]. The advantage of our resource is that it can be used at any location in the hospital, and parents can use the resource to prepare their child at home.

Limitations

The purpose of our survey was to provide feedback on our preparation resource to improve and further enhance the patient experience. We did not consider a research-based approach involving, for example, a control group, and so our results are not generalizable without further related work. Likewise, no control group was considered when we applied our resource to the patient case studies who were booked for GA, as our focus was on evaluating the potential for the app to avoid GA. The benefits of preparation resources have previously been investigated in controlled studies that have concluded such interventions can successfully obviate the need for patient sedation [8,28]. In future work, we aim to follow a similar

methodology using our VR-based preparation and considering anxiety scores, GA rates, and the presence of motion artifact in images for patients who have been prepared using our VR resource compared to traditional preparation techniques such as preparation booklets and pamphlets.

Conclusion

The VR preparation resource presented in this article is a novel tool for hospital staff and parents to relieve anxieties of pediatric

patients and potentially increase awake MRI scan compliance. The resource is freely available for download on multiple platforms and as such could easily be used by any site scanning children. The method developed could be recreated by others with little effort and has the potential to be expanded to other patient journeys. Our initial experiences using the resource provided nearly unanimous positive feedback, and it was shown for some patients that it potentially helped avoid the need for GA while undergoing MRI.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Preparation book.

[\[PDF File \(Adobe PDF File\), 911KB - *pediatrics_v2i1e11684_app1.pdf* \]](#)

Multimedia Appendix 2

Patient questionnaire.

[\[PDF File \(Adobe PDF File\), 156KB - *pediatrics_v2i1e11684_app2.pdf* \]](#)

Multimedia Appendix 3

Staff questionnaire.

[\[PDF File \(Adobe PDF File\), 185KB - *pediatrics_v2i1e11684_app3.pdf* \]](#)

Multimedia Appendix 4

Patient survey results.

[\[PDF File \(Adobe PDF File\), 15KB - *pediatrics_v2i1e11684_app4.pdf* \]](#)

Multimedia Appendix 5

Staff survey results.

[\[PDF File \(Adobe PDF File\), 19KB - *pediatrics_v2i1e11684_app5.pdf* \]](#)

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Abbreviations

GA: general anesthesia
MRI: magnetic resonance imaging
MRSE: Magnetic Resonance Safety Expert
NHS: National Health Service
VR: virtual reality

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Original Paper

Cyberbullying Among Adolescents: Stakeholder-Driven Concept Mapping Approach

Megan Andreas Moreno¹, MD Pediatrics, MPH (Epidemiology), MEd; Nikita Midamba², MS; Henry S Berman³, MD Pediatrics; Peter S Moreno⁴, JD; Mike Donlin⁵, BA; Erik Schlocker³, MSW

¹Department of Pediatrics, University of Wisconsin Madison, Madison, WI, United States

²Seattle Children's Research Institute, Seattle, WA, United States

³Seattle Children's Hospital, Seattle, WA, United States

⁴Department of Continuing Studies, University of Wisconsin-Madison, Madison, WI, United States

⁵The School Safety Center, Office of the State Superintendent, Olympia, WA, United States

Corresponding Author:

Megan Andreas Moreno, MD Pediatrics, MPH (Epidemiology), MEd

Department of Pediatrics

University of Wisconsin Madison

2870 University Ave

Suite 200

Madison, WI, 53705

United States

Phone: 1 608 263 2846

Fax: 1 608 263 3770

Email: mamoreno@pediatrics.wisc.edu

Abstract

Background: Cyberbullying includes bullying behaviors on the Web; these behaviors are inconsistently measured and lack standardized definitions. The Uniform Definition of Bullying provides a consensus-based definition of bullying, and it highlights the need for an evidence-based definition of a model for cyberbullying.

Objective: Toward understanding the key elements and constructs defining cyberbullying, the objective of this study was to develop a stakeholder-driven conceptual model of cyberbullying.

Methods: Concept mapping is a validated research method that leverages both qualitative and quantitative approaches to integrate stakeholder input on complex topics. This process was used to develop a concept map and adapt it through participant input to a conceptual model. The validated concept mapping approach includes 5 steps: preparation, generation (brainstorming), structuring (sorting), representation (statistical analysis), and interpretation. We recruited stakeholder participants, including adolescents, as well as parents and professionals representing education, health, and the justice system. Analysis included hierarchical cluster analysis to develop a cluster map representing cyberbullying, followed by adaptation of that map to a conceptual model through qualitative participant feedback.

Results: A total of 177 participants contributed to the concept mapping process, including 69% females, 50% adults, and 68% Caucasian, representing each of our stakeholder groups. A total of 228 brainstorming items were generated and sorted into a concept map that included 9 clusters. Clusters included topics that had strong overlap with traditional bullying, such as consequences for perpetrators and targets, with example items "alienating" and "crippling." Some clusters were unique, such as cyberbullying techniques, with example item "excessive messaging," and characteristics of the cyberbullying experience, with example item "constant." Through the interpretation step, a conceptual model emerged, illustrating connections and distinctions between traditional bullying and cyberbullying.

Conclusions: We found that in generating a stakeholder-driven concept map of cyberbullying, participants could not describe cyberbullying without integrating key concepts from traditional bullying. On the basis of our conceptual model, there are unique characteristics of cyberbullying that suggest that uniform definitions of bullying need to be evaluated to ensure their application to cyberbullying.

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KEYWORDS

cyberbullying; adolescent

Introduction

Background

Bullying is both a public health and a criminal justice problem that occurs throughout the world, and bullying can happen at many stages in the life course, from childhood to adolescence, even into adulthood. Although traditional “schoolyard” bullying remains problematic, over the past decade, technologies have provided new platforms on which bullying can occur. It is estimated that 19.6% of children of ages 14 to 18 years were bullied on school property, and 14.8% of children aged 14 to 18 years were electronically bullied [1]. These electronic forms of contact may include social networking websites (eg, Instagram, Twitter), Web-based games, instant messaging, short message service text messaging, and mobile phone pictures. This phenomenon has come to be known as cyberbullying. It is estimated that 1% to 41% of US adolescents have perpetrated cyberbullying and 3% to 72% have been targets [2].

Consequences of Bullying and Cyberbullying

Previous studies have examined the substantial negative effects that cyberbullying can have on both targets and perpetrators. Adolescents who have experienced cyberbullying report higher levels of depression and lower self-esteem [3]. Furthermore, emotional distress, anger, sadness, detachment, externalized hostility, and delinquency are more common in targets of cyberbullying than in the general population [2]. Many of these effects are also seen in targets of traditional bullying, suggesting similarities in the negative consequences of these phenomena [4].

Current Challenges in Understanding Cyberbullying

Assessing the prevalence of cyberbullying remains challenging, partly as the field lacks a conceptual approach or an operational definition of the term [5]. A consistent definition can support tracking of cyberbullying over time, and it has been called out as one of the major challenges in the field [6]. In the realm of traditional bullying, collaboration across experts in the field led to the development of a consensus-driven definition. Led by the Centers for Disease Control and Prevention (CDC), the Uniform Definition of Bullying is as follows: Bullying is any unwanted aggressive behavior(s) by another youth or group of youths who are not siblings or current dating partners; bullying involves an observed or perceived power imbalance, and it is repeated multiple times or is highly likely to be repeated. Bullying may inflict harm or distress on the targeted youth, including physical, psychological, social, or educational harm [7]. Within this definition, 4 different types of bullying behavior are commonly identified: physical, verbal, relational, and damage to property [6]. Observational studies have shown that the different forms of bullying of youths may overlap [8,9]. Within the CDC definition, cyberbullying is considered bullying by digital electronic means. Thus, cyberbullying is considered a context in which bullying occurs.

The extent to which the Uniform Definition can be applied to cyberbullying remains uncertain. A previous study that used focus groups with college students to discuss whether the Uniform Definition applied to cyberbullying found that students were wary of applying the definition. Participants in this study described elements of cyberbullying that they felt were distinct from the Uniform Definition, including their perception that cyberbullying often involves less emphasis on aggression, intention, and repetition than other forms of bullying [10]. A conceptual model describing key elements of cyberbullying could contribute to understanding the key components of cyberbullying and assessing how it may be similar or different compared with traditional bullying. A data-driven conceptual model could potentially provide evidence to inform definitions, measurement approaches, or future interventions.

Study Purpose

Thus, the purpose of this study was to develop a stakeholder-informed conceptual model for cyberbullying. To fulfill this purpose and ensure the model was driven by participant views and data, concept mapping methodology was applied. This validated methodology has been applied toward developing conceptual frameworks to describe complex topics [9-11]. Previous concept mapping studies have been applied to complex topics, such as intimate partner violence, physical rehabilitation experiences, and adolescent sexuality [12-14]. This method has also been used in previous health research to provide insights into mental health and illness [10,12,14,15]. The outcome of this process is a concept map, a visual representation of the key concepts and their interrelationships. The final map that is created is entirely in the language of the participants, and it produces an easily interpreted visual representation that can be adapted to represent a conceptual model.

Methods

Study Setting and Design

This study was conducted in Washington State, and this study recruited participants from academic and community settings. The study design was concept mapping. The Western Institutional Review Board approved this study.

Participants and Recruitment

The concept mapping approach is ideally suited for data collection from stakeholders relevant to the concept under investigation. To ground our conceptual framework in views of stakeholders involved in cyberbullying, participants included adolescents and young adults, aged 12 to 21 years, as these youth are those who directly experience cyberbullying. We also included parents of the youth of these ages, as parents are often involved when their children are cyberbullying. In selecting additional stakeholders for this study, we considered the evidence that cyberbullying can occur at home, at school, and in the community [16,17]. Thus, we included educators, including teachers and administrators. We also included

professionals typically involved in cyberbullying prevention and identification or intervention: health professionals, such as physicians, nurses, social workers, researchers and counselors, and professionals involved in law and policy, including attorneys. Additional eligibility criteria included English speaking. Concept mapping studies typically use qualitative-sized samples of approximately 50 to 80 participants in total [9], often with higher numbers of participants at the data generation and interpretation steps (brainstorming and interpretation steps). As we had several stakeholder groups involved in this study, we planned to include a larger number of participants to ensure we achieved stakeholder representation across each concept mapping step and across the number of groups involved in this study [11]. All participants were recruited through purposeful sampling from academic and community organizations between March 2013 and December 2015. Purposeful sampling included contacting local schools, parent organizations, and universities to identify participants. Each adult participant gave written consent for participation; parental consent and adolescent assent were obtained for youth participants. Before the start of each data collection, participants completed a survey that included questions about age, gender, race/ethnicity, and role (ie, student, professional, and parent). Participants who completed the survey were provided a US \$5 incentive, and participants who completed all other stages of data collection were provided a US \$20 incentive.

Concept Mapping

The concept mapping methodology was chosen, as it directly involves participants and balances group consensus with individual contribution, as some steps require group participation, whereas others are done individually. The method also allows for the consolidation of key concepts from a broad array of initial data points. A total of 5 steps are involved with the concept map creation process: preparation, generation, structuring, representation, and interpretation [9]. As we wanted to use our concept map to and wanted it to translate to a draft conceptual model, we also added a final step to propose and get feedback on a conceptual model.

Preparation

The goal of preparation was to develop a focus prompt to encourage brainstorming statements from participants in the generation step. The prompt was specifically designed to be an open-ended question that required participants to complete a sentence to achieve consistent phrasing. We developed a focus prompt of "A behavior or characteristic of cyberbullying is...". This prompt was pilot tested with a convenience sample of adolescents, researchers, and health care providers before its use for data collection.

Generation (Brainstorming) Sessions

The goal of the brainstorming step was to generate a list of participant-generated items with sufficient breadth and depth to represent the full spectrum of ideas related to what defines cyberbullying. The concept mapping literature describes 2 approaches to collect brainstorming responses: Web-based survey and focus groups. To develop a brainstorming list with sufficient breadth and depth to inform our concept map, we

used both approaches. First, individual brainstorming responses were conducted using a secure Web-based survey tool. The goal of the Web-based brainstorming approach was to allow for greater reach in participant sampling among the adult professional population. Second, brainstorming was conducted using a semistructured focus group format. Focus groups allowed for interaction among participants, as well as opportunities for participants to build on each other's thoughts [18]. Each focus group included 5 to 8 participants and lasted between 45 and 90 min. Focus groups with youths were held separately from focus groups with adults. During focus groups, after obtaining consent and providing instructions, the facilitator presented the focus prompt to the group. Participants were initially given 10 min to write individual responses to the prompt on paper. Thereafter, the topic was opened for group discussion toward further idea generation and revision. At the conclusion of the session, all written responses were collected from the participants; any additional ideas that were discussed by the group as a whole were recorded by the facilitator through transcription of the audio recording. All focus groups were audio recorded and transcribed verbatim. A total of 2 investigators reviewed the transcripts to identify items to contribute to the brainstorming list. The brainstorming list was reviewed by 2 investigators to eliminate redundancy, and it was compiled into 1 revised list, representing all ideas and statements generated by the brainstorming step.

Structuring (Sorting) Sessions

The goal of the structuring step was to sort the statements generated in the brainstorming step. To form overarching constructs, this process provides insights into how individual ideas are related. In the sorting step, participants were given a stack of index cards, each of which had a single written item from the revised brainstorming list. Individuals were asked to sort the cards into categories that made sense to them and create a label for each pile. All groups were determined by the participants, each item could be sorted into only 1 group, and every group needed at least 1 item within it.

Representation

The goal of representation was to apply quantitative approaches to analyze the data toward creation of a visual point map representing individual items. Analyses were conducted using the Concept Systems Core software Build 2016.062.11 (Concept Systems Inc) and SAS software version 9.3 (SAS Institute). Sort data were organized into a square symmetric-similarity matrix (SSSM) for each participant. In this process, pairs of brainstorming ideas were tested to determine if they had been grouped together. An overall SSSM was constructed by summing the matrices for all participants. Multidimensional scaling (MDS) of the overall SSSM was used to produce a 2-dimensional point map [19]. The point map represented all items in a 2-dimensional plane; items that were commonly grouped together were closer together on the point map. Items that were rarely or never grouped together were further apart on the point map. Stress index was calculated to assess the fit of the MDS solution to the data. Stress indices ranging from 0.10 to 0.35 indicate acceptable fit for concept mapping, with lower values indicating better fit [9,12]. The cluster map was

created by applying hierarchical cluster analysis over the overall SSSM. During this step, the software analyzes the data to perform cluster analysis and MDS to create a visual representation of the ideas in the form of clusters. The analysis process groups the ideas according to the results of the MDS into clusters. Items that were similarly categorized by participants appear closer together on the map than items that were not commonly categorized together. We then reviewed the point map overlaid with a range of clusters generated by the Concept Systems software. The role of the investigators was to use a consensus-driven iterative process to identify the cluster arrangement with the strongest theoretical support. Using the point map, the concept mapping software generates sequential versions of the concept map with a change of 1 cluster per version. The upper bound of the range of cluster arrangements examined was 2 SDs above the mean number of statement groups produced during the sort process. The lower bound of the range of number of clusters was the minimum number of clusters created by any participant. The analysis process included reviewing cluster arrangements sequentially and identifying the optimal cluster solution through an iterative process. Finally, the investigators assigned a label to each cluster on the basis of the theoretical construct described by its constituent statements. Each cluster was initially named by the software on the basis of the ideas generated by participants; names were reviewed and revised for clarity by 3 raters. The draft concept map was reviewed by all investigators to ensure it was qualitatively consistent and logical. Any revisions to the map were based on consensus of the investigators.

Interpretation

The first goal of these sessions was to conduct focus groups to allow participants to view, discuss, and interpret the concept map. The discussion was led by a facilitator and began with an introduction and review of the concept mapping methodology. The steps of the project and the focus prompt were reviewed; thereafter, the preliminary concept map was introduced. Participants were asked to discuss cluster groupings and labels, as well as to explore the overall structure of the map. Each group was asked ways in which the map represented the definition of cyberbullying and the ways it could be improved. After concluding focus groups, the data were transcribed verbatim and evaluated by 2 investigators. All focus groups were analyzed

for comments reinforcing elements of the concept map, as well as suggesting edits to the map. A total of 2 investigators identified areas of consensus and used these to modify the concept map. If consensus was not reached via 2 investigators, a third was asked to review data and determine a decision on whether to modify the concept map. Following finalization of the concept map, the investigators then identified feedback specific to a conceptual model. The draft conceptual model was developed on the basis of feedback from participants in the interpretation groups. Similar to the abovementioned, 2 investigators identified areas of consensus and used these to modify the model. If consensus was not reached via 2 investigators, a third was asked to review data and determine a decision.

Translation to a Conceptual Model

We concluded focus groups in the interpretation step by asking about the transition to a conceptual model. We wanted to ensure the conceptual model was representative of the concept map and get input on the transition to such a model. Using a draft conceptual model, we then conducted a final series of key informant interviews to obtain feedback on both the concept map and the conceptual model to ensure alignment. These interviews were also recorded and transcribed verbatim. A total of 2 investigators reviewed transcripts. They identified areas of consensus around elements of the conceptual model and proposed edits to the model to reflect participant feedback.

Results

Participants

A total of 177 participants contributed to the study. A total of 80 participants contributed the generation step; this included 37 Web-based survey participants and 43 focus group participants across 6 groups. In the structuring session, 26 participants completed sort activities. In the interpretation step, a total of 71 participants contributed to a focus group or key informant interview. Youth had an average age of 17 (SD 2.25), and adults had an average age of 43 (SD 12.9). There were 50% of adults over age 21; adult professionals included 24% health professionals, 22% clinical researchers, 12% educators, and 2% attorneys. [Table 1](#) provides demographic information of our participants across the concept mapping process.

Table 1. Participant demographics across steps of the concept mapping process.

Demographics of participants across concept mapping steps	Step 2: Brainstorming <i>focus groups</i> (n=43)	Step 2: Brainstorming <i>surveys</i> (n=37)	Step 3: Sorting <i>activity</i> (n=26)	Step 5: Interpretation <i>focus groups</i> (n=63)	Translation to conceptual model <i>key informant interviews</i> (n=8)	Total
Gender, n (%)						
Female	34 (79)	32 (86)	17 (65)	34 (54)	5 (62.5)	122 (69)
Male	8 (19)	5 (14)	8 (31)	29 (46)	3 (37.5)	53 (30)
Unknown	1 (2)	0 (0)	1 (4)	0 (0)	0 (0)	2 (1)
Age, n (%)						
Adults over 21 years of age	5 (12)	35 (95)	19 (73)	21 (33)	8 (100)	88 (50)
Youth aged 21 and under	21 (49)	0 (0)	6 (23)	37 (59)	0 (0)	64 (36)
Age unknown	17 (40)	2 (5)	1 (4)	5 (8)	0 (0)	25 (14)
Race/ethnicity, n (%)						
Black/African American	3 (7)	2 (5)	2 (8)	4 (6)	1 (12)	12 (7)
Asian/Pacific Islander	1 (2)	8 (22)	2 (8)	11 (17)	0 (0)	22 (12)
Caucasian	31 (72)	25 (68)	20 (77)	40 (64)	5 (64)	121 (68)
Hispanic/Latino	2 (5)	1 (3)	1 (4)	2 (3)	1 (12)	7 (4)
Native American	3 (7)	0 (0)	0 (0)	4 (6)	0 (0)	7 (4)
Mixed race	1 (2)	0 (0)	0 (0)	3 (4)	1 (12)	4 (2)
Other/unknown	2 (5)	1 (3)	1 (4)	0 (0)	0 (0)	4 (2)
Role, n (%)						
Student	22 (51)	1 (3)	5 (19)	28 (44)	0 (0)	56 (32)
Health professional	13 (30)	8 (22)	1 (4)	15 (24)	2 (25)	39 (22)
Educator/teacher	3 (7)	1 (3)	5 (19)	0 (0)	0 (0)	9 (5)
Administrator/librarian	0 (0)	9 (24)	0 (0)	0 (0)	0 (0)	9 (5)
Researcher	0 (0)	13 (35)	6 (23)	14 (27)	6 (75)	40 (24)
Social worker	0 (0)	2 (5)	0 (0)	1 (2)	0 (0)	3 (2)
Counselor	0 (0)	3 (8)	1 (4)	1 (2)	0 (0)	5 (3)
Law professional	0 (0)	0 (0)	3 (12)	0 (0)	0 (0)	3 (2)
Other/unknown	5 (12)	0 (0)	5 (19)	3 (3)	0 (0)	13 (7)
Parent/nonparent, n (%)						
Parent	4 (9)	0 (0)	13 (50)	7 (12)	2 (25)	26 (15)
Nonparent	0 (0)	0 (0)	11 (42)	52 (83)	6 (75)	63 (35)
Unknown	39 (91)	37 (100)	2 (8)	10 (0)	0 (0)	88 (50)

Step 2: Generation

A total of 311 statements were produced during the generation step of data collection. Refining the statement list led to removing of duplicate statements (n=18) and merging of similar statements (n=65). The final list of brainstorming statements included 228 unique aspects of cyberbullying.

Step 3: Structuring

During the sorting procedure, participants sorted the statements into individual groups, the number of groups ranged between 4 and 30 individual groups (mean 12.9, SD 6.1, median 11).

Step 4: Representation

The stress value for the fit of the MDS solution to the structuring data was 0.3 for the 9 cluster solution, indicating adequate fit. Overall, the 9 cluster solution presented in [Figure 1](#) was found to represent the best fit for the data after assessing a total of 10 unique cluster solutions, ranging between 2 and 12 clusters. The 9 clusters depicted on the Cyberbullying Concept Map are described in [Table 2](#).

Figure 1. Cyberbullying concept map developed by stakeholders including adolescents and young adults, parents, community members such as educators, clinicians and attorneys. Each number represents a single item proposed by participants, and the clusters represents how participants sorted items into groups of alike concepts.

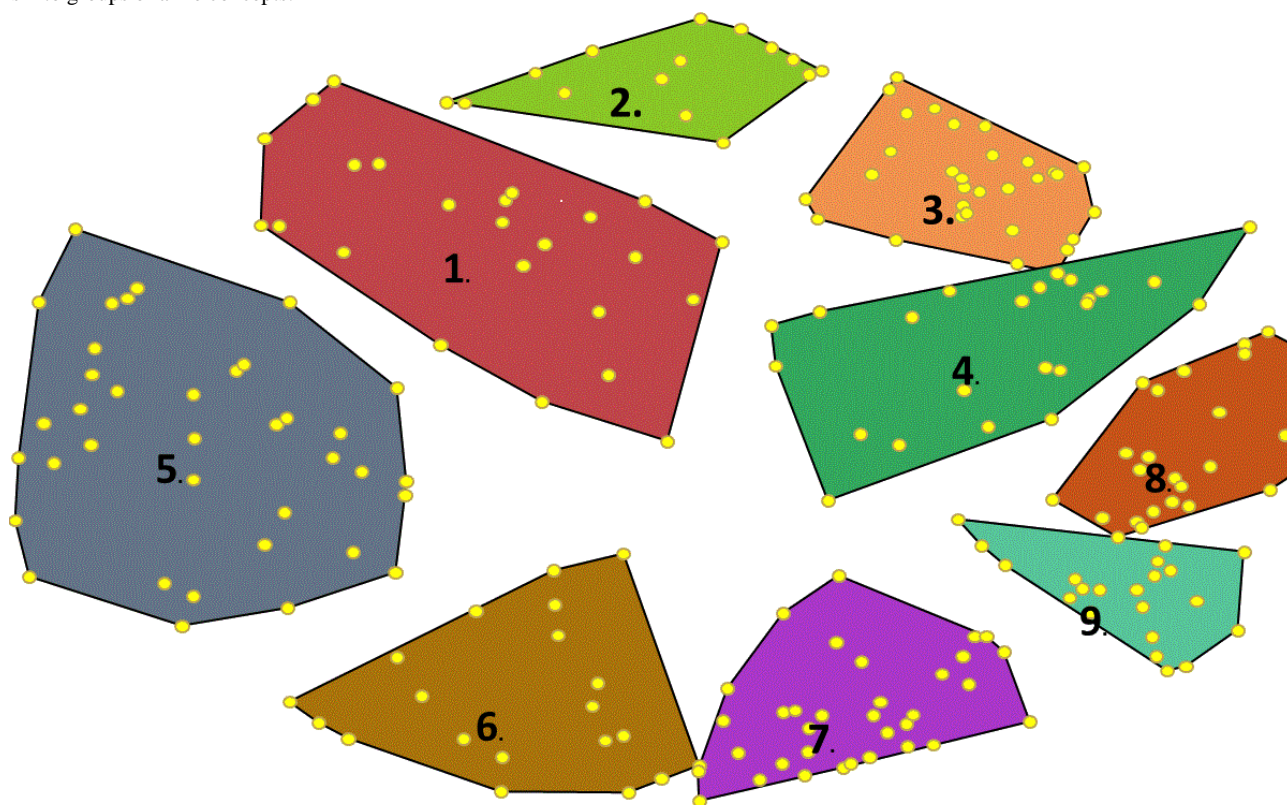


Table 2. Cyberbullying concept map clusters.

Cluster number	Proposed name	Example items
1	Characteristics of perpetrators and targets	Lack of empathy, afraid to go back to school, and “small minds”
2	Consequences for perpetrators and targets	Alienating, crippling, and devastating
3	Characteristics of the bullying experience	Aggressive, intent to harm, disrespect, and hostile
4 and 8	Bullying techniques	Ostracize, antagonize, and “mean girls”
5	Characteristics of the cyberbullying experience	Anonymous, constant, and perceived lack of consequences
6	Cyberbullying techniques	Making unwanted posts go viral, excessive messaging
7	Cyberbullying cases	Sending rude messages from someone else’s account to get people mad at the person
9	Perceived vulnerabilities	Negative statements about clothes, family situation, intelligence, social status, appearance, and sexuality

Step 5: Interpretation

The interpretation step first involved reviewing the concept map and discussing participant perceptions of that map. Discussions by participants consistently centered on how to describe cyberbullying as a phenomenon that was perceived as both similar to and distinct from traditional bullying. Common topics of discussion included that many characteristics and motivations for bullying were considered to be similar and sometimes identical for both cyberbullying and traditional bullying. However, participants felt strongly that there were unique aspects to cyberbullying, including novel methods or situations in which bullying could arise, as well as providing new tools for bullying perpetrators. For example, participants described

that a unique aspect of cyberbullying was that cyberbullying situations could arise from innocuous comments on the Web that are taken out of context or jokes that go too far. These messages can be virally spread, such that they then represent bullying. As an example, an adolescent described how compliments posted on the Web can be twisted to become “backlash compliments, like oh your hair looks *great* [emphasis added].” The adolescent further described that these sarcastic comments were more likely to be “liked” or “shared,” allowing them to be seen and disseminated by others. Another example described by a parent was learning that her son’s school was having a Web-based “draft,” described as follows: “they are actually, like, doing a draft, a first round draft, about which girls they want to take to the prom and ranking them, it is all done

online.” It was described that this scenario may not be considered a traditional bullying situation but that it could have similar negative impacts on youth who were the targets. In these scenarios, the initial communication or situation may not have been unwanted or aggressively hurtful, but the situation could devolve into bullying because of the format of Web-based communication. Another area in which participants noted unique aspects of cyberbullying was how the Web-based environment provides tools so that a target of bullying can “turn the tables” to become a perpetrator. A quote from an adolescent described the following:

...cause when you're in person you can see the physical build of the person and if they're bigger than you, you don't usually want to pick a fight with them. But on the internet, it's just a screen in front of you with a username and they're all the same that way.

This quote describes participants' views of how a target of bullying can achieve power by using a “screen in front of you” to bully his/her perpetrator. Participants frequently discussed their perceptions of heightened fluidity of the roles of perpetrator and target in cyberbullying situations. The interconnectedness of traditional in-person bullying and cyberbullying was also a common topic. One example quote from an adolescent described the following:

Umm so the people I know that, or the people that I've known that have been cyberbullied usually they're the targets from like bullying at school and they go and try to pass the pain on the internet to someone else, so it's kind of like a circle going around like that cause they can't like, they're not like, the smaller guy can't beat up the bigger guy, so he goes on the internet and destroys him on the internet, and the bigger guy comes back and destroys the little guy at school, so it's just like a circle between the two.

A notable trend in participant contributions to the topic is that so many spoke from personal experiences with cyberbullying scenarios. Adolescents spoke about situations they or their peers had experienced. Parents often shared situations their children had experienced. A parent described the following:

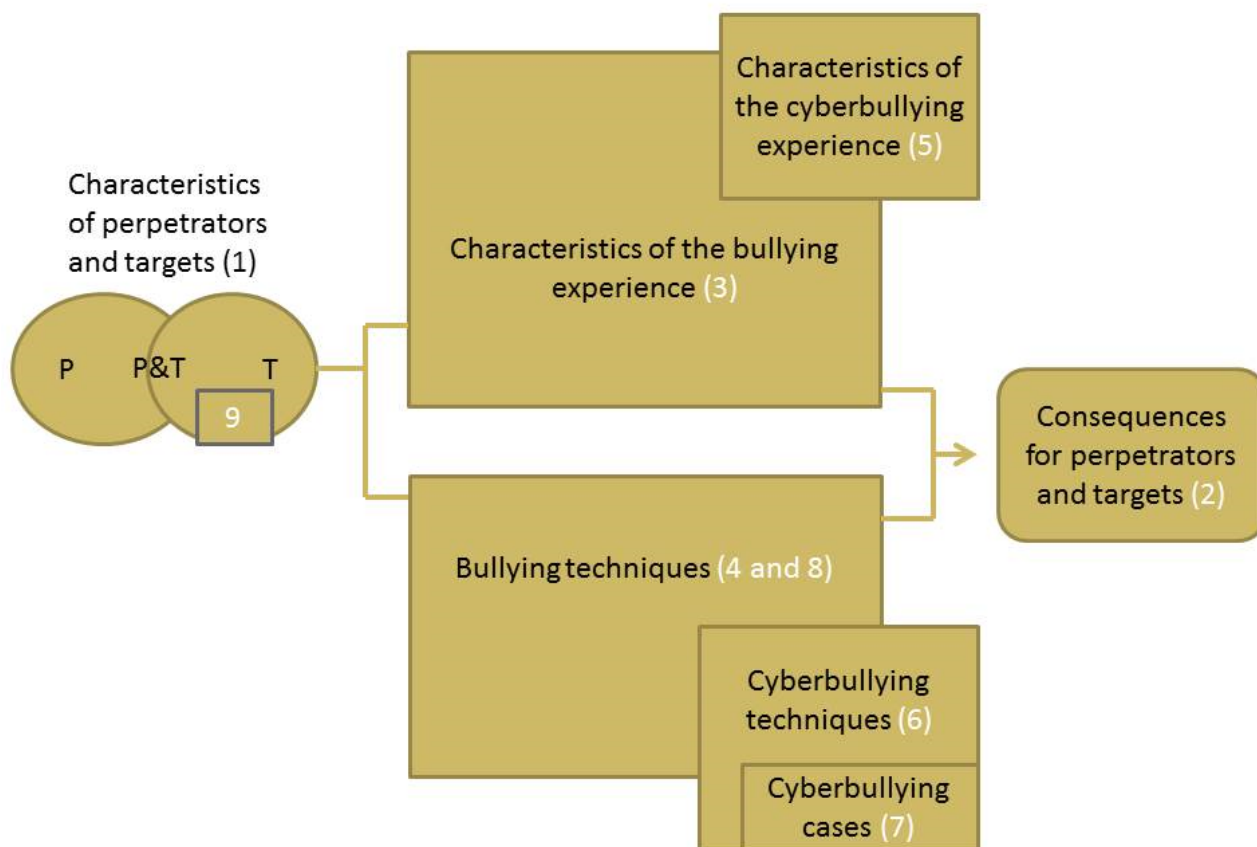
I wrote down some based on, um, experience one of our daughters had about a year ago. Uh, repeated contacts that were unwanted, so, just continuous contacting, right, um, when not asked for, attempt to push beliefs on to the recipient that are not those of the recipient, uh, profane language if, of course it's

not wanted, uh, yelling in the electronic message if that's not the, ya know, normal tone of the message, and just threats or blackmail.

Translation to a Conceptual Model

On the basis of participant input, the conceptual model of cyberbullying included the relationship between cyberbullying and bullying (Figure 2). Key aspects of the conceptual model included the overlap in bullying perpetrators and targets, which includes clusters 1 and 9 from the concept map. Important characteristics of bullying perpetrators suggested by participants included bullying as “a way to deal with insecurities,” which was suggested by a teacher. A characteristic of bullying targets nominated by a legal professional was “afraid to go back to school.” Within the circle describing bullying targets were specific characteristics that were nominated as denoting particular risk for bullying, including being of racial or sexual minority groups. Some shared characteristics of both perpetrators and targets included “depression risk,” suggested by several participants, including adults and adolescents. The conceptual model also included 2 overlapping boxes, with the larger describing characteristics of the bullying experience; these included descriptors, such as disrespectful, mean, and aggressive. Overlapping this box was a smaller box representing unique characteristics of cyberbullying proposed by participants, such as “hides behind screen” (adult, parent). Similarly, a larger box described bullying techniques, including false information, public shaming, or belittling. Overlapping this box was a smaller box representing techniques that were specific to cyberbullying, including “displaying negative images” (adult, health professional) “covering with false names” (adult, social worker), and “virtual clique” (adult, administrator). Nestled within this box was a smaller box in which specific examples of cyberbullying cases were described, including “photo-sharing without consent” (adult, parent). The construct describing consequences to bullying perpetrator and targets was a shared construct. Participants reflected that they did not perceive specific differences between cyberbullying and traditional bullying for this construct. An area of discussion in which there was a lack of consensus was whether the concept map or conceptual model appropriately represented the role of bystanders. A quote from an older adolescent was, “I feel like this entire thing is just focused on the bully and the victim and not just, it's just on them, and not the bystanders.” However, other youth discussed viewing cluster 4 on the concept map as adequately representing the role of bystanders.

Figure 2. Conceptual model of cyberbullying and its relationship with bullying. Cluster numbers on the diagram are from cyberbullying concept map in parentheses.



Discussion

Summary

This study used a concept mapping approach to gain insights and perspectives from stakeholders toward a concept map and a stakeholder-driven conceptual model of cyberbullying. During the brainstorming step, stakeholders generated a diverse and expansive list of statements describing cyberbullying. The sorting procedure yielded a robust concept map of 9 clusters that comprised characteristics of the people involved, actions, and consequences that define bullying and cyberbullying. After our concept mapping process, we utilized stakeholder insights to develop a conceptual model that illustrates areas in which cyberbullying is similar to and unique from traditional bullying. This conceptual model represents participants' perception of cyberbullying and suggests that cyberbullying can be best understood within the context of all bullying behavior, with recognition of the unique challenges it presents.

Principal Findings

A major finding of this study is the several ways in which bullying and cyberbullying were aligned. This finding is aligned with emerging literature supporting strong connections between bullying and cyberbullying. Recently studies have illustrated that individuals involved in bullying often experience different types of bullying within a given situation, which may include

verbal, physical, and cyber experiences [18,20]. Similarly, we found that a key area of overlap between cyberbullying and traditional bullying includes characteristics of the individuals involved. This study's participants described characteristics of both bullying perpetrators and targets that applied to traditional bullying and cyberbullying, including describing bullying as a way to address insecurities. Participants emphasized the fluidity of roles between perpetrator and targets for both cyberbullying and bullying. They noted that an adolescent's ability to engage in cyberbullying would not be limited by physical or social power; thus, cyberbullying may augment the fluidity of roles between perpetrator and target. This fluidity in roles is supported by Olweus' descriptions of "the bullying circle" in which targets may become perpetrators (and vice versa) depending on situations and circumstances [21]. The Uniform Definition of bullying describes that bullying behavior involves an actual or perceived power imbalance. In this study, the fluidity in roles of perpetrator and target does not seem to represent a shift in the actual power of the individual, but it could represent power derived from the tool that is used to bully: the internet. Another area of similarity between cyberbullying and traditional bullying was that the consequences of both were described in a single construct in the interpretation diagram. This single construct implies that our diverse stakeholders, including educators, legal experts, health professionals, as well as teens themselves, perceive that significant and similar negative consequences

result from both cyberbullying and traditional bullying. A second critical finding is the areas in which stakeholders elucidated their perceptions of differences between cyberbullying and traditional bullying. These included characteristics of the bullying experience, including the capacity for anonymity by “hiding behind screens” in cyberbullying. The role of anonymity in cyberbullying has been noted in previous studies [2]. However, traditional bullying is not without the capacity for anonymous actions, including sending threatening notes anonymously or damaging property secretly. Even so, the perceptions of participants about anonymous bullying via the internet was a topic of concern and even alarm for many participants. Finally, the concept map and accompanying conceptual model serve as data-driven visual representations of the complexity of bullying. This complexity is illustrated in our concept map, and it includes shared characteristics among perpetrators and targets, a variety of tools and approaches to consider, and negative consequences for both actors. Our findings support a need for research that considers mechanisms or processes that can explain how an individual may experience bullying and its consequences differently, depending on the context of that bullying event or situation. A “person by situation by context” interaction has been applied to research in other areas, and the recent National Academies of Science, Engineering, and Medicine report supports integration of these frameworks into research on bullying [21]. This study’s findings provide a conceptual model to understand an individual’s journey through these experiences, but further work is needed to understand how context plays a role in determining outcomes of a bullying event or experience.

Limitations

Several limitations to this study should be considered. Traditional concept mapping methodology provides guidelines for small numbers of participants at each stage. To provide additional depth to this process, we included a larger number of participants than is typically involved in concept mapping to represent the various stakeholders who are involved in cyberbullying. As we used a purposeful sample, this study’s participants are not generalizable, and they may have had similar perspectives. However, this study’s findings that many participants provided insights and quotations from direct experience with cyberbullying support our purposeful sampling approach to engage a stakeholder involved in cyberbullying situations. Furthermore, the majority of data collection was focused in 1 geographic location. This study focused on cyberbullying applied to adolescents; we did not specifically target or include cyberbullying as applied to children or adults. Further work should investigate whether findings may generalize to young-adult age groups, in which cyberbullying has been shown to be common [22,23]. Finally, we modified the traditional concept mapping approach by adding a translation to the conceptual model step using key informant interviews. This step adds value to this study’s outcomes, but this is by definition outside the typical 5-step concept mapping process.

Implications

Despite these limitations, this study has important implications in illustrating the key factors that define cyberbullying from the

perspectives of stakeholders. The conceptual model developed in this project illustrates what key factors have been internalized by stakeholders both through direct experience and through exposure to sources, such as schools, media, and patients. The arrangement of concepts in our conceptual model suggests that cyberbullying cannot be considered a distinct entity from bullying, which is supported by the recent National Academies report [21]. However, stakeholders perceive that there are aspects of cyberbullying that support it as more than just another bullying context. Although the Uniform Definition of bullying was created to apply to bullying across all types and contexts, this study illustrates that there is still a strong public perception that cyberbullying presents distinct opportunities and challenges compared with traditional constructs of bullying. To unify efforts to prevent and intervene with bullying, as well as to measure and assess it over time, future work must address these stakeholder perceptions. To promote acceptance and uptake of the Uniform Definition of bullying among stakeholders, it is possible that the definition would benefit from evaluation for the context of cyberbullying or consideration toward adding language to clarify its application to cyberbullying. This study’s findings suggest that clarifications to the Uniform Definition may include acknowledgment that power imbalance may be created by tools such as the internet rather than cyberbullying being solely considered as a preexisting condition within a perpetrator. As the Uniform Definition is meant to be used by educators, policy makers, and researchers in the realms of both traditional bullying and cyberbullying, it is important to ensure consistency in interpretation and application of this definition across these stakeholder groups. Implications for policy include providing clarity and consistency in language when measuring bullying and in policies that address bullying. Assessment tools may need to clarify whether questions about bullying behavior include cyberbullying, and they may need to use consistent terms and language to ensure responses are valid across populations and over time. Furthermore, most states currently have separate policies for addressing bullying and cyberbullying, which may contribute to public perceptions that these represent separate entities [21]. This study’s findings support that integration of these concepts is supported by the overlap in key concepts. Implications for health providers working with teens and their parents include understanding that assessments for bullying need to address both traditional bullying and cyberbullying. Asking questions in a clinic that encompass both experiences or are open ended—such as “have you ever had any experiences with bullying?”—may promote open discussion about the different types of bullying or different roles a teen may have played. Furthermore, providers can acknowledge that experiencing either or both types of bullying is common and consequential. Fortunately, newer studies suggest that interventions designed to address cyberbullying also affect bullying, further illustrating the strong connection across bullying behavior [20,24].

Conclusions

In conclusion, findings support that cyberbullying is best understood in the broader context of bullying, but findings also support that stakeholder perceptions about the uniqueness of cyberbullying are strong. Bullying presents a complex set of

behavior within roles that may be fluid and may lead to negative consequences for both perpetrators and targets. Findings may be applied toward achieving greater consistency in our definitions, assessments, and policies regarding bullying, and

findings may be applied toward working toward a shared understanding of key concepts in bullying with stakeholders who are in the field, addressing bullying with teens and their parents as part of their everyday jobs.

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Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention

MDS: multidimensional scaling

SSSM: square symmetric-similarity matrix

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